"Either you conquer it, or it conquers you": An applied anthropological approach to veterans with a spinal cord injury

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"Either You Conquer It, or It Conquers You": An Applied Anthropological Approach to Veterans With a Spinal Cord Injury

by

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“Either You Conquer It, or It Conquers You”: An Applied Anthropological Approach to Veterans with a Spinal Cord Injury

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ABSTRACT

Veterans with a spinal cord injury (SCI) engage in a complex and, often times, difficult dialogue within and through interactions in American society. That is, American society holds dear certain traditional values (ideals, beliefs, and customs) that promote the steady functioning and fabric of society. Through the process of enculturation and acculturation, likely, the majority of American citizens have already internalized many of these values. These values are cultural constructs of American society that can certainly influence and shape the myriad ways in which individual identity is formed.

By identifying these value sets and analyzing the ways in which SCI veterans interact within society, I hope to achieve three goals; (1) discover the ways in which SCI veterans create and negotiate a unique sense of identity in American society, (2) illustrate the overall implications from this study to the general SCI population in America, and (3) provide a set of recommendations for healthcare providers for the purposes of creating and engaging in meaningful dialogues with SCI patients as well as aiding in more successful and sustainable health interventions.
Chapter One

Introduction

Background and Descriptive Epidemiology

In the United States population, approximately 250,000 to 400,000 people live with a spinal cord injury (NSCIA, 2006), and approximately 25,000 of these are veterans (VA QUERI, 2007). According to the National Spinal Cord Injury Association (NSCIA) (2006), spinal cord injury (SCI) is damage to the spinal cord that results in a loss of function. The spinal cord does not need to be severed in order for a loss of functioning to occur. In most people with SCI, the spinal cord is intact though the damage to it results in loss of function. The severity of the injury depends on the part of the spinal cord that is damaged. The higher the SCI is to the brain, the greater the effects are to the body and functioning. Tetraplegia or quadriplegia results from injury in the cervical or neck region of the spinal cord. This results in loss of functioning in all four extremities. Injuries at the thoracic level and below result in paraplegia. Paraplegics retain hand and arm control and sensation while abdominal and trunk functioning may be limited based on level of injury. Furthermore, SCI can be classified as complete or incomplete. Complete SCI results in total loss of all motor and sensory functions below the level of injury, while incomplete SCI is characterized by partial functioning below the level of injury (NSCIA, 2006). Even though SCI is a condition that affects up to 400,000 people in the United States, published epidemiological data on SCI is sparse.
One of the priority health objectives for unintentional injuries by the year 2000 in the United States was to reduce the number of nonfatal spinal cord injuries to 2.4 per 100,000 people from 3.2 per 100,000 in 1986 (Brown et al., 1990). It is unknown whether this goal was met in 2000 due to the unavailability of published data. However, according to the National Spinal Cord Injury Statistical Center (NSCISC) (2005) in 2005 the incidence of SCI was 4.0 per 100,000 or approximately 11,000 new cases each year. This statistic is an increase of almost 1 person per 100,000 (3.2 per 100,000 in 1986 compared to 4.0 per 100,000 in 2005) in SCI in the United States from almost 20 years ago. The majority of the SCI population in the United States is male (82%). Those injured were 63.0% Caucasian, 22.7% African American, 11.8% Hispanic, and 2.4% were from other racial/ethnic groups.

Though most injuries occur between the ages of 16 to 30, the average age at the time of injury is 28.7 years. In the United States, the average age of persons with SCI is 40 years. Veterans with SCI, however, are on average even older with eighty percent of this population aged 50 years or older (Samsa, Hoenig, and Branch, 2001; VA QUERI, 2007). The causes surrounding the difference in average age between the general population with SCI and the veteran population with SCI are currently unidentified. The main causes of SCI in the United States are car accidents (42%), violence (24%), falls (22%), sports (8%), and other causes (2%) (NSCIA, 2006).

Life expectancy estimates for persons with SCI remain difficult to calculate. This is due to a number of factors inherent to SCI that need to be considered before life expectancy estimates can be made. Such factors include age at injury, as well as level and completeness of injury (McColl et al, 1997; NSCISC, 2006). Life expectancy for
persons with SCI has been increasing in the United States over the past two decades (NSCISC, 2006; Robinson-Whelen and Rintala, 2003). McColl et al. (1997) found that the median life expectancy of persons with SCI to be 68 years, which is a slight increase from 1983, which was 64 years. Additionally, McColl et al. (1997) found that younger age at injury was also found to have higher life expectancy, while life expectancy was lower with older age at injury. Compared to the general population, the life expectancy for person with SCI remains below the normal life expectancy average (77.9 years).

Published data on mortality, morbidity, and their respective rates on the SCI population are scarce. The NSCISC (2006) published data regarding mortality in 23,683 patients with SCI that were followed since 1973. From 1973 to 2006, 7,579 patients with SCI have died. According to the NSCISC, the average mortality rate for persons with SCI is 9.7 per 100,000 per year, which is higher than the general population mortality rate in 2005 (8.5 per 100,000). The five primary causes of mortality among the SCI population were: diseases of the respiratory system (22.0%), other heart disease (unexplained acute myocardial infarction) (12.2%), infective and parasitic diseases (9.9%), hypertensive and ischemic heart disease (7.9%), and neoplasms (7.2%). Compared to the general population, the SCI population has higher mortality in regards to respiratory diseases (SCI=22.0%, general=5.35%) and infective and parasitic diseases (SCI=9.9%, general=2.2%). The general population, however, has higher mortality in both heart disease (general=26.53%, SCI=20.1) and neoplasms (general=22.85%, SCI=7.2%).

Morbidity associated with SCI includes acute and chronic complications and outcomes. These include: pressure ulcers, pneumonia, deep vein thrombosis, pulmonary
embolism, urinary tract infections, scoliosis, joint degeneration, muscle atrophy, spasticity, pain, depression, and obesity (CDC, 2006; NSCISC, 2006; VA QUERI, 2007). According to the NSCISC (2006), pressure ulcers were the most frequently observed complication, which increases steadily by each post-injury year. Specifically, pressure ulcers occurred in 14.7% of persons with SCI in their first year post-injury and in 30% of those in their thirtieth year post-injury. Pneumonia was the next most common complication, which also steadily increased from 2.7% to 4.1% over time. Though a number of co-morbidities exist among persons with SCI, there have been no published data on morbidity rates.

The annual and lifetime costs of SCI are enormous. SCIs cost the nation $9.7 billion each year (CDC, 2006). The estimated lifetime costs of SCI range from $0.5 million to almost $3 million, depending on age at injury and level and completeness of injury. The estimated average yearly expenses for a person with SCI cost up to $130 thousand (NSCISC, 2006). Additionally, the national cost of treating pressure ulcers alone is $1.2 billion (CDC, 2006).

Objective

The purpose of this thesis is to explore life issues among a sample population of United States veterans with a spinal cord injury. The sample population for this study is composed of wheelchair-bound veterans with SCI who were recruited into a research study conducted in Augusta, GA and Tampa, FL by the Veterans Affairs (VA) Patient Safety Center of Inquiry in Tampa from 2004 to 2006. The age range of the sample includes adults ages 18 to elderly veterans in their eighties. Veterans with both complete
and incomplete SCI were included. The cause of the SCI for this sample was not collected in this research study. Essentially, this study sought to better understand what it means to be a veteran with SCI living in American society today through examining the values and meanings inherent in their lives. Though broad in its scope, the lives of veterans and persons with SCI are not well represented in the literature. This is especially true regarding literature from this population’s own perspective, which will be discussed in more detail in this study’s literature review.

Public Health and Anthropological Significance

The discipline of public health is concerned with the prevention of disease morbidity and mortality as well as the promotion of health within the general population. Taking into account the descriptive epidemiology and costs of SCI, it is clear that SCI is a major public health concern. Medical care, such as pharmaceutical and rehabilitation interventions and assistive technology, involving persons with SCI have minimized many of the complications associated with SCI. However, complex long-term outcomes (pressure sores, urinary tract infections, joint degeneration, spasticity, and pain) remain in people surviving with SCI. Living with disability becomes a life-long process for persons with SCI (Hallin et al., 2000).

In regards to the anthropological difference or significance of my research study, the general principles and goals of applied anthropology, especially medical anthropology, are certainly pertinent in this area of study. Applied anthropology, as a professional field and discipline, seeks to ameliorate social issues and problems through the application and utilization of anthropological theory and methods. According to
Brown et al., medical anthropology is “the application of anthropological theories and methods to questions of health, illness, medicine, and healing” (Brown et al.:10 1988). Therefore, an applied medical anthropological approach seeks to address social problems and issues regarding health, illness and disease, medicine, and healing through anthropological means.

The beliefs held by anthropologists that culture is all encompassing and dynamic indicate that studies concerning veterans and persons with SCI (and disability in general) will offer numerous theoretical and applied research opportunities in a historically underrepresented area. First and foremost, it should be noted that different conceptions and definitions of disability in anthropology, other disciplines, and the general population exist. This is likely due to the multifaceted and highly abstract concept of disability. The different ways in which disability is conceptualized may influence the numerous interactions between those populations labeled as “disabled” and the general population. For instance, issues of stigma and discrimination may also play a role in the lives of persons with SCI as it does within other disabled populations. These issues of stigma and discrimination result from societal norms placed on attributes that are labeled undesirable. Additionally, the concept of the “culture of disability” indicates that persons sharing a disability or disabled condition share similar perspectives and abide by shared rules of conduct amongst each other (Pederson, 2005). Whether or not this is the case for persons with SCI is unknown. It is not clear whether or not persons with SCI share a similar set of values, and, if so, what these values are. My research study will hopefully attempt to address and identify the myriad social issues and concerns within this sample population. Therefore, such cultural knowledge gained through this study can further
illuminate anthropologists’ and health researchers’ knowledge of the culture and lifestyle associated with spinal cord injured persons.

Outline of Thesis

The thesis is divided into seven chapters. This chapter introduces the research objective, the population, and background information regarding SCI. The second chapter presents an extensive public health and epidemiological literature review in order to compliment the qualitative nature of the thesis. Topics include a discussion of the quality of life concepts and definitions and a review of quality of life studies in persons with SCI. The third chapter presents an anthropological literature review. The topics include: anthropological definitions of disability; the “culture of disability”; stigma; and the anthropology of values. The fourth chapter discusses the overall methodology of the research project. The internship experience, in which this thesis is situated within, is presented. The research questions, sampling, data collection, analysis, and limitations of this thesis are discussed. Chapter Five presents the results of this study in the form of ten vignettes, which illustrate the various life issues of participants. Chapter Six discusses the results in the context of the research questions. Chapter Seven synthesizes the conclusions generated from the study’s results and themes in the context of the previous anthropological literature. Recommendations for health policy makers and researchers are made. Finally, the contributions of this thesis in the fields of anthropology and public health are presented.
Chapter Two
Epidemiological Literature Review

Background

Despite a potentially bleak outlook, SCI medical care, such as pharmaceutical and rehabilitation interventions and assistive technology, has minimized many of the complications (thrombosis, embolism, etc.) associated with SCI as well as optimizing the conditions for long-term survival (Wood-Dauphinee et al., 2002). However, complex long-term outcomes (motor sensory impairment) and morbidities associated with SCI (pressure ulcers, pneumonia, joint degeneration, muscle atrophy, pain, etc.) remain in people surviving with SCI. Therefore, living with SCI, a potentially serious disability, becomes a life-long process with different sets of problems presenting themselves at different stages of life (Hallin et al., 2000).

Quality of Life Concept

The life long process with SCI and disability often leads to changes in the usual patterns of daily living among persons with SCI. For example, social (marriage, employment, etc.) and environmental (physical barriers to mobility) barriers are factors that contribute to this altered state of affairs (Wood-Dauphinee et al., 2002). Increased life expectancy necessitates the need for life-long follow-up. Expanded medical and rehabilitation outcome parameters have been created in order to better understand and promote the physical, psychological, and social well-being after a SCI (Hallin et al., 2000).
Specifically, these outcome parameters include: the facilitation of functional recovery and personal independence, the promotion of community reintegration, and a high satisfaction with life, which are all concepts well accepted by medical and rehabilitation professionals (Wood-Dauphinee et al., 2002). Taken together, these life-long outcome parameters constitute the aspects and dimensions of the complex concept, quality of life (QOL). SCI affects, directly or indirectly, these aspects and dimensions of QOL (Dijkers, 1999a). Assessments of QOL are becoming increasingly used in medicine, especially in health care interventions and in the rehabilitation of physically disabled persons (Leduc and Lepage, 2001; Westgren and Levi, 1998). In the past two decades, measurement tools have been created to measure QOL (Leduc and Lepage, 2002).

The term, quality of life, is one used in many disciplines. Consequently, the definitions and conceptualizations vary from discipline to discipline. This is primarily due to conceptual issues since a universal definition of QOL has not been adopted, and the terminology used varies between disciplines (Hallin et al, 2000). Some QOL definitions stress different concepts and topics over others (Dijkers, 1999b). For example, one definition of QOL is the value assigned to life duration through the modification of impairments, functional states, perceptions, and social opportunities influenced by disease, injury, and treatment (Wood-Dauphinee et al., 2002). On the other hand, Manns and Chad (2001) define QOL in a subjective manner. Simply, quality of life is a representation of how good one’s life is based on one’s own subjective perceptions and evaluation. Both types of definitions demonstrate the multidimensionality of the QOL concept. The multiple definitions and
conceptualizations results from the fact that QOL is a highly abstract concept, and a number of fundamental and philosophical values and issues are tied to its definition and measurement (Dijkers, 1999b). As a result, two traditions exist concerning the study and measurement of QOL.

*The Objective Tradition*

The objective approach is synonymous with health-related quality of life (HRQOL), and defines HRQOL as the sum total of a person’s scores on characteristics that can be objectively determined. The objective approach includes components of HRQOL that directly or indirectly focus on and are affected by health, disease, disorder and injury. These components include: symptoms, treatment side effects, physical, cognitive, emotional and social functioning (Dijkers, 1999b). Essentially, the objective tradition centers on HRQOL as a set of characteristics and components of persons and their environments. These characteristics and components are those that can be measured independently from personal subjective reactions, such as personal judgments and feelings. This point of view is inherent in policy and program evaluation and research studies. Objective measures of HRQOL assume that all people to a large extent share the same essential opinions and values as to what constitutes a good and desirable life (Dijkers, 1999b). Commonly used, validated objective HRQOL measurement tools include: the Medical Outcomes Study Short Form (SF-36), the Short Form-12 Health Survey (SF-12), and the Craig Handicap Assessment and Reporting Technique (CHART).
Measurement Tools (SF-36 and SF-12, and CHART)

A well-known and widely used HRQOL measurement tool of the objective tradition is the Health Status Questionnaire or the Medical Outcomes Study Short Form (SF-36). The SF-36 is a short health survey with only 36 questions. These 36 questions were created in order to represent eight scales or dimensions of health. These scales are meant to represent the basic human values that are relevant to a person’s quality of life. The eight scales of the SF-36 are: physical functioning; role limitations due to physical health problems; bodily pain; general health; vitality (energy/ fatigue); social functioning; role limitations due to emotional problems; and mental health (psychological well-being and distress) (Forchheimer et al, 2004). Each scale is scored (0-100, higher score represents better health), and the overall scores of the eight scales can determine a person’s health profile. The SF-36 can also provide two composite scores, which measure the physical health component and the mental health component of the person (Leduc and Lepage, 2002). The SF-36 has been translated, adapted, and validated in 40 different languages. The widespread adoption of the SF-36 tool in research studies and clinical trials is evidence for the need of more practical measurement tools. The standardization of measurement across studies is producing a considerable amount of information, which allows comparisons between different populations and estimating the burden of specific conditions (Ware, 2000).

Additionally, the Short Form-12 Health Survey (SF-12) is a questionnaire derived from the SF-36. The SF-12 was created in order to provide quicker and easier administration without sacrificing the sound clinimetric properties of the SF-36. The SF-12 scoring is similar to the SF-36, which is based on eight scales and two composite
physical and mental functioning scores. The use of either the SF-36 or the SF-12 is a matter of research study practicality (Tate et al., 2002).

The Craig Handicap Assessment and Reporting Technique (CHART) is a measurement instrument, which conceptually follows the World Health Organization’s model of handicap dimensions (Hicken et al., 2001). CHART measures the degree to which individuals with disabilities are reintegrated back into the community (Holicky and Charlifue, 1999). CHART consists of 27 questions, which covers five dimensions: physical independence (managing physical needs); economic self-sufficiency; social integration (social interaction with others); mobility (physical movement in their environment); and occupational functioning (occupying time in socially beneficial activities) (Holicky and Carlifue, 1999; Putzke, 2001). Each of the dimensions is scored on a 100-point scale. Lower scores indicate less community reintegration and more “handicap”. “Handicap” in the context of CHART refers to a lack of community integration or, specifically, the degree to which individuals with disabilities are prevented from fulfilling expected social roles based on their age, gender, and culture (Holicky and Carlifue, 1999).

The Subjective Tradition

In contrast to the objective tradition, the subjective QOL tradition believe that QOL should be understood from the individual’s perspective (Tate et al., 2002). The subjective tradition affirms that only the person involved can validly judge his or her own QOL, and therefore the only approach to measuring QOL is a self-reported one. Researchers in this tradition argue that various people, based on their own contexts, life
experiences, values, and aspirations, may experience the same objective reality in completely different ways. As a result, researchers have developed a number of indicators to capture personal subjectivities (Dijkers, 1999b). Subjective indicators of QOL include: successful coping, social adjustment, depression status, perceived control, disability acceptance, and life satisfaction (Tate et al., 2002). A commonly used and validated subjective QOL measurement tool is the Satisfaction with Life Survey (SWLS).

Measurement Tool (SWLS)

The Satisfaction with Life Survey (SWLS) is a well-validated measurement and consists of five statements measured on a 7-point Likert scale (ranging from completely agree to completely disagree). Scores may range from 5 to 35 with higher scores indicating greater life satisfaction. This instrument assesses life assessment as a single, global score rather than rating different life domains. This approach is believed to reflect the respondent’s own perspective in terms of their own values. It is also believed that SWLS scores are stable and not completely dependent on the respondent’s affective or emotional state at that point in time (Putze and Richards, 2001; Wood-Dauphinee et al., 2002).

Objective

Both the objective and subjective traditions of QOL are important in order to assess persons with SCI. While the objective tradition emphasizes functional performance, the subjective tradition allows the patient to take his or her own life satisfaction into account. Both traditions attempt to express the patient’s point of view (Wood-Dauphinee et al., 2002). In light of these two QOL traditions and their respective
measurement tools, there has been an increase in HRQOL and subjective QOL studies in persons with SCI by public health researchers (Tate et al., 2002). However, many studies have included QOL measurement tools that have not been validated. This is due to the fact that many of these tools are disease specific, and their clinimetric qualities and validation has not been well established. On the other hand, generic QOL measurement tools (SF-36, SF-12, CHART, and SWLS) have also been used in QOL studies of persons with SCI. These generic QOL measurement tools have been fine-tuned and validated over years of research. However, it remains that there has been little published data on the HRQOL and subjective QOL in persons with SCI using validated measurement tools from both traditions (Dijkers, 1999a).

Quality of life outcome measures have gained acceptance among rehabilitation specialists and are frequently used to evaluate patient recovery and long-term health status. However, the reality of living with SCI as it relates to HRQOL and subjective QOL is still unclear. This is due to the lack of published studies using validated instruments on the subjective QOL and HRQOL in persons with a SCI. The current descriptive epidemiology of SCI illustrates that it is a negative public health outcome affecting up to 400,000 people. Persons in this population have a lower life expectancy and higher mortality rate than the general population. The annual costs of SCI medical care is staggering for both the patient and the national government. Additionally, the occurrence of severe co-morbidities associated with SCI, like pressure ulcers and pneumonia, actually increase in this population with age. Taken in its wider context, SCI and the implications of living with disability affects the facets of life that comprise the concepts and definitions of quality of life. A critical literature review was conducted to
assess the quality of life, both in the objective and subjective traditions, among adult persons with SCI.

Search strategy for identification of studies

Pubmed, Medline, Ovid, and PsychINFO electronic journal databases were searched in June 2007 for eligible studies. Only studies published from the 1997 to 2007 were searched for relevancy. Studies from 1997 to 2007 were searched in order to gain the most current information on QOL in persons with SCI. Articles were downloaded directly from these databases. Those articles unavailable for electronic download were obtained from the Shimberg Health Sciences Library at the University of South Florida campus. Keyword search terms included: “quality of life”, “veterans”, “spinal cord injury”, and “SCI”. Articles were then selected after reviewing their abstracts for relevancy.

Criteria for considering studies for this review

Studies that were eligible for inclusion in this review were all descriptive and analytic cross-sectional, case-control, and prospective and retrospective cohort studies that examined QOL in persons with SCI in the United States and in other countries. Hospital, clinic, and population-based studies were also eligible for review. Only epidemiologic studies utilizing QOL assessments with validated QOL measurement tools were considered. Studies were included whose primary outcome was measured using the following widely used and validated QOL measurement tools: SF-36, SF-12, CHART, and SWLS. These scores indicate levels of life satisfaction either through multidimensional scores or a single, global life satisfaction score. Studies which included
multiple QOL assessment tools were included if at least one of the QOL assessment tools were the above mentioned validated tools. No secondary outcome measures were considered.

This review is limited to these four assessment tools based on the recommendations by Wood-Dauphinee et al. (2002) and Dijkers (1999b). These recommendations are based on the tools’ clinimetric and psychometric quality. Essentially, clinimetrics and psychometrics are scientific fields concerned with the development, application, and evaluation of the quality of measurement tools in clinical and medical settings. Specifically, these four assessment tools were evaluated based on clinimetric and psychometric criteria, which included validity, reliability (including test-retest reliability), responsiveness, applications in SCI patients, and availability of translations. All four measurement tools were found to have sound and well supported clinimetric and psychometric qualities (Dijkers, 1999b; Wood-Dauphinee et al., 2002).

Studies with adult men and women participants ages 18 and over, regardless of race or ethnicity, with a SCI were eligible for inclusion. All levels of SCI injury (tetraplegia/quadriplegia and paraplegia) and both complete and incomplete injuries were considered for inclusion. All SCI participants were considered for inclusion regardless of whether persons were mobile or immobile. This was done in order to gain the widest perspective of QOL in persons with SCI.

No randomized or non-randomized, controlled or uncontrolled clinical trials or interventions were eligible for review. Studies that only included data on children or adolescents were excluded. Experimental and animal studies were also excluded.
Methods of review

The investigator independently examined each article’s abstract identified through the electronic database search. Articles were screened based on study quality and study design. The quality of the studies was assessed according to the suggestions and recommendations by Wood-Dauphinee et al. (2002) and Dijkers (1999b), which were previously discussed.

Description of studies

A total of fifty-nine eligible studies were identified through the electronic database search. Nine studies with a total of 6,834 participants (range 74 to 2,726) met the inclusion criteria (Benavente et al., 2003; Carpenter et al., 2007; Dijkers, 1999a; Elfstrom et al., 2005; Hicken et al., 2001; Holicky and Charlifue, 1999; Leduc and Lepage, 2002; Putzke and Richards, 2001; Westgren and Levi, 1998). Seven studies were cross-sectional studies (Carpenter et al., 2007; Dijkers, 1999a; Elfstrom et al., 2005; Holicky and Charlifue, 1999; Leduc and Lepage, 2002; Westgren and Levi, 1998; Whiteneck et al., 2004). The last two were case-control studies (Hicken et al., 2001; Putzke and Richards, 2001). Thirty-five studies were excluded due to inappropriate study design (case series and qualitative methodology) or use of non-validated measurement tools. Seven studies were either efficacy or validation studies of measurement tools and were also excluded.
Main Results

This section presents the main findings of the nine studies included in this literature review. For each study, the research objective, methodology and design, study population, measurement tools, and statistically significant results are reported. Summary tables for each study are presented. When possible, reported levels of statistical significance are presented. Table 1 provides a summary of QOL studies.

Table 1: Summary of QOL studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Research Design</th>
<th>Measure of QOL</th>
<th>Findings &amp; QOL predictors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Westgren and Levi (1998)</td>
<td>Cross-sectional</td>
<td>SF-36</td>
<td>(1) Study sample scored significantly less than Swedish norm. (2) QOL predictors: sex, married/cohabitating, full-time employment</td>
</tr>
<tr>
<td>Leduc and Lepage (2002)</td>
<td>Cross-sectional</td>
<td>SF-36</td>
<td>(1) Study sample scored significantly less than normative mean. (2) QOL predictors: sex, employment, hospitalization in past year</td>
</tr>
<tr>
<td>Elfstrom et al. (2005)</td>
<td>Cross-sectional</td>
<td>SF-36; Spinal cord lesion-coping strategies questionnaire</td>
<td>(1) Study sample scored significantly less than Swedish norm reference group. (2) QOL predictors: Acceptance and social reliance coping strategies</td>
</tr>
<tr>
<td>Dijkers (1999a)</td>
<td>Cross-sectional</td>
<td>SWLS; CHART</td>
<td>(1) Respondents that scored high statistically significant SWLS scores also scored higher statistically significant CHART HRQOL scores (2) QOL predictors: age, level of injury, sex, race, marital status, employment, private residence</td>
</tr>
<tr>
<td>Carpenter et al. (2007)</td>
<td>Cross-sectional</td>
<td>SWLS; Open-ended survey</td>
<td>(1) Respondents were generally satisfied with life (mean SWLS=18.6) (2) QOL predictors: three areas of participation (socializing with friends and family; volunteering; and vehicle possession)</td>
</tr>
<tr>
<td>Holicky and Charlifue (1999)</td>
<td>Cross-sectional</td>
<td>CHART; Life satisfaction index;</td>
<td>(1) Married participants scored have better QOL than single participants (2) QOL predictor: marital status</td>
</tr>
</tbody>
</table>
Cross-sectional Studies

Westgren and Levi (1998) conducted a study in order to determine the associations between sociodemographic and clinical variables in Swedish adults with SCI and QOL. A Swedish version of the SF-36 was used to determine HRQOL for the study sample of 320 Swedish adults with SCI. Participants were recruited from the Stockholm Spinal Cord Injury Study, which constitutes 93% of the regional persons with SCI in the greater Stockholm area. The study sample SF-36 scores for the eight health dimensions were compared to Swedish normative scores of the general population (See Table 2a).

<table>
<thead>
<tr>
<th>SF-36 subscore</th>
<th>Study sample mean</th>
<th>Swedish normative mean</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>42.5</td>
<td>87.9</td>
<td>0.001</td>
</tr>
<tr>
<td>Role function, physical</td>
<td>57.2</td>
<td>83.2</td>
<td>0.001</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>57.2</td>
<td>74.8</td>
<td>0.001</td>
</tr>
<tr>
<td>General health</td>
<td>63.9</td>
<td>75.8</td>
<td>0.001</td>
</tr>
<tr>
<td>Vitality</td>
<td>61.4</td>
<td>68.8</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Table 2a: Westgren and Levi (1998) SF-36 subscore comparison with Swedish normative scores

1 Adapted from Westgren and Levi (1998)
Social functioning 76.7 88.6 0.001
Role function, emotional 70.4 85.7 0.001
Mental Health 74.8 80.9 0.001

The study sample scored significantly less than the Swedish normative scores in all eight dimensions of health as measured by the SF-36. Several statistically significant results were found between study sample subgroups (see Table 2b). In regards to sex, female participants scored significantly lower than males in the vitality and mental health dimensions. Single participants scored significantly lower in the vitality, emotional role function, and mental health dimensions as compared with married/cohabitating participants. Additionally, participants working less than full time or who were not employed scored significantly less in all eight-health dimensions compared to full-time employed participants.

Table 2b: Westgren and Levi (1998) SF-36 mean subscores comparison between subgroups

<table>
<thead>
<tr>
<th>SF-36 subscore</th>
<th>Sex (Male)</th>
<th>Sex (Female)</th>
<th>Civil status (Married/cohabitating)</th>
<th>Civil status (Single)</th>
<th>Full-time employment (Yes)</th>
<th>Full-time employment (No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>66.3 (p=0.001)</td>
<td>33.9 (p=0.001)</td>
</tr>
<tr>
<td>Role function, physical</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>74.7 (p=0.001)</td>
<td>50.9 (p=0.001)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>67.1 (p=0.001)</td>
<td>54.0 (p=0.001)</td>
</tr>
<tr>
<td>General health</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>72.8 (p=0.001)</td>
<td>60.8 (p=0.001)</td>
</tr>
<tr>
<td>Vitality</td>
<td>63.2 (p=0.002)</td>
<td>53.1 (p=0.002)</td>
<td>63.3 (p=0.002)</td>
<td>53.1 (p=0.002)</td>
<td>67.7 (p=0.003)</td>
<td>59.1 (p=0.003)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>86.3 (p=0.001)</td>
<td>73.3 (p=0.001)</td>
</tr>
</tbody>
</table>

2 Adapted from Westgren and Levi (1998)
Leduc and Lepage (2002) was the first study to assess HRQOL in Canadian adults with SCI living in the Quebec area. The sample consisted of 587 participants from the Quebec Paraplegic Association. Participants completed the SF-36 HRQOL tool. Each of the eight dimensions of health as well as the physical and mental composite components was scored for each participant. Participant scores were compared to the normative values for the general population, which was described and documented in the SF-36 manual and interpretation guide. General population normative scores of 50 ± 10 was used for each of the eight dimensions and the physical and mental components.

The study population scored significantly less than the general population normative scores in all eight dimensions of health as well as in the physical component summary score (See Table 3a). Statistically significant results were also found between study sample subgroups (See Tables 3b and 3c). Male participants scored significantly higher than female participants in the physical functioning, vitality, and mental health dimensions. Also, SF-36 scores were significantly higher in all eight health dimensions and physical summary and mental summary scores in participants who were employed and had not been hospitalized in the previous year.

Table 3a: Leduc and Lepage (2002) SF-36 subscores comparison with the normative mean

<table>
<thead>
<tr>
<th>SF-36 subscore</th>
<th>Study sample mean</th>
<th>Normative mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>All study participants (n=587)</td>
<td>75.9 (p=0.47)</td>
<td>77.9 (p=0.007)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>70.0 (p=0.47)</td>
<td>71.8 (p=0.007)</td>
</tr>
</tbody>
</table>

3 Adapted from Leduc and Lepage (2002)
<table>
<thead>
<tr>
<th>SF-36 subscore</th>
<th>Male</th>
<th>Female</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning (PF)</td>
<td>23.86 ± 13.39 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Role function, physical (RP)</td>
<td>38.32 ± 12.83 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Bodily pain (BP)</td>
<td>39.01 ± 12.19 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>General health (GH)</td>
<td>42.23 ± 12.22 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Vitality (VT)</td>
<td>45.70 ± 9.77 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Social functioning (SF)</td>
<td>38.68 ± 12.24 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Role function, emotional (RE)</td>
<td>45.72 ± 13.11 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>44.31 ± 10.80 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
<tr>
<td>Physical component summary (PCS)</td>
<td>31.43 ± 10.03 SD*</td>
<td>50.0 ± 10.0 SD</td>
<td></td>
</tr>
</tbody>
</table>

*p<0.05

Table 3b: Leduc and Lepage (2002) SF-36 mean subscores comparison between sex

All study participants (n=587)

<table>
<thead>
<tr>
<th>SF-36 subscore</th>
<th>Male</th>
<th>Female</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>24.29 ± 13.77 SD</td>
<td>21.62 ± 11.03 SD</td>
<td>0.038</td>
</tr>
<tr>
<td>Vitality</td>
<td>46.25 ± 9.51 SD</td>
<td>43.52 ± 10.58 SD</td>
<td>0.013</td>
</tr>
<tr>
<td>Mental Health</td>
<td>44.90 ± 10.57 SD</td>
<td>42.09 ± 11.50 SD</td>
<td>0.011</td>
</tr>
</tbody>
</table>

Table 3c: Leduc and Lepage (2002) SF-36 mean subscores comparison between subgroups

All study participants (n=587)

<table>
<thead>
<tr>
<th>SF-36 subscore</th>
<th>Employment (Yes)</th>
<th>Employment (No)</th>
<th>Hospital stay in past year (Yes)</th>
<th>Hospital stay in past year (No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>26.02 ± 11.70 (p=0.006)</td>
<td>22.80 ± 14.00 (p=0.006)</td>
<td>22.70 ± 13.87**</td>
<td>24.11 ± 13.07**</td>
</tr>
<tr>
<td>Role function, physical</td>
<td>43.65 ± 12.40**</td>
<td>35.82 ± 12.26**</td>
<td>33.91 ± 11.55**</td>
<td>39.73 ± 12.93**</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>42.57 ± 11.67**</td>
<td>37.43 ± 12.15**</td>
<td>34.18 ± 11.51**</td>
<td>40.74 ± 11.95**</td>
</tr>
<tr>
<td>General health</td>
<td>46.45 ± 10.80**</td>
<td>40.31 ± 12.47**</td>
<td>37.75 ± 12.53**</td>
<td>43.67 ± 11.85**</td>
</tr>
<tr>
<td>Vitality</td>
<td>48.68 ± 9.10**</td>
<td>44.38 ± 9.84**</td>
<td>42.55 ± 9.49**</td>
<td>46.71 ± 9.66**</td>
</tr>
<tr>
<td>Social functioning</td>
<td>43.24 ± 11.50**</td>
<td>36.69 ± 12.00**</td>
<td>34.36 ± 12.26**</td>
<td>40.16 ± 11.89**</td>
</tr>
<tr>
<td>Role function, emotional</td>
<td>50.34 ± 10.31**</td>
<td>43.69 ± 13.70**</td>
<td>41.39 ± 14.22**</td>
<td>47.10 ± 12.43**</td>
</tr>
<tr>
<td>Mental Health</td>
<td>47.36 ± 9.36**</td>
<td>43.08 ± 11.17**</td>
<td>41.76 ± 11.19**</td>
<td>45.22 ± 10.50**</td>
</tr>
<tr>
<td>Physical component summary</td>
<td>34.86 ± 9.94**</td>
<td>29.68 ± 9.67**</td>
<td>27.85 ± 8.66**</td>
<td>32.57 ± 10.11**</td>
</tr>
<tr>
<td>Mental component</td>
<td>53.74 ± 10.87**</td>
<td>47.85 ± 13.16**</td>
<td>45.89 ± 13.35**</td>
<td>50.97 ± 12.34**</td>
</tr>
</tbody>
</table>

4 Adapted from Leduc and Lepage (2002)
In the study by Elfstrom et al. (2005), the main objective was to investigate relationships between SCI coping strategies and HRQOL when controlling for sociodemographic, disability-related and social support variables. The sample included 256 Swedish persons with SCI in a rural/ urban community. Participants were recruited from the Gothenburg Spinal Injuries Unit. The SF-36 tool was used as a generic HRQOL measurement. The SF-36 scores from this sample were compared to a matched age and sex reference group from the Swedish norm database. SF-36 scores from the study population were significantly lower than the age and sex matched reference group on all eight dimensions of health (See Table 4).

**Table 4: Elfstrom et al. (2005) study results**

All study participants (n=256)

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Study sample mean</th>
<th>Reference group mean</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>33.0</td>
<td>91.5</td>
<td>-17.6**</td>
</tr>
<tr>
<td>Role functioning-physical</td>
<td>58.9</td>
<td>89.5</td>
<td>-8.5**</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>50.9</td>
<td>77.2</td>
<td>-8.1**</td>
</tr>
<tr>
<td>General health</td>
<td>59.6</td>
<td>77.8</td>
<td>-7.0**</td>
</tr>
<tr>
<td>Vitality</td>
<td>52.9</td>
<td>68.0</td>
<td>-5.7**</td>
</tr>
<tr>
<td>Social functioning</td>
<td>67.1</td>
<td>88.4</td>
<td>-6.5**</td>
</tr>
<tr>
<td>Role functioning-emotional</td>
<td>73.1</td>
<td>89.0</td>
<td>-4.8**</td>
</tr>
<tr>
<td>Mental health</td>
<td>68.9</td>
<td>80.5</td>
<td>-4.8**</td>
</tr>
</tbody>
</table>

**p<0.001

5 Adapted from Elfstrom et al. (2005)
Participants were also given a spinal cord lesion-coping strategies questionnaire focusing on 3 factors: acceptance (revaluation of life values), fighting spirit (efforts to minimize SCI consequences), and social reliance (tendency towards dependent behavior). Of the three factors, acceptance and social reliance were the strongest covariates of overall HRQOL. Respondents who scored high on the acceptance factor and low on the social reliance factor, also scored better on all eight dimensions of the SF-36 tool. That is, respondents who were more able to reevaluate their life values (acceptance) and tended towards less dependent behavior (social reliance) reported a better HRQOL.

The study by Dijkers (1999a) was the first publication to use the SWLS with an SCI sample. The main objective was to analyze the correlates of life satisfaction for individuals with SCI. A total of 2,183 participants were recruited through the National Spinal Cord Injury Database (NSCID). The NSCID consists of 18 contributing SCI model systems healthcare centers dispersed throughout the United States and reflect both urban and rural catchment areas. Surveys completed by the respondents included the SWLS subjective QOL tool and the CHART HRQOL tool.

The mean SWLS score in this population was 19.4 ± 7.9 SD (slightly dissatisfied). Using ANOVA a number of demographic and social predictor values were found to have a statistically significant relationship with life satisfaction SWLS scores (See Table 5a). Life satisfaction was highest in the lowest (ages 0-19) and highest age (age > 60) groups. Level of injury was also related to life satisfaction. Participants with a lower level of injury scored significantly higher than participants with a higher level of injury. Female participants scored slightly higher life satisfaction than males. In regards to race, the highest statistically significant SWLS scores were found in the “other”
category group, which included Asians, Pacific Islanders, and American Indians. African Americans had the lowest statistically significant score. Additionally, statistically significant SWLS scores were found to be the highest in individuals who were married, employed, and living in a private residence. On the other hand, statistically significant SWLS scores were found to be the lowest for individuals who were separated, unemployed, and living in a hospital or nursing home.

Additionally, respondents who had high statistically significant SWLS scores also had higher statistically significant CHART HRQOL scores (see Table 5b). Specifically, respondents who scored high on the CHART physical independence, mobility, social integration, and occupation domains also had high SWLS scores. In contrast, respondents who scored low on these same CHART domains also had significantly lower SWLS scores.

Table 5a: Dijkers (1999a) SWLS mean scores by subgroup

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Mean Results</th>
<th>ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>All study participants (n=2,183)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. SWLS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Score</td>
<td>19.4 ± 7.9 SD</td>
<td>--</td>
</tr>
<tr>
<td>Age (0-19)</td>
<td>21.2 ± 8.0 SD</td>
<td>F=8.79, p&lt;0.001</td>
</tr>
<tr>
<td>Age (&gt;60)</td>
<td>20.3 ± 7.4 SD</td>
<td>F=3.58, p=0.003</td>
</tr>
<tr>
<td>Level of injury (C1-C4)</td>
<td>17.2 ± 7.1</td>
<td></td>
</tr>
<tr>
<td>Level of injury (L1-S5)</td>
<td>20.6 ± 7.5</td>
<td></td>
</tr>
<tr>
<td>Sex (Male)</td>
<td>19.2 ± 7.8 SD</td>
<td>F=5.39, p=0.02</td>
</tr>
<tr>
<td>Sex (Female)</td>
<td>20.2 ± 8.4 SD</td>
<td></td>
</tr>
<tr>
<td>Race (White non-Hispanic)</td>
<td>20.0 ± 8.1 SD</td>
<td>F=15.77, p&lt;0.001</td>
</tr>
<tr>
<td>Race (White Hispanic)</td>
<td>18.9 ± 7.4 SD</td>
<td></td>
</tr>
<tr>
<td>Race (African American)</td>
<td>17.4 ± 7.4 SD</td>
<td></td>
</tr>
<tr>
<td>Race (All other)</td>
<td>22.3 ± 8.1 SD</td>
<td></td>
</tr>
<tr>
<td>Marital status (Married)</td>
<td>20.9 ± 8.0 SD</td>
<td>F=12.4, p&lt;0.001</td>
</tr>
<tr>
<td>Marital status (Separated)</td>
<td>16.0 ± 7.6 SD</td>
<td></td>
</tr>
</tbody>
</table>

6 Adapted from Dijkers (1999)
<table>
<thead>
<tr>
<th>Occupational status (Employed)</th>
<th>23.0 ± 7.4 SD</th>
<th>F=44.01, p&lt;0.001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational status (Unemployed)</td>
<td>17.3 ± 7.6 SD</td>
<td></td>
</tr>
<tr>
<td>Residence (Private)</td>
<td>19.6 ± 7.9 SD</td>
<td>F=13.9, p&lt;0.001</td>
</tr>
<tr>
<td>Residence (Hospital or nursing home)</td>
<td>13.9 ± 7.2 SD</td>
<td></td>
</tr>
</tbody>
</table>

**Table 5b: Dijkers (1999a) Mean CHART in relation to mean SWLS scores**

<table>
<thead>
<tr>
<th>CHART subscore</th>
<th>Cases (%)</th>
<th>SWLS mean</th>
<th>ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical independence score (0-57, low)</td>
<td>411 (18.83%)</td>
<td>14.9 ± 7.1 SD</td>
<td>F=85.1, p&lt;0.001</td>
</tr>
<tr>
<td>Physical independence score (100, high)</td>
<td>616 (28.22%)</td>
<td>23.1 ± 7.5 SD</td>
<td></td>
</tr>
<tr>
<td>Mobility score (0-56, low)</td>
<td>423 (19.38%)</td>
<td>14.3 ± 6.8 SD</td>
<td>F=159.18, p&lt;0.001</td>
</tr>
<tr>
<td>Mobility score (100, high)</td>
<td>868 (39.76%)</td>
<td>23.1 ± 7.1 SD</td>
<td></td>
</tr>
<tr>
<td>Social integration score (0-67, low)</td>
<td>410 (18.78%)</td>
<td>15.1 ± 7.4 SD</td>
<td>F=84.3, p&lt;0.001</td>
</tr>
<tr>
<td>Social integration score (100, high)</td>
<td>991 (43.40%)</td>
<td>21.7 ± 7.5 SD</td>
<td></td>
</tr>
<tr>
<td>Occupation score (0-15, low)</td>
<td>411 (18.83%)</td>
<td>14.9 ± 7.1 SD</td>
<td>F=85.18, p&lt;0.001</td>
</tr>
<tr>
<td>Occupation score (100, high)</td>
<td>616 (28.22%)</td>
<td>23.1 ± 7.5 SD</td>
<td></td>
</tr>
</tbody>
</table>

The study by Carpenter et al. (2007) described participation in Canadian adults with SCI and explored the relationship between participation and life satisfaction/subjective QOL. Three hundred fifty seven participants with SCI were recruited through the British Columbia Paraplegic Association. Participants had been living with SCI for an average of 13 years. Participants were mailed two surveys, the SWLS and a descriptive open-ended survey on topics such as community participation, social involvement, transportation, and relationships.
Table 6 presents the results of the study. The mean SWLS score in this population was 18.76 ± 7.6 SD (slightly dissatisfied). Responses to the open-ended questions were compared between participants scoring higher SWLS (top quartile) to those scoring the lowest SWLS (bottom quartile). The participants scoring higher SWLS cited three areas of participation (socializing with friends and family; volunteering; and vehicle possession) at least twice as more than the lower scoring participants. The lowest scoring group identified the consequences and complications of SCI and financial funding as the primary limiting factors to life satisfaction.

Holicky and Charlifue (1999) described the role of marital status and its impact on QOL for persons with SCI. The study included 225 British adults with SCI, and the participants were recruited through the Regional Spinal Injuries Centre in Southport and the National Spinal Injuries Centre at Stoke Mandeville Hospital in Aylesbury, England. The authors utilized the CHART measurement tool to measure HRQOL. Of the five dimensions measured in CHART, the social integration dimension was excluded due to marital status’ classification as a component of social integration. Since the social integration sub-score measures how extensively an individual interacts with others, all

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7 Adapted from Carpenter et al. (2007)
married individuals would presumably have higher social integration scores. The Life Satisfaction Index (LSI-Z), and a single item QOL scale were used to measure subjective QOL. The LSI-Z is a validated, 13 item self-reported assessment of life satisfaction. Scores range from 0 to 26 with higher scores indicating greater life satisfaction. The single item QOL score ranges from 0 to 4 (0=very poor, 4=excellent).

**Table 7: Holicky and Charlifue (1999) study results**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Married group mean</th>
<th>Unmarried group mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHART subscore (Age&lt;49)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>88.2**</td>
<td>77.7**</td>
</tr>
<tr>
<td>Occupation</td>
<td>83.2**</td>
<td>63.3**</td>
</tr>
<tr>
<td>Life satisfaction index</td>
<td>11.3**</td>
<td>10.0**</td>
</tr>
<tr>
<td>Single item quality of life</td>
<td>3.2**</td>
<td>2.8**</td>
</tr>
</tbody>
</table>

**p<0.001

Chi-square tests were used to compare individuals who were married with a non-married group (single, separated, divorced, or widowed) (See Table 7). Mean CHART scores comparing married with non-married participants showed no statistically significant differences. However, in regards to age, married participants aged < 49 years scored significantly higher than non-married groups in the same age category in mean CHART mobility and occupation scores. Additionally, married participants scored significantly higher than non-married participants in the subjective QOL measurement outcomes, LSI-Z and the single item QOL scale.

Benavente et al. (2003) sought to assess the existence of disability/ HRQOL and functional results in 90 Spanish patients at 5 years post-SCI. Participants were recruited

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8 Adapted from Holicky and Charlifue (1999)
from the Hospital Nacional de Paraplejicos in Toledo, Spain. The participants completed the CHART community reintegration tool and a demographics survey. Each of the five dimensions of CHART was included and participant scores were summed. A maximum score of 500 (0 to 100 for each dimension, five dimensions) was possible. Scores were cutoff to establish three levels of handicap: Level 1 high-handicap (<333); Level 2 handicap (333-438); Level 3 low-handicap (>438). Thirty percent of the participants scored a total CHART score less than 333 (severely handicapped/ severely disabled). Twenty three percent of participants scored Level 2 (moderately handicapped). Forty seven percent of participants scored higher than 438 on total CHART scores (low handicap/ high social reintegration) (See Table 8a).

<table>
<thead>
<tr>
<th>Level of handicap</th>
<th>Percentage of study sample</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1: high-handicap (&lt;333)</td>
<td>30%</td>
<td>27</td>
</tr>
<tr>
<td>Level 2: handicap (333-438)</td>
<td>23%</td>
<td>21</td>
</tr>
<tr>
<td>Level 3: low-handicap (&gt;438)</td>
<td>47%</td>
<td>42</td>
</tr>
</tbody>
</table>

Statistically significant differences in CHART subscores were related to impairment and age (See Tables 8b and 8c). Lumbar and thoracic level injured participants scored significantly higher CHART physical independence and mobility scores compared to cervical level injured participants. Older patients scored significantly lower in CHART physical independence, mobility, and occupation scores.

<table>
<thead>
<tr>
<th>CHART subscore</th>
<th>Cervical</th>
<th>Thoracic</th>
<th>Lumbar</th>
<th>p-value</th>
</tr>
</thead>
</table>

9 Adapted from Benavente et al. (2003)
Table 8c: Benavente et al. (2003) CHART subscore by age

<table>
<thead>
<tr>
<th>All study participants (n=90)</th>
<th>CHART subscore</th>
<th>0-18 years</th>
<th>19-40 years</th>
<th>&gt;40 years</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical independence</td>
<td></td>
<td>60.0</td>
<td>65.0</td>
<td>45.0</td>
<td>0.046</td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td>75.0</td>
<td>75.0</td>
<td>50.0</td>
<td>0.021</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td>55.0</td>
<td>45.0</td>
<td>20.0</td>
<td>0.033</td>
</tr>
</tbody>
</table>

Case-control studies

Hicken et al. (2001) examined the subjective QOL and HRQOL among individuals with SCI requiring assistance for bowel and bladder management (dependent group) vs. those with independent control of bowel and bladder (independent group). Participants were recruited from the 18 SCI model systems healthcare centers dispersed throughout the United States. Two groups of 53 individuals were matched case for case on functional independence measures of bowel and bladder control, age, education, sex, race, and SCI level. When two or more matching cases were identified, the matching case was randomly selected. Outcome measures included the SWLS subjective QOL tool, the CHART HRQOL tool, and the SF-12 (shorter version of SF-36 scored similarly).

Table 9: Hicken et al. (2001) Subjective and HRQOL outcome measures

<table>
<thead>
<tr>
<th>All study participants (n=106)</th>
<th>Instrument</th>
<th>Dependent mean</th>
<th>Independent mean</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SWLS</td>
<td>17.58 ± 7.75*</td>
<td>22.28 ± 8.13*</td>
</tr>
<tr>
<td></td>
<td>CHART subscore</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10 Adapted from Hicken et al. (2001)
Several statistically significant results were reported between the dependent and independent groups (See Table 9). Satisfaction with life as indicated by the SWLS subjective QOL tool was significantly lower in the dependent group compared to the independent group. Similarly, the dependent group scored significantly lower than the independent group in the following CHART scores: total score, physical independence, mobility, and occupation. The physical component summary score of the SF-12 was significantly higher in the independent group compared to the dependent group. However, no statistically significant differences were found in the SF-12 mental health summary scores between the two groups.

The case-control study by Putzke and Richards (2001) examined the QOL in individuals with SCI living in a nursing home vs. community residence. Participants were recruited from the NSCID, composing of 18 SCI model systems healthcare centers in the United States. Nursing home and community residents were matched case for case on numerous demographic and medical characteristics to form two groups of 37 individuals with SCI. The matching case was randomly selected when two or more matching cases were identified. Outcome measures included the SWLS subjective QOL
tool and the CHART HRQOL tool. ANOVA was used to compare the community
residents group to the nursing home group in terms of SWLS and CHART scores.

Table 10: Putzke and Richards (2001) Subjective and HRQOL outcome measures

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Community residents mean</th>
<th>Nursing home residents mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWLS</td>
<td>18.3 ± 7.9*</td>
<td>14.0 ± 7.2*</td>
</tr>
<tr>
<td>CHART subscore</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total score</td>
<td>337.0 ± 85.7**</td>
<td>181.5 ± 34.5**</td>
</tr>
<tr>
<td>Physical independence</td>
<td>75.6 ± 29.3**</td>
<td>41.2 ± 33.4**</td>
</tr>
<tr>
<td>Mobility</td>
<td>70.3 ± 26.0**</td>
<td>41.8 ± 23.9**</td>
</tr>
<tr>
<td>Occupation</td>
<td>41.1 ± 35.3**</td>
<td>16.5 ± 15.6**</td>
</tr>
<tr>
<td>Economic self-sufficiency</td>
<td>56.3 ± 39.2*</td>
<td>22.5 ± 32.2*</td>
</tr>
</tbody>
</table>

*p<0.05
*p<0.001

Results between community residents and nursing home residents can be seen in
Table 10. Community residents with SCI scored significantly higher SWLS scores
compared to nursing home residents with SCI. Similarly, community residents scored
significantly higher CHART scores compared to nursing home residents in following
dimensions: total score, physical independence, mobility, occupation, and economic self-
sufficiency. No statistically significant differences were found between both groups
regarding CHART social integrations scores.

Discussion

In this review, three studies (one cross-sectional and the two case-control)
(Dijkers, 1999a; Hicken at al., 2001; Putzke and Richards, 2001) actually utilized both
objective HRQOL and subjective QOL measures in their data collection methodologies.
The results of these studies offer a wider and, perhaps, more accurate view of overall

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11 Adapted from Putzke and Richards (2001)
QOL in their respective study samples by including both HRQOL and subjective QOL measures, which when taken together are complimentary. The remaining four studies utilized either a HRQOL or subjective QOL measurement tool for data collection. While these studies only implemented one type of QOL outcome measure, this does not denote that the studies were any less successful or less valid. The choice of implementing a HRQOL or subjective QOL measurement tool (or even implementing both tools) may reflect a combination of the investigator’s own professional philosophy, study objective, and practical concerns. For instance, some researchers may not have utilized both HRQOL and subjective QOL measures due to the increased burden on respondents to answer more than one survey. Convenience to potential study subjects is important in order to maximize response rates as multiple surveys, each with their own instructions and jargon, may prevent potential study samples from participating.

Overall, the studies found that persons with SCI scored high HRQOL and subjective QOL scores based on several domains and dimensions of health and life (See Table 1). A number of statistically significant QOL predictors were found from all of the studies in this literature review. These QOL predictors include: sex, age, race, marital status, level of injury, employment status, housing residence, and hospitalizations in the past year. The results of these studies are important in light of the descriptive epidemiology of SCI.

While the majority of persons with SCI in the United States are male (82%), studies report differences between males and females in terms of HRQOL and subjective QOL/ life satisfaction. Males have been reported to have higher HRQOL, which focus on clinical measures of physical and mental functioning (Westgren and Levi, 1998;
Leduc and Lepage, 2002). This was especially the case in the SF-36 dimensions: physical functioning, vitality, and mental health. However, females reported higher subjective QOL and life satisfaction (Dijkers, 1999a).

Unlike the studies by Westgren and Levi (1998) and Leduc and Lepage (2002), which utilized only HRQOL measures, the study by Dijkers (1999a) had the opportunity to display and explore both HRQOL and subjective QOL scores for both male and female study participants. However, HRQOL scores were only reported in relation to subjective QOL scores (See Table 4b), thereby eliminating the opportunity for comparisons between male and female participants, as well as for other sociodemographic variables, in both HRQOL and subjective QOL scores. These contrasting HRQOL/subjective QOL results in male and female participants may illustrate fundamental differences between the objective and subjective QOL traditions, their definitions of QOL, and their respective outcome measures. Be that as it may, the reasons surrounding the differences between males and females in terms of HRQOL and subjective QOL remain unknown. However, Dijkers (1999a) does offer a possible explanation regarding these differences. That is, there may be a large gender effect since disability due to SCI imposes a lifestyle that is more readily acceptable within the traditional female societal role (passive) as opposed to the traditional male role (active). Therefore, females with SCI may adjust to disability better than their male counterparts. While this explanation is certainly plausible, further research, perhaps qualitative, would be needed in order to shed light on the topic. Regardless, further research on the differences or similarities on HRQOL and subjective QOL scores between men and women is needed.
Similar to the contrasting QOL differences between sexes, there are also contrasting differences of QOL based on age. Dijkers (1999a) reports high subjective QOL in younger (aged 0-19 years) and older (aged > 60 years) participants. Benavente et al. (2003), however, report higher HRQOL in persons aged < 40 and lower HRQOL in persons aged > 40. The differences in HRQOL may be due to a loss of motor functioning in older individuals as compared to younger individuals. However, the differences in SWLS scores are unknown. Again, Dijkers (1999a) had the opportunity to display and report HRQOL and subjective QOL comparisons among age groups but chose not to. Additionally, the study by Benavente et al. (2003) employed age categorizations, which may have been inappropriate for analysis. Specifically, the study’s age categorizations (0-19 years, 20-40 years, > 40 years) may not have been sensitive enough to detect QOL differences between the three groups. If age categorizations were further divided into smaller groups, possible QOL differences may have been reported. Considering the average age of persons with SCI in the United States is 40 years, these results are especially concerning. Namely, for a large percentage of persons with SCI, there is no consensus on both HRQOL and subjective QOL within this demographic. Additionally, the life expectancy of persons with SCI is increasing, and the need exists to better understand the changes in life among this aging population as it relates to QOL.

In regards to race, only one study (Dijkers, 1999a) included and reported statistically significant QOL scores. This is surprising as race is an important health category for public health researchers. Dijkers (1999a) reported the highest subjective QOL scores in the “other” category followed by white non-Hispanics, white Hispanics, and lastly African Americans. Persons with SCI in the United States include: 63.0%
Caucasian, 22.7% African American, 11.8% Hispanic, and 2.4% other racial/ethnic groups. A possible explanation for lower subjective QOL scores in white Hispanics and African Americans may be due to socioeconomic and other institutional inequalities that exist both before and after SCI, which continue to affect minority populations. However, this does not explain why members of the “other” race category (Asians, Pacific Islanders, and American Indians), which also consists of minorities, scored the highest subjective QOL. Be that as it may, socioeconomic and institutional inequalities have been widely reported in both the public health and social science fields. Further investigations in how these inequalities may affect QOL in persons with SCI are needed in order to implement more meaningful rehabilitation strategies.

Marital status was cited by three studies (Westgren and Levi, 1998; Dijkers, 1999a; Holicky and Charlifue, 1999) to be a strong HRQOL and subjective QOL predictor. Specifically, married participants were found to have higher HRQOL and subjective QOL. Social support, especially for disabled persons, is a crucial component of quality of life in terms of coping and positive long-term adjustments to life. Specifically, marriage serves as a positive effect on health and well-being. Additionally, marriage serves as a stress-reducing buffer, which leaves individuals receiving such support less susceptible to the negative stressors of SCI (Holicky and Charlifue, 1999). How this applies to the greater population with SCI is unknown as there are no published statistics on the percentages of marital status in this population. While the positive effects of a successful or healthy marriage has been documented by these three studies, the effects of divorce or even being widowed in the population with SCI has not been
documented. Therefore, the impact of marital status is another area of concern for future research.

The studies by Dijkers (1999a) and Benavente et al. (2003) were the only studies that found statistically significant correlations between level of injury and QOL. Specifically, HRQOL and subjective QOL increase with descending injury level or from highest to lowest: cervical, thoracic, lumbar, and sacrum. It is known that severity of SCI depends on the part of the spinal cord that is damaged. The higher the SCI is to the brain, the greater the effects are to the body and functioning. Examining the results physiologically, QOL in persons with a lower level of SCI, resulting in more functional independence, would have a higher QOL as opposed to a person with a high level of injury with less motor function. Though level of injury is correlated with QOL, completeness of injury was not found to be a statistically significant QOL predictor in all of the studies. Hypothetically, as with completeness of injury, persons with an incomplete injury (more motor function) would have higher QOL than persons with a complete injury (less motor function) with respect to level of injury. However, studies have failed to determine a statistically significant relationship. As with many characteristics of persons with SCI, there have been no published national data on the percentage of the SCI population based on level of injury and completeness of injury.

Employment status was found to have a positive effect on QOL (Westgren and Levi, 1998; Dijkers, 1999a; Leduc and Lepage, 2002). Particularly, persons with SCI that were either employed full-time or part-time reported higher HRQOL and subjective QOL. These finding seem to be in line with the concept of the healthy worker effect, or simply that people who are employed are generally healthier than those who are not
employed. Significant differences in QOL between employed and unemployed persons with SCI indicate employment status is a value also held high by the population with SCI. Additionally, employment status (and subsequent income) may help alleviate the high annual costs of SCI (as high as $130 thousand annually), while those unemployed may experience greater stress and decreased QOL due to financial difficulties. Additionally, it should be noted that employment opportunity among the SCI population might be affected by discrimination by employers under the assumption that persons with SCI may not be able to useful additions to the workforce. Employment discrimination in persons with SCI should also be a topic of concern for public health researchers.

Persons with SCI living in a private residence were found to have higher HRQOL and life satisfaction as opposed to either residing in a hospital or nursing home (Dijkers, 1999a; Hicken et al., 2001). Hicken et al. (2001) postulate that living in a nursing home results in a loss of QOL due to decreased independence, reduced privacy, and diminished social support, particularly family and friend support. Furthermore, the type of social support (family member vs. friend vs. casual acquaintance) one receives may also affect the beneficial influence of social support on QOL. Then again, there may have been a lack of available and/ or meaningful social support from family members and friends, which may have been a primary reason for nursing home or hospital placement for some individuals (Hicken et al., 2001). Certainly, the quality of care and social support will differ in nursing homes and hospitals, which may lead to significant differences in QOL among its residents. Likewise, private residence and settings can differ as well, which may also affect degrees of QOL in SCI persons living in community residents.
The study by Leduc and Lepage (2002) was the only one to find statistically significant results in terms of QOL and hospitalizations in the past year. Individuals who had been hospitalized in the past year scored significantly less in all eight-health dimensions of the SF-36 HRQOL tool. In spite of this, there may be differences in HRQOL based on the actual number of hospitalizations in the past year. Leduc and Lepage (2002) did not tabulate the number of hospitalizations, and, consequently, did not conduct subgroup analysis on SF-36 scores based on number of hospitalizations. Hypothetically, increased hospitalizations could lead to decreased QOL. Additionally, Leduc and Lepage (2002) did not report the cause of hospitalization. Considering the co-morbidities associated with SCI, primarily pressure ulcers and pneumonia, the causes of hospitalization may also lead to differences in QOL among individuals. Mainly, pressure ulcers and pneumonia are the two most cited co-morbidities in this population, and the incidence of these two conditions steadily increases with age (NSCISC, 2006). Future research should focus on number of hospitalizations as well as the causes for hospitalization. Furthermore, studies should also include both HRQOL and subjective QOL measures, which has not been determined for individuals hospitalized in the past year.

The studies by Elfstrom et al. (2005) and Carpenter et al. (2007) both incorporated supplemental questionnaires in addition to their QOL measures. Elfstrom et al. (2005) utilized a spinal cord lesion coping strategies questionnaire in addition to the SF-36 HRQOL. The study results indicated that the coping strategies, acceptance and social reliance, were the strongest covariates of overall HRQOL. The acceptance strategy refers to a reevaluation of life values after SCI and subsequent disability. Acceptance
implies that the individual actively changes their life values in order to accommodate living with a disability. The acceptance or value shift strategy restructures the emphasis of certain values, such as physical beauty or income, for others, like the quality of interpersonal relationships or artistic beauty (Dijkers, 1999a). The social reliance strategy reflects a tendency towards less dependent behavior. By tending towards more independent behavior, a lack of social reliance on others increases psychological well-being. Individuals tending towards independent behavior are active agents in seeking to meet their life needs. While the study by Elfstrom et al. (2005) sheds light on the importance of coping strategies in relation to HRQOL, the concepts and definitions of acceptance and social reliance are highly abstract and complex. What explicitly constitutes the components each coping strategy were not discussed in-depth, but would have been a welcome addition. However, discovering the successful coping strategies in this population may offer promise to rehabilitation specialists concerned with QOL.

Similarly to the study by Elfstrom et al. (2005), Carpenter et al. (2007), in addition to the SWLS subjective QOL tool, utilized a descriptive open-ended survey on topics such as community participation, social involvement, transportation, and relationships. Three areas of participation (socializing with friends and family; volunteering; and vehicle possession) were cited as subjective QOL predictors. The consequences and complications of SCI and financial funding were cited as the primary limiting factors to life satisfaction. Methodologically, a supplemental open-ended questionnaire with the SWLS subjective QOL tool is a sound combination. The individual determines their own subjective QOL, based on the individual’s own perspective and values. By allowing individuals to expound on their views on their own
QOL allows researchers to expand their knowledge on the components of QOL that are held dear to individuals.

Three studies (Westgren and Levi, 1998; Leduc and Lepage, 2002; and Elfstrom et al., 2005) compared SF-36 HRQOL scores between SCI study samples and general population normative scores. Both Westgren and Levi (1998) and Elfstrom et al. (2005) used Swedish normative population scores to compare with their Swedish SCI sample. Leduc and Lepage (2002) used the Canadian general population normative scores for comparison with their Canadian sample. All three studies concluded that their respective study samples scored significantly less than the general population normative scores in all eight SF-36 dimensions. That HRQOL, which attempts to objectively measure clinical outcomes of physical and cognitive functioning, was scored higher in the general population as compared to the population with SCI should not be surprising. The population with SCI (a population living with potentially serious disability) is inherently at a disadvantage in terms of motor functional independence, social functioning, and mental health when comparing against the general non-disabled population normative HRQOL scores. Additionally, when comparing study sample HRQOL scores to the general population normative scores, all three studies did not utilize a matched control group in order to control for potentially confounding sociodemographic variables, such as age, sex, race, employment status, etc. Therefore, any comparisons between study samples and the general population should be made with caution. Though these three studies illustrate that HRQOL may be lower among persons with SCI as compared to the general population, subjective QOL differences, if any, have not been established. It is possible that subjective QOL in the SCI population may be equal or even higher than that
of the general population. None of these studies used subjective QOL measures for comparisons between their study samples and respective general population normative scores. Furthermore, no studies compared population QOL differences in the United States general population and the population with SCI (both civilian and veteran). Future comparative research between the SCI population and general population should include both HRQOL and subjective QOL measures in order to capture a larger perspective of QOL in both populations.

The studies in this review had several limitations. The potential for selection bias was present in all of the studies. However, the studies by Benavente et al. (2003) and Carpenter et al. (2007) are most concerning due to their low response rate (Benavente et al. (2003)= 37.0%; Carpenter et al.=44.0%). Respondents volunteering to take part in these studies may be different from non-respondents on potentially important characteristics. Non-respondents may not have been physically or mentally able to complete the HRQOL and/ or subjective QOL surveys. Non-respondents with a high level of injury (complete or incomplete), which would severely impair motor function, may not have been physically able to complete the survey. In this case, there may be a positive bias in reported HRQOL and subjective QOL scores. In essence, the observed measure (QOL) may be larger than the true measure of QOL in study samples. This may also be the case for non-respondents who could not complete the survey due to a brain injury in addition to SCI, which could severely affect both motor and cognitive function. Additionally, with co-morbidities associated with SCI (pressure ulcers and pneumonia) increasing with age, older individuals may have had a limited ability to complete the QOL surveys. Again, this could lead to an under representation in the samples of people
with poor HRQOL and subjective QOL. Additionally, recruitment of participants was conducted through various healthcare centers, hospitals, and SCI associations. It may be that persons who are dissatisfied with life and/ or the quality of care received disappear from their respective healthcare center, resulting in loss to follow-up. Consequently, respondents may be satisfied with the quality of care they receive and possess a higher QOL. None of the studies reported any attempts to provide information on non-respondent demographics or medical characteristics, such as age, sex, injury level, completeness of injury, etc. Such data on non-respondents could aid readers in better understanding and assessment of study results.

Information bias, specifically recall bias, was also a potential limitation in all of the studies. This was due to the fact that all of the QOL measurement tools were in the form of mail delivered surveys and questionnaires to be completed by the respondent. Respondents could either overestimate or underestimate both their HRQOL and subjective QOL. While HRQOL tools attempt to measure overall physical and mental health, the fact remains that these tools are self-administered and subject to the respondent’s feelings and personal judgments. This is also the case for subjective QOL tools as well since the tools are also self-administered and are dependent upon the respondent’s own subjective outlook and perspective, which can change from day to day depending on factors such as mood or current health status. Additionally, surveys and questionnaires may not have been completed by the person with SCI but by an individual acting as a proxy, such as a spouse or other family member. Proxies could potentially complete surveys when the individual of interest would not be physically or mentally able to. In this case, the proxy might complete the survey without input from the
individual of interest. This too could overestimate or underestimate the reported HRQOL and/or subjective QOL scores in study samples.

In both case-control studies (Hicken et al., 2001; Putzke and Richards, 2001) participants were selected on the basis of the availability of a matching case rather than with regard to a stratified sampling of the SCI population. The observed QOL outcome measures may not generalize to the overall SCI population. The study by Hicken et al. (2001) only assessed QOL in individuals 1 year post-injury. Therefore, the study results may not generalize to the population with SCI with more than 1 year post-injury. In the case-control study by Putzke and Richards (2001), community residents were defined broadly, including individuals living in a variety of settings ranging from independent living to assisted in-home care. The study would have benefited by providing a more specific assessment of community residence in order to better identify characteristics associated with higher QOL among various groups with SCI.

To the extent that selected cases are not representative of cases in general, population selection bias may occur if the relationship between cases and overall QOL is different in the selected cases than in the cases that were not selected. The study by Hicken et al. (2001) reported that a higher number of hospitalizations occurred in the bowel/bladder dependent group than in the bowel/bladder independent group. The results of this literature review suggest that increased hospitalizations are associated with lower QOL. Consequently, decreased QOL in the dependent group may be due in part to increased hospitalizations rather than bowel/bladder impairment. However, both case-control studies attempted to minimize bias and increase validity by matching cases and controls on a variety of medical and demographic characteristics.
By matching on a variety of characteristics, cases and controls were as similar as possible in regards to potentially confounding factors. For example, in the study by Putzke and Richards (2001) age could be a potential confounder when considering that more individuals who are older may reside in nursing homes than younger individuals, and, therefore, age was a matched demographic between cases and controls. Also, in the study by Hicken et al. (2001) level of injury and completeness of injury, which affects motor function including bowel/bladder control, was a matched demographic. While both studies attempted to limit confounding through matching cases and controls on demographics and medical characteristics, it is arguable that the study by Putzke and Richards (2001) overlooked the role of socioeconomic status or household income as a potential confounder when considering nursing home residence. Individuals with lower socioeconomic may not have the financial support to reside in community settings as compared to individuals with the financial security to do so. Therefore, socioeconomic status could be related to both nursing home residence and QOL.

Conclusion

The descriptive epidemiology of SCI illustrates that persons living with SCI undergo a life-long process of subsequent disability with its own unique set of challenges and health issues. Though rehabilitation and medical advances have increased life expectancy and minimized long-term health complications, the quality of life in the population with SCI is still a topic of great concern. The purpose of this literature review was to assess the HRQOL and subjective QOL in persons with SCI. The results of this
review demonstrate the complexity underlying studies of quality of life in persons with SCI.

This review included studies from both the objective and subjective QOL traditions in order to gain a greater perspective of QOL in this population. Overall, the studies illustrated that a number of statistically significant sociodemographic and medical characteristics were correlated with higher HRQOL and subjective life satisfaction (See Table 10). These QOL predictors include: sex, age, race, marital status, level of injury, employment status, housing residence, and hospitalizations in the past year. These predictors paint a picture of the factors, that when taken together, that constitute a good quality of life.

These results are significant to public health researchers and rehabilitation specialists by providing topics of concern in which to focus on either through strengthening current rehabilitation strategies or by addressing topics that may not have been previously recognized as a factor for QOL. While the identification of these predictors is important, there should be further research into all of these QOL predictors. Though directions for further research of these predictors were discussed in the previous section, it is important to recognize that these QOL predictors are inherently complex variables with a wide range of possible responses and implications. For example, the studies in this review indicate that marriage status is correlated with higher QOL. However, marital status and its relationship to QOL may be more complex than simply having respondents answer “yes” or “no” on a survey and comparing QOL scores between married and non-married individuals. Married individuals with SCI may differ in their respective relationships with their spouses, and some marriages may be better or
worse than others for a number of reasons. For instance, sexual dysfunction in married individuals with SCI may result in a change in QOL. Additionally, societal roles between spouses can change due to SCI, which could also affect QOL. It is quite possible that some married individuals with SCI have significantly lower QOL than single individuals with SCI. Simply, the health and quality of a marriage may be more important as a predictor of QOL in individuals with SCI than simply being married. Therefore, marriage counseling may be a potential rehabilitation strategy for this population.

While there were very few contrasting differences in terms of results between HRQOL and subjective QOL tools in certain demographics (sex, age, and race, etc.), the majority of studies from both traditions found similar predictors of QOL. This is an important finding since it illustrates that both QOL traditions may be more similar than they are different. That is, both traditions seek to study QOL in their own respects, based on their own philosophical proclivities. Possibly, both traditions are essentially studying different sides of the same coin. If that is the case, than, therefore, both HRQOL and subjective QOL may be interrelated, which might explain similar results in QOL predictors in studies from both traditions. The relationship between the characteristics of clinical importance in both the objective tradition and the aspects that make up subjective well-being is still unknown.

While further research into this topic would be illuminating, there are many foreseeable challenges. Firstly, researchers from both traditions would need to set aside philosophical differences in order to come together on common ground. Furthermore, the fact that two traditions do exist with their own respective measurement tools indicates that a high degree of specialization has occurred in both traditions. This may further
complicate efforts to conceptualize a single, all encompassing definition of quality of life, as well as increasing difficulties regarding QOL measurement issues. While debate on QOL conceptualizations may be healthy to a degree, the need exists for a single agreed upon definition of QOL. Otherwise, the only suitable alternative is for researchers to incorporate both HRQOL and subjective measurement tools into their study designs. While, this practice may result in a wide QOL perspective in study populations, it may also leave many researchers at a loss to describe similarities and differences in scores from both traditions. This may indeed be the case today for many QOL researchers.

The majority of studies in this review were cross-sectional studies though two case-control studies were also included. The cross-sectional studies provided snapshots of quality of life in persons with SCI, while the case-control studies tested hypotheses regarding quality of life with respect to different groups of SCI persons. Both types of studies provided detailed and useful information on QOL assessments in the population with SCI. However, QOL assessments over time in the population with SCI have not been well established. Quality of life, both objective and subjective definitions, may be seen as a dynamic measurement or value. Therefore, as time passes quality of life in this population may fluctuate depending upon individual and systematic changes in life.

Prospective cohort studies of quality of life in this population may provide greater insights into the quality of care and rehabilitation of persons with SCI. However, prospective cohort studies are known to be both expensive and time consuming. Furthermore, difficulties in minimizing losses to follow-up can threaten study validity. These practical concerns may have been the reason why a single prospective cohort study was not identified in the study selection process. Perhaps more practical would be a
retrospective cohort study, given that availability of adequate records. For example, this would also depend on whether or not SCI healthcare providers collect QOL data on a regular basis, such as during annual evaluations. The lack of available records precludes the possibility of conducting retrospective cohort studies, which also may explain the lack of identified retrospective cohort studies in this review.

Finally, it should be noted that there are still gaps in knowledge regarding the descriptive epidemiology of SCI. For example, it is unknown whether or not there are seasonal or geographical differences in the incidence and prevalence of SCI. Furthermore, a vast gap of knowledge exists in the differences between general United States population with SCI and the veteran population with SCI, which accounts for at least 10% of the SCI population. This may be due to a lack of published data from the U.S. Department of Veterans’ Affairs (VA) or even a lack of collaboration between the VA healthcare system and other healthcare systems like the NSCID, which manages data from the 18 model SCI care systems. Increasing the knowledge pool of the descriptive epidemiology of SCI can only benefit public health researchers and rehabilitation specialists treating the population with SCI.
Chapter Three

Anthropological Literature Review

Introduction

The discipline of Anthropology has traditionally advocated multiple perspectives in the study of complex sociocultural phenomena such as racism, medicine and medical practice, and human rights. Disability, a similarly broad subject, has been a topic of study for many anthropologists. However, disability in general and persons with SCI have not been heavily represented in the medical anthropological literature. Groce and Scheer touch on the slow development of disability research in anthropology and the need for increased holistic conceptualizations and approaches to disabled persons in their cultural contexts (1990). Additionally, Altman and Barnartt assert that the humanities have historically been more successful in developing disability related research and curriculum than the social sciences, and that there is, as of 2000, no journal that is dedicated to the study of disability using the theories, perspectives, and methodologies of the social sciences (2000). Be that as it may, the substantive anthropological literature on disability does provide a historical framework and potential future trends on which SCI can be examined.

In this literature review, the pertinent works of anthropology in the study of disability and culture are presented. This chapter will be divided into four sections. Each section builds upon the ideas and concepts presented in previous sections. First, definitions of disability in the field of anthropology are examined. The second section
explores the “culture of disability”. The third section discusses the role of stigma among persons with a disability. Finally, the fourth section investigates the role of values among American society as well as within the “culture of disability”. This literature review is not a comprehensive review of all anthropological literature pertaining to disability. Rather this literature review focuses on issues relevant to this research study.

Anthropological Definitions of Disability

Anthropological definitions of disability encompass a broad range of possibilities and perspectives that contrast with the more limited biomedical perspective. A well known anthropological definition of disability comes from Robert Murphy, who asserted that disability is both a condition of the body and an aspect of social identity; a process triggered by somatic causes, but socially defined and given meaning through culture (1987). That is, disability lies within the realm of cultural norms relating to bodily, cognitive, and behavioral ideals. Disability refers to limitations resulting from dysfunctions of mind and/ or body. The core meaning of disability is biopsychological.

Any such deviation from the biopsychological norms can be viewed as an impairment or disability in which society responds to in a designated manner (Ingstad and Whyte, 1995).

In a very similar sense, Shuttleworth and Kasnitz (2004) use the term “impairment-disability” in order to emphasize their relationships and their need for separation as well as problematizing anthropology’s use of the terms. In this sense, impairment is a negatively constructed, sociocultural perception of a physical, mental, or behavioral abnormality or some form of ethnophyschological or ethnophysiologica
status. Disability, then, is a negative social response to impairment, perceived or otherwise. Disability is not located in the impaired person; rather it is a process that disables (Shuttleworth and Kasnitz, 2004). Social activist, James Charlton (1998) also asserts a corresponding view of disability. To be sure, disability is predicated on social and functional criteria, which is to say that disability is not a medical category. Disability is a social category and, therefore, socially constructed with socially defined functional limitations (Charlton, 1998).

As a result, questions arise about the nature of disability that go beyond etiology and into the realm of function and circumstance. For instance, when is a physical, mental, or behavioral difference indicative of disability, and under what conditions, how, and for what reasons (McDermott and Varenne, 1995)? Additionally, culture may also affect how disability is both conceptualized and responded to as well as the manner in which individuals, families, and communities interact with rehabilitation professionals (Groce, 2005). Paradoxically, people with disabilities are a marked group with a dual social identity, injured beings and citizens with the same social and legal rights as everyone else (Ingstad and Whyte, 1995). As Murphy notes, disabled people are conditioned by society to be an invisible, yet painfully obvious, population, never to be spoken of (1987). Even through rehabilitation, which emphasizes integration into society through individual effort and compensation, there is an unspoken agreement to identify difference among disabled people and to pretend it does not exist (Whyte, 1995).

Contrast anthropology’s broad definition of disability and its characteristics with that promulgated by the Americans with Disabilities Act (ADA) of 1990: “The term ‘disability’ means with respect to an individual (a) a physical or mental impairment that
substantially limits one or more of the major life activities of such individual; (b) a record of such impairment; (c) being regarded as having such an impairment” (1990).

Essentially, the ADA definition is rooted in Western biomedicine. By “biomedicine”, I adopt Hahn and Kleinman’s definition that it is “a name for this medicine, referring to its primary focus on human biology, or more accurately, on physiology, even pathophysiology” (1983:306).

A panel at the Institute of Medicine (IOM) of the National Academy of Sciences has strongly recommended a conceptualization of disability that takes into account environmental factors as a primary factor in creating disability. The panel recommends shifting the focus of the definition of disability from the individual impairment to the interaction between impairment and environment. That is, an impairment is a disability determined by the interaction of that impairment relative to a given environment. Therefore, a person cannot be labeled, “disabled”, without considering the environment in question. Such a concept does seem to be much more in line with social science conceptions, which focus on the process or creation of identity, as opposed to the ADA definition or a strict medical definition of disability based on etiology and physical function (Altman and Barnatt, 2000).

The “culture of disability”

Given anthropology’s views of disability in the previous section, a brief discussion of culture and its dynamic nature is warranted, especially as it relates to disability. To be sure, many definitions of culture exist; however a popular definition states that culture comprises the ideas, beliefs, and knowledge that characterize a
particular group of people. However, it is important to note that cultures are not static, nor are they homogenous.

Rather, culture is a dynamic process encompassing and constantly involving members of its society. The coherence of a culture is created through the partial and mutually dependent knowledge of its collective members. Culture is not as much a product of sharing as it is a product of people hammering others into shape, and, in this sense, culture is a process of hammering the world (McDermott and Varenne, 1995).

With regard to disabled people, researchers have argued that a distinct “culture of disability” does indeed exist (Pederson, 2005). Within this culture is a unique perspective shared by persons with a disability that encompasses explicit and implicit rules for interaction, the use of a preferred vocabulary to express thoughts and meanings, as well as other markers indicative of a cultural group unfamiliar to persons without a disability. This is a culture, whose unique perspective, is acknowledged and celebrated by the community of persons with a disability as a legitimate group regardless of judgment by other groups (Pederson, 2005). Within this perspective are conceptual frameworks that affect the ways in which individuals with disabilities view themselves as well as the world around them. These frameworks also influence the interactions between people with disabilities with their families, friends, and communities (Groce, 2005).

Given this, there exists an interaction between different cultural elements and their repetitions in culture, which ingrains these attitudes and beliefs into society and its members. Such attitudes and beliefs in regards to disability include the multitude of cultural explanations of disability, disability in the media, and disability definitions/
descriptions. These then interact and produce a means in which society at large is socialized to think about disability. Socialization occurs through these symbols and their repetitions or iterations among society’s members (Charlton, 1998). Indeed, Groce states, “In all societies, individuals with disability are not only recognized as distinct from the general population, but value and meaning also are attached to their condition” (2005:6). That is, three categories of social beliefs seem to appear regularly in terms of disability. Specifically, these include: causality, valued and devalued attributes, and anticipated adult status. Causality involves the cultural explanations surrounding the causes of disability as well as influencing and perpetuating how members of society treat disabled people. Valued and devalued attributes are simply those qualities society finds important, desirable or undesirable. Finally, anticipated adult status refers to whether disabled people are involved in family, community, and other social interactions, or whether they are denied such activities by society. Accepting disability as a social interpretation moves the issue from the realm of health into the arena of human rights (Groce, 1999a).

Be that as it may, research in medical anthropology has focused on a therapeutic theme. That is, the focus has been on concepts of disease and illness, healing, rehabilitation, and the relationships and interactions between patient and health practitioner or professional. Ingstad and Whyte (1995) advocate a move in disability studies from the clinical setting to the community setting. The community setting is one in which the cultural assumptions about disability come into play within the context of ordinary social interaction. Concerns center less on disease, but rather long-term consequences to disability, adjustments and adaptations regarding rehabilitation and
therapy, as well as issues of disability meanings, autonomy, dependence and identity. These are complex cultural issues, and their answers by varying degrees are made consequential through society by enabling or disabling people (McDermott and Varenne, 1995).

Stigma

One of the social aspects of healing that has been gaining much attention is the role of stigma and its impact on health. This is one area that Western biomedicine does not provide enough focus or services to support the social aspects of healing. Like many terms in anthropology and public health, stigma has come to hold many different meanings.

Erving Goffman is well known for his research on stigma and deviance. Goffman established a typology of stigma based on the central idea that stigma are deeply discrediting attributes, that reduce the bearer to something less, tainted persons. Goffman’s typology divides stigma into three categories: physical abnormality, disability, or infirmity; character weakness (mental illness, addiction, criminal behavior, etc.); and tribal stigma, which encompasses groups or classes of people (1963).

While Goffman’s classical definition is widely accepted, Link and Phelan’s definition of stigma incorporates an element of power. Link and Phelan (2001: 3) state, “we apply the term stigma when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows them to unfold”.

Essentially, Link and Phelan touch on a number of ways or components in which stigma can come into play in people’s daily lives. Breaking the four components down, one can
begin to observe the complexity of the issue. Human differences are distinguished and labeled. Under society and its dominant cultural beliefs, labeled persons are stereotyped to possess undesirable characteristics. These people are further separated into distinct categories. Finally, they undergo status loss and discrimination (Link and Phelan 2001).

Stigma as a concept and a social phenomenon proves useful in disability studies. The anthropological literature generally demonstrates that people with impairments and various chronic illnesses in different societies are often stigmatized and socially devalued due to this difference or attribute. In American culture, specifically, the more value placed on an attribute, the more a person who lacks or is deficient of this attribute will experience a greater stigma response and a lowering of self-esteem (Shuttleworth and Kasnitz, 2004). To be sure, there is much more to be learned in regards to stigma as it relates to disability. For instance, what is the nature or perceived characteristics of disabled conditions and what are the sources that create and perpetuate stigmatizing conditions (Ablon, 2002)?

Documenting personal cases of stigma and exclusion from social realms of disabled people is important, however there are indeed larger social actors in the context of stigma. The role of the state/ political and medical institutions as a driving and influencing force in disability and stigma is an area that must be continually examined. It is equally important to acknowledge that diseases, new and old, present threats and anxieties of blame and other stigmatizing conditions that can be expressed through the political, popular, and scientific avenues of discourse (Das, 2001). Especially in the case of scientific or medical systems, it is significant to note that such systems are not culture or value free. These systems or institutions are the products of specific historical,
political, social, and economic developments. Most importantly, when observing the health consumer and the rehabilitation system, not one but two culturally defined and bounded systems are interacting (Groce, 2005).

The Role of Values in American Society

Historically, the study of values of other cultures and societies has been one of the main interests of cultural anthropologists. Like many concepts, a definition of values is difficult. However, for the purposes of this study, a definition by Barnouw as well as Spradley and Rynkiewich will be employed. According to Barnouw, the role of values and their importance are situated within the realm of personality. That is, personality is an enduring organization of forces within individuals associated with a complex and consistent organization of values, corresponding attitudes, and modes of perception, all of which underlie a constancy of behavior among individuals (Barnouw, 1985). Simply, values are conceptions and assumptions of what is desirable, which shapes aspects of people’s lives. The sum total of a society’s cultural values produces a particular worldview or framework, which creates an integrated conception of reality (Spradley and Rynkiewich, 1975). The rest of this section present a brief history of the anthropological study of values as well as a discussion on the “core” American values in relation to the “culture of disability”.

A History of the Anthropological Study of Values

Within the last century there have been many attempts to study the values of different cultures and societies. One of the best known cross-cultural studies of values is Kluckhohn and Strodtbeck’s research on values in five Southwestern cultures (Morman,
Texan, Spanish-American, Zuni, and Navaho). Their study attempted to utilize an empirical intensive approach by employing random sampling, categorically defined questionnaires, and statistical analyses (Kluckhohn, 1961). According to Kluckhohn and Strodtbeck (1961), every person has a rank order of value orientations, and the nature of the rank order is influenced by the culture one is born into. Much of the findings did support Kluckhohn’s theories about value orientations and his predictions of the value orientations of the five Southwestern cultures (Barnouw, 1985).

Be that as it may, there are some criticisms of their approach to discovering value-orientations. A problem with questionnaires is that a person’s answers may not necessarily represent their actual values (Barnouw, 1985). This is a classic example of real vs. ideal culture that anthropologists should be constantly aware of when working with key informants. Similarly, Albert states, “especially in the case of values, there is usually some discrepancy between what is believed and what is said and done, between what is asserted and what may be consciously or unconsciously believed” (1956: 223). Finally, there are those values that are implicit or fundamental to such a degree that they are not even recognized as values and, perhaps, the most fundamental and influencing of all (Pengra, 2000; Spradley and Rynkiewich, 1975).

In the case of studying the American value system, the historical and most widely used approach is one stemming from Max Weber, his philosophical descendants, especially Talcott Parsons, and Alexis de Tocqueville (Moffatt, 1992; Peacock, 1995). Weber’s key theme is ideational configurations or cultural systems, which consist of religious beliefs, ethical values, and aesthetic forms. These configurations contain a certain coherence and autonomy irreducible to their social, economic, or political
contexts. The Weberian Approach emphasizes textual analysis and a large scale, long term comparative approach to cultural systems as opposed to an anthropological approach emphasizing ethnography and culture in more immediate, experiential contexts. The Weberian approach attempts to extract from the complexities of the American cultural system a pattern of guiding meanings, containing ideas, values, and symbols, in order to formulate a coherent and autonomous system. Essentially, the Weberian approach seeks to abstract the core culture from the totality of American society. It seeks traditions grounded in history as well as values contained in founding and dominant figures and institutions (Peacock, 1995).

Though not necessarily in opposition to the Weberian approach, anthropologists Shepard Forman and James Peacock (1995) sound a call to action for an alternative, complimentary approach to studying the American value system using anthropological means and methods. According to Peacock (1995), an ethnographic approach is better situated to discover and account for ethnic, racial, class, and gender differences within the American cultural system. Furthermore, Peacock (1995) emphasizes that anthropological studies of the United States need to push beyond cultural diversity as a catchall and investigate the differences and multiple aspects of American culture in order to gain an understanding of their interrelationships. Throughout history, environmental and socio-cultural stressors have threatened the fabric of American society only to reassert equilibrium within society due to resilience of American society. Rather than idly watching as such stressors threaten American society time after time, Forman issues a challenge to American anthropologists. The call is, as Forman states, “to understand and lay bare an anthropological search for meaning and action in American life, an effort to
reformulate a vibrant statement of key American values and goals that points in the
direction of the kind of society in which we care to live” (1995: 14).

Core American Values in relation to the “culture of disability”

Though the core American values may be difficult to strictly define, like the study of cultural value systems and orientations, there have been researchers that attempt to do so. Essentially there are four core American values: independence/self-reliance, individualism, goal-oriented activism, and community collectivism (Angrosino, 2006; Arensberg and Niehoff, 1971; Hsu, 1972; Moffatt, 1992; Murphy, 1987; Peacock, 1995;). One should note, however, that core values are predicated upon high levels of generality within the respective culture. This is not to say that there is no variation among values and actual behaviors as well as among different groups or persons with differing values (Albert, 1956; Peacock, 1995).

Much of these core values were identified in an earlier era of American history that emphasized a melting pot viewpoint in regards to the diversity of America. Currently, however, a popular viewpoint emphasizes multiculturalism and its recognition. Therefore, core American values, as social and historical constructions, are subject to different interpretations contingent on changing and evolving social conditions (Angrosino, 2006). Additionally, Forman (1995) points to the growing trend of pluralism in American society as well as a recognition and celebration of multiculturalism and different ethnic heritages. An anthropological re-examination of the core American values and their relationships with a growing pluralistic America is in order (Forman, 1995).
On the topic of pluralism in America, the “culture of disability” can be seen as a unique cultural group within American society. To complicate matters, some cultural values are explicit while others are hidden or denied, and some are simply unrecognized. Even as values serve to integrate society, however values may also create or represent conflicts in society (Spradley and Rynkiewich, 1975). The anthropological literature does provide some insights of the conflicts between persons with disabilities in relation to the dominant American culture. Murphy (1987) cites a number of issues regarding clashes of values among people with disabilities including: independence, employment, identity, and marriage and family. On the issue of independence, lack of functional autonomy and over-dependence are seen as a debasement of American culture, which is one reason why the severely disabled suffer a reduction of status. In American society the fear of dependence is so great that one who is not self-reliant is viewed as a misfit (Hsu, 1972). Specifically, when people with disabilities are stripped of their privacy and autonomy, they are relegated to a marginalized and devalued status and prevented from living on terms of their own values (Pengra, 2000). The basic value orientations of self-reliance, independence, and individualism creates contradictions (denial of the importance of others in one’s life) and problems for the individual, the most ubiquitous of which is insecurity (Hsu, 1972). By its very nature, such values create frustration in all those who do not or cannot live by these values (Arsenberg and Niehoff, 1971).

In terms of economic employment, a large proportion of the motor-disabled are unemployed economic dependents, supported by Social Security disability insurance and family incomes (Murphy, 1987). Opportunities for employment and job training are some of the major problems identified by Americans with disabilities (Suarez de Balcazar et
Employment discrimination is illustrated by the following findings: people with disabilities are thirty percent as likely to be employed, if unemployed they are one fifth as likely to gain employment, and if employed they are three times as likely to leave work as compared to persons without disabilities (Yelin and Trupin, 2000). Further related to the issue of economic independence is the issue of identity, especially among males with a disability. The identity of males in a Euro-American society rests more heavily on employment and occupation than it does for a female (Murphy, 1987).

Much of what is known about the clash in values between people with disabilities and dominant American culture occurs through the rehabilitation and therapy settings. For instance, Pengra (2000) describes clashes in values between service providers and health consumers with disabilities. Often times, non-compliance to medical and healthcare regimens by people with disabilities are seen mostly as flaws in character or discipline rather than a clash in values concerning the specific health regimens. In actuality, a cross-cultural miscommunication has occurred (Pengra, 2000). Such cross-cultural miscommunications are mostly unintentional. Health service providers and other change agents may not realize that their natural tendencies and recommendations for action are inevitable limited by their own cultural experience and unconscious assumptions (Arensberg and Niehoff, 1971). Instead of assuming shared values between health care providers and health consumers, Pengra (2000) advocates for a systematic and dynamic approach to discovering patient schemas, which are sets of values, attitudes, and meanings, in order to better serve this population. Finally, Rodman’s (1971) writing on culture of poverty in Trinidad may have some generalities applicable to the persons with disabilities. The impoverished share the same general values of the society with
members of other classes, but the impoverished have stretched these values in order to fit their circumstances. This stretching of values is a one-way process where the poor develop a new set of values to cope with deprivation without totally abandoning the values of mainstream society (Rodman, 1971).

Summary

Overall, though there is very little anthropological literature on veterans or persons with a spinal cord, the substantive anthropological literature on disability does provide significant insights on the “culture of disability” as well as directions for future research. What is clear is that there is a growing, organized population of people with disabilities, who face a number of considerable obstacles. Such obstacles range from environmental challenges, such as, accessibility issues, to socio-cultural difficulties. Specifically, the struggle for recognition of a meaningful identify based not on stigmatizing conditions or biomedical concepts but on humanitarianism is one of the major socio-cultural issues facing persons with a spinal cord injury. As such, studies of the values as well as identity within these groups are necessary in order to better understand and effectively serve this population. Additionally, such studies may discover and describe the relationships, conflicts, and, hopefully, solutions between different value systems and the core American values. As long as the dominant American value, individualism/ self-reliance, remains the cherished ideal that governs human relations, the United States will not even remotely come to a solution to the problem of prejudice (Hsu, 1972). In this regard, this thesis does attempt to address these issues of identity and the value systems of veterans with a spinal cord injury.
Chapter Four
Methodology

Introduction

This Chapter serves three purposes. First, the chapter introduces and summarizes my internship experience and setting. My formal duties, expectations, and immediate supervisor are addressed in this section. Second, my thesis study’s main research questions and context are presented and explored. Finally, through the internship experience, the formal basis of data collection, analysis, and study limitations are presented and discussed.

Summary of Internship

Setting

The James A. Haley VA Medical Center in Tampa, FL. established the federally funded VISN 8 Patient Safety Center of Inquiry in 1999. The mission of the center is to support clinicians in safe patient care through the designing and testing of clinical innovations, technology-based solutions, and patient safety improvements. Their research efforts center on two target populations: frail elderly and persons with disabilities (VISN 8 Patient Safety Center of Inquiry, 2006a). The Center focuses on safe mobility, and, specifically, the Center goals include: (1) promoting personal freedom and safety among frail elderly and disabled persons, across the continuum of care and (2)
building a "culture of safety" for clinician support in providing safe patient care and working environments (VISN 8 Patient Safety Center of Inquiry, 2006b).

To this end, one of the research studies conducted by the Center is entitled, *Epidemiology and Cost of Falls in Veterans with a Spinal Cord Injury*. The study is a multi-site, three-year epidemiological prospective cohort study that began in the spring of 2004. The goals of the study are: (1) to determine the etiology and risk factors for wheelchair-related tips and falls among community dwelling spinal cord injured veterans and (2) to determine the cost outcomes and consequences of these falls (Nelson: 2003). In this study, a wheelchair-related fall is defined as any event in which a patient intentionally or unintentionally drops from the wheelchair or the wheelchair tips over with the patient remaining seated. A wheelchair fall can be in any direction, forwards, backwards, or laterally. A fall may or may not result in injury and/ or damage to the wheelchair. A fall-related injury is defined as an injury resulting from a wheelchair tip or fall event including bruises, abrasions, lacerations, head trauma, and fractures (Nelson, 2003).

While the study is first and foremost an epidemiological study, the study does include a qualitative component though it is limited. In order to achieve its goals, the study employed two primary forms of data collection. In order to achieve the first goal, quantitative data (monthly patient follow up surveys) on participants were collected over the phone, compiled into a database, and statistically analyzed. To help facilitate the second goal, qualitative telephone interviews were conducted with a group of SCI veterans, who have experienced a wheelchair-related fall.
Internship Roles and Responsibilities

From the spring of 2004 to the spring of 2006, I was employed at the VA Patient Safety Center of Inquiry as a part time research assistant intern the research project, *Epidemiology and Cost of Falls in Veterans with a Spinal Cord Injury*. Where the VA research study utilized both a quantitative and qualitative approach to data collection, my role was to help facilitate qualitative data collection and analysis. All of my duties were conducted at the Center. My duties included conducting all of the qualitative telephone interviews with SCI veteran wheelchair fallers. The content or focus of the interviews centered on patient perceptions on falls, fall consequences, and quality of life issues related to falling. Additionally, my duties included transcribing, developing a coding scheme, coding the data, and analyzing the interviews for relevant themes as well as general qualitative data management. Furthermore, during peak weeks and/or months, my duties also included facilitating monthly follow up phone surveys, which is the primary method of data collection for the entire study.

Internship Supervisor

My immediate supervisor was Deborah Rosenberg, a project co-investigator. Dr. Rosenberg has a Ph.D. in Applied Anthropology, with an emphasis on medical anthropology and is well versed in qualitative data collection methods. Dr. Rosenberg has also completed her M.P.H. in health policy and management. For this VA study, Dr. Rosenberg assumed the immediate responsibility of the qualitative component including: developing the interview tool with associate director of the Center, Dr. Gail Powell-Cope (Ph.D., ARNP), data analysis, final conclusions, and recommendations. In terms of qualitative data analysis, Dr. Rosenberg, Dr. Powell-Cope, and I separately coded and
analyzed the interview transcripts, which served to triangulate the data by confirming and cross-checking significant and relevant codes and themes. From there, Dr. Rosenberg assumed overall responsibility for qualitative data analysis with Dr. Powell-Cope and I assisting. Both Dr. Rosenberg and Dr. Powell-Cope provided me with training and mentoring on ethnographic interviewing and data analysis as well as guidance in real world problems and difficulties associated with applied health research.

**Thesis Statement of Problem/ Research Questions**

While the VA study focused on the etiology, cost, and consequences of falling among veterans with SCI, my interests in this population are focused on the broader topics of life as a veteran with a SCI. Specifically, my interests lie in how meanings are constructed, reconstructed, and attributed to the daily life activities among veterans with SCI. As stated in the literature review, there has been little research conducted on people with SCI and, much less, on the broader culture of SCI. From this point on, discussion in this thesis centers solely on my own research unless noted and is not to be confused with the VA study. My methodology is intrinsically linked and situated within the VA study, specifically the qualitative component, which I will explain in greater detail in the next section.

SCI veterans engage in a complex and, often times, difficult dialogue within and through interactions in American society. As a result, my main research interest involves exploring the qualitative data responses from the study participants in order to understand what it means to be a disabled, SCI veteran in American society. That is, American society holds dear certain traditional values (ideals, beliefs, and customs) that promote
the steady functioning and fabric of society. Through the process of enculturation and acculturation, likely, the majority of American citizens have already internalized many of these values. These values are cultural constructs of American society that can certainly influence and shape the myriad ways in which individual identity is formed.

If so, than many questions arise regarding the overall population of disabled SCI persons (veterans or otherwise). How do veterans as American citizens deal with life as a disabled SCI person, and how do they view themselves in light of America’s cultural values? What are the similarities and differences between the value systems of American society and the culture of SCI persons? Where do disabled SCI veterans situate themselves in American society, and where may they be situated according to American society? What does it mean to disabled SCI veterans when they cannot meet the cultural values and standards of American society, and where does this lead them? How do SCI veterans maintain either a positive or negative outlook on life?

There are numerous factors that can be observed and analyzed in order to shed light on these questions. Some of these factors include: issues regarding mobility, age, employment status, meaningful relationships, medical treatment, activity level, personal outlook on life, and, perhaps most importantly, identifying traditional American values as well as those values prized by disabled SCI persons. By identifying these value sets and analyzing the ways in which SCI veterans interact within society, I hope to achieve three goals; (1) discover the ways in which SCI veterans create and negotiate a unique sense of identity in American society, (2) illustrate the overall implications from this study to the general SCI population in America, and (3) provide a set of recommendations for healthcare providers for the purposes of creating and engaging in meaningful dialogues
with SCI patients as well as aiding in more successful and sustainable health interventions.

Data Collection

As stated earlier, the data collection for this thesis is intrinsically linked and situated within the qualitative component of the VA study. The qualitative component of the VA study consisted solely of qualitative telephone interviews, all of which I conducted. Again, the VA study focused on falling and tipping, and as such the qualitative telephone interview tool focused on patient perceived fall consequences. However, through secondary data analysis of the qualitative telephone interviews I attempt to discover relevant themes regarding life as a veteran with a SCI and the broader culture of SCI.

Sampling

A brief discussion of the VA study’s qualitative sampling procedures is warranted in order to better understand the study population. In regards to the qualitative data sampling for the VA study, a convenience sample of the first thirty five SCI veterans from the cohort study, who have sustained a wheelchair-related fall, were included in the qualitative component of the study. An additional four SCI veterans, who have sought medical care due to a fall-related injury, were also interviewed. Participants’ age ranged from late twenties to the seventies. The majority of participants were males though there were female participants.
Qualitative Telephone Interviews

As stated in the sampling, a convenience sample of the first thirty fallers was chosen as candidates for participation within the qualitative study component. The first thirty fallers were identified by a data collector, either myself or another researcher, through the monthly follow up surveys. The monthly follow up survey asks participants whether or not they had a fall during the monthly period. If participants answered “yes”, they were asked to participate in the qualitative component of the study, and they were informed that I would give them a call within the month to conduct or schedule a qualitative telephone interview. Once I received their participant file containing information on their fall context, I called the patient, introduced myself as an assistant researcher (if they did not know me already), asked them to participate in the qualitative component of the study, and, if they accepted, read the informed consent and conducted the interview.

The qualitative telephone interviews were conducted using the interview tool found in Appendix A. The interview tool focuses on patient perceived causes and short-term and long-term consequences of falls. For example, such questions include: “What does it mean to you to have fallen?” and “How has your quality of life changed since you fell?”. The interviews were open-ended, semi-structured interviews. The interviews were tape-recorded and transcribed verbatim with the patient’s informed consent. If the patient refused to be tape-recorded, field notes were taken during the interview in order to document the patients’ responses, and the field notes were immediately written out and expounded upon for clarity and greater contextual depth. The interviews were conducted within a month after the fall in order to minimize participants’ recall bias on the fall and
its contexts. Additionally, a six-month follow-up interview was conducted with the fallers in order to gain a long-term perspective on the patient-perceived fall consequences, such as overall functioning and quality of life six months after the fall.

A total of sixty-four interviews were conducted. Thirty-five initial interviews were conducted. Twenty-five six-month follow-up interviews were conducted. A total of ten participants were either lost to follow-up or refused to participate in the six-month follow-up interview. An additional four participants, who as a result of their fall injuries sought medical attention, were interviewed only once (see Table 1 for total interviews by category). The interviews lasted between fifteen minutes to an hour and a half.

**Table 11. Total Number of Interviews by Category**

<table>
<thead>
<tr>
<th></th>
<th>Initial</th>
<th>Six-Month Follow-up</th>
<th>Lost to Follow-Up or Refusal for Six-Month Follow-Up</th>
<th>Sought Medical Treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=</td>
<td>35</td>
<td>25</td>
<td>10</td>
<td>4</td>
<td>64</td>
</tr>
</tbody>
</table>

Although my duties did not initially include the monthly follow up phone surveys, conducting the phone surveys month-to-month helped to build rapport with many, but not all, the study participants, especially those who were or would become wheelchair fallers. By conducting the monthly telephone follow up surveys, I began to build, at best, a friendly, and at worst, respectful, relationships with many study participants. As a result, when the time came to conduct qualitative telephone interviews, I was able to broach deeper into the potentially sensitive subjects of falling, the various fall contexts, and their subsequent fall meanings with many participant fallers. If I had not had the opportunity
to create these relationships, I would likely have had a more difficult time conducting and receiving context rich information from participant fallers. Indeed, there were a fraction of interviewed fallers forwarded to me from another data collector, with whom I did not have an already established relationship.

As a methodological approach, open-ended, semi-structured interviews, should serve as an excellent means of discovering cultural categories, revealing shared values through similar and differing opinions, and building rapport. Specifically in the case of six-month follow ups, semi-structured interviews should serve as a means of further elaboration on shared group beliefs and data collection for specific questions and hypotheses (Fetterman 1998). However, the use of telephone interviews in qualitative research is uncommon due to concern regarding the quality of the data collected and whether telephone interviews are well suited to the task. Be that as it may, telephone interviews can be used successfully in qualitative research (Sturges and Hanrahan, 2004). A more detailed discussion on qualitative telephone interviews will be presented in the “Limitations” section further below.

Secondary Data Analysis

Again, while the qualitative component of the VA study focused on fall consequences, my thesis topic concerns values among veterans with a SCI. In fact, I am analyzing the qualitative data generated from the VA study in order to search for relevant themes and trends in the data pertaining to shared values among veterans with a SCI. Therefore, my analysis of the qualitative data constitutes a secondary data analysis.
The telephone interviews yielded a great deal of information. From the interview transcripts, I developed a coding scheme and categories based on the questions and answers. According to LeCompte and Schensul, coding “involves organizing data into categories related to the framework and questions guiding the research so that they can be used to support analysis and interpretation” (1999a:45). In this sense, attention was focused on patient experiential data, perceptions, and value meanings surrounding their lives. In particular, participant responses relating to the core American values or its variants of self-reliance, independence, individualism, and activism as well as any other emerging values were of special interest. Passages and paragraphs in the interview transcripts were assigned a code in order to represent cultural concepts, themes, and categories. Once all of the qualitative data had been coded and re-coded, the data were examined in order to ascertain relevant themes and how they related to each other. The qualitative software package, NVIVO, was used to aid in identifying relevant and underlying themes and their interrelationships within the transcripts.

Limitations

As in many studies, real world challenges and methodological issues can arise to create constraints and limitations. My study is no different. There are a number of limitations in this study, which concern data quality data and the conclusions that can be drawn from it. There are two issues: the use of qualitative telephone phone interviews as a means of data collection and the appropriateness of secondary data analysis of the qualitative telephone interviews in order to address my research questions.
In terms of qualitative telephone interviewing, as a methodological approach, I would, ideally, not choose this as my primary form of data collection. Rather traditional face-to-face interviewing and participant observation would be ideal. However, at the time, as a research assistant for the VA I was not in a position to effectively advocate or, much less, change the study protocol and/or research design in favor of additional qualitative data collection.

However, telephone interviewing has been found to be effective and successful in research. Sturges and Hanrahan (2004) describe several instances or circumstances in which telephone interviewing is suitable. These instances include sensitive topics, access to difficult to reach participants, and cost effectiveness. The topic of SCI and its consequent lifestyle can potentially be an extremely sensitive matter, especially considering issues of mobility and dependence. As a result of potentially embarrassing topics, participants may have preferred the relative anonymity of telephone interviews over face-to-face interviews, and the data quality may have increased (Sturges and Hanrahan, 2004). In regards to difficult to reach participants and cost effectiveness, the sampling of qualitative component contained participants from other states, which would make face-to-face interviewing considerably more difficult.

With regards to these circumstances, telephone interviewing of veterans with SCI seem to be justified. Be that as it may, many participants did and do visit the Tampa, FL. James A. Haley VA Medical Center regularly where face-to-face interviewing could have taken place. Though I was not in a position for change, I did make my concerns known to both Dr. Rosenberg and Dr. Powell-Cope. However, like many real world challenges,
perhaps the methodological choices made were matters of convenience and/or best fit at the time.

The use of secondary data analysis as a methodological tool is also far from ideal. The basic premise underlying secondary analysis is to evaluate, analyze, and interpret previously collected data for answering research questions other than the original questions the data were collected for. While some situations and circumstances concerning both data collection methods and new research questions may obviate the appropriateness of secondary data collection, I believe my thesis does not fall into this category. Though it is true that the interview tool does focus on patient perceived fall consequences and meanings, this does not mean that the answers and responses given by participants fall only within the categories of interest to the VA. As the qualitative data collector, it was my experience that the interviews were never strictly about falls and fall consequences among the participants. Rather, many participants situated and described the falls as a part of life as a person with a SCI. Other issues concerning life with a SCI definitely arose during the interviews, and rather than following a format based solely on the interview tool, many participants began to converse with me on a broad range of topics. As a result, the qualitative data collected does contain rich contextual information. However, ideally and for future studies an interview tool focusing on values and concerns among veterans and persons with a SCI would be both a more valid data collection tool and should yield a larger range and richer variety of responses and information.
Summary

This thesis research study consists of qualitative data collected during my two-year tenure as a research assistant for the VA Patient Safety Center of Inquiry study, *Epidemiology and Cost of Falls in Veterans with a Spinal Cord Injury*. Though the original interview tool focused on patient perceived consequences of falls, much of the data included varied responses on a number of topics not strictly related to falls or tips. As a result, I conducted a secondary data analysis on the qualitative data in order to attempt to answer questions of shared values among veterans with a SCI. From the sixty-four collected and transcribed interviews, I coded and categorized passages and responses from participants using the qualitative software package, NVIVO. The results of my analysis will be presented in the next chapter.
Chapter Five

Results

Introduction

The purpose of this chapter is to present the results and findings of my study.

First, participant demographics will be presented in order to display a better picture of the study population and their overall characteristics. Second, pertinent themes discovered from the qualitative telephone interviews will be presented through vignettes. A discussion of the results presented here will be the subject of the next chapter.

Demographics

In this section, study participant demographic data are presented. A total of thirty-nine (N=39) participants took part in this study (See Table 11). Thirty-five participants completed the initial interview. Out of the thirty-five participants that completed the initial interview, twenty-five (71%) completed the six-month follow-up interview. Ten participants (29%) were lost to follow up regarding the six-month follow-up. An additional four interviews were conducted with participants who had suffered a fall-related injury and had consequently sought medical treatment.

Overall, the study sample was composed mostly of males. In fact, thirty-six (92.31%) males and three females (7.69%) comprised the study sample (See Table 12). The majority of participants were also white (N=34, 87.18%) while the remainder of the sample was composed of black (N=4, 10.26%) and other (N=1, 2.56%) race/ethnicity
categories with no Hispanic participants (See Table 13). The average age of the
participants was 52.56 years. The minimum (youngest) age was 25 while the maximum
(oldest) age was 88. The average years since SCI was 19.36 years with the minimum
being 3 years and the maximum as 58 years (See Table 14). The breakdown of
participant marital status was: married (N=23, 58.97%), divorced (N=7, 17.95%), never
married (N=7, 17.95%), widowed (N=2, 5.13%) (See Table 15). Finally, self-reported
health status of the sample indicated that the majority of individuals were in good health
(N=14, 35.9 %) with the rest falling under very good health (N=11, 28.21%), fair health
(N=9, 23.08%), excellent health (N=4, 10.25%), and poor health (N=1, 2.56%) (See
Table 16).

**Table 12. Study Sample Categorized by Sex**

<table>
<thead>
<tr>
<th>Sex</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>36</td>
<td>92.31</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>7.69</td>
</tr>
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</table>

**Table 13. Study Sample Categorized by Ethnicity/ Race**

<table>
<thead>
<tr>
<th>Race/ Ethnicity</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>34</td>
<td>87.18</td>
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<tr>
<td>Black</td>
<td>4</td>
<td>10.26</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.56</td>
</tr>
</tbody>
</table>

**Table 14. Study Sample Average Age and Years since SCI**

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Min</th>
<th>Max</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>52.56</td>
<td>16.29</td>
<td>25</td>
<td>88</td>
</tr>
<tr>
<td>Years since SCI</td>
<td>19.36</td>
<td>15.56</td>
<td>3</td>
<td>58</td>
</tr>
</tbody>
</table>

**Table 15. Study Sample Marriage Status**

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>23</td>
<td>58.97</td>
</tr>
<tr>
<td>Divorced</td>
<td>7</td>
<td>17.95</td>
</tr>
<tr>
<td>Never Married</td>
<td>7</td>
<td>17.95</td>
</tr>
</tbody>
</table>
Table 16. Study Sample Categorized by Self-Reported General Health Status

<table>
<thead>
<tr>
<th>Health Status</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>4</td>
<td>10.25</td>
</tr>
<tr>
<td>Very Good</td>
<td>11</td>
<td>28.21</td>
</tr>
<tr>
<td>Good</td>
<td>14</td>
<td>35.90</td>
</tr>
<tr>
<td>Fair</td>
<td>9</td>
<td>23.08</td>
</tr>
<tr>
<td>Poor</td>
<td>1</td>
<td>2.56</td>
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</tbody>
</table>

Vignettes

This section presents the results of the qualitative telephone phone calls conducted with the study sample. Through the use of vignettes, everyday themes, issues and behaviors surrounding the lives of veterans with a SCI are portrayed and discussed. According to LeCompte and Schensul, a vignette is a short dramatic description or snapshot of events or people that evoke the overall picture the ethnographer is trying to paint (1999). Specifically, Van Maanen describes three types of vignettes: impressionist tales, realist tales, and confessional tales (1988). Impressionist tales recount memorable and notable events, which the researcher deems reportable. Realist tales attempt to capture every day life. Finally, confessional tales incorporate an element of reflexivity within narratives of fieldwork (Van Maanen, 1988). The vignettes presented are a combination of Van Maanen’s three typologies.

I chose to present the qualitative data collected in the form of vignettes in order to situate the reader in a context that most closely resembles the context of the participants. Rather than presenting a detailed codebook, vignettes may be a more appropriate method of conveying the everyday issues and themes by pulling the reader into the stories of the study participants. The following ten vignettes are categorized by general themes that
emerged from the interviews related to specific veterans with SCI. To be sure, many stories and narratives could be composed from the qualitative data. I chose to tell the stories of these ten veterans since they represent many of the issues, problems, and behaviors associated with the rest of the study sample in such a content specific and rich manner.

I. Goals of Independence

The vignettes in this section focus on how two participants, Aileen and Wren, attempt to achieve their goals of functional/mobile and financial independence within their own contexts.

Aileen: “It’s like putting a ball and chain around me.”

Aileen often spoke of this fall when discussing her dependency on using a wheelchair for her primary means of mobility. While discussing disability and the perils of falling in a wheelchair, Aileen confessed that her self-confidence had been shot ever
since the fall in 1996. She angrily spoke of how embarrassing and shaming it was that she, a 36 year old woman, was “butt naked” on the bathroom floor crawling like a two year old towards the telephone in her bedroom in order to seek help. Though Aileen, like many others, was taught how to recover from a wheelchair fall, she found getting up more difficult than she was taught. On this topic, Aileen said, “Over in rehab, they teach you how to get up. But rehab and the real world are two different things. I tried and tried, but I couldn’t get up, and I was frustrated.” Consequently, Aileen has developed several fall recovery strategies based on her relative location within her apartment and its surrounding furniture. For example, depending on which room she is in, Aileen has identified specific pieces of furniture that she can crawl to and climb onto after a fall.

Aileen’s disabled condition and fear of injury had also spilled into areas affecting her friendships and relationships. Previous to her traumatic fall, Aileen had a number of friends that would take her out to the town or go shopping. These days, Aileen told me that her friends are now more cautious of her in light of her worsening condition, and many of her friends now avoid her for fear that she may fall and hurt herself. About a particular friend, Aileen stated,

“She’s more or less given me the excuse that either the roads are too slick or something. And, then she come out one day and said, ‘I can’t come and get you because you might fall’. I took that as, ‘I don’t want to come get you because I’m scared of you’. She was scared that I would try to cause trouble. For me, the way I understood it and the way I’ve perceived it was that I would try and start a lawsuit against her. And they ought to know me better than that.”
Coupled with this situation, many of Aileen’s friends and family often try to convince her to have someone live with her in case of emergencies. However, Aileen has told them she won’t give up her freedom. Aileen explained this to me, “they won’t let me do the things I know I can do, or things that I could to give me a chance to try and do them. They mean well, but it’s like putting a ball and chain around me.”

While not as blatant as the episode with her former friend, Aileen recounted an incident at church where many of her friends and acquaintances also treated her in a manner she found demeaning. Though Aileen’s primary form of mobility is a wheelchair, she did have limited walking capacity with forearm or Canadian crutches. While in church one day, Aileen fell while walking with her crutches. Of this instance she recounted, “It was everybody wanting to help me. I said, ‘No, just let me be myself and get up’. But now it’s, ‘Aileen, can I do this? Aileen, can I do that’, or ‘let me do this. Let me do that for you’. They’re scared of me. They don’t want me to do anything, and that’s what hurts.” Aileen has likened her situation to that of a child, though she is clearly an adult and does not appreciate being treated like a child.

Understandably, Aileen’s battle and cry for independence (or even a chance of) with her friends and acquaintances had left her increasingly frustrated, angry, and depressed. During our last conversation, Aileen even confessed that she didn’t even desire to try using crutches to walk anymore for fear of injury. On her condition, Aileen revealed, “Being a spinal cord injured person, if I could be any other injury this is the one I wouldn’t want. Because anything could happen. You have to be like an hourglass. You have to be so fragile with it, and I guess that’s it there.”
Wren: “I was a manager at a store, and I had everything under control.”

Wren was another female participant in the study. She had two daughters, a nine year old and a twenty two year old, who had moved out of the house. When I first conducted the initial interview with her, she was in the process of moving out of her old, wheelchair inaccessible house in a poor section of her hometown. There were many characteristics of the house that hindered Wren’s capacity to be mobile. The hallways in the house were very narrow and difficult for her to travel through. The bathroom was also terribly narrow, which hindered Wren’s personal care greatly and required her to use a catheter every four hours. Outside the house was not much better. The driveway was both steep and composed of gravel, making it very difficult for Wren to travel in and out of the house. However, through our conversations I discovered that her situation at home was actually quite low on her priority list.

From speaking with Wren, I ascertained that her SCI was a relatively recent trauma though I was not able to discover the nature of her SCI or when it happened. Before her injury she described her life to be, at the very least, financially independent and employed. Specifically, Wren stated about her previous life, “It was a big change cause I had been working like sixty to seventy hours a week. I was a manager at the store, and I had everything under control. I was paying bills, and everything was going okay. And, this happened and life came to a standstill. I’m still trying to get out of it.” Life with a SCI has left Wren relying financially on the federal government and worker’s comp from her previous job. This constituted a major lifestyle and philosophical change in Wren’s life. According to Wren, she had been working at one job or another since she was nine years old, she did not want her SCI to bring her down or slow down her life.
On the issue of employment, Wren’s major barrier and obstacle to employment is discrimination. Wren’s perspective is that potential employers are discriminating against her based upon her disabled status. However, Wren found that therapy and rehab could only help her out so much, and though she could walk a limited distance with a walker, she would need to rely on a wheelchair for mobility. Wren related one of her stories on seeking employment to me,

“I want to be able to get up and go to work. I even applied for a job, and my wheelchair got turned down. This lady packs candy in these dishes, and she was getting really far behind on her orders. I asked her if I could help her, and she told me that she couldn’t use me even though she needed the help. She got somebody that was walking that could help, and that kind of hurt my feelings.”

Wren also mentioned applying for another job, which she was turned down for as well. During our last conversation, Wren was still unemployed.

Like Aileen, Wren had limited capacity for walking, and also like Aileen, one of Wren’s goals was to gain a greater capacity for walking. However, throughout the study year, Wren began to slowly lose her upper body strength resulting in difficulty pushing her wheelchair, much less walking with a walker. On one instance when Wren was in town, she attempted to cross some railroad tracks, however she did not have the strength to cross them. She ended up stuck in the middle of the tracks though she did eventually cross over by herself after minutes of rest. Though Wren remained optimistic about walking, with her voice breaking she told me, “I just, I want to walk, and I’m not going to give up wanting to walk and trying. But, then I have people on my back about don’t try
to do this because you could fall and hurt yourself more. I just got to find me an adult that’ll walk with me.”

II. The Discriminating Urban Environment, Activism, and the Quest for Healthcare

The vignettes in this section describe three participants, Felix, Harper, and Basil, as they encounter environmental obstacles and the consequences of these environmental barriers.

Felix: “He just let me fall on my back.”

Felix was a middle-aged full time salesman, who professed to be living the American dream. He was married to a beautiful Ukrainian wife and living in a nice house. They were expecting to have children soon. As a fully financially independent veteran with a SCI, our conversations revolved around his work and, especially, on his working trips to England.

On this one occasion, he chronicled a fall event that occurred while trying to flag and get into a British black taxicab, the British equivalent to American yellow taxicabs. While these black cabs were equipped with wheelchair ramps, the driver of the cab must assemble the ramp, which is a tedious process. Instead of assembling the ramp, many British cab drivers prefer to help the individual transfer into the cab. Felix agreed to this and went over the details with me as he recounted, “I told him I was going to pop a wheelie, and he said he would push me in. So I popped a wheelie, and the door’s about a
foot off the ground. So, I was expecting him to catch me and push me up. He didn’t. He just let me fall on my back.” Felix eventually recovered when the cab driver and another driver pulled over to help. The driver apologized to Felix and stated that he was confused because Felix’s wheelchair did not have handlebars. Regardless of handlebars, Felix wondered how “he could just kind of stand by with his hands in his pockets as I’m falling.”

Apparently, the situation with British black taxis was not necessarily an isolated incident. During our last conversation, Felix told me he had visited London since our first conversation. While visiting in January 2005, a snowstorm struck London and taxicabs kept driving past him as he attempted to flag them down. Felix told me they kept driving past him for approximately three hours, at which point he promptly rented a car and drove himself. Felix had also stated that calling for a taxi on a telephone did not help either since when they saw that he was in a wheelchair “they’ll leave you.” He hypothesized that “They generally don’t like pulling the ramp out. It takes a bunch of tools. They’ll drive on past you”. While Felix has had pleasant experiences traveling in Prague and Las Vegas, his only solution for travel accommodations in England is to either drive himself or find a taxi service that is accommodating to his wheelchair status. As for the black cabs, Felix’s final comment was, “I just kind of avoid them, you know?”

Harper: “Because society already knows what you need.”

Harper was a Floridian, who for the past twenty-nine years has been disabled. Only in the past five years has he relied on his wheelchair for mobility. During these past five years, Harper experienced what he called a “rude awakening” concerning traveling
in and around his hometown of Key St. Thomas while in his wheelchair. Specifically, what brought about this rude awakening was the lack of curb cuts in the sidewalks of Key St. Thomas. Looking back, Harper told me, “I never looked at where the curb cuts was at, or I didn’t pay attention. I could walk over a curb. So when I sit down on the chair and start riding around, I was like, ‘holy shit’! You want to go one block, you go to go three.” The placement of these curb cuts and ramps were very inconsistent, according to Harper. While there may be curb cuts and ramps on some street corners, others would not. This often would require Harper to either jump off a curb in his wheelchair to get across a street, or he would have to pop a wheelie in order to get onto a sidewalk.

However, according to Harper the most dangerous element to traveling Port St. Thomas was the fact that at times sidewalks would merely end and become part of streets. As a result, Harper has had, and continues to, ride his power chair on the sides of streets and roads, which is all in a normal day for him.

However, throughout his first years in the power chair, several events led Harper to develop a defiant and contemptuous attitude towards his local city government. The fact that Harper had to travel on potentially dangerous sidewalks and roads put both his body and his power chair under more stress and duress than needed. The constant jumping of curbs and traveling on roads wore both him and his power chair down faster than it should. Couple with this was the treatment that Harper received by people in cars and trucks while he traveled on the side of the road. On this topic, Harper commented, “If you’ve already got a bad back, every bump you hit is, ‘oh, eh, uh, ugh, ah!’, you know what I mean? You got to ride on the road, and I’m telling you what, I’ve gotten yelled at, cussed out, and everything. I’ve had people yell out their cars, ‘hahaha, you’re crippled!’
You know what I mean?” Finally, Harper told me he had had enough, and decided he needed to ride what was safest for him, his ATV.

Harper felt safer on the sidewalks and roads of Port St. Thomas while riding his ATV. Additionally, while on the ATV Harper felt free of his disabled status. Harper reminisced, “When I get in the wheelchair, I’m riding down the sidewalk, and I feel disabled. When I want to ride, I hop on my ATV and take off. My disabilities stay back where I left it.” Additionally, with his then newfound freedom on his ATV, Harper became more active and independent by accomplishing more family activities and chores. Using his ATV, Harper was able to go grocery shopping, take part in his son’s school activities, as well as going on camping and fishing trips with his family. Many of these activities were ones he could not do without placing additional burdens on his family and friends. However, Harper’s freedom and self-reliance were not to last.

These days, Harper told me he doesn’t ride his ATV much anymore. It all came to a head one day when Harper was delivering bananas to his son’s school for a function. While traveling on the sidewalk, Harper passed a police car. He saw the officer do a double take at him and turned the patrol car around, lights flashing and sirens blaring. At this point Harper began to take back and country dirt roads in order to avoid the policeman. On a dirt path behind his son’s school, Harper, who had driven down this path many times before, lost his attention for a split second and flipped his ATV end over end. The ATV landed on his right leg, fracturing his femur. Harper was barely able to locate and crawl to where his cell phone had landed to call for help. On this incident, Harper commented,
“It makes me mad because I could have been on the pavement doing a couple miles an hour instead of trying to outrun a cop, hiding and sneaking. I wouldn’t have gotten hurt. I feel bad about it so I quit riding it on the streets and roads because I was sneaking around. That’s one of the reasons why I’m so mad about the curbs and the cuts and the sidewalks. They’re not going to let me have reasonable accommodations until they can fix sidewalks and curb cuts.”

As a direct result of this incident, Harper had made it a personal quest to inform his local city government about the dangers of traveling in a wheelchair in Port St. Thomas. Though he had many disheartening stories, one is quite memorable. On this occasion, while Harper was at the county courthouse he was able discuss issues of wheelchair safety with the zoning commissioner. During their conversation, they were able to see and document several city employees parked in handicap parking as well as blocking wheelchair accessible ramps to the courthouse. Unfortunately, Harper tells me that during the last few years his complaints and suggestions have fallen on deaf ears and that no meaningful or suitable actions have taken place. His complaints had been getting less civil and more confrontational towards many city workers often prompting heated exchanges, insults, and threats of violence. On this topic Harper declared,

“I’m getting stressed out about it, but you try to run around and be safe, and they won’t let you ride when it’s safe. Because society already knows what you need, and they don’t even know you. That’s what gets me. The hardest thing is that the people making decisions on people in wheelchairs are not in wheelchairs. If they were in wheelchairs, they would probably do things a lot more differently than they do.”
Though Harper did entertain ideas of moving out of Florida, he has assured me that he takes every opportunity to file a complaint against the city. Harper has even threatened to organize a wheelchair rally in Port St. Thomas in order to bring attention to the issue.

Basil: “They act like they don’t see what you’re seeing or feeling”

Like Harper, Basil, a wheelchair bound veteran for twenty-two years, was also a political and social activist veteran. However, Basil’s activist interests and activities at the time of our conversation centered mainly on hurricane relief efforts in Florida in the aftermath of the 2005 hurricane season. Basil also expressed interest in political activism regarding the Iraq War due entirely to his son’s role as a soldier in the war. According to Basil, his motivation as a hurricane relief worker came from his disenchanted views of the actions of Congress and FEMA regarding the then recently homeless victims of the 2005 hurricane season. Basil stated that the actions of Congress and FEMA were all economically based and inhuman, resulting in “the poor getting screwed.” Furthermore, Basil went on to state, “the forefathers are turning in their graves” as a result of policies of the Bush Administration.

As a hurricane relief worker for the Army Corp of Engineers, Basil experienced a fall that left him in a distressed state both physically and mentally. Basil fell from his van lift from a height of approximately five feet to land on his back, which Basil described, “It was like getting tackled from behind by an NFL football player.” Consequently, after the fall Basil began sweating profusely and his level of pain had increased noticeably. Immediately, Basil sought medical care in order to diagnose and remedy the situation. However, after thirty days and three visits to the emergency room, a visit to an orthopedic
surgeon, an MRI scan, blood tests, urinalysis, X-rays, and bone scans, Basil’s condition has yet to be diagnosed.

Understandably, Basil’s health condition and the lack of diagnosis warranted great duress and concern on his part. Basil expressed to me, “I just want to know why I’m perspiring because I don’t want to die tomorrow, you know? I don’t want to wake up and somebody says you been sweating because you have a blood infection, and you got three days to live. Someone tell me what’s wrong.” Given his situation, Basil stated that he could only go to his local VA clinic three or four times without receiving a diagnosis on his troubling condition from his doctors. Consequently, Basil stated he was “about over with that crap”, referring specifically to the quality of his healthcare at the VA clinic. Basil stated that he would much rather visit a Mayo clinic, especially if his condition was more traumatic than he expected or required surgery.

During our conversation, Basil eagerly discussed his opinion of doctors, both non-SCI and SCI. In his opinion, while some SCI units seemed impressive superficially, Basil did not get the impression that they were very knowledgeable in the field. Many of these doctors were neither personable nor did they have much confidence in their ability to make diagnoses. Basil’s main issues with doctors were that, “They act like they don’t see what you’re seeing or feeling. And, they’re just trying to say what they think they know going by tests and stuff. I guess, not by going on what I say, or how I look, or how I feel. They’re just going by what they read in a book. You’re just their quota.” Basil harkened back to when he first received care for his SCI decades ago in Florida. He told me that unlike today, back then,
“These people, they really cared about you, and they really tried to listen to you. And, they try to explain what you are telling them back at you in medical terms. So it really made you feel like somebody was really paying attention, and they were trying to tell you what you needed to know. I don’t know whether that’s just an art. If you’re a doctor, you’re supposed to be there for the people.”

At the end of our conversation, Basil told me he was willing to do whatever it took to diagnosis and alleviate his problem. He only hoped that his doctors were just as willing.

III. Disability and SCI: Short Term, Transitional, and Long Term Views

In this section three different views of life with SCI and disability are presented. Locke, Jack, and Arona, respectively, present their short term, transitional, and long term views on SCI and disability.

Locke: “Either you conquer it, or it conquers you.”

While the issue of disability and life with a SCI has been portrayed by Aileen and Wren as a depressing and generally negative condition, there were several participants that attempted to make the best of their lives regardless of SCI. One of the most memorable study participants was Locke, a forty-three year old male, whose optimism in life sprang from an inner inspiration. Through discussing disability and falling, Locke steadily revealed his thoughts on the matter. I asked Locke to describe his life after his most recent fall, and he jokingly told me, “It’s been a living hell!” He then explained, “I have a sort of a weird, wacky, comedy attitude about my life. Either you conquer it, or it
conquers you. Either you have control of it, or it controls you. The pain controls you.
The what-it’s-doing-to-you controls you.”

Throughout our conversations, Locke kept his light-hearted and positive attitude, especially when discussing his life with SCI. He frequently touched on how to make the best of life through “conquering” or “controlling” conditions and obstacles in life. On an injury he had to his leg, Locke explicated,

“Look, I’m going to make it. This leg’s going to get better. I’m going to do something. I’m going to take care of it. I’m going to do what I have to, and it felt better in a few days because I took care of it. I conquered it. I didn’t sit there and go, ‘oh, my leg! Oh, woe is me! The chair!’ No. Now, it’s conquering me. I’m not going to live that way. The brain’s in charge not the leg. If you believe it, you can accomplish it.”

In this manner, Locke’s attitude in life was very goal oriented and reminiscent of a go-getter attitude typically held by the military.

As our conversation progressed, finally Locke revealed his source of inspiration to me. Locke told me he had taken part in a large scale rescue operation involving logging ships and their crew members during his military days. He recounted how several logs had tipped over on a ship, which made it sink. As a result, hundreds of logs and lumber were spread across about a mile of the river with crew members “thrown right in the middle of it, and that’s where I was going to pull them out.” From this experience, Locke had been able to draw from it when faced with adversity relating to SCI. Locke described the experience and its ramifications further,
“I mean, the intensity of that rescue and the level that it put me on as a human being in awareness, that’s one of the things that I have to pull on if not my number one. Basically, it’s my comparison about, well, how can you stay negative when you look at what you know a human being can do? You know what I’m saying? What level we can rise to. Maybe that’s the way a guy looks at his kid when he’s born. It’s so intense that it automatically reduces the size of it. Things that are negative or bad happens to me, I automatically make them small. Wait a second. Boom. Perspective. Small. We’ve got it under control. If that makes any sense.”

Through our monthly conversations, Locke while at times was less than upbeat was rarely if ever negative about his life.

Jack: “I came from a superman world of disability...”

Out of all of the study participants, Jack was one of the most exceptional in terms of sheer individualism. Though Jack had been in wheelchair bound for more than twenty-five years, for a majority of those years Jack was one of the most competitive wheelchair racers in the nation. Jack’s greatest athletic accomplishment was participating in the Paralympics as a wheelchair racer. And, though Jack’s eventually retired from competitive wheelchair racing, he continued in the field as a sports commentator for televised races. However, Jack noticed that life in the mid forties to be a different than what he’s used to, especially in terms of personal health care, injury recovery, and functional independence.
In terms of personal health and injury recovery, an old shoulder injury had come back to haunt him from his athletic days, and Jack realized, “My body will never heal the same way at forty-six as it did when I was twenty or even thirty. I’m a little more cautious just because I want to maintain the highest level of quality of life for the good years I’ve got left.” And though Jack realized this, he also realized that increased caution was also a trade off as he commented, “I came from a superman world of disability being involved in the whole racing thing and traveling. I never had a common disabled life. So for me when I have to slow down, it means I’m not living my life to the fullest. It’s going to keep my life from being as active and full and rich as I would like for it to have been.”

Also related to Jack’s new attitude towards personal care and recovery was a greater dependence on his wife for care. During one of his latest falls, Jack commented, “It hurt my family because my wife had to step in so much more than I think she was ready to at the time. We all had to pull together to get through a rough stretch, and the hurricanes couldn’t help. We got though those too.” Jack had also begun a slow change to add more precautions in his life, such as adding a modified chair for his car. In this case, Jack stated, “I’ve made that one change based upon the idea that I could make not only my life easier but also easier on my family.”

Arona: “I would have been in the river.”

The active 2004 and 2005 hurricane seasons damaged much of the state of Florida, including the San Pacifica city park, which was a riverfront park that Arona, an elderly veteran, visited weekly and sometimes even daily. One day like any other, Arona was visiting the park and in a moment of distraction, drove his power chair off a seven
inch curb. Though Arona knew of the curb drop, the hurricane seasons rearranged much of the park’s landscape. The landmarks that Arona recognized to avoid obstacles and hazardous terrain were no longer there. As result, Arona fell out of his chair and landed on his face and right arm. Arona began yelling for help, but soon his voice gave out. Arona saw a city worker not too far away in a lawn mower. But, the worker did not see Arona on the ground struggling for help, and Arona guessed the worker thought his power chair “was some piece of equipment that was working down there.” Eventually, after about forty minutes on the ground, someone came by and helped Arona up. Arona’s wife was quickly contacted, and he was taken to the hospital and diagnosed with a spiral fracture in his right humerus.

Specifically, Arona mentioned how his life had changed since his fall in terms of acute pain, dependency, and helplessness. The first days after the fall “were really horrendous” since “regular hospitals do not know how to deal with quadriplegics.” At home Arona had to deal with transfers that were considerably more painful. His sleeping was erratic since he could not sleep on his right side due to his injury. Pressure sores were another concern since he was spending so much time on his back sleeping. Furthermore, his wife was also his aid and care-giver, and their relationship was described by Arona, “The family, there’s one thing that’s changed. I’ve been very irritable due to the pain and sometimes I can be depressed. She keeps forgetting that I’ve got a broken arm. I am more demanding, and therefore she’s more defensive and irritable.”

In terms of how Arona interpreted his fall experience and consequences, he stated that he’s very down on himself since he “prides himself as very independent person” and
he “did a very stupid thing.” He said this was especially true considering the fact that if
he had fallen five feet further he “would have been in the river. That would have been
disastrous. Sleeping with the fishes.” Finally, about his life after the fall, Arona said, “I
don’t think normality is on the horizon”. Arona stated that he feels like a prisoner in his
own body. Feelings and thoughts of hopelessness and helplessness often find themselves
occupying Arona’s mind, bringing to the forefront his vulnerability, which he imagined
that “many spinal cord injured persons experience and feel similarly about.” Despite all
this, Arona continued to visit his favorite riverside park.

IV. Artifacts of the Military: Depression, Deception, and the Devil

This section describes two participants, Marlon and Reynard, and their own
unique difficulties in adjusting to life as a civilian after their military discharge.

Marlon: “I’ve had the gun in my mouth and all that stuff, you know?”

As a result of his war experiences, Marlon had suffered a tremendous amount of
physical and mental trauma. Currently in his late seventies, Marlon suffered from post
traumatic stress disorder (PTSD), anxiety attacks, decreasing health, intense physical
pain, depression, and had seriously considered suicide. Marlon believed that his
worsening overall condition stemmed from his experiences in the Navy and his
subsequent fifty-six years of medical treatment from the VA healthcare system.

Marlon recounted to me the story of how he first injured his back. He stated that
everyday he was on that ship, he was scared to death. On his ship, Marlon accidentally
fell, which lead to his back injury that would later paralyze him. His fellow crew
members helped him up, and rather than report his injury to the doctor he took a few aspirin and “hobbled it off.” When I asked him why he didn’t report his injury, Marlon stated, “We was in Hawaii, and we was going to get a long weekend. I hadn’t been on shore for ten months, and you’d have to be dead to give that up.”

Eventually, as Marlon’s back injury worsened, he attempted to get the care and compensation that he felt he justly felt deserved. However, Marlon had to battle with the VA healthcare system on the veracity of his disability claims. This battle with the VA lasted for decades, and only Marlon’s wife health insurance was able to provide him with the care he needed. Eventually, though, the VA did grant him fifty percent disability status. Marlon had this to comment, “I didn’t know how to go about getting my disability. I didn’t have no help, and I am classified as illiterate. Them people knew I was illiterate, and they could have helped me out. Them bastards turned me down. They denied it. I didn’t get disability until I finally went to the right doctors.”

Another issue regarding Marlon’s health is that he suffers from mental health conditions as well. Specifically, Marlon suffers from anxiety attacks as well as exhibiting suicidal tendencies. Marlon described his anxiety attacks, “I’m here by myself, okay? I get to hollering, screaming, and crying. I just let my hair down. Try to get it out. That’s what I try to do. You know, when you get started it takes a long time to get over them things.” Marlon confessed that he does not like to be in crowds and that he is especially wary of people walking behind him. He reasoned, “It’s dangerous, someone coming up behind me, and me not knowing what’s back there.”

At this point in his life, Marlon believed his life to be at “the end of the rope”. He’s entertained ideas of shooting himself or eating “some rat poison.” However,
Marlon stated that he is a religious man, and he at times stays up entire nights praying to the Lord to allow him to live long enough to see his grandson graduate college. Indeed, Marlon revealed to me his attempted suicide and the reasons why he desisted,

“I’ve had the gun in my mouth and all that stuff. Up beside my head and all that stuff. Wanting to end it all. But, I get to thinking about this boy, and they talked to me about it. They said ‘that boy needs you. Your wife needs you, and your family needs you.’ They try to put it off. So anyhow, they got the gun, and they hid it. Done away with it. I don’t know where it’s at. So I watch myself pretty close.”

During our last conversation, Marlon told me he hopes to live long enough to see his grandson complete his studies to become a minister. At that point, Marlon stated, “Then he can preach at my funeral.”

Reynard: “I was a soldier of the Devil.”

Reynard was an Air Force veteran who became paralyzed after a motorcycle accident. Though he did not tell me the exact details of his accident, apparently, Reynard was traveling at a hundred miles per hour at the time of his accident, and that no one else was hurt or injured except himself. He is proud of the latter statement. On his accident, Reynard said, “Out of a hundred people, two come out alive. I’m one of them. I didn’t lose no facial parts, no eyes, no lips, no nose, no nothing. I didn’t have no helmet on, no shirt, no nothing. The only thing I did was break everything on my right side and my back. A hundred miles per hour wide open. Most people would’ve got killed.”
According to Reynard, he had always lived life “wide open”, and that this lifestyle contributed to his motorcycle accident and spinal cord injury.

Like many veterans with SCI in this study, Reynard has traveled the world and has seen as well as participated in combat. However unlike many veterans, Reynard was quite forthright discussing his combat experience, military training, and his life post-military. According to Reynard, he saw combat in several South American skirmishes, mainly, in Honduras and Nicaragua during the early 1980s.

During one mission near the Honduras/Nicaragua border, Reynard described a story that revealed a slice of Reynard’s personality. He and his unit of thirty men were very close to engaging enemy forces in the jungle early Christmas morning. Reynard’s position was point, the first soldier on the front lines. Reynard said, “That’s where I wanted to be when the action started. I wanted to be on the front rocking and rolling, baby!” Ever vigilant, Reynard and his unit stayed up all night ready for an attack. However, the attack never came. Instead, U.S. marines had intercepted the enemy forces before they attacked Reynard’s unit. Though they avoided combat, Reynard stated that he and many of his unit were, oddly enough, both mad and sad that they did not get the chance to kill enemy soldiers. Disappointingly, Reynard said, “I could have been the first to take a bullet! I was ready!” The fleeting opportunity to kill (or be killed) aroused such powerful emotions in Reynard that he and a friend drank a half-gallon of Jack Daniels whiskey and a case of beer while crying on each other’s shoulders. Reynard explained his reaction and mixed emotional response, “Because we didn’t kill nobody, that’s how hyped up they had us. And, then boom! they kick us out on the street feeling that way, and they wonder why we act crazy.”
From here, the conversation naturally segued into what Reynard had referred in the previous statement as “acting crazy” and life post-military. During our conversation, the current Iraq War became a topic of discussion. This particular discussion revolved around suicide bombers and segued into Reynard discussing his views of life post-military. Reynard proclaimed,

“I’m a natural born killer, and trained by the government. I was a soldier of the Devil. That’s something else I told the psychiatrist. Ya’ll get us in there, and ya’ll give us these big, bad weapons and just take human tragedy. Life. Whatever. And ya’ll train us and train us and program us, and the next thing you know, boom! It’s time for us to get out. And, ya’ll let us go out on the streets. Ya’ll ain’t letting out nothing but killers on the streets. You’re all programming us to kill, taught us how to do it effectively, but you didn’t de-program us or give us counseling. You got a lot of crazy people walking around. They can kill you in an instant, and it ain’t nobody’s fault but the government’s because they didn’t deprogram us. You program somebody, and you don’t de-program, you got a problem.”

To prove his point further, Reynard told me that for a time his neighborhood was victim to a series of robberies and thefts, and his son’s special “trick bicycle” was stolen as well. As a result, Reynard became a self-appointed neighborhood guard, which consisted of him staying up all night with a loaded 9mm pistol “looking for trouble.” Reynard viewed himself as a “vigilante” and even so far as a “dad gum wrecking crew”. He told me only the Lord knew how dangerous he was, and that if anyone “messes with” his loved ones and friend that he would, “light them up so quick. I’ll show them
something they didn’t even know existed.” Yet again, the topic of killing was brought up as Reynard said, “I’m not just out there to kill nobody. You can’t do that, but I know how to fix that if it came down to it. I hope it don’t come down to that.” Listening to Reynard, I had no doubt that his intentions were genuine and that he meant every word he said. Finally, Reynard confessed, “I’ve been a warrior forever for the Devil. I mean a big time warrior. I’m going to flip it over and be a warrior for the winning team, on the Lord’s team. I just felt like the Lord has put it on me to testify sometimes. And that’s what I just finished doing.”

Summary

The chapter presented both the demographic and qualitative data generated from this study. Overall, the study population of veterans with a spinal cord injury consisted mainly of white, married men with an average age in the low 50s in self-reportedly good health. From the qualitative interviews a number of themes emerged, which were presented in this chapter in the form of vignettes. The themes illustrated several issues that veterans with a spinal cord face on a daily basis. The themes and issues included: functional independence in the form of employment and mobility; social relationships; the urban environment and wheelchair-friendly access and services; social and political activism; quality of healthcare; short term, transitional, and long term views on disability and spinal cord injury; depression; and life post-military.

As a tool for presenting qualitative findings, vignettes can illustrate and paint the everyday activities, behaviors, and issues that surround the lives of veterans with a spinal cord injury. The question of how to present the data in a manner that is both meaningful
to the reader and respectful to the study participants is an issue of great importance for me as it surely is for many anthropologists. The decision to employ vignettes was due to its potential ability to draw the reader into the lives of veterans with a spinal cord injury while presenting the emergent themes in a manner that emphasizes experiential and contextual representation. Most importantly, the method of presentation of the results should be based on an approach that best addresses the research questions and the study population. The discussion of the research questions will be discussed in the next chapter.
Chapter Six

Discussion

Introduction

This section discusses and interprets the results from the qualitative data in light of the five main research questions. Each question is addressed below. Some questions are addressed more fully than others due to both the overlapping nature of the individual research questions and to the results of the study. Though the discussions for each question may intersect other research question discussions, it is important to view the questions and their discussions as a greater cohesive and related whole. Finally, it should be noted that much of the qualitative data results can be classified as exploratory in nature, and should be treated as such. Recommendations and conclusions will be presented in the next chapter.

Discussion

Research Question One: How do veterans as American citizens deal with life as disabled SCI person, and how do they view themselves in light of America’s cultural values?

The veterans with a SCI in this study represented many different types of lifestyles. Included within these lifestyles are their own unique issues, concerns, aspirations, goals, and unmet needs, all of which are related contextually for each veteran with a SCI. Therefore, the ways or strategies each veteran employs in order to deal with life are varied for each case. Again, what is important to note is that each case is
intrinsically related to both its social context and its specific moment in time. That is, at the time of the study each veteran was dealing with his or her own life issues, and therefore the context of their situations at that moment in time is as significant and important as their strategies for addressing those issues. Capturing the specific context was one of the most important factors for choosing to present the data as vignettes.

There were a number of general life issues and concerns surrounding the lives of veterans in this study population. These issues include: functional independence; mobility in urban environments; health and healthcare including wheelchair-related injuries; discrimination; and depression. In this study, functional independence refers to the ability of the participant to perform daily acts of self-care and wheelchair activities as defined by the participant and their situation rather than a clinically defined functional independence measure based on motor skills and cognitive tests. No doubt that clinically based measures are important, however this research question seeks to explore and identify participant perceived life issues, concerns, and meaningful outcomes. Functional independence also refers to the participant’s ability to propel and function in their wheelchair; ability to perform transfers from their wheelchair to other surfaces; and their ability to recover from a wheelchair related-fall or injury.

The issues and concerns of decreased functional independence can readily be seen in the cases of Aileen and Wren. Both women have expressed troubles and difficulties while participating in social activities in their wheelchairs, fall recovery, and a general weakened state and diminished strength. While both women have strongly expressed a desire to achieve a greater sense of independence, as of our last conversations neither one had taken significant action to achieve their goals. Additionally, former Paralympian,
Jack, could no longer live his former lifestyle and rely solely on his athleticism to pull him through life’s obstacles. Instead Jack has had to steadily maintain his ability to be independent by “slowing down”, becoming “more cautious”, and relying on more technology in his everyday life. Unfortunately, by his own admission, Jack stated that the implementation of these strategies for negotiating health and independence would lead to a life less active and rich, a life that couldn’t be experience to the fullest.

The issue of mobility in urban environments centers on the obstacles presented to veterans that prevent or hinder them from traveling in their wheelchairs without risk of injury. This can include the physical environment as in the cases of Arona and Harper. Both Arona and Harper, and possibly other participants, have had to navigate their powerchairs through damaged sidewalks or wheelchair inaccessible sidewalks, which lead to a serious wheelchair fall and injury to Arona. Additionally, traveling on high traffic roadsides was a normal occurrence according to Harper. For Arona, the fall and injury significantly affected his quality of life and mental state, and a “sense of normality” was not on the horizon for Arona. In Harper’s case, his strategy to avoid potentially dangerous sidewalks and roads was to ride his ATV. However, such a strategy also provided its own problems, namely, the police and the legality of his actions. Like Arona, Harper’s actions led to a serious injury. According to Harper, he has returned to riding his powerchair instead of utilizing his ATV. Mobility issues can include social contexts such as with Felix during his business trip in England. Felix’s problem centered on his inability to hail a English taxicab after hours of trying were due, according to Felix’s observations, to his wheelchair bound status. The difficulty to assemble wheelchair accessible ramps was cited by Felix to be a hassle for taxicab
drivers. The one instance where a driver did assemble the ramp for Felix resulted in a fall when Felix attempted to enter the cab. Rather than spend further hours attempting to hail a taxi, Felix now spends more time to make travel arrangements by either hiring private drivers or renting a car himself.

Health status and access to healthcare was a constant and almost implicit concern among all the participants as life with SCI also entails a number of secondary health conditions or co-morbidities such as pressure sores, weakening physical strength, constant pain, and wheelchair-related injuries and falls. Indeed, all of the participants of this study were recruited into the VA study due to the growing importance and burden of wheelchair-related falls and injuries. The ability to receive quality healthcare is also related to health as health status must be, at best, constantly and vigilantly maintained by veterans with a SCI.

The participants were in their own ways concerned with their health status and/ or accessing proper and meaningful healthcare. Aileen and Wren were both concerned with their diminished health status and growing inability to either propel their wheelchair or partially walk. Jacke, Locke, and Felix focused their attentions on their own individual strategies to maintain their health and independent status. At the time of the interviews, Arona and Basil were both actively pursuing quality healthcare services though both stated that their doctors either did not know how to treat them (SCI status) or did not care about them and essentially disrespected their own personal observations. Finally, for both Marlon and Reynard issues of mental health, depression, and post-traumatic stress disorder were cited as major concerns. For Marlon a barrage of both mental and physical health problems were taking their toll on him. And in Reynard’s case, a problem of re-
adjusting to civilian life after years of military service discharge due to a lack of what he called “de-programming” has haunted him and affected his behavior ever since. At the time of our conversations, Reynard was seeing a psychiatrist for this problem.

The discussion of this research question has centered mainly on the general life issues and concerns of veterans with a SCI. Strategies as to how the participants dealt with these issues is also touched upon in this question’s discussion; however the strategies and how life is approached by the participants will also be discussed more specifically in the rest of this chapter. The discussion of American values, the values of veterans with a SCI, and the relationships between the two will also be discussed in the rest of the chapter.

Research Question Two: What are the similarities and differences between the value systems of American society and the culture of SCI persons?

From the qualitative results generated, the values of the veterans with SCI in this study were not much, if any, different from the values held dear in American society. Within the core American values, a broad range of expressions exists for each of the individual core values within members of society. This can be illustrated through each of the study participants within their own respective social contexts. Each participant displays their own individual expression or interpretation of the core American cultural values. Again, it should be stressed that the participants’ expressions of their values are rooted within their specific social contexts.

Independence in its many varied forms, from functional and mobile independence to financial independence, is very much prized by this sample of veterans with a SCI.
Definitely, the two most cited and prized values among this study group are independence and self-reliance. Participants also touched upon other core American values such as individualism, and goal-oriented activism. From the results, veterans with a SCI also stressed the value of their health as well as healthy practices access to proper and meaningful healthcare.

Specifically, functional, mobile, and financial independence and self-reliance were cited most among participants. However, not all of the participants at the time were able to “achieve” this goal (as defined by each participant). Rather, independence and self-reliance were values and ideals that had either yet to be reached or was still in the process of being achieved or negotiated. For example, in terms of functional mobility both Aileen and Wren held to the belief that they could become more independent and active if only they were given the chances and opportunities to do so. In Aileen’s case, the main barriers to functional independence with using both a wheelchair and crutches were her fear of falling due to a previous fall-related injury as well as an overly protective attitude adopted by some of her friends and church acquaintances. Both barriers effectively limited her ability to take part in social activities with her friends and acquaintances. For Wren, her ability to partially walk and even propel her wheelchair had been severely limited by the continued weakening of her upper body strength as well as her difficulty in finding an active participant to help her walk. Additionally, financial independence was also a value strongly stressed by Wren as she had been continuously employed since she was nine years old until the time of her SCI. For veterans like Aileen and Wren, these are values still held high but at the moment appear to be unreachable. Indeed, perhaps these two women cherished the values of independence and self-reliance
more than any other study participant simply because they have either yet to achieve it or have lost it.

From the results, it can be strongly inferred that functional mobility and financial independence are also values held high by participants like Jack and Felix, who are both successful in their own right. Jack, who is a sportscaster and former Paralympian, and Felix, a globe traveling salesman and self-proclaimed achiever of the American dream, can be characterized to be highly independent and self-reliant by perhaps any American standard. Independence and self-reliance, while not stated or defined explicitly, was an underlying theme within both their accounts. Both of their accounts centered on maintaining their own respective ideas and concepts of independence and self-reliance. Stated again, Jack was concerned about incorporating new assisted technology into his lifestyle while Felix was confronting his traveling difficulties in London.

Regarding both the American values of independence and individualism, one of the most obvious examples of this value exhibited within a participant is Harper. Particularly, Harper’s philosophy and action concerning his ability to safely travel on the roads of his hometown, which has in the past led him to operate his ATV on roads and sidewalks, a practice which I documented only once in the entire VA study population. The issue for Harper was safety from environmental obstacles and cars. Additionally, riding the ATV has the added benefit of providing Harper a sense of freedom from his disability. By riding his ATV, Harper also felt that he achieved a greater sense of independence by being able to achieve more household duties as well as take part in more social functions with family and friends. The desire to achieve safe mobility, a sense of
freedom, and greater independence led Harper to utilize his ATV in ways, which may have been lawfully ambiguous at best.

Other notable cases of individualism can be seen in Basil, Locke, and Jack. Being both a political activist and hurricane relief worker can be seen as noteworthy, but considering Basil’s SCI status these achievements might be seen as even more exceptional to some people. While Basil did injury himself as a hurricane relief worker for the Army Corps of Engineers, our conversation indicated that his desire to further pursue his political and social activism had not diminished but increased due to his son’s military status in the current Iraq War. Locke’s individualism was clearly exhibited by his attitude towards life and, especially, SCI and disability. Essentially, Locke has adopted a very pro-active, mind-over-matter attitude and philosophical outlook on life and any obstacles in his path. Interestingly enough, Locke’s philosophical outlook on life incorporated many military and battle metaphors to the effect of conquering life’s obstacles. Such an outlook is reminiscent of the attitudes adopted by cancer support groups or other self-help groups. By drawing on his past military experiences, Locke’s demeanor and outlook on life was unique compared to other participants.

As with the American value of individualism, the American value of goal-oriented activism is most readily seen exhibited through Harper. Particularly, Harper’s years long ongoing battle with his local government regarding the shoddy state of his city’s sidewalks and curb cuts is a clear example of goal-oriented activism. Additionally, Basil’s search for proper and meaningful healthcare regarding his injury along with his subsequent pain and profuse sweating is another strong example of goal-oriented activism and behavior demonstrated among study participants. For Reynard, the crime in
his neighborhood has driven him to become a self-declared armed, one-man neighborhood watch. Additionally, Reynard seemed to genuinely regret his past military behaviors and actions, and at the time of interviews, he was seeking psychiatric as well as religious help in order for him to overcome these personal issues. The desire to be functionally mobile and independent on the part of Aileen and Wren can also be viewed as a form of goal-oriented activism.

Finally, from the discussion of the first research question, health and healthcare was identified to be an important issue. Given that values are conceptions and assumptions of what is desirable, and that they help shape aspects of people’s lives, then health and healthcare can be seen as a value prized among SCI veterans in this study group. This may be especially true since many, if not all, of the participants engage in maintaining their health constantly. Within the realm of health and healthcare, the role of family and/ or social support as well as professional caregivers of veterans with a SCI becomes a topic of great interest. Though family and social support were mentioned briefly, participants did not expound on the significance of their role. Health and access to healthcare are likely to also be valued among Americans in general. However, the differences in opinions and views on health and access to healthcare, if any, of the majority of Americans and persons with a SCI are unknown. Therefore, health, healthcare, and social support among persons with an SCI should be an avenue of further research.
Research Question Three: Where do disabled SCI veterans situate themselves in American society, and where may they be situated according to American society?

Again, while there have been many lifestyles reported through the results, where exactly veterans with SCI situate themselves is dependent on the individual case. Though almost all of the veterans did not speak of this issue directly, their stories offer clues and inferences. While some members of the study sample were active either in their community, families, and/or occupations, the opposite was also true. Many study participants were not active in any well-defined community, though it is possible that some participants did not mention their community participation. For example, while Jack (sportscaster), Felix (salesman), Basil (relief worker), and even Reynard (as a neighborhood enforcer) were actively participating in a goal-oriented environment with a positive mindset, others like Aileen, Wren, Arona, Marlon, Reynard, and Locke were not though they may have been at one time. Though Locke did not indicate whether or not he is actively participating as a member of society, his resilience and optimism has not diminished.

Consequently, Aileen, Wren, Arona, Marlon, and Reynard have exhibited the generally more negative outlooks on life within this study population. The influence of gender and age of the participants may play a role in their negative outlooks. Aileen and Wren were two of only three female veterans with SCI in the study, so the influence of gender on participants’ outlooks on life and overall situations in life is not clear. It may be that younger male participants in the study are better able to achieve their goals and maintain positive outlooks on life in light of their own conditions and problems. On the other hand, it may be harder for women and older participants to achieve similar
standings in society. For example, Arona and Marlon were elderly participants with negative life attitudes and mental health issues. However, their age as an influencing factor in their outlooks was not explored in-depth. Be that as it may, the depression and negative outlooks of both Arona and Marlon cannot be denied. Thoughts of vulnerability and feelings of helplessness pervaded Arona’s thoughts at the time of the interview, and he believed that other persons with SCI experienced similar thoughts and feelings. Marlon’s account revealed an almost fatalistic outlook on life, the pinnacle of which would be Marlon’s desire to have his own grandson preach at his own funeral. Indeed, before Marlon dies one of his goals in life is to see his grandson graduate college. In his account feels survive until and then he can let go of life From his account, Marlon seems as if he is holding onto life until his grandson graduates, and then Marlon can let go of life. Undoubtedly, gender and age can affect veterans and persons with SCI in terms of their outlook on life, whether positive or negative. However, the effects of these two factors are beyond the scope of this thesis, and their roles in the focus population are points that could be explored in further studies.

In regards to where veterans with SCI are situated according to American society, this is a much more difficult question to answer. The general American public was not directly surveyed on their opinions in this study. Be that as it may, the stories of Aileen and Harper do point at how some Americans view persons with a SCI. In the case of Aileen, the members of her church may excessively pamper her in terms of her “safety” and whether they can serve her in some manner. Though, the members of the church may be acting with genuine sincerity, their overbearing attitudes and behaviors denied Aileen the opportunities to achieve or even attempt to achieve everyday type activities.
These activities may be meaningless to members of the church and “able” bodied people, but for persons with a SCI or to the disabled population in general, such activities may reaffirm identities by creating a sense of independence and self-reliance, which are core American values.

Through Harper’s story, discrimination and even hate towards persons with a SCI are evident. In Harper’s hometown, persons with a SCI can be quite limited in their ability to travel the city in their wheelchair due to the inconsistency of curb cuts and ramps in sidewalks. According to Harper’s experiences, the entire state of Florida is equally inaccessible to wheelchair users. Most disturbing is Harper’s accounts of hateful slurs and insults. As stated in his story, while traveling on the side of the road, people in cars would honk and yell insults. Though not explicitly mentioned in Harper’s story, while on his crusade to inform the city on the safety issues surrounding wheelchair users, he would often receive derogatory responses and engage in heated exchanges. Harper’s experiences do reflect a historical animosity towards disabled people in America by viewing them as second-class citizens.

Like Harper, discrimination has played a part in Wren’s life post-SCI. According to Wren, her inability to find gainful employment was due to potential employers’ views on her SCI and disability. In her account, Wren stated that one potential employer did not hire her because the employer was doubtful at how useful Wren could be in her wheelchair. According to Wren, her potential employer had hired “somebody that was walking” instead of her. Again, Wren’s account also reflects a view in America that people in wheelchairs, and perhaps people with other disabilities, might be somehow less productive and/ or efficient in the workplace. One avenue for further exploration could
center on the affects of the American with Disability Act (ADA) of 1990 in regards to both the implementation or lack thereof wheelchair accessible construction and planning as well as employment trends and issues.

Finally, Reynard seems to be a unique case in that he has admitted to a having a difficult time adjusting to life after his military career. An issue that has haunted Reynard since his military discharge was the Air Force’s inability to “de-program” him and ease him into life as a civilian. From our conversations, Reynard often spoke of his desire to live “wide open”, which eventually led to his SCI. Whether or not this lifestyle of living “wide open” was one cultivated in the military is unknown, however Reynard has indicated that the lack of “de-programming” veterans has affected others besides him. Without this “de-programming” or counseling, Reynard has stated that he and other veterans “act crazy” at times. It may be that for years Reynard and other veterans like him have been living life outside of the military, but not as civilians per se. For these veterans, it is very plausible that they occupy a liminal state somewhere in between life as a member of the armed forces and as a member of American civilian society. The implications of the effectiveness of military “de-programming” or counseling on the transitioning of veterans into civilian life is an area of great importance for both veterans and civilians, especially considering the veterans returning from the current Iraq War.

Though the discussion here centers mostly on negative attitudes towards persons with SCI, this research question does bear further exploration. Further research is also needed on how and where veterans with SCI situate themselves in American society, and also the attitudes of American society regarding veterans and persons with a SCI. Hypothetically, the level of independence, self-reliance, and resiliency one has may affect
how veterans with SCI generate meaning as members of society and as American citizens. How each veteran or person with a SCI approaches their own issues and problems may influence how other members of American society view them. Observational data and further research on this issue is needed in order to better understand the dialogue and social interactions between veterans and persons with a SCI and American society as well as the influence and affects of historical and political institutions on American society in relation to veterans and persons with a SCI.

Research Question Four: What does it mean to disabled SCI veterans when they cannot meet the cultural values and standards of American society, and where does this lead them?

As stated earlier, the research questions and their discussions are certainly related to each other in the greater context of the culture of veterans with a SCI. This question can be linked to the discussion of research questions one and three. Specifically, the topics of questions one and three discussed how veterans with SCI dealt with in Americans and where they situated themselves in society. Again, values are concepts and ideas adopted and developed by society in order to determine desirable behaviors and actions. As a result, when the study participants discussed their life issues and concerns and how to approach them, their values became readily apparent. This was especially true for those participants who were in the process of negotiating and attempting to achieve life goals that were important to them. With these particular study participants, depression and anger were the conditions or consequences.
Those study participants who suffered depression were Arona, Aileen, and Wren. At the time of the interview, Arona, an elderly veteran, was in the process of recovering from his injury (fracture). Arona’s level of pain had increased significantly, he was having difficulty resting, and his ability to be mobile had decreased since the injury. Add to this, Arona, who already relied on his wife as his caregiver, added further burdens and duties on her as a result of his injury, which added strains to their relationship. Arona prided himself as a very independent person, and his injury brought him down to a level of increased dependency. The consequences of Arona’s injury, the fact that he almost fell into a river, and his dependency had brought in him feelings and thoughts of hopelessness and helplessness.

In the cases of Aileen and Wren, the sources of their depression stemmed from social interactions and their diminished health, both of which affected their ability to be independent. With Aileen, her stifling and overbearing friends and church group prevented her from conducting everyday activities. These activities may be seen as trivial to her friends and church group were activities that Aileen wished to accomplish. The fact that such activities were viewed as normal and daily occurrences was the very reasons why Aileen wanted to do them. Given that independence was Aileen’s goal, such actions and their completion could serve to reaffirm her identity.

Similarly, Wren’s failed efforts to find gainful employment were the source of her depression. This is made more apparent when considering that Wren had been continuously employed since a early age and a store manager at the time of her SCI. Rather than being able to financially support herself and her daughter, Wren has had to receive welfare and worker’s compensation. Like Aileen, the act of working and
providing for her family was seen as a normal and everyday activity that Wren used to conduct before her SCI. To not be able to do so was the source of her shame and depression.

Furthermore, for both women their relative conditions were made even worse due to their diminishing health. Both women were losing upper body strength as well as confidence in their abilities to be mobile in their wheelchairs and walkers/crutches. For Aileen and Wren, a sense of independence had yet to be achieved.

Harper and Basil both exhibited anger towards their respective life situations and concerns. Harper’s anger stemmed from his issue of safe mobility. Specifically, Harper gained a level of safe mobility and increased independence when utilizing his ATV for transportation. Additionally, when Harper rode his ATV he felt a sense of freedom from his disability. However, this was short lived as Harper was involved in an accident that resulted in an injury when he tried to evade police under the assumption that riding an ATV in town was illegal. Consequently, Harper no longer rides his ATV. Unlike Aileen and Wren, Harper felt that he achieved a level of independence and well-being, which he lost once he stopped riding his ATV. What’s clear is that Harper perceives the local government to be at fault for his “regression” from independence. Rather than allowing Harper to ride what he believes to be the safest form of transportation, the local government imposes “inappropriate” guidelines for wheelchair and damaged sidewalks add insult to injury. Though Harper has become more involved in city affairs concerning damaged sidewalks and wheelchair friendly access, his approach to city officials has been an angry one.
Basil’s situation is similar to Harper’s in that Basil felt an intense frustration towards his many healthcare providers and their inability to diagnose his unknown and potentially serious ailment. After a month, multiple doctor visits, and a battery of tests, Basil’s condition had yet to be identified. Understandably, Basil became frustrated and angry in that he felt his doctors were neither as smart nor as competent as they portrayed themselves to be. As stated earlier, good health and, subsequently, healthy practices and access to healthcare was often mentioned by study participants as a value. On his part, Basil felt that he was doing all that he could in order to facilitate his recovery. Basil also voiced his opinion that his doctors were not taking his own insights and observations into consideration.

Though both Jack and Felix had obtained a high level of independence, it should be noted that such a state of independence is not merely a static condition, but one that is always in flux. Both Jack and Felix are still maintaining their functional and financial independence, however, they are continually maintaining and negotiating their own sense of functional or mobile independence. Jack, by his own admission from former superman status, has stated that lifestyle changes are in order for him to maintain a level of functional independence as well as easing duties and burdens on his wife and family. However, as stated in the discussion for the first research question, this also entails a life not lived to its fullest for Jack. Felix on the other hand must continue to negotiate his ability to be functionally mobile while traveling abroad, especially in England and in their taxicabs. This entails a greater degree of travel planning and accommodations as well as potential further discrimination on Felix’s part. So while Jack and Felix may
have achieved a level of independence, the balance between independence and dependency can, and likely does, shift throughout life depending on one’s circumstances.

Research Question Five: How do SCI veterans maintain either a positive or negative outlook on life?

The fifth and final research question is very much related to the fourth research question. That is, both questions seek to explore the issues of achievement and/or maintenance (or lack thereof) of cultural values and standards and their subsequent consequences among veterans with SCI. Though each case or participant should be viewed in their own specific circumstances, the issue of participant-perceived control over their lives is related to their overall positive or negative attitudes in life. The topic of participants’ perception of control over their own life as it relates to their values and life concerns are briefly discussed here.

The data suggests that the participants’ perceived level of self-control over their life influences their reaction to life issues and obstacles. Whereas Arona, Aileen, and Wren seem to have mostly personal problems and obstacles to their independence, Harper and Basil must contend with mostly outside forces in the form of local government and healthcare providers. It’s possible that Arona, Aileen, and Wren view their “failures” as a reflection of their own personal character, which led to their depression. This is explicit in Arona’s case as he prided himself on his independence and that he viewed his fall and resultant injury as a “very stupid thing.” On the other hand, Basil was carrying out his role as a patient, and his doctors were not as successful at living up to his ideas of their roles as healers. Both Basil and Harper’s cases are similar
in that they both, according to their accounts, were not entirely at fault for their situations. Rather, their situations were mostly dictated by their social environments, which came in the form of the healthcare providers and the local government respectively. Jack and Felix’s stories also reflect a personal achievement in the face of adversity as well. Both of their accounts stress their own personal achievements and ability to tackle their life issues, and both have a generally positive attitude towards life. While the data in this study only hint at the role of participant-perceived control of their own lives in relationship to their life goals, this topic bears further investigation.

While these generalities may be true for the above study participants, the cases of Locke, Marlon, and Reynard are less clear in regards to how their life events, concerns, and achievements affect or influence their attitudes in life. Locke’s humorous nature and “conquering” outlook on his SCI and the obstacles presented by his disability clearly demonstrate his positive outlook in life. However, at the time of the interview Locke’s life concerns, if he had any at all, were not revealed. So while his positive attitude towards life was clear, the application of his attitude towards his obstacles in his life was unclear. Locke only briefly mentioned how his attitude helped his recovery of a past leg injury by motivating himself to better care for it instead of letting it “conquer” him. That such positive, proactive attitudes exist among persons with a SCI are not surprising. However, the ways in which these attitudes are developed (pre or post SCI?) and negotiated (balance between positive and negative outlooks) in light of life’s obstacles should be a topic of further research.

Both Marlon and Reynard were participants whose military experiences had lasting effects on their lives after their discharge. In Marlon’s case, he endured a decades
long battle with the Veterans Health Administration concerning his disability health coverage. In addition to his SCI, Marlon is an elderly veteran suffering from a number of other health conditions such as PTSD, anxiety attacks, depression, and has seriously considered suicide at times. Essentially, much of Marlon’s life has been a struggle to receive the proper healthcare and mental health services to address his myriad conditions, which he states stems from his life in the military. Like Marlon, Reynard has had a difficult time adjusting to life post-military. Reynard’s difficulty is his inability to limit his military inclinations and training from his current civilian life. Specifically, Reynard’s battle experiences and tendency to live life “wide open” have led him to “act crazy” at times. Regardless of whether or not his tendency to live life “wide open” was developed or cultivated in the military is unknown, Reynard has explicitly stated in his interview that the problem was the military’s failure in “de-programming” him (and others) in preparation for civilian life.

Clearly, both Marlon and Reynard suffer from chronic issues, which stemmed in part from their lives in the military. Unlike the other participants, whose life issues revolve mainly around the cycle of achieving, negotiating, and maintaining independence and self-reliance, the life issues of Marlon and Reynard are ones of complex behavioral problems. These behavioral problems are deeply embedded in their previous lives, and both participants feel that their respective military branches have mistreated them by denying them timely rehabilitation services. While the other participants’ life issues and strategies for approaching them are more clearly identifiable, the issues surrounding Marlon and Reynard are topics that bear the need for further research. The role and extent of their SCI in relation to their behavioral problems was not revealed in the interviews.
Though it is entirely possible that their behavioral problems are not related to their SCI, the fact remains that these two participants are indeed veterans with SCI that do suffer from mental and behavioral issues. Though these issues were only present in two participants, other veterans with a SCI may also be experiencing similar concerns, which if true presents a greater problem than this study indicates. It should also be noted that both Marlon and Reynard were also the only two participants who expressed a deep belief in God and the potential power of religion as a form of coping with their problems. For Marlon, his grandson, a minister in training, provides him with social support and a goal in life. Reynard also states that he has recently discovered God as a means and goal to turn his life around. The role of religion as a strategy for healing among veterans with SCI is also a topic that bears further need for research.

Summary

Analysis of the qualitative data revealed several insights into the lives of the veterans with SCI population in this study. The participants in this study, as Americans, shared many of the same core American cultural values (independence, self-reliance, and goal-oriented activism) identified in the literature review. Values can be viewed as society’s conception of desirable behaviors, which help shape aspects of people’s lives and identity. Therefore, the behaviors (ideal and real) of people are inherently linked to their own interpretations of these core values within their own experiential context. While participants shared these same core values, each participant’s views on these values were manifested through the narratives of their own lifestyles and situations.
Each of the participants experienced their own unique life issues, concerns, and unmet needs. Overall, though, these life issues and needs centered mainly on participants’ constant desire and activism towards achieving independence and self-reliance.

Independence and self-reliance, while broad in their scope, encompassed achieving ideals of functional and mobile independence as well as financial independence. Additionally, the issue of maintaining and/or improving health and access to healthcare was an underlying issue among participants.

The actual process that participants undertook in order to achieve their ideal states or goals (which were influenced by their core values) is a topic of significance. It should be noted that the process is not a static one, but rather it is a dynamic process. Participants were either attempting to achieve their own goals or were in the process of maintaining and negotiating their “successful” attempts. While some participants may have “achieved” a level of independence, others were seen to have lost a level of independence and were in the process of regaining it. Therefore, this process of achieving their goals and ideal states is not a linear process where once an ideal state, such as independence, is gained it cannot be lost. Rather, this process should be seen as a cyclical feedback loop embedded in both the participants’ social and environmental contexts as well as in the greater scheme of American society. That is, within the greater context of American culture, this process of negotiation between both society and the individual occur. This process of negotiation centers on how the individual creates and maintains an identity in light of society’s values. This manifested in participants as either positive or negative outlooks on their own lives in the context of their own struggles in life and how well they perceived their own progress. Inherently, the ways in which
participants viewed themselves were influenced by their conceptions of the core American cultural values.

Finally, it should be noted that this study was exploratory in nature, and the conclusions should not be viewed to be representative of the entire population of persons with SCI in America. The population of veterans and persons with SCI is one that is not well represented in anthropological literature. Therefore, this study sought to explore general topics among veterans with SCI. The exploratory data generated from this study can provide further avenues of research within the focus population of persons with SCI as well in the field of disability studies.
Chapter Seven

Conclusions and Recommendations

Introduction

This chapter briefly recaps the results, analysis and discussion of the qualitative data generated in this study. Synthesizing the central themes of this study, several conclusions about the study population can be drawn and are discussed in this chapter. The results of this study are discussed within the context of the previous literature. The policy recommendations and implications are made within the context of the research and the focus population of veterans and persons with SCI as well as the general “disabled” population. Finally, anthropological and public health contributions of this thesis and their roles in the field of disability studies, especially within this focus population, are also presented.

Conclusions in the Context of the Previous Anthropological Literature

This section discusses the results of this thesis in the context of the previous anthropological literature on the topic of disability. Conceptions of disability from this study are compared to definitions found in the anthropological literature. The “culture of disability” as it relates to focus population of veterans and persons with SCI is discussed. The topic of stigma in the lives of the focus population is addressed. Finally, the values of this population is compared to findings from the previous literature on the anthropology of values.
From the results of this thesis, conceptions of disability drawn from the study participants are very much in alignment with previous anthropological definitions of disability. That is, anthropological definitions of disability stress the socio-cultural perceptions of cultural norms surrounding the body (Murphy, 1987; Shuttleworth and Kasnitz, 2004; Whyte and Ingstad, 1995). Disability is defined and given meaning by one’s society and culture. The results of this study portrayed participants, who in their own ways, were very resourceful in terms of navigating through their daily life activities and hardships. On the other hand, the results revealed that a number of daily environmental and socio-cultural obstacles faced by participants were beyond their control. Such obstacles included such as broken sidewalks and discrimination. This also supports the idea that it is society and culture that defines certain people as disabled. Based on arbitrary social and functional criteria, disability is the process by which society and culture define and influence social identity for a large number of people.

The focus population of veterans and persons with SCI is a unique cultural group of people within the United States. However, its standing among the greater “culture of disability” is not clear. It is true that the participants of this study shared a unique perspective through their veteran and SCI status. This perspective included specialized terminology related to their SCI and concepts of identity. This also included similar experiences and feelings of participants interacting with their friends, family, and cultural group as well as within the general American population. Though it is clear that a “culture” existed among this group, it is unclear whether or not this culture is one strengthened by their connections as United States veterans (including their continued treatment at VA medical hospitals and clinics) or through their SCI or through both
commonalities. Additionally, it is not clear how this focus population of veterans and persons with SCI view themselves in relation to the greater “culture of disability”. This is discussed in more detail in the recommendations section of this chapter.

The concept of stigma, a discrediting negative attribute, is tied to socio-cultural beliefs and notions of disability. Consequently, the population of persons with SCI is also a stigmatized group. The role of stigma in the lives of the study participants manifested in the form of discrimination, both in social and environmental aspects. As a whole, the stories of the participants illustrated society’s discriminatory behaviors against them. These behaviors ranged from insults on the street to bias in the job hiring process. Comparable to other stigmatized groups, much of the stigma and discrimination towards the persons with SCI resulted in depression, anger, and negative outlooks on life. Implicit in the behaviors and discrimination towards this population, and all stigmatized groups, is the role of power and politics within social institutions and levels of government. This can most readily be seen in Harper’s description of his city, which is one of damaged sidewalks and inconsiderate city officials. Certainly, other cities like Harper’s exist. Whether by conscious decision or not, such policies continue to perpetuate institutionalized discrimination against this group as well as other groups.

On an underlying level this discussion of persons with SCI and disability is one centered on society’s value system and core cultural values. From the humble beginnings of anthropology as a discipline, the study of a society’s values has been a major focus of study (Barnouw, 1985; Kluckhohn, 1961; Peacock, 1995). Like most of the American population, the core cultural values of the United States (independence/ self-reliance,
individualism, goal-oriented activism, and community collectivism) are also held dear by persons with SCI.

However, taking their stigmatized status in consideration, these core cultural values take on even greater meaning and worth in this population. A society’s values as a motivating and driving force of action cannot be denied, and it is no understatement that many conflicts in society are due to a clash of values between different groups. As Murphy (1987) stated, a number of conflicts between people with disabilities and the dominant American culture have centered on independence, employment, identity, and social relationships. These same conflicts are also a clearly present in this study’s sample of veterans with SCI. For example, almost all of the participants cited independence and self-reliance (functional and/or financial) as highly prized values. However, at the time of the study some of the participants (Aileen, Wren, Harper, and Arona) were not able to achieve their own goals of independence and self-reliance. Even those participants (Jack and Felix) who did achieve a level of independence, the effort required to maintain it called for constant vigilance.

The consequences of not being able to achieve or uphold the core cultural values of America may have a more devastating effect on this population based solely on their stigmatized SCI and wheelchair bound status. That is, for an attribute highly prized in society the less one possess it results in greater stigmatized response from society. Again, using independence as the most salient example, dependence, by contrast, especially over-dependence, and reliance on others is seen as a negative attribute in American society. As a core American value, independence is so highly prized that the fear of being overly dependent is so great that those who are not self-reliant are viewed in
a negative light (Hsu, 1972). This is especially true for disabled populations, who have been relegated to a marginalized and devalued status in American culture. In this study population, this can be seen through issues of achieving and maintaining independence (Jack and Felix) and avoiding over-dependence or reliance on family support, caregivers, and unemployment benefits (Aileen, Arona, and Wren). The very value system of this society can have a disabling effect on its members, who have internalized these values and yet cannot or do not live by them. This can be seen in the depressed and negative outlooks adopted by participants such as Aileen, Wren, Basil, Harper, Arona, Marlon, and Reynard, who are all trying to achieve and/or maintain the core American values in light of their own unique life contexts.

Finally, it should be noted again that a limitation of this study is the use of qualitative telephone calls for data collection. Through the use of telephone interviews, participants only revealed their values and life contexts, which they wished to divulge to me. In this sense, the real vs. ideal culture reported by key informants is a methodological issue of concern regarding the use of telephone interviews. The difficulty in studying cultural values stems from their complexity. There may be discrepancies between what key informants have stated and what has been said and done, and what key informants believe consciously or unconsciously (Albert, 1956). This is especially true for this study as ethnographic methods such as participant observation were not employed.

At best, this study has generated exploratory data on the values of veterans and persons with SCI. However, ideally, the increased use of ethnographic methods in order to obtain a more accurate portrayal of the life issues and values of persons with SCI is
highly recommended. For example, a value underlying many of the participants’ lives was that of their health status and the quality of health care they received. An exploration of the topic of health and healthcare and the values surrounding it can be further illuminated through increased ethnographic methods. Other values held by this group may be hidden or unrecognized by the dominant American culture, and it is these values that may shed more light on the interactions between persons with SCI and the dominant American culture.

Recommendations

This section presents four recommendations based on the conclusions of this study and my internship experience. Applied anthropology as a discipline has long advocated for evidence based social change and provided policy recommendations based on research findings. This thesis attempts to maintain that tradition by providing two types of recommendations. First, recommendations for the field of healthcare in terms of policies and interventions are provided. Second, recommendations for further anthropological research are made.

Recommendation I: Create open dialogue and discussion of values and meanings.

Applied anthropologists have long recommended that policy and decision makers seek and incorporate the focus population’s input in policy designs/implementation and health interventions. Specifically, the focus population’s shared ideas, beliefs, values, and overall perspectives are significant factors that, if incorporated, can create more meaningful and sustainable changes. Minkler and Wallerstein (1997) advocate the
principle of relevance or “starting where the people are” as a fundamental tenet of health education. Essentially, the health educator who begins with the community’s felt needs and concerns will be far more likely to succeed in the change process rather than if he or she were to impose an outside agenda. Additionally, Groce states, “Understanding sociocultural models of disability is of more than academic interest. Unless programs for individuals with disabilities are designed in a culturally appropriate way, the opportunity to make real and effective change is often lost” (Groce 1999b: 38).

This recommendation has come to be seen as a best practice among many applied anthropologists and has been made by many researchers. Accordingly, this same recommendation of incorporating the target population’s input is made in regards to this study’s population of disabled veterans or persons with SCI. However, an emphasis on creating an open dialogue and discussion of values and meanings is stressed. Specifically, an open dialogue between both parties of intervention/research staff and persons with SCI is recommended. It is important to note that interventions involve two distinct cultures (medical/health staff and SCI population) interacting with each other. It is important for staff to try and discover the values, meanings, and input of the target population for the above stated reasons.

However, this dialogue should be a two-way street. Staff should also take the time and effort to communicate their professional values, goals, and vision to the target population in a jargon free and meaningful manner. As a research assistant for the VA, time and again I answered questions by patients on the nature and purpose of our research. Though these points were presented during patient recruitment, obviously patients still had lingering questions, which were often more suspicious in nature rather
than inquisitive. By creating an open dialogue and being more transparent in regards to research objectives and the “culture of medical/health research”, interventions can reach yet a new level of participatory success and sustainability as well as a creating a sense of ownership among the target population.

Recommendation II: Promote mixed method research designs in medical and health related research and interventions.

As a graduate student completing his first year in 2004, I was lucky enough to have developed a good professional relationship with Dr. Deborah Rosenberg, my then graduate assistant supervisor and a researcher at the VA Patient Safety Center of Inquiry. This led to my employment as a qualitative research assistant and data collector for the VA study, *Epidemiology and Cost of Falls in Veterans with a Spinal Cord Injury*. I felt privileged to take part in multidisciplinary/interdisciplinary research study. To take part in such a study was one of the ideals of applied anthropology. However, terms like multidisciplinary and interdisciplinary have often been used interchangeably where they should not be. Multidisciplinary research involves vertical communication from supervisor to research staff, each member contributing discipline specific conclusions during the analysis stage. On the other hand, interdisciplinary research refers to horizontal communication between research staff and supervisor in terms of knowledge and discipline specific findings, analysis, and program evaluation (Russell, 2006).

Taking these definitions into consideration, the study I took part in at the VA could be seen as somewhere between both multidisciplinary and interdisciplinary research. Communication between research staff occurred during scheduled meetings
and one on one conversation. However, the qualitative component of the study, and thus the qualitative researchers, were at times viewed in a harsh light by research staff. These researchers acknowledged and promoted the strengths of their disciplines while disregarding the strengths of qualitative research, and even going so far as sarcastically calling the qualitative results “interesting stories”. Be that as it may, the research staff included high level members that did indeed foster the inclusion of qualitative research. In fact, the qualitative component of the study, which focused on patient perceptions of fall consequences, is currently being implemented in the design of a new falls intervention at the VA Patient Safety Center. That the VA Patient Safety Center incorporated interdisciplinary research should be applauded.

Instead of petty arguments over discipline superiority, researchers should attempt to see past their differences in order to better serve their target population. From my observations, most of these arguments are not based on rationale discussion over the merits and contributions of disciplines. Rather the basis of these arguments lies in the power and politics behind the grant writing and grant funding processes. No doubt, these are important and practical issues. Much like the first recommendation, by recognizing and promoting interdisciplinary collaboration researchers can better serve their target population, which was and should be the main focus of any applied health research study. Otherwise, applied research serves a purpose and vision that is disingenuous to their target population. Recognition of the strengths of interdisciplinary research should also benefit the practical issues grant writing and grant funding. On an even greater scale, there needs to be increased promotion of transdisciplinary research, which incorporates cross discipline education; vertical and horizontal communication; and patient
collaboration. While such a move towards transdisciplinary research will encounter numerous difficulties, a movement for this type of research is already under way (Russell, 2006).

Recommendation III: Continue to investigate the larger culture of persons with SCI.

Since the population of veterans and persons with SCI has not been well represented in the anthropological literature, this study was conceived and conducted as an exploratory research design. The results and conclusions of this study have opened many avenues and possibilities for further research among this focus population. Two general areas of research bear the need for further investigation: the American value system; and cultural aspects of veterans and persons with SCI.

Stated earlier, the study of socio-cultural values has been a major focus in anthropology. This thesis illustrated the need for further research concerning the values of this focus population as well as in the American value system. This thesis revealed that persons with SCI hold to and try to live by the basic American values despite of their SCI. However, the interactions of this focus population with the general American public bear the need for further scrutiny. Conceptions of disability in light of the value systems in both of these populations and their interactions are complex issues that are not clearly understood. Most importantly is to discover the ways in which society “disables” some groups while “enabling” others.

Furthermore, discussion of the American value system and their overall implications as a driving and influencing force has been sporadic since the mid 1970s. A return to the rigorous study of the American value system and is core cultural values is
needed, especially considering today’s volatile political atmosphere. The promotion of pluralism is commendable; however the study of society’s values and how they clash may shed light on new ways to solve complex societal problems.

In regards to the study population, a number research issues were discovered by this study, which could benefit from increased ethnographic research. This study included veterans from a range of ages. A number of differences to how life is approached among this population may be illuminated by examining strategies and perceptions based on age ranges. The same can be done by sex and gender as well. The majority of this study population was men, and life as a female veteran or person with SCI has only been touched on by this study. It is conceivable that the ability to succeed or “make it” in American society as a person with SCI is highly influenced by one’s age and gender. Finally, a very important topic to consider is the role of family and social support in the lives of persons with SCI. The amount of family and social support and its affects can certainly lead to greater understanding in this target population. Further studies and investigations are needed overall in order to both verify the results of this study as well as expanding the scope of research in this area.

Recommendation VI: Reconsider the “culture of disability”.

The fairly recent anthropological concept of the “culture of disability” is one that may need to be reevaluated. Specifically, it is unknown whether or not this thesis’ focus population of veterans and persons with SCI (or other “disabled” groups) views their collective identity as part of the “culture of disability”. It is quite possible that many wheelchair bound veterans and persons with SCI do not wish to be associated with a
“culture of disability” or even other “disabled” groups. Furthermore, whether or not a “culture of disability” actually exists is up for debate. Is the concept of a collective “culture of disability” one that was created by an international group (progressive or otherwise) of social activists, lobbyists, and researchers in line with the many groups and many nations “represented” within the “culture of disability”? What was and is the role of power and politics in the conception and promotion of a “culture of disability”. Who are the stakeholders and who gains from such a conceptualization? The actual disenfranchised and “disabled” groups or others? These are difficult questions to answer, but their importance should compel researchers to investigate them.

While open dialogue and humane treatment of people with “disabling” conditions, ailments, and diseases is a progressive step forward, the danger of this lies in reifying concepts of disability and the overall “culture of disability”. Previous attempts to embrace diversity have led to cultural competency trainings in many workplaces. While such trainings are conducted with good intentions, the question becomes one of valid measurement. How much “competency” in a culture becomes enough? How does one validly measure cultural competency? Handouts on various cultural groups can merely become a checklist of items that denies the dynamic nature of culture. A static view of cultural groups may ensue, which place disenfranchised groups from one stereotypical box into another.

A “culture of disability” may exist just as much as any collective culture may exist, such as a “culture of Asian Americans”. However, while there may be similarities within these groups that comprise their greater culture, there may exist just as many or more differences among these groups. Instead, recognition of the various groups as
dynamic entities should be encouraged more. An emphasis on the dynamic nature of
cultural groups should also help prevent static and unrealistic perceptions and tendencies
to term these cultural groups as sub-cultures, which would be the exact opposite of the
collective “culture of disability” term. Therefore, the need lies in more research and
promotion among these unique cultural groups.

Anthropological Contributions

This thesis began as an attempt to explore the broader topics of life surrounding
veterans with SCI in response to a lack or disparity of research within the anthropological
literature. The majority of relevant literature on the topic of wheelchair bound persons
with SCI was subsumed under the broader topic of disability (Charlton, 1998; Groce,
1999; Groce, 2005; Pederson, 2005). While this literature was very useful in establishing
a knowledge base, the lack of literature on persons with SCI remained. Considering the
previous statements, this thesis has succeeded in adding to the knowledge base of this
specific group. Hopefully, increased interest in this group will lead to further research.

Though further research may be needed, it is important as applied anthropologists
and public health practitioners that the ultimate purpose of research is to benefit the target
population. Otherwise, research solely for the sake of knowledge can be viewed as
academic hedonism. The focus of this thesis was to illustrate the ways in which veterans
with SCI generated, negotiated, and renegotiated meanings within their daily life
activities. Specifically, this thesis sought to understand what it means to be a veteran
with SCI in American society, especially considering the American society’s core
cultural values. By design and practical limitations, this thesis generated rich, exploratory data.

The results and conclusions of this thesis can most readily benefit applied researchers in healthcare and intervention settings. That is, the results center on this populations’ unique lifestyles; life issues and concerns; and perceived meanings and values in their own community contexts. In the case of value systems, the results of this study illustrate that while there are a number of core cultural values, their interpretation and expression, differ from person to person based on their own specific context. While values may seem abstract and difficult to realize, the results of this thesis discovered that health, healthcare, and rehabilitation were values that were prized among this population. By discovering and expounding on these values, more meaningful and sustainable interventions and policies can be implemented by healthcare researchers and policy-makers.

Summary

Essentially, within this study’s sample population of veterans with SCI, a number of unique life perspectives, concerns, and issues exist. This study established that veterans with SCI hold dear the same basic American core cultural values (independence, self-reliance, and goal-oriented activism). Embedded in and representative of the American value system, the sample’s participants endeavored to achieve a number of goals based on their own unique situations and context. Whether or not a sense of success was achieved in these pursuits greatly influenced the attitudes and outlooks of the participants. On a larger scale, the pursuits of the participants represented a constant
cycle of action, whose ultimate goal is to achieve and maintain a sense of success despite the environmental, socio-cultural, and biological barriers presented.

The results and conclusions of this study support the previous anthropological literature on definitions of disability (Murphy, 1987; Shuttleworth and Kasnitz, 2004; Whyte and Ingstad, 1995). The results of this thesis helped to support the concept that it is society and culture that processes people as “disabled” individuals. Related to society and culture’s ability to “disable” or “enable” individuals is the role of stigma and the core cultural values as underlying motivational forces. Those who cannot live by the core cultural values are diminished, and for persons with SCI, a stigmatized condition, shame and depression become a difficult and complex problem, which affects many facets of their lives.

Finally, a set of recommendations are provided. Recommendations are made for both healthcare professionals and the field of anthropology. Healthcare professionals should include creating an open dialogue among the target population on the matter of value systems, emphasizing both healthcare and patient values. Additionally, there is a need for increased interdisciplinary research in order to better grasp and serve target populations. For the field of anthropology, increased research in this study’s focus population is needed in many areas. Finally, the usefulness of the overarching concept, “culture of disability”, is challenged due to a number of potential dangers. Rather the cultural groups subsumed under the “culture of disability” should be studied in order to portray a more realistic picture of each group.
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APPENDICES
Appendix A: Qualitative Interview Schedules

Introduction: We are interested in learning about what your fall means to you in terms of your overall functioning and quality of life. I have a series of open-ended questions to ask about this. Please keep in mind that I want to hear your opinions, thoughts, and feelings. There are no right or wrong answers. You are the expert on your experiences and what they mean to you.

1. To get started, would you tell me about your fall, such as what you were doing, how it happened, where it happened, who was with you?
2. Tell me what your life has been like since you fell.
3. What does it mean to you to have fallen?
4. How has the fall affected your ability to be mobile?
5. How has the fall affected your ability to perform activities of self-care such as transferring, bathing, etc.?
6. How has your quality of life changed since you fell?
7. How has your relationship with your family changed since your fall?
8. Tell me about how you sought medical treatment after your fall.
9. Compared to before you fell, how do you view yourself, your capabilities, and your outlook on life?
10. Can you tell me of a particular incident that happened to you that would help me to understand how your fall affected your life?
11. Is there anything else you would like me to know about your fall experience?
12. If you think of anything else you would like to tell me about your experience related to your fall, please feel free to e-mail me at, gail.powell-cope@med.va.gov.

General Interview Guidelines

1. Make sure the tape recorder is working.
2. The interviewer is a research instrument in the qualitative research process. Be attuned to body language and non-verbal communication.
3. Allow participant to direct the content and flow of the interview. Avoid interrupting the participant; however, make notes to remind yourself to ask for clarification as needed at a later point during a natural break in the interview.
4. Use generic prompts such as, “tell me more” and “can you say more about that” to elicit responses.
5. Effectively use silence to give the participant time to think about what he/she is going to say. Be careful not to move too quickly to avoid your own discomfort of silences.
6. Complete the field note form as soon as possible after the interview.
Appendix A: (Continued)

Introduction: It has been six months since we last talked about your fall. We are now interested in learning about what your fall means to you in terms of your overall functioning and quality of life, six months later. I have a series of open-ended questions to ask about this. Please keep in mind that I want to hear your opinions, thoughts and feelings. There are no right or wrong answers. You are the expert on your experiences and what they mean to you.

[Note: The following questions are samples of what might be asked. Based on the concurrent analysis of interview data, the content of the six-month follow-up questions will change.]

1. Tell me how your life has changed over the six months since you fell.

2. Thinking back on the past six months, what does it mean to you now to have fallen?

3. How has the fall affected your ability to be mobile during the six months since your fall?

4. How has the fall affected your ability to perform activities of self-care such as transferring, bathing, etc. in the past six months?

5. How has your quality of life changed in the six months since you fell?

6. How has your relationship with your family changed in the six months since your fall?

7. Tell me about how you sought medical treatment in the six months after your fall.

8. Compared to before you fell, how do you view yourself, your capabilities, and your outlook on life?

9. Can you tell me of a particular incident that happened to you during the past six months that would help me to understand how your fall affected your life?

10. Is there anything else you would like me to know about your life during the six months since your fall?

11. If you think of anything else you would like to tell me about your experience related to your fall, please feel free to e-mail me at, gail.powell-cope@med.va.gov, until [close of data collection date].