

University of Nevada, Reno

**An Exploration of the Lived Experiences of Sexual Function and Satisfaction in
Adult Males Following Traumatic Spinal Cord Injury**

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Science in
Nursing

by

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August 2014

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ABSTRACT

Injury to the spinal cord is devastating, leading to permanent, debilitating, and life altering injuries that can be fatal in some instances. Research suggests there are approximately 250,000 people living in the United States with some form of spinal cord injury (SCI) with approximately 11,000 new cases occurring annually. Men are four times more likely than women to sustain a spinal cord injury and account for 82% of those injured. Spinal cord injuries have significant impact on the individual's physical, emotional, and sexual wellbeing. Studies evaluating sexual activity potentiality in males with SCI date back to 1948 where Munro and associates completed extensive research on the sexual function of 84 paraplegic men injured in World War II. Since the earliest studies, regaining sexual function has consistently been identified as the highest priority for individuals with SCI, ranking above improving bowel and bladder function, extremity function, independence, and performing activities of daily living. Approximately 42% of men living with SCI are dissatisfied with their sexual lifestyle, and nearly 50% experience feelings of sexual inadequacy. More importantly, studies show that the vast majority of persons with SCI never discussed their sexual concerns with health providers, and 90% of these individuals had unrealistic expectations of sexual function and satisfaction. However, there is a paucity of research found within the literature regarding sexual function and satisfaction in individuals with SCI.

The purpose of this phenomenological inquiry was to explore, describe and gain a deeper understanding of the lived experiences of adult males regarding sexual dysfunction and dissatisfaction following spinal cord injury. Utilizing Heidegger's seven concepts of qualitative inquiry, this research will contribute to the current literature.

Purposeful sampling was used to recruit participants. A total of eight participants were recruited for this study, six of which completed the study. Face-to-face, audio-taped interviews were conducted. Finally, Diekelmann and colleagues 7-step approach was utilized to analyze the data. Seven main themes and two subthemes were identified throughout the interviews to produce the overall essence.

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“Do not go where the path may lead, go instead where there is no path and leave a trail”---Ralph Waldo Emerson

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CHAPTER I

INTRODUCTION

Background and Significance

Annually more than 11,000 cases of spinal cord injury (SCI) occur in the United States. Spinal cord injuries are traumatic life-altering events commonly associated with loss of both motor and sensory function. The result of SCI has significant impact on the individual's physical, emotional, and sexual wellbeing (Hess & Hough, 2012; Hess, Hough, & Tammaro, 2007). Studies evaluating sexual activity potentiality in males with SCI date back to 1948 where Munro and associates completed extensive research on the sexual function of 84 paraplegic men injured in World War II (Munro, Horne, & Paull, 1948). Modern day studies continue to evaluate the sexual activity potentiality of individuals with SCI and suggest that top priorities among the male SCI population include: methods and techniques to achieve sexual satisfaction, assisting their partner to cope emotionally with limitations on sexual activity, and the ability to father children (Abramson, McBride, Konnyu, & Elliott, 2008). It can be argued that a person is defined by sexual function and satisfaction. According to Firestone, Firestone, and Catlett (2006), "A healthy sex life is central to one's sense of well-being and a potential source of pleasure, happiness, and fulfillment. The enjoyment of passion, eroticism, and sexual intimacy and the giving and receiving of affection are fundamental aspects of being human" (p. 11). It is imperative that clinicians and patients alike understand that no injury eliminates the individual's chance and possibility to experience attraction between two people leading to the experience of love and to have a relationship; emotionally, physically, and sexually (Paralyzed Veterans of America, 2011).

Problem Statement

Injury to the spinal cord is devastating, leading to permanent, debilitating, and life altering injuries that can be fatal in some instances. Trauma is the leading cause of SCI that result from motor vehicle accidents, acts of violence, falls, and high-risk sport and recreation-related injury. Non-traumatic causes of spinal cord injury include cancer and underlying bone or joint disorders such as arthritis and osteoporosis (Burns, Hough, Boyd, & Hill, 2009). According to Burns, Mahalik, Hough, & Greenwell (2008) there are approximately 250,000 people living in the United States with some form of spinal cord injury with approximately 11,000 new cases occurring annually. Men are four times more likely to sustain a spinal cord injury than women and account for 82% of those injured. The population at highest risk of sustaining and accounting for the largest percentage of SCI patients are athletically active men aged 16 to 30 (Burns, Hough, Boyd, & Hill, 2009).

Acute treatment of spinal cord injury includes immobilization, surgical stabilization, prevention of shock, and avoiding complications of respiratory and cardiovascular compromise. A comprehensive spinal cord injury rehabilitation program requires lifelong commitment from the individual. These programs treat both physiological and psychosocial side effects of the injury including bowel and bladder control, impaired skin sensation, circulatory and respiratory control, muscle tone, mobility, fitness and wellness, pain management and sexual health (Paralyzed Veterans of America, 2011). Additionally, the impairment or complete loss of motor movement and sensation secondary to SCI, impairs sexual arousal, erection functionality, and orgasm of the male, and sexual arousal, vaginal lubrication functionality, and orgasm of

the female (Hess & Hough, 2012). According to Burns, Mahalik, Hough, & Greenwell (2008) 42% of men living with SCI are dissatisfied with their sexual lifestyle, and approximately 50% experience feelings of sexual inadequacy. More importantly, studies show that the vast majority of persons with SCI never discussed their sexual concerns with health providers, and 90% of these individuals had unrealistic expectations of sexual function and satisfaction (Hess, Hough, & Tammaro, 2007; Kendall, Booth, Fronek, Miller, & Geraghty, 2003; Sipski-Alexander, Brackett, Bodner, Elliott, Jackson, & Sonksen, 2009). Sexual counseling is a key component of top-rated SCI rehabilitation programs which is often overlooked in lower ranked programs. These top-ranked programs provide information and resources about decreasing sexual dysfunction while providing strategies to increase overall sexual satisfaction.

Purpose of Study

The purpose of this phenomenological study was to explore and describe the lived experiences of adult males' sexual function and satisfaction following traumatic spinal cord injury. The results of this inquiry will benefit both clinicians and patients alike with detailed information of what individuals in this vulnerable population face as they struggle to redefine themselves so they can proceed with healthy physical, emotional, and sexual relationships.

Research Question

The question that guided this study was: What is the meaning and significance of the lived experiences of adult males as it relates to sexual function and satisfaction following traumatic spinal cord injury?

Chapter Summary

This chapter provided a brief background of the significance of sexual function and satisfaction in adult males following spinal cord injury. Included is the purpose of the study along with the research question that guided this phenomenological study. Chapter II will provide an in depth analysis of current literature surrounding sexual function and satisfaction in SCI patients.

CHAPTER II

LITERATURE REVIEW

A computerized review of the literature was conducted utilizing Academic Search Premier, CINHALL, DynaMed, ProQuest, Pub Med, and Google™ prior to initiation of this study. Key search words used included spinal cord injury (SCI), spinal cord injuries, SCI abbreviation, sexual function, sexual dysfunction, sexuality, paraplegia, quadriplegia, male, and trauma patient. Over 50 articles dating from the 1980's through current date were located regarding this population of interest. Special attention and primary focus was placed on those articles produced after the year 2000. This search revealed a paucity of qualitative literature regarding sexual function and satisfaction in individuals with SCI.

The literature published to date (Appendix A) concentrates on four categories/themes designated by this author, which includes anatomy and physiology overview, physiological barriers, psychological distress, and adjustments and motivations of sexual function and satisfaction following SCI. Despite overlapping of categories/themes occurring within the articles, this author attempted to classify the articles to the categories/themes in which the majority of the research was performed. These categories/themes will allow for basic comparative knowledge and analysis of male SCI patients and their perception of sexual function and satisfaction.

Anatomy and Physiology

Virtually all of the literature reviewed contains some anatomy and physiology overview of the human body nervous system. The extent and depth of that content depends widely on the research focus of the literature. The nervous system should be thought of as the control center of the body controlling all voluntary and involuntary

actions of the body. The nervous system consists of two parts, the central nervous system (CNS) and the peripheral nervous system (PNS). The CNS is made up of the brain and spinal cord while the peripheral nervous system consists of sensory neurons, clusters of nerves referred to ganglia, and axons that lie outside the CNS (Craggs, Balasubramaniam, Chung, & Emmanuel, 2006). The spinal cord is a bundle of nerves that extends from the foramen magnum at the base of the skull to an area known as conus medullaris found between the first and second lumbar vertebra. The nerves that continue past the vertebral column of the spine are often referred to as the cauda equine, or horse's tail. The vertebral column that protects the spinal cord consists of seven cervical, twelve thoracic, and five lumbar vertebral segments (Sarhan, Saif, & Saif, 2012). Electrical impulses produced in the brain travel through nerve fibers of the spinal cord known as neurons via axons into further neurons that lie in peripheral nerves to produce movement and sensation (Porth, Gaspard, & Noble, 2011).

The term spinal cord injury refers to any physiologic insult, occurring by trauma rather than disease, to the neural elements within the spinal canal; the region from the foramen magnum to the conus medullaris (Sarhan et al., 2012). The regions on the spinal cord around cervical spine 4 to 6 (C4-C6) and the thoracolumbar junction, thoracic spine 12 to lumbar spine 1 (T12-L1), are the most prone to traumatic SCI (Porth et al., 2011). The effects of SCI are the result of compression and/or stretching of the spinal cord itself. Sarhan et al. (2012) have identified distraction, compression, and torsion as the leading mechanisms of traumatic SCI. Distraction is the hyperextension of the bony spine as a result of rapid acceleration and deceleration. Compression is encroachment of vertebral body fragments or intervertebral discs onto the spinal cord caused by axial loading.

Torsion is the twisting and tearing of spinal cord tissue as the result of high-impact collisions (Sarhan et al., 2012).

Acute traumatic SCI of any type and severity can be divided into two pathologic processes; primary and secondary injury. Primary injury includes the initial neuronal and vascular damage caused by mechanical force. Secondary injury results from the body's physiological and biochemical reactions to the primary mechanical injury. Causes of secondary injury include edema of the spinal cord and decrease in vasculature circulation (Sarhan et al., 2012). Injury to the spinal cord delays, impairs, or if severe enough, ceases nerve transmission impairing motor function and physical sensation (Valtonen, Karlsson, Siosteen, Dahlof, & Viikari-Junture, 2006). Individuals with SCI report impaired or ceased motor function and physical sensation, paresis, below the level of their injury (Burns, Mahalik, Hough, & Greenwell, 2008). The severity of the individual's paresis is directly related to the level of the spinal cord where the injury occurs and whether the injury results in complete or incomplete spinal cord involvement (Paralyzed Veterans of America, 2008). Complete versus incomplete SCI refers to the extent of the diameter of the spinal cord injured. Complete cord involvement injuries result in no sensory or motor function preservation in the sacral segments S4 to S5 while incomplete cord involvement injuries result in full or partial preservation of motor and sensory function in the sacral segments S4 to S5 (Sarhan et al., 2012). Injuries occurring from C1 to C4 result in tetraplegia, formally quadriplegia. Individuals with C1 to C4 tetraplegia have no motor function or physical sensation in the arms or legs and often require long-term ventilator support. Individuals with C5 to C7 regain varying levels of arm function and sensation with no motor function or physical sensation in the legs and

are often able to live and function semi-independently with the use of assistive devices and caregivers. Individuals with thoracic and lumbar paraplegia have full motor function and physical sensation of their arms with no motor function or physical sensation of their legs and are often functionally independent (Swope Rodante, 2012).

Physiological Barriers

Erectile dysfunction (ED), difficulty or inability to orgasm and ejaculate, infertility, and complications of the SCI are physiological barriers identified that prevent or impair sexual function and satisfaction in the male SCI patient. Erectile dysfunction (ED) has been identified as one of the leading physiologic barriers the male individual with SCI must overcome for sexual function and satisfaction to occur (Burns et al., 2008; Burns, Hough, Boyd, & Hill, 2009; Hess, Hough, & Tammaro, 2007; Hess & Hough, 2012; Johnston & Ducharme, 2010; Reitz, Tobe, Knapp, & Schurch, 2004; Sipski-Alexander et al., 2009; Sorenson et al., 2012; and Valtonen et al., 2006). The National Institutes of Health (NIH) (as cited in Johnston and Ducharme, 2010) defines ED as the inability to achieve or maintain an erection sufficient for satisfactory sexual intercourse. According to Burns et al. (2008) almost 48% of male individuals with SCI interviewed reported never experiencing erection to central sexual stimulation following injury. Men are capable of achieving two different types of erections; 1) psychogenic erections and 2) reflex erections. Psychogenic erections are mentally induced beginning in the brain when the male sees, feels, or hears something that is sexually stimulating. With psychogenic erections the brain sends a chemical message to the penis to create the erection via the spinal cord. The nerves that innervate the penis branch off the spinal cord around the thoracic T10 to lumbar L2 region, therefore any male patient with SCI occurring above

these levels cannot physically achieve a psychogenic erection. Reflex erections are produced by physical stimulation and occur involuntarily without specific sexual thought and/or stimulation. Common causes of reflex erections include physical contact to the penis with articles of clothing or blankets when sleeping. Male SCI individuals with preservation of sacral S2 to S4 neural circuitry are capable of achieving reflex erections; however, reflex erections are often not adequate for intercourse (Johnston & Ducharme, 2010; Paralyzed Veterans of America, 2008). Erectile dysfunction treatment options for the male SCI individuals are discussed in further detail later in this chapter.

Difficulty or inability to orgasm and ejaculate have also been identified as leading physiologic barriers the male individual with SCI must overcome for sexual function and satisfaction to occur (Abramson, McBride, Konnyu, & Elliott, 2008; Burns et al., 2008; Burns et al., 2009; Courtois et al., 2012; Hess et al., 2012; Reitz et al., 2004; Sipski, Alexander, & Gomez-Marin, 2006; Sipski-Alexander et al., 2009; Sorenson et al., 2008; Sorensen, Hansen, & Sorensen, 2012; and Valtonen et al., 2006). Orgasm is medically defined as the climax of sexual excitement usually accompanied by ejaculation of semen in the male and by vaginal contractions in the female (Medline Plus, 2013). According to Firestone, Firestone, and Catlett (2008) most individuals judge the “success” of their sexual performance in terms of whether their sexual encounter results in orgasm for both partners involved. While orgasm and ejaculation are often associated together in males especially, it is important to differentiate the two. Orgasm can occur in men who are not capable of ejaculation and vice versa (Hess & Hough, 2012). Ejaculation is a motor function controlled by nerves originating in the thoracic T12 to lumbar L2 region of the spinal cord. The higher level of SCI the more common it is for the male to experience

difficulty or inability to ejaculate. It is not uncommon for the male SCI individual to experience retrograde ejaculation where semen enters the bladder instead emerging through the penis during the point of ejaculation (University of Miami, 2009). Some male individuals with SCI report heightened spasticity during ejaculation (Paralyzed Veterans of America, 2011). Orgasms are psychological in nature (Sipski et al., 2006). Very few male individuals with SCI report the ability to experience post-injury orgasm on the same level of pre-injury orgasm force or intensity (University of Miami, 2009). Burns et al. (2008) identify that 45% of male individuals with SCI report no post-injury capacity for orgasm while Sorenson et al. (2012) identify 44% of male individuals with SCI report inability to achieve ejaculation. Ejaculation disorder treatment options for the male SCI individual are discussed in further detail later in this chapter.

For most individuals having a family and children are a key part of the individual's life plan (Paralyzed Veterans of America, 2011). Spinal cord injury most often occurs in the most productive years of one's life prior to reproduction. Most male individuals with SCI have an interest in sexual function for the purpose of reproduction in addition to recreation pleasure (Sipski-Alexander et al., 2009). According to Firestone, Firestone, and Catlett (2008), "The biological imperative to reproduce and to multiply still gives shape to our sexual desires" (p. 45). While it is possible for the male SCI individual to biologically father children, the incidence of infertility among male SCI individuals appears higher than the general population as identified by Abramson et al. (2008); Burns et al. (2009); Ducharme (2006); Klebine (2008); Sipski et al. (2006); Sipski-Alexander et al. (2009); Sorensen et al. (2012). A study of 199 male individuals with SCI reported only 8% fathering children post SCI (Sipski-Alexander et al., 2009).

The vast majority of male individuals with SCI experiencing infertility are the direct result of the individual's difficulty or inability to ejaculate (Ducharme, 2006). However, a large percentage of male individuals with SCI capable of ejaculation have found to have decreased semen quality, poor sperm motility, and low concentrations of sperm found in their semen. In these cases it is widely debated whether physiologic insult of SCI actually causes decreased quality of semen (Sipski-Alexander et al., 2009). One hypothesis to this cause is low testosterone levels, the male sex hormone produced in the testicles. A decreased testosterone level can affect the male patient's sex drive, ability to achieve erection, and quality of semen. Decreased testosterone can occur as the result of a variety of reasons, and has been shown to occur more frequently in male individuals with SCI (Paralyzed Veterans of America, 2011). There is currently insufficient evidence to make recommendations regarding hormone replacement in male individuals with SCI (Hess & Hough, 2012). Infertility treatment options for the male individuals with SCI are discussed in further detail later in this chapter.

Courtois et al. (2012); Hess et al. (2012); Sale et al. (2012); Sorensen et al. (2012); and Valtonen et al. (2006) identified that in addition to the effects of the physiologic insult of SCI, complications such as urine and fecal incontinence, neuropathic pain, spasticity, decubitus ulcers and autonomic dysreflexia greatly affect the male SCI individual's potential for sexual function and satisfaction. Bowel and bladder training is a main component of virtually all spinal cord rehabilitation programs in existence (Paralyzed Veterans of America, 2011). Urine and stool leakage can interfere with sexual activity posing great concern for SCI patients (Hess & Hough, 2012). Bowel and bladder continence have been positively associated with increased sexual satisfaction

for both male and female individuals with SCI (Sale et al., 2012). Sorensen et al. (2012) and Valtonen et al. (2006) identify that neuropathic pain, spasticity and the presence of decubitus ulcers greatly affects physical and social functioning for male individuals with SCI and is correlated with decreased sexual satisfaction. Autonomic dysreflexia is an emergent life threatening condition that can be experienced by SCI individuals with injuries at thoracic T6 level and above (Paralyzed Veterans of America, 2011).

Autonomic dysreflexia is an abnormal sympathetic response to noxious or non-noxious stimuli occurring below the SCI level and is characterized by severe hypertension, bradycardia, profuse sweating, nasal stuffiness, headache, anxiety, and flushing of the skin above the injury level. Ejaculation is one of the main triggers for autonomic dysreflexia in the male individual with SCI (Courtois et al., 2012; Hess & Hough, 2012).

Psychological Distress

Virtually all preexisting literature identifies the incidence of psychological stress in the male individual with SCI with regards to sexual desire, performance, and satisfaction. Valtonen et al. (2006) identify male individuals with SCI are less satisfied with their sexuality than female individuals with SCI. This may be due in part to the fact that sexual issues affecting men with SCI primarily focus on physical capabilities of erection ejaculation potential while women with SCI primarily focus on psychological components that stress emotional closeness, desires to express and receive love, and to share physical pleasures (Sorensen et al., 2012). The thought or anticipation of loss of sexual expression threatens the male SCI individual's self-esteem and sense of value as a sexual being (Hess & Hough, 2012).

Dating back almost 2000 years the ancient Egyptians described SCI as, “An ailment not to be treated” (Sarhan et al., 2012, p. 319). For centuries individuals with SCI were viewed to have, “A bleak future confined to a wheelchair and a lifetime of comorbidities and poor survival rates” (Sarhan et al., p. 319). As a result, persons with disabilities (PWD) such as individuals with SCI are often refused masculinity or femininity by society, and are therefore viewed as asexual lacking the desire, ability and/or capacity for sexual relationships (Milligan & Neufeldt, 2001; Sakellariou, 2006). Throughout time disability has been defined by a medically oriented approach arising solely from biological causes within the individual. However, in recent decades concepts of disability have transitioned to a sociological perspective defined by a dynamic, interactive relationship between individual impairment and his or her surrounding environment (Sakellariou, 2006). According to Swain, French, Barnes, and Thomas (2004), for males with SCI, “Paralytic disability constitutes emasculation of a more direct and total nature. For the male, the weakening and atrophy of the body threaten all the cultural values of masculinity” (p. 76). In general, society views PWD as inappropriate candidates for sexual relationship. Psychologist and quadriplegic Ellen Stohl (as cited in Milligan & Neufeldt, 2001) argues that in general, individuals with SCI are seen as a wheelchair first and a person second.

From very early ages boys are taught that manhood is signified by the possession, size, and use of their genitals. Additionally men are taught that the males should initiate sexual activity, and that males should possess and exhibit insatiable sexual desire. In society powerful, prestigious, and competent men are viewed as sexually achieved and in complete control of their sexual function (Burns et al., 2008; Burns, et al., 2009). Male

sexuality is often perceived in an exclusive, phallogentric, and oppressive way commonly based on physical performance which leads male SCI patients to feelings of castration and emasculation (Sakellariou, 2006). Male individuals with SCI often associate changes in their sexual function to a loss of their masculinity resulting in depression and anxiety as well as feelings of hopelessness, insecurity, shame, humiliation, decreased self-worth, anger, low self-confidence, and poor self-esteem due in part to decreased penetrative capacity (Burns et al., 2008; Burns, et al., 2009). Men with SCI, as disabled persons in general, often find that their identity as a person is submerged in their identity as disabled (Sakellariou, 2006). The divorce rate among individuals with SCI is higher than that of the general population during the first several years following SCI, and most people with SCI remain single 15 years after time of injury (Klebine, 2008). According to Burns et al. (2009) male individuals with SCI are at increased risk of experiencing significant psychological distress, developing major depressive disorders, and are two to six time more likely to commit suicide than members of the general population.

Adjustments and Motivation

Traumatic SCI completely changes the individual's life. Following SCI the male individual must find motivation to live and make adjustments in just about every aspect of his daily life including his sexual life. The frequency of sexual activity and intercourse declines after SCI. The decrease of sexual expression should not be confused for the individual's absence of sexuality and the need for sexual expression and intimacy should remain a focus for the male individual with SCI (Hess & Hough, 2012). While not being satisfied with sexual life after SCI does not directly correlate to overall quality of life, regaining sexual function has been identified as the highest priority for paraplegics,

ranking above improving bowel and bladder function, extremity function, independence, and performing activities of daily living (Burns et al., 2009; Hess et al., 2007; Reitz et al., 2004; Sale et al., 2012; Simpson, Eng, Hsieh, & Wolfe, 2012; Sorensen et al., 2008; Sorensen et al., 2012). According to Reitz et al. (2004); and Valtonen et al. (2006) no association has been found between the level of SCI and sexual impairment.

Additionally sexual satisfaction of individuals with SCI has been proven to decrease with age, and those whose injury occurs at younger age adapt their sexual activity more easily than those whose injury occurs at older age (Reitz et al., 2004; Valtonen et al., 2006).

Sexuality and intimacy changes immensely following SCI. The male individual with SCI effect on sexual response greatly depends on personal attributes such as partnership status, pre-morbid sexual experiences, and attitudes and openness to sexual experimentation (Hess & Hough, 2012). Erectile dysfunction, ejaculation disorders, and infertility are barriers to sexual function and satisfaction previously identified in this chapter. It is important that male individuals with SCI understand his options to overcome these barriers to fulfill a satisfying sexual life. Erectile dysfunction treatment options for the male individual with SCI include; oral medications such as Viagra, Levitra, and Cialis, intracavernosal injections such as Alprostadil and Prostaglandin E1, topical agents and creams, penis rings, vacuum devices, and even penile implants (Johnston & Ducharme, 2010). One emerging technique to overcome ED in the male individual with SCI is the “stuffing technique” in which the flaccid or semi-erect penis is “stuffed” into the partner’s vagina which may elicit reflexive erections and/or satisfaction for both partners involved (Hess & Hough, 2012). Ejaculation disorder treatments for the male SCI individual include; penile vibratory stimulation, rectal probe stimulation, and

electroejaculation (Sipski-Alexander et al., 2009). Infertility treatment options for the male individual with SCI include; oral medications, vibrostimulation, electroejaculation, and surgical sperm retrieval vitro and in vitro fertilization (Ducharme 2010; Paralyzed Veterans of America, 2011). Most of these treatment options require a physician's prescription, and all of these treatment options should be discussed at great length with a physician as they carry individual risks and benefits (Paralyzed Veterans of America, 2011).

Following SCI the male SCI individual's reasons for pursuing sexual activity often changes to the need to experience intimacy and closeness to his partner as his top priority (Hess & Hough, 2012). For male individuals with SCI, post-injury preference of sexual activity includes kissing, hugging, caressing, and oral sex verses pre-injury preference of penetrative intercourse (Hess et al., 2007; Reitz et al., 2004; Valtonen et al., 2006). Limiting sexual activity strictly to intercourse greatly reduces the male SCI individual's opportunities for sexual satisfaction and pleasure. To elicit the most sexual pleasure it is imperative that the male individual with SCI incorporate all his senses including imagination and to take time and experimentation to figure out exactly what works for him and his partner (Paralyzed Veterans of America, 2011).

Chapter Summary

This chapter provided a detailed summary and description of the current literature surrounding male individuals with SCI and the barriers they face with sexual function and satisfaction. Numerous quantitative studies were identified and analyzed which statistically analyzed male SCI individuals' sexual dysfunction and dissatisfaction. While studies were found identifying the psychological impact of SCI on the male

patient's sexual function and satisfaction, there appears to be paucity of literature surrounding the lived experiences of male SCI individuals' sexual desire, function, and satisfaction. The literature reviewed by this author provided a starting point for the phenomenological study.

CHAPTER III

METHOD OF INQUIRY: GENERAL

Hermeneutic phenomenology provided the methodological approach for this study. Polit and Beck (2010) defines phenomenology as, “A qualitative research tradition, with roots in philosophy that focuses on the lived experience of humans” (p. 563). The researcher’s goal in phenomenological studies is to question the essence of the experienced phenomenon or to identify the meaning of the phenomenon to those experiencing the phenomenon. At the core of phenomenology theory there is respect for the uniqueness of human experience (Polit, & Beck, 2010). Hermeneutics utilizes the uniqueness of the individuals’ lived experiences as a means for better understanding the social, cultural, political, or historical context in which the experiences occur (Polit, & Beck, 2010; Richards, Tepper, Whipple, & Komisaruk, 1997). Cohen, Kahn, and Steeves (2000) state, “Phenomenological research is used to answer questions of meaning. This method is most useful when the task at hand is to understand an experience as it is understood by those who are having it” (p. 3). Benner (as cited in Wilson & Hutchinson, 1991) states, “The goal of hermeneutics is to discover meaning and achieve understanding, not to extract theoretical terms or concepts at a higher level of abstraction” (p. 266).

Heidegger describes phenomenology as being-in-the-world rather than knowing the world (Reiners, 2012). The goal of phenomenology is to achieve a profound understanding “of the nature or meaning of our everyday experiences” (van Manen, 1990, p. 9). According to Heidegger (as cited in Cohen et al., 2000), “Human beings understand worlds in a way that involves their perceptions of self as the center of the

world present at hand, inseparable, and stretching in all directions” (p. 74).

Phenomenologists like Heidegger and van Manen strive to value and validate the individual’s experience and their whole being (Reiners, 2012). The underlying purpose of this research was to attain a rich understanding of young males’ experience with sexual function and satisfaction following SCI.

Historical Foundations of Phenomenology

Phenomenology arose in Germany prior to World War I as both a research method and a philosophy. German philosopher Edmund Husserl is often referred to as the founder of phenomenology. There exist three schools of phenomenology. The first school, guided by Husserl, is eidetic or descriptive phenomenology; which has a strong psychological foundation. The goal of descriptive phenomenology is to obtain fundamental knowledge of the phenomena. The second school, guided by Husserl’s student Martin Heidegger, is referred to as interpretive phenomenology, hermeneutic phenomenology, or hermeneutics. The goal of hermeneutics is to interpret the phenomena to uncover hidden meanings. Hermeneutics originated in the 17th century as method of interpreting biblical and classical literary texts. Two major assumptions of hermeneutics are that humans experience the world through language, and that this same language provides understanding and knowledge (Dowling, 2004; Dowling, 2007). “Language does not exist apart from thought or perception, for language generates and constrains the human life world” (Munhall, 2012, p. 129). According to Dowling (2004) the primary difference between Husserlian and Heideggerian phenomenological approaches is Husserl’s use of “bracketing.” Polit and Beck (2010) define bracketing as, “...the process of identifying and holding in abeyance any preconceived beliefs and

opinions about the phenomena under study” (p. 548). The third and final school of phenomenology is often referred to as Dutch Phenomenology, guided by scholar Max van Manen. Dutch Phenomenology is a combination of descriptive and interpretive phenomenology.

Researching Lived Experiences by Martin Heidegger

Ontology, the nature of existence, was the Heidegger’s primary focus of philosophy while Husserl’s primary focus was epistemology, the nature of knowledge (Dowling 2004). Heidegger expanded Husserl’s theory of phenomenology beyond the description of core concepts of the experience and seeks meanings that are embedded in everyday occurrences (Reiners, 2012). Heidegger did not believe in Husserl’s practice of bracketing because hermeneutics presumed prior understanding (Reiners, 2012). Reiners (2012) states, “Heidegger believed it was impossible to negate our experiences related to the phenomenon under study, for he believed personal awareness was intrinsic to phenomenological research” (p. 2). Heidegger’s theory of phenomenology is to uncover the meaning of beings for humans (Dowling, 2004). The main focus of Heideggerian hermeneutics is interpretation, and modern day hermeneutic phenomenological approach utilizes features of both descriptive and interpretive phenomenology (Cohen et al., 2000). According to van Manen (1990) phenomenology is defined as, “Pure description of the lived experience,” while hermeneutics is defined as, “The interpretation of the experience though ‘text’ or some symbolic form” (p. 25).

Phenomenological Activities Related to This Study

Hermeneutic phenomenology should not be considered a special process separated from everyday life for it is one of the methods people use to make sense or

understanding of their everyday world (Walters, 1995). Reed (as cited in Walters, 1995) states, “Heidegger’s analysis of the human condition is that people are in and of the world, rather than subjects in a world of objects” (p. 793). According to Benner (as cited in Wilson & Hutchinson, 1991), “The goal of hermeneutics is to discover meaning and achieve understanding, not to extract theoretical terms or concepts at a higher level of abstraction” (p. 266). The seven concepts of Heidegger’s hermeneutic phenomenology guided this study and are defined as follows:

Concept One: *Dasein*. At the center of Heidegger’s hermeneutic phenomenology is the concept of *Dasein*. The German term literally translates to *being there*, as in being-in-the world (Reiners, 2012). *Dasein* refers to, “Bio, psycho, social, and spiritual beings seamlessly connected to the world through past, present and potential lived experience” (Standing, 2009, p. 22). To Heidegger *Dasein* is the answer to the questions about the meaning of being (McConnell-Henry, Chapman, & Francis, 2009). Heidegger’s interpretation of being-in-the-world is written with hyphens to symbolize unified nature. Some phenomenologists, as Heidegger often did, capitalize the “B” in being to denote the ontological nature of existence (Dowling 2004; Walters, 1995). This researcher’s introduction to being-in-the world of sexuality and sexual expression in male patients following SCI began between 2009 and current date while caring for multiple adult male SCI patients in a Northern Nevada Level II Trauma Center. Through the development of a therapeutic relationship, these patients often felt comfortable with this male clinician, and the topics of sexuality and sexual expression inevitably came up during the acute care process. Due to the sensitivity of this topic and paucity of available resources, topics of sexuality were not covered to the extent of the patients’ deserving.

The goal of this study was to be-in-the world to gain a profound understanding through listening, reflecting, describing, and interpreting the stories told by male individuals with SCI struggling with the effects their injury has on their sexual function and satisfaction.

Concept Two: *Zeit*. *Zeit* translated to English is time. *Zeit* refers to, “Enabling and constraining [the phenomenon] in relation to completing tasks, stage of individuals life cycle, and moment in world history” (Standing, 2009, p. 22). Heidegger’s philosophy was that the concepts *Dasein* (being-in-the-world) and *Zeit* (time) exist together and are dependent of one another because the past, present, and future senses of time, directly corresponds to the individual’s level of being-in-the-world (Johnson, 2000). Time is the horizon in which the phenomenon is understandable in its meaning. Human beings are occupied in various worlds of purposes, concerns, and interests, all of which ultimately point to the final horizon of concern and interest in self (Johnson, 2000). According to Johnson (2000), “One might become what one already is and choose to live one’s life with explicit awareness that one’s life is limited” (p. 138). According to McConnell-Henry et al. (2009), “Heidegger suggested that, when reflecting on a phenomenon chronological time did not matter. What mattered was what, or why, it stood out from the general flow of time.” By gaining a profound understanding of being-in-the world this researcher actively explored how male individuals with SCI experiences with sexual function and satisfaction stand out above the flow of time following SCI.

Concept Three: *Raum*. *Raum* is the German term for space and refers to, “Enabling and constraining [the phenomenon] in relation to location, social context, and opportunities for interactions with others” (Standing, 2009, p. 22). According to Heidegger (1971), “Space as neither an external object nor an inner experience” (p. 7)

and adds, “Even when we relate ourselves to those things that are not in our immediate reach, we are staying with the things themselves. We do not represent distant things merely in our mind.” Heidegger did not intend for *raum* to be physical place, but rather how it feels to be in a place of mind. “When one talks of ‘being in love’, love is not a geographical place, but rather a sense of being in a particular space” (McConnell-Henry et al., 2009). It is not the space that matters so to say; it is the meaning of being-in-the space. The goal of this research was to gain comprehension of being-in-the space of sexual function and satisfaction in male individuals following SCI. Close observations, conversational interviewing, and reflecting on experiences allowed this researcher to be-in-the *raum* as experienced through the eyes of the participants.

Concept Four: *Fore-conception*. Standing (2009) identifies fore-conceptions as, “A person’s assumptions or pre-conceptions about the world that are derived from previous lived experience” (p. 22). Heidegger identifies personal awareness as intrinsic to phenomenological research (Reiners, 2012). Heidegger (as cited in Walters, 1995) argues, “It is only possible to interpret something according to one’s own lived experience” (p. 794). Acknowledging the researcher’s own experience with sexual function and satisfaction, this study was conducted allowing male individuals with SCI to openly share their own experiences with what is unique and significant to them.

Concept Five: *Hermeneutic Circle*. Hermeneutic circle refers to, “A continuous process of interpreting lived experience and reinforcing or revising perceptions about oneself and others” (Standing, 2009, p. 22). In hermeneutic phenomenology the researcher enters the world of the person and attempts to interpret the meaning the individual assigns to the study. It is imperative that throughout the research process the

researcher steps back, reads between the lines, and evaluates how each component of the research process contributes to the true essence of the experience (McConnell-Henry et al., 2009).

Concept Six: *Inter-subjective Understanding.* Inter-subjective understanding is identified as, “Mutual process of interacting, empathizing with feelings, experiences and views of others, and learning about oneself” (Standing, 2009, p. 22). Through inter-subjective understanding the researcher will determine what is “real” through the eyes of the individual living the experiencing (Lavery, 2003). As male individuals with SCI share their stories, the uniqueness and originality of each experience with sexual function and satisfaction “showed itself.” This researcher had to remind himself of the possible effects of research on the participants and to not become focused on the research question at hand, but rather the uniqueness of the lived experiences for each individual involved regarding this sensitive subject.

Concept Seven: *Co-constituted Meaning.* The, “Collaborative process of sharing experiences, pooling ideas, creating new insights, and agreeing what the outcomes are” refers to the methods which Standing (2009, p. 22) identifies as co-constituted meaning. Heideggerian phenomenology views people and the world as inseparable from cultural, social, and historical contexts (Munhall as cited in Lavery, 2003). Heidegger believed that all encounters involve an interpretation influenced by the involved individuals’ background or historicity (Lavery, 2003). Throughout the course of this study, both the researcher and the individuals involved expanded upon lived experiences to truly understand the uniqueness of the phenomena at study.

Research Plan

Participant Selection

Purposeful sampling was utilized to recruit individuals who had experienced the phenomena in order to provide thick, rich descriptions of their unique personal experiences (Ayres, 2007). It was the hopes of the researcher that the individuals recruited would provide the essence of what it is like to be them as they made sense of the lived experiences regarding sexual function and satisfaction following SCI. After Institutional Review Board (IRB) approval (Appendix B/Appendix C) participants were recruited from the private practice of a local Clinical Sexologist as well as word of mouth from participants themselves. Inclusion criteria included; 1) male gender, 2) English speaking 3) 18 years of age and older, 4) residing in northern California or Nevada, 5) traumatic mechanism of action, 6) spinal cord injury resulting in paraplegia or quadriplegia, and 7) living with SCI for a minimum of one year. Recruitment continued until data saturation occurred. Polit and Beck (2010) define data saturation as, “The collection of qualitative data to the point where a sense of closure is attained because new data yield redundant information” (p. 567). When data saturation occurs the researcher has ample thematic information to produce a thick, rich description of the participants’ lived experience (Cohen et al., 2000).

Data Generation and Analysis Procedures

Data Generation

According to Cohen et al. (2000), “A basic premise of the hermeneutic phenomenological method is that a driving force of human consciousness is to make sense of the experience” (p. 59). Participants were viewed as experts of their own

sexuality and were asked to evoke lived experiences of sexual relationship(s) and experience(s) from their personal view through conversational interviewing and reflection of those lived experiences. Close observations, focused listening, and interpretation by this researcher provided a better understanding of the participants' lived experiences. Building trust and creating rapport with each individual was essential to ensuring successful interview processes. The interviews conducted in this study may be viewed as a conversation between the researcher and the recruited individual, but the relationship between the two is not equal, and it is imperative that trust and rapport were established very early in the process (Ryan, Coughlan, & Cronin, 2009). The exchange relationship is best described as one where each individual provides a benefit to the other individual building trust through gradual expansion of exchanges over time (LoBiondo & Haber, 2006). In the exchange relationship of this study the researcher attempted to put the individual at ease by being attentive, confident, and relaxed to create a comfortable, non-threatening environment that allowed the individual to feel safe sharing intimate details of their life (Ryan et al., 2009). The strength of the exchange relationship is what allowed the participants to explore the meaning and significance and provide a thick, rich description of the phenomena.

The conversational interview methods utilized in hermeneutic phenomenology differs from those methods used when collecting analytic data. Cohen et al. (2000) states, "In this kind of interview, information is exchanged between informant and interviewer in both directions...the emphasis of the interviewer is on listening to whatever the informant says as opposed to guiding and controlling the conversation" (p. 61). The data collected in a conversational interview allows the researcher to be-in-the

world where the lived experience can be explored. Because of the sensitive nature of the phenomena, all interviews were conducted at a mutually agreed upon location where the participants felt most comfortable and at ease. Asking concrete questions (Appendix H) increased the possibilities of data that were rich in anecdotes, stories, incidents, and personal experiences regarding sexual function and satisfaction. In accordance with van Manen (1990) the recruited individuals were invited to describe specific instances, situations, people, and/or events that enhance the individuals' ability to share lived experience to fullest potential.

Data Analysis

Cohen et al. (2000) states, "The goal of analysis is a thick description that accurately captures and communicates the meaning of the lived experience for the informants being studied" (p. 72). Data was analyzed utilizing Diekelmann and colleagues seven-stage process of hermeneutic data analysis, which operationalizes Heidegger's approach to hermeneutic phenomenology (Diekelmann, 1992; Diekelmann, Allen, & Tanner, 1989). Data that emerged from initial analysis was scrutinized as subsequent data were collected leading to further refinement of initial understandings (Cohen et al., 2000). The data were approached with openness to emerging meanings and concern for comprehensiveness and depth of understanding of salient themes and consistent patterns of those studied capturing the experience from the perspective of the informant in its fullest and richest complexity (Cohen et al., 2000; Richards et al., 1997).

The lived experiences of sexual function and satisfaction in adult males following SCI were explored to the deepest extent possible. The general process of these principles as outlined by Diekelmann (1990) is as follows:

1) *All the interviews or texts are read for an overall understanding.* In this phase of analysis the researcher got a feeling for the “whole” experience of being-in-the world (Diekelmann, 1990 as cited in Wilson and Hutchinson 1991). Qualitative studies produce a large amount of data so transcriptions of audio recordings were produced as soon as possible following data collection. This researcher then read and reread the transcriptions to get a sense of the lived experience experienced by the individuals. As van Manen (1990) suggests meaningful significances of the phenomena emerged the more readings occurred creating a clearer picture of the phenomena as an experience.

2) *Interpretive summaries of each interview are written.* In this phase the goal of the researcher was to gain a clear sense of what the individuals were expressing by moving beyond what the individuals were saying and begin describing and interpreting what the individuals were saying (Green et al., 2007). To accomplish this, the researcher summarized each interview using specific excerpts from the interview supporting the emerging themes beginning to “get the story right” (Diekelmann, 1990 as cited in Wilson and Hutchinson 1991). Here the researcher analyzed the interview by asking, “What does this sentence or sentence cluster reveal about the phenomenon or experience being described” (van Manen, 1990, p. 93). According to Cohen (2000), “The process of writing and rewriting is crucial to interpretive phenomenology” (p. 81).

3) *A team of researchers analyzes selected transcribed interviews or texts.* The hallmark of Diekelmann and colleague’s data analysis method is the collaborative team approach (Polit & Beck, 2010). This allows members of the research team to discuss differences and similarities in their understanding of the phenomena (Wilson &

Hutchinson, 1991). In this study the researcher performed the data collection and analysis with validation from members of the thesis committee.

4) Any disagreements on interpretation are resolved by going back to the text.

This phase of data analysis involved determining what was relevant in relationship to the research question eliminating digressions and abrupt topic changes (Cohen et al., 2000). When difficulties in understanding translations arose, the researcher returned to the text or the participant to solicit additional information and clarification (Wilson & Hutchinson, 1991).

5) Common meanings and shared practices are identified by comparing and contrasting the text. During this phase of data analysis thematic clarification occurs by immersing oneself in the collected data (Wilson & Hutchinson, 1991). Through this immersion phenomenologists search for common patterns and themes shared by participants (Polit & Beck, 2010). Because all experiences are unique, the researcher identified contraindications and exceptions, which were then placed in different categories producing explanations for all data received.

6) Relationships among these themes emerge. According to Diekelmann and colleagues (as cited in Polit and Beck, 2010, p. 476), “Constitutive patterns, patterns that express the relationships among relational themes is present in all the interviews or texts, forms the highest level of hermeneutical analysis.” Construction of generated themes served as a guide for writing the research study results.

7) A draft of the themes and exemplars from texts are presented to the team.

Responses or suggestions are incorporated into the final draft. The final written report presents the data revealing interpretive strategies of paradigm cases, exemplars, and

thematic analysis producing a profound description of the lived experience (Wilson & Hutchinson, 1991). This contributed to the overall essence of the studied phenomena. “The aim...is to transform lived experience into textual expression-in such a way that the effect of the text is at once a reflexive reliving and reflective appropriation of something meaningful...” (van Manen, as cited in Wilson & Hutchinson, 1991, p. 273).

Ensuring Trustworthiness

Phenomenological studies are not widely accepted in many fields of research because of the absence of traditional scientific methodology (Polit & Beck, 2010). According to Sanders (2003) when evaluating rigor of phenomenological studies the researcher must question if, “..the study is believable, accurate, and right, and whether it is useful to people beyond those who have participated in the study” (p. 293). The rigor and validity of qualitative studies is highly controversial and should be assessed based on sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance (Pringle, Drummond, McLafferty, & Hendry, 2011).

Overtime phenomenologists have come to use the concept of trustworthiness to validate reliability of their studies. Polit and Beck (2010) defines trustworthiness as, “The degree of confidence qualitative researchers have in their data, assessed using the criteria of credibility, transferability, dependability, confirmability, and authenticity” (p. 570). To ensure a trustworthy study, Guba (1981) identifies four criteria essential to qualitative research: Truth Value, Applicability, Consistency and Neutrality. Truth Value is identified as the most essential criteria imperative to qualitative studies. Guba (1981) defines these four criteria as follows: Truth Value is both the internal validity and credibility of the research completed. Applicability refers to the external validity of the

study, the extent which the study can transfer to other situations or phenomena.

According to Guba, “Concern over consistency stems from the fact that instruments must produce stable results if those results are to be meaningful” (p.81). Neutrality, or objectivity, is guaranteed by adherence to the methodology of the study. Finally, each of this study’s participants were revisited and asked if this researcher’s interpretation accurately reflected the individual’s true experience as a method to safeguard the trustworthiness of the study (Speziale & Carpenter, 2007).

Chapter Summary

This chapter began with a historical overview of hermeneutic phenomenology and its importance as a methodology for qualitative studies. A description of Heidegger’s approach to researching the lived experience utilizing Diekelmann and colleagues steps of data analysis, as well as the processes of data collection and management were also covered. Lastly, a description of ensuring trustworthiness in qualitative studies was described.

CHAPTER IV

METHOD OF INQUIRY: APPLIED

Sample: Participant and Recruitment

Participants knowledgeable with the content of this phenomenological inquiry were selected through purposeful sampling. This method of sampling allowed the researcher to seek participants best capable of contributing to the informational needs of the study (Polit & Beck, 2010). The goal was to recruit approximately 5 to 10 participants with recruiting efforts ceasing once data saturation has occurred. Of the eight participants recruited for this study, six completed the study. Data saturation occurred once the narratives revealed no new information, and the researcher obtained enough data to have a complete, thick, rich description of the experiences at question (Cohen, Kahn, & Steeves, 2000; LoBiondo & Haber, 2006).

At the time of recruitment the inclusion criteria for this study included: 1) male gender, 2) English speaking 3) 18 years of age and older, 4) residing in northern California or Nevada, 5) traumatic mechanism of action, 6) spinal cord injury resulting in paraplegia or quadriplegia, and 7) living with SCI for a minimum of one year.

All participants agreed to a face-to-face, audio taped interview conducted in a mutually agreed upon private location convenient for both the participant and researcher. Additionally, all participants agreed to follow-up communication face-to-face or via private telephone calls for review of their initial narratives. Prior to the follow-up visit each participant was mailed their transcription for review and asked to make any corrections, clarify points, and to ensure it was an accurate account of their experience.

At this time participants were asked to provide any additional thoughts regarding their lived experience.

Gaining Access

Protection of Human Subjects

Initial approval for this research was sought and granted from the Institutional Review Board (IRB) at the University of Nevada, Reno in the Summer of 2013 (Appendix B). Due to difficulties finding available participants due to initial participant inclusion criteria (age range), follow-up IRB application with modification was sought and obtained from the IRB at the University of Nevada, Reno in Fall of 2013 (Appendix C).

Recruitment

Approximately 25 recruitment fliers were distributed to patients at the private office of a local Clinical Sexologist following formal IRB approval (Appendix D). The primary researcher was available for clarification and explanation of the study when needed. Additional participants were recruited by word of mouth from previous participants who self-selected for this research and met the selected inclusion criteria.

Individuals interested in participating in the research were next contacted by the researcher to verify inclusion criteria, further explain the purpose of the research, interview structures, protection of privacy and confidentiality, consent to audio-taped interviews, verbatim transcription of the data, handling of data, and final reporting of data following conclusion of the research as well as the availability to answer any questions participants may have regarding the research. All of this information was included in the recruitment letter (Appendix E) and the informed consent (Appendix F) provided to the

interested participants for review prior to the formal consenting process. All interested participants were informed that participation in this research was on a voluntary basis and that refusal or withdrawal from the research at any time was without penalty or risk. All men who met the selected inclusion criteria were informed they would be treated fairly, equally and without discrimination. If at this time interested individuals chose to continue with participation a mutually agreed upon time and location were chosen for formal consenting and interviewing. Of the eight participants recruited for this study, six completed the study.

Privacy and Confidentiality

All information gathered throughout the duration of this inquiry was and continues to remain confidential. All research participants were given a pseudonym upon formal consenting, and any identifying information was removed from all transcripts to protect privacy and confidentiality. Both the researcher's field notes and the transcripts only referred to the participants by their assigned pseudonym. The key for participant contact information and the recorded interviews were and continue to be stored in a locked file cabinet accessible by the researcher and faculty advisor. Lastly, a confidentiality statement was signed by the transcriptionist who had access to the interview data (Appendix G).

All information gathered throughout the duration of this inquiry including recorded interviews, demographic data, and consent forms were and will continue to be stored in accordance to University of Nevada, Reno IRB protocols. Upon completion of the allotted storage time, all the material will be destroyed accordingly.

Consent

Informed consents were developed in compliance with the requirements of the University of Nevada, Reno's IRB. The developed consent forms thoroughly explained the purpose of the research with a specific discussion of the selected inclusion criteria. Additionally, the consent forms detailed that participation in this inquiry was on a voluntary basis and each participant had the right of refusal or withdrawal from the research at any time without penalty or risk. The research procedures were clearly stated along with details related to the protection of privacy and confidentiality. Lastly, benefits and risks of the study were explained. All individuals who met inclusion criteria and chose to participate in this study completed the consent process prior to the interview process.

Data Generation and Analysis Procedures

Data Generation

Through a guided approach, data for this scientific inquiry were collected through comprehensive, in-depth, face-to-face interviews held with each participant lasting between 21 and 59 minutes. All interviews were conducted at a mutually agreed upon private location convenient for both the participant and the researcher where privacy and confidentiality were protected throughout the duration of the interview. Prepared interview questions were utilized to facilitate the dialogue between the participant and the researcher (Appendix H). The initial interview questions focused on demographic information to categorize specific characteristics of the participants interviewed. All interviews were audio-taped with a digital voice recorder, transcribed verbatim by a transcriptionist, who signed an agreement of confidentiality, within one week of the

interview, and with follow-up review by the researcher for accuracy. Field notes and journaling were also maintained by the researcher to depict aspects such as the physical environment, body language, demeanor, dress of the participant, and other observations that could not be discerned from the transcript of the recording.

Data Analysis

Characteristic of hermeneutic phenomenology, data analysis for this inquiry began with data collection. Data analysis involves moving from the field text to a narrative text meant to stand alone for other readers (Ricoeur, 1981). This dialectic process of guided interpretive process is often referred to as the hermeneutic circle. The hermeneutic circle utilizes immersion of the researcher into the data, data transformation or data reduction, and thematic analysis forcing the researcher to reflect on the meanings of the smallest units of data in terms of ever-increasing larger units of data allowing for the emergence of salient themes within each of the participant's interview (Cohen et al., 2000). This circular movement from the whole to the parts and deconstructing and reconstructing of the text results in a shared understanding between the researcher and the participant (McConnell-Henry et al., 2009). Through the use of the circle, the researcher discovered the true meaning of the experience of the participant (Tuohy, Cooney, Dowling, Murphy, & Sixmith, 2013). The hermeneutic circle (researcher immersion, data transformation or reduction, and thematic analysis) was demonstrated in this inquiry through observation and listening to each participant, through reading and re-reading the verbatim transcripts, and through thoughtful reflection and analysis of the emerging salient thematic statements within each text. The process and utilization of these techniques allowed for an individualized view of each participant's text. Finally,

Diekelmann and colleagues seven-stage process of hermeneutic data analysis, which operationalizes Heidegger's approach to hermeneutic phenomenology, was utilized in analyzing the data (Diekelmann, 1992; Diekelmann, Allen, & Tanner, 1989):

1) All the interviews or texts are read for an overall understanding. All participants involved with this inquiry were personally interviewed by this student researcher.

Following each interview, the audio-tape recordings were transcribed verbatim by a transcriptionist who previously signed a confidentiality statement. Once transcribed, the verbatim transcript was read and re-read multiple times by the researcher while listening to the audiotapes to validate accuracy of the transcript. Additional time was also allotted for reflection and review of all involved field notes. During this phase of data analysis the researcher became immersed into the data at hand. Through immersion of oneself into the data, the researcher began to get a feeling for the "whole" experience of being-in-the world of the participant (Cohen et al., 2000; Diekelmann, as cited in Wilson and Hutchinson 1991).

2) Interpretive summaries of each interview are written. Following thorough review and re-review of each participant's verbatim transcript, the researcher wrote interpretive summaries of each transcript produced. This process allowed the researcher to read between the lines gaining a clear sense of what the individuals were expressing by moving beyond what the individuals were saying and uncovering the true essence of being-in-the world of the participants' lived experiences (Green et al., 2007; McConnell-Henry, Chapman, & Francis, 2009).

3) A team of researchers analyzes selected transcribed interviews or texts. All

verbatim transcripts and subsequent interpretive summaries were next reviewed by a team of researchers primarily consisting of faculty thesis committee members. This allowed members of the research team to identify and discuss variances and similarities in their understanding of the phenomena (Wilson & Hutchinson, 1991).

4) Any disagreements on interpretation are resolved by going back to the text.

During this phase of data analysis, data transformation or data reduction occurred allowing the research team to discern what data were relevant and which data were not (Cohen et al., 2000). When difficulties in understanding the texts arose, the researcher returned to the current literature and the participants involved; soliciting additional information and clarification (Wilson & Hutchinson, 1991). The processes involved during this phase of data analysis generated refinement and a complete understanding of the phenomenon experienced (Cohen et al., 2000).

5) Common meanings and shared practices are identified by comparing and contrasting the text. Thematic analysis of all printed transcripts and field notes occurred during this phase of data analysis. The researcher searched for common patterns and themes shared by participants (Polit & Beck, 2010). Similar words and phrases found in multiple transcripts represented a theme amongst the participants lived experiences (van Manen, 1990).

6) Relationships among these themes emerge. The researcher organized the aggregate themes previously identified into clusters which were then compared to the original transcripts for validation. A chart of the thematic analysis across all participants was created to ease the researcher with thematic analysis (Appendix I). The construction

of generated themes ultimately served as a guide for writing the final research study findings.

7) *A draft of the themes and exemplars from texts are presented to the team. Responses or suggestions are incorporated into the final draft.* The final phase of analysis yielded the researcher's exhaustive description of the lived experience of sexual function and satisfaction in adult males following traumatic spinal cord injury. The researcher's final written report represents a profound description of the lived experience contributing to the overall essence of the studied phenomena (Wilson & Hutchinson, 1991).

Ensuring Trustworthiness

Trustworthiness and accuracy of this phenomenological inquiry was ensured by following Guba's (1981) approach to Truth Value, Applicability, Consistency and Neutrality. The use of these four principles validated the quality, rigor, and overall trustworthiness of this study.

Truth Value

The researcher guided this phenomenological inquiry utilizing reputable and trustworthy qualitative research methods developed by Heidegger who is accredited with the development of hermeneutic phenomenology (Dowling, 2004). Shenton (2004) denotes that the researcher must have familiarity of the organization and the culture of the participating organization. The involved researcher had familiarity with the local Clinical Sexologist having previously had her as a professor for the class of *Advanced Human Sexuality* at the University of Nevada, Reno. Familiarity with the culture of individuals with SCI originated with the researcher's experiencing with caring for SCI patients at a

Northern Nevada Level II Trauma Center. Additionally, Shenton (2004) discusses the importance of tactics to ensure honesty of all participants involved. All participants were given the opportunity to refuse participation once the research purpose and details were explained. This ensured certainty that the participants legitimately wanted and agreed to participate. The researcher strove to build a rapport with the participants very early on in the interview process signifying that there are no wrong or right answers and reiterating that the participants could still withdraw from the study at any point. Lastly, participants were encouraged to converse openly and freely, conveying both negative and positive experiences without any judgment from the researcher.

Applicability

According to Guba (1981) applicability refers to the external validity of the study, the extent which the study can transfer to other situations or phenomena. The findings of this qualitative inquiry are specific to the males with SCI and their experiences of sexual function and satisfaction. The data reported cannot be universal to an entire population of men because each experience is individualized and unique to the participant. This research does, however, serve as an example of the broader group of sexually active men following SCI. The researcher's goal was to provide a rich, thick description of the phenomena allowing readers to gain proper understanding of the experiences (Cohen et al., 2000; Shenton, 2004; van Manen, 1990).

Consistency

Guba (1981) states, "Concern over consistency stems from the fact that instruments must produce stable results if those results are to be meaningful" (p. 81). To protect and preserve consistency in this qualitative inquiry, it was imperative that the

researcher report detailed research processes within the study. To ensure this, the researcher provided a comprehensive, in-depth account of the planning process, the execution of the study, the details of the field experience, and evaluation of the inquiry. Shenton (2004) notes that following these steps enables the reader to evaluate the extent that proper research practices were followed.

Neutrality

Guba (1981) explains that neutrality, or objectivity, is guaranteed by adherence to the methodology of the study. According to Shenton (2004) a key criterion for neutrality is for the researcher to acknowledge his or her own predispositions of the question guiding the research. Unlike Husserlian's school of phenomenology and the use of "bracketing," Heideggarian's phenomenology is characterized by the disregard of this practice (Dowling, 2004). Polit and Beck (2010) define bracketing as, "...the process of identifying and holding in abeyance any preconceived beliefs and opinions about the phenomena under study" (p. 548). Heidegger did not believe in Husserl's practice of bracketing because hermeneutics presumed prior understanding (Reiners, 2012). Reiners states, "Heidegger believed it was impossible to negate our experiences related to the phenomenon under study, for he believed personal awareness was intrinsic to phenomenological research" (p. 2). As a result, hermeneutic phenomenology should not be considered a special process separated from everyday life, as it is one of the methods people use to make sense or understanding of their everyday world (Walters, 1995). To guarantee neutrality in this inquiry, the researcher provided a detailed explanation of the methodological approach, in addition to continuing reflective annotations in the form of an audit trail. In this study, the researcher frequently discussed with the thesis committee

members researcher biases in order to hold in abeyance any predispositions regarding the phenomenon, thus producing a narrative text that as accurately as possible, reflected the dialogue of the participants.

Chapter Summary

This chapter presented the application of Heidegger's approach to phenomenological inquiry with explanation of Diekelmann and colleagues seven-stage process of hermeneutic data analysis. Additional discussion identified specific components of the study where truth value, applicability, consistency and neutrality were applied to ensure trustworthiness within the research.

CHAPTER V

FINDINGS

The purpose of this phenomenological inquiry was to explore, describe, and gain an overall deeper understanding of the lived experiences of adult males' sexual function and satisfaction following traumatic spinal cord injury. The question that guided this study was: What is the meaning and significance of the lived experiences of adult males as it relates to sexual function and satisfaction following traumatic spinal cord injury?

The following anecdotes come from six adult males reliving their experiences with sexual function and satisfaction following traumatic SCI. The insight provided provides the reader a sense of the lived experience of sexual function and satisfaction in adult males following traumatic SCI.

Description of the Participants

A total of eight participants were recruited for this study, six of which completed the study. The participants ranged in age from 22 to 58 years old. All of the participants suffered SCI between the ages of 14 and 39 years old; two participants were injured in diving accidents, one participant was injured in a motor vehicle accident (MVA), one participant was injured in an all-terrain vehicle (ATV) accident, one participant was hit by a drunk driver while walking in a crosswalk, and the final participant was injured while tumbling and performing in competitive cheerleading. Four of the participants had cervical spine injury and classified themselves as quadriplegic, while the remaining two participants had thoracic injury and identified themselves as paraplegic. Two participants were injured outside of the U.S. and Mexico. All of the participants identified themselves as male and having been born naturally male. Three of the participants

identified themselves as Caucasian, one participant identified himself as Hispanic, one participant identified himself having Spanish descent, and the remaining participant identified himself having German descent. One of the participants identified himself as homosexual while the remaining participants stated they were heterosexual. Four of the participants identified themselves as being “single” at the time of the interview while one of the remaining participants identified himself as married and one identified himself as divorced. None of the participants had children in their lifetime.

Data Collection

The six participant interviews were conducted between September and October 2013. Four of the participants were not known by the researcher. One of the participants was known to the researcher through a mutual acquaintance. One of the participants was known to the researcher having been a previous patient, and the final participant was known to the researcher as a fellow colleague in a Northern Nevada hospital. The participants were given the option of a telephone or face-to-face interview, whichever was most convenient for the participants. Three of the participants chose telephone interviews in which the researcher conducted in the privacy of his own home. The four face-to-face interviews occurred at a mutually agreed upon private location, convenient for both the participant and the researcher which allowed for privacy and confidentiality throughout the duration of the interview. Three of the four face-to-face interviews occurred at the private homes of the participants. The final interview occurred in a hospital room while the participant was hospitalized in order to receive daily intravenous (IV) antibiotic treatment. All of the chosen interview settings allowed for a private, quiet environment conducive for the interviews to occur. Three of the face-to-face interviews

occurred with the participants sitting in their wheelchairs diagonally across from the researcher. The third and final face-to-face interview occurred with the participant in his hospital bed and the researcher sitting next to the bed. For all the face-to-face interviews, the digital voice recorder was placed centrally to both the researcher and the participants. The researcher was not aware of the environment of the participants' for those interviews that occurred via telephone.

All participants were provided copies of the recruitment letter and consent form via e-mail at least 24 hours prior to the scheduled interview. For those participants who chose to participate in telephone interviews, the researcher was available for questions and clarification via telephone and e-mail. Those participants choosing to participate in telephone interviews faxed or e-mailed the completed consent form back to the researcher prior to the start of the interview. For the face-to-face interviews each participant was asked if they had any questions or needed clarifications for the consents previously e-mailed to them. Prior to the signing of consents, all participants were reminded that the study was voluntary and they could withdraw from the study at any time during the research process without penalty. Additionally, each participant was reminded that he would be given a pseudonym that he would be referred to protecting his true identity. Finally, each participant was provided a copy of the original consent form he signed prior to initiation of the interview.

Prior to initiation of the interview, an open dialogue session lasting 10 to 15 minutes occurred to build rapport and put the participant at ease with sharing of their personal information. Following the initial discussion the researcher asked, "Do you have any last questions before we get started" followed by "Are you ready to start?"

Once the participant agreed “yes” the recorder was turned on and the formal part of the interview was initiated. At the start of each interview the researcher stated the date, time, and pseudonym assigned to that particular participant. Prior to the conclusion of each interview, the researcher asked, “Is there any of the questions I have asked that you would like to revisit and expand upon” followed by, “Is there anything else you would like to share about your experience with sexual function and satisfaction following your injury?” Once the participant acknowledged he was completed with his thoughts, the researcher stated, “Thank you for your participation, this concludes the interview with [assigned pseudonym] and the recorder was turned off signifying the end of the interview. If at any point during the opening and closing discussions the participant made comments that the researcher felt pertained to the study, the recorder was turned back on and the participant was asked to repeat those comments for the record.

Follow-up meetings were conducted with each participant between October and November 2013. The follow-up reunions were performed through e-mail, phone conversations, or face-to-face meetings based on availability and scheduling of both the involved participant and the researcher. During the follow-up meetings, the participants were asked to review their verbatim transcripts to clarify any errors of the verbatim transcription, misinterpretations of the researcher regarding themes, and time to add any additional thoughts they had about their lived experiences. Of the eight participants recruited for this study, six completed the study.

Data Analysis

Following each interview, the data was transferred to the researcher’s computer converted to a MPEG-1 Audio Layer III (MP3) file and burned to a compact disc (CD)

which was hand delivered to the transcriptionist. The transcriptionist produced the verbatim transcript of each interview and returned all materials to the researcher within 7 to 14 days of the time of the interview. All data produced by the researcher was hand coded and analyzed utilizing Diekelmann and colleagues seven-stage process which operationalizes Heidegger's approach to hermeneutic phenomenology.

Immersion

The researcher listened to each recorded interview multiple times while awaiting the verbatim transcription to be completed. Additional time was also spent analyzing the researcher's field journal which included thoughts, feelings, and ideas that the researcher identified during the interview process. After the transcripts were produced, each transcript was reread multiple times while listening to the audio file to verify accuracy. Repetitious listening of the audio files and reading of the transcripts allowed for a deeper, comprehensive understanding of each experience. This phase of the research immersed the researcher into the data allowing for the sense of being-in-the world of the participants involved.

Interpretation of Data

Each transcript of the six interviews produced between 6 and 13 pages of transcription. Through the process of writing interpretive summaries of each interview, the researcher identified significant words, statements, or phrases pertaining to the sexual function and satisfaction in adult males following SCI (Green et al., 2007; McConnell-Henry, Chapman, & Francis, 2009). Throughout this phase the researcher read between the lines gaining a clear sense of what the individuals were expressing by moving beyond

what the individuals were saying and uncovering the true essence of being-in-the world of the participants' lived experiences.

Identification of Common Meanings and Shared Practices

The researcher next formulated common meanings and shared practices for each significant word, statement or phrases previously identified. Extra effort was taken to ensure that each identified meaning or practice remained associated to the participant's original interview statements. The researcher viewed similar words, statements and phrases found in multiple transcripts as a theme amongst the participants lived experiences.

Organization of Relationships among Common Meanings and Shared Practices

The formulated common meanings and shared practices were then analyzed and organized for similarity. The researcher organized the aggregate themes previously identified into clusters. As a result, clusters of themes from the data emerged. The emergent clusters of themes represented the individual and group experiences of sexual function and satisfaction in adult males following SCI. Validation of this phase was achieved by revisiting the original interview transcripts probing whether any original data was omitted or not accounted for in the clusters of themes identified.

Discrepancies and contradictions were identified during the data analysis phase of this inquiry. Identifying such variances is a normal expectation in qualitative research (Guba, 1981). In order to overcome such variances and ensure the researcher's complete understanding, each verbatim transcript was returned to the participant. Each participant was then asked to validate the researcher's findings of themes and encouraged to add any

additional thoughts or clarifications of their individual experience. The following participant statements exhibit how the participants confirmed the researcher's findings.

Everything looks good! Thanks for including me in the survey. Let me know if you ever need more information. (Aaron)

This looks great. Very precise. (Brandon)

Yes everything looked great, thank you. Just hoping either you or I can go back and clean some of it up...like all the uh's. (Cameron)

Looks good, no changes, nothing more to add! (Daniel)

Awesome, let me know if you need any further follow-up. (Evan)

It looks good except meaning is lost or confused due to my poor speaking style. Please remove the "um's" and "uhs" where they have no meaning in the sentence, and you're right on track. (Frank)

The participants' validation of the researchers' interpretations signifies the researcher's true and accurate understanding of being-in-the world of each participant involved.

Essence, Themes and Subthemes

The researcher identified seven main themes and two subthemes reflecting the experiences of sexual function and satisfaction in adult males following traumatic spinal cord injury. The themes include: 1) accepting disability, 2) rejecting asexuality, 3) resetting expectations, 4) maintaining relationships, 5) cautious exploration, 6) whole body experience, and 7) regaining masculinity through humanity. The theme whole body experience was further divided into two subthemes; 1) "penisless" sex, and 2) mindful orgasm. The identified themes and subthemes contributed to the overall essence of male sexual function and satisfaction following traumatic SCI--*The Journey to Holistic Pleasure: Mind, Heart, and Body*. Figure 1 depicts the essence and themes. The graphic depicts the sequelae of overlapping themes which must be overcome to achieve sexual

function and satisfaction even though participants may have experienced them at different times throughout their individual experience. This journey is complex and time intensive. Many men may find themselves stranded in various stages of the journey forced to overcome barriers and obstacles required to move along. Various barriers and obstacles may cause set-backs or delays in the journey; despite years since initial SCI, and some men may never complete their journey to sexual satisfaction following traumatic SCI.

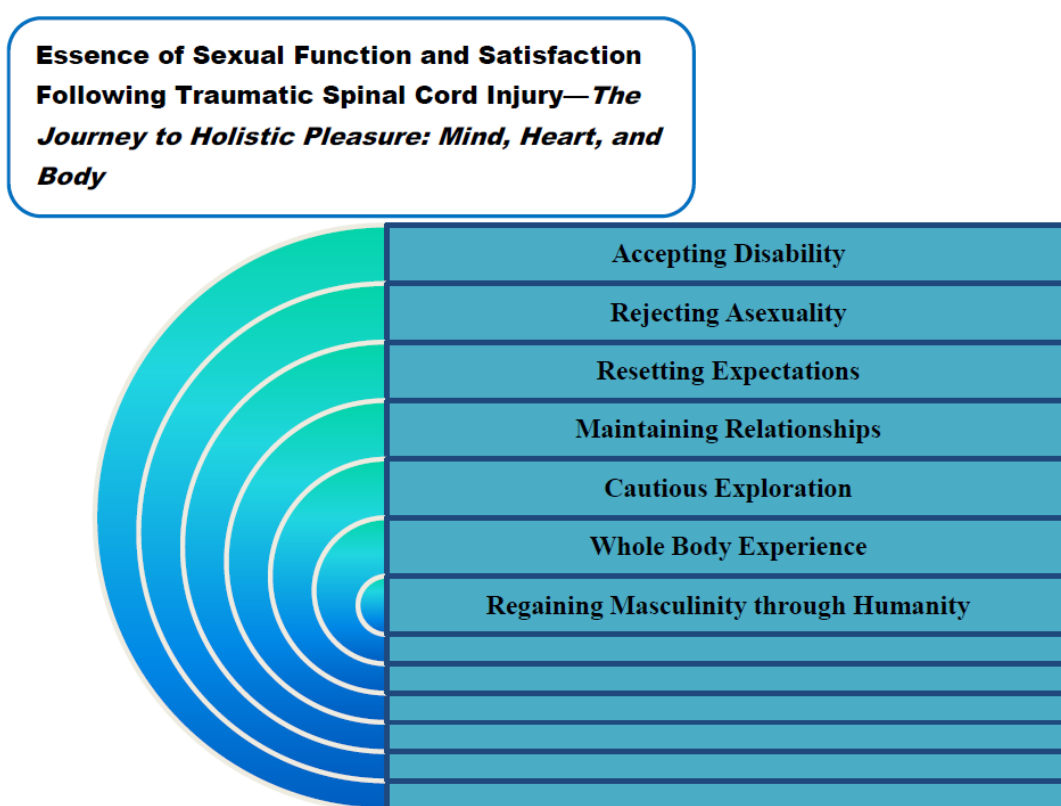


Figure 1. Essence of Male Sexual Function and Satisfaction Following Traumatic Spinal Cord Injury--*The Journey to Holistic Pleasure; Mind, Heart, and Body*

Theme: Accepting Disability

The emerging theme of accepting disability was resonant in all six participant interviews. It was evident that the question, “What has been the biggest change, challenge, or difference you’ve experienced since your injury” brought forth a great deal of emotions within each participant. All of the participants discussed the many stages of their injury and rehabilitation with great passion and sentiment, many of them coming to tears as they shared their individual experiences with the researcher. Prior to facing their injury and overcoming the barrier and obstacles the injury created, the participants were left feeling incomplete as a human being. The following statements from the participants personify this theme as a central part of their experiences.

I would say just dealing with, or learning how to deal with day-to-day stuff.
(Aaron)

The participant then elaborated upon his statement.

I’ve gained some movement since my injury, a little bit, more movement back in my arms and I have full movement of my shoulders and that’s about it. (Aaron)

Other participants contributed.

...to quadriplegia on an immediate basis when you’re on the cusp of independency, just right there about to be independent you have to change your entire lifestyle, your mindset because your mind now has to accept this new body. “Cuz the body is not what you grew up with. The body is not what you ever could prepare for. ...Mentally, for the first three years I was never depressed, but I was frustrated. And I was frustrated with myself because it wasn’t anyone else’s fault that did this. It was my fault. And I depend now on others to do everything from getting me out of bed to wiping my [explicit]. And, and that was the toughest part about this...I had to accept this new body and at first, when I was first injured, I just couldn’t accept it. You know sometimes I would look in the mirror and I’d look at it like God this is me. I’m just—it –it –it was a hell of an adjustment and still to this day it’s an adjustment. (Brandon)

I think life—life –the life change. I think is the biggest change, just not being able to get up in the morning and jump out of bed and walk over—It’s—you gotta

live life, you gotta go to work every day and you have to do what you do to stay alive and pay the bills, but it's challenging... (Cameron)

I have to learn to live with that, so something that eventually it's just in the back of my head and I continue on living. That was not the end of the world for me so I learned how to live with it. Yeah. (Daniel)

When I first got injured the doctors told me I would never be independent, I could do this, couldn't do that. (Evan)

The participant, Evan, then added.

There wasn't anything I couldn't do...I think a lot of people see me as being a normal man—it's—I—I don't have a disability when I meet my friends, people don't see me as being disabled. (Evan)

The final participant concluded.

Well, everything in my life changed with the exception of who I was...My injury, my quadriplegia condition, paralysis has not affected or harmed my purpose in life, my sense of purpose is intact, is every bit as strong as ever. Some things inside of us, you know they don't get affected by the outward. If they're good, you know, they remain good. And I can grow and you know that's an amazing discovery. You know that I've proven over the years—the last 20 years of my injury that what's inside counts a little more than the outward. (Frank)

Theme Summary

The first theme “accepting disability” identifies one of the most difficult phases the participants had to overcome following their SCI and throughout their rehabilitation process. Each example provided, illustrates what the participants had to overcome in their quest to regain the feelings of humanity.

Theme: Rejecting Asexuality

The theme of rejecting asexuality surfaced as participants described and discussed their earliest premonitions of their injury and its possible effects on their sexuality.

Additional dialogue depicted how the participants refused to allow their injury to inhibit

or revoke their sexual lifestyle. The following selections are provided to exemplify this theme.

I don't really know how long I was incoherent in the ICU, but as soon as I was able to think straight is probably when I started thinking about it [sex] and how things would work. (Aaron)

I mean I was 17 years old, my testosterone was still going crazy. My libido was still there...Just because somebody uses a wheelchair doesn't mean that they are asexual. Doesn't mean that everything just stops right there. Regardless if you are in a wheelchair, if you use a wheelchair, or if you are walking, in every relationship a very, very important factor of a relationship is compatibility with everything. It's irrelevant if it is with politics, family, activities, sports, but you have to also incorporate sexual activities. (Brandon)

So the thought was there immediately. I mean it was like holy [explicit] what's going to happen now, how am I going to be able to do it [sex] now. So it's—the thoughts never—never, not been on my mind for sure—being a young guy's mind. (Cameron)

So after, I actually finished going to rehab and you know, I started becoming more independent myself, moving around, and that's when I started realizing you know, started thinking about it [sex] basically....You have to find new ways you know, to be able to satisfy your partner in other ways...You know somehow it works. (Daniel)

I resigned the fact that I would just be, you know living by myself in a sexless relationship, or not relationship but existence. And then the—the nurses told me a completely different story and I met a girl that—that one day came in and asked me out, and that was awesome, you know I didn't have any apprehension after that. (Evan)

I'm sure it was early on—you know wondering if there would be any sexual afterlife, yeah that was the question that I had—I had, I'm sure early on. (Frank)

The participants also divulged information related to the time span between the occurrence of their injury and rehabilitation and their first post-injury sexual encounter occurring. The variances in time between the two occurrences amongst the participants represent the individual struggles the participants had with accepting disability and rejecting asexuality.

Let's see—not very long. I don't remember when it was that I was transferred to the neuro floor, but that was when it happened. (Aaron)

So I probably wasn't thinking being completely sexually active, probably—four years post. I mean, yes, kissing, holding, hugging—but I always made sure I had a blanket over my stomach. (Brandon)

I would say within the first year I had a—yeah I guess I would say it was within the first year. (Cameron)

Probably like eight years after. Yeah that was when I had my first relationship—yeah. (Daniel)

So that was about—almost a year after I was injured. (Evan)

Uh probably about 3 years—3 or 4 years after, I was married. (Frank)

Theme Summary

The theme rejecting asexuality describes the male mind's inherent quest as a sexual being (Burns et al., 2008; Burns, et al., 2009). Additional discussions provide that the participants, despite the severity of their SCI, refused to allow their newly accepted disability their right to sexual pleasure. Lastly, each participant revealed that while sexual function and satisfaction occur following SCI, they occur at various times according to the individual experience.

Theme: Resetting Expectations

The theme of resetting expectations evolved as the participants conversed about their rehabilitation processes and the sexual counseling or education offered within. Resetting expectations was identified as a major factor each participant faced as they acknowledged their paralysis and moved forward in life. Each participant spoke of how they reset expectations for life in general before they reset their expectations as a sexually

active male. Discussions of resetting general expectations following SCI were offered in the following dialogues.

I would say that I have a high self-esteem since the injury, I think I have learned so much more about myself and who I truly am than what I thought I was before my injury so I think that I am much more of a grounded person than your typical 22 year old. I think that I am extremely determined and I know what I want with my life and refuse to let a little dilemma stop me from what I really want to go for. (Aaron)

And actually the day of my—the day I broke my neck my mom was holding my hand going into surgery and she said, “Well you know you might be paralyzed?” I’m like what the hell is that. She says, “Well you may never walk again, so whatever you’re going to do walking, just do it in a wheelchair.” (Brandon)

I wanted to go forth and just you know workout, do like stuff that I used to do, or they teach you to think we’re more susceptible to you know the doctor saying, “No—let’s take it easy” rather than—literally for 30 days they treated me as if I was a thing, you know I was delicate and couldn’t be bent or moved or anything. (Cameron)

...To learn how to live not only not being able to walk cause I mean that is just something that is—I’m not able but I can do basically whatever you know, 99% of the stuff that I need to, but, other than that there is a lot more that comes with not being able to walk. There are other things you have to worry about. You have to be strong and learn how to live with them. (Daniel)

The participant later added.

The biggest challenge would be, in my case, would be not being able to—to be, to feel like a complete man, cause due to the fact that my injury was preventing me from being —sexually—active...I have to learn to live with that, so something that eventually it’s just in the back of my head and I continue on living. That was not the end of the world for me so I learned how to live with it. (Daniel)

The participant Evan specifically spoke of recent complications following the development of a spinal cord cyst.

It’s—it’s continually losing feeling and function...That’s the cyst. When, when—I was a very, very happy full functioning quad. There wasn’t anything I couldn’t do and—you know each day, I—while I’m faced with that fact of losing the ability to drive and be independent. (Evan)

The final participant contributed.

I am paralyzed below my shoulders. It affects my breathing—my—temperature regulation, I’m utterly affected. ..Um lots of physical challenges—with health and breathing and such...I used to function as a normal male...It’s just a matter of words and perspective. (Frank)

Theme Summary

The theme of resetting expectations discussed how participants were forced to acknowledge the extent of their injury and its effect on their daily living. As a result the participants had to accept what was and would be “normal” for them through the duration of their lives. This central theme ultimately contributed to how satisfied the participants were with their post-injury sexual lifestyle.

Theme: Maintaining Relationships

The theme of maintaining relationships emerged as all six participants extensively discussed both past and current relationships. The participants not only spoke of sexual relationships, but of general relationships with friends and family that the participants heavily rely on for activities of daily living. The participants openly identified the value of strong relationships prior to initiation of sexual activities, but they also identified their struggle to initiate relationships and barriers preventing sustainable relationships as a major component of this theme. The theme of maintaining relationships is evidenced by the following expressions.

If I’m gonna have sex with someone it’s gonna be with someone that I truly have feelings for and that I a) am either in a relationship with or b) see myself being in a relationship with them. And, so there is so much more meaning that goes behind sex than just having sex with a random person that you have no connection—emotional connections with. (Aaron)

‘Cuz now you have to be dependent on individuals to get you up, showered, dressed, in and out of bed, you have to utilize a catheter for—to urinate, you have to have an individual to help you on and off the toilet to expel your bowels and the transferring of that power to a person, to a person who is reliable, that’s difficult, that’s very difficult...But I have an extremely close and extremely tight family who supported me through this. The physical part was taken care of by my best friend. One of the best—he never looked at me in the chair. If you’re—if I’m doing it, you’re doing it...If it wasn’t for him, I wouldn’t have assimilated so easy after the injury...I believe that family is first and they are everything for me. They are everything for me, my family, my friends. If it wasn’t for them I would not be where I am today. (Brandon)

Brandon later added.

...If you don’t have a strong communication you’re not going to have a strong relationship, you’re not going to have a strong sexual relationship—that’s all. (Brandon)

One participant was visibly shaken when discussing a relationship he had at the time of his injury, and tearfully stated.

I think the outcome of that weekend would have been much different if she were there...Before I left the rehab hospital, she had moved to college up in Oregon so we separated right then. She’d never even seen me out of the rehab hospital. It was—it was one of the worst case scenarios for her. She took—she took it a lot harder than I did. (Cameron)

Other participants contributed.

...Once I came to this country, my brother brought us here to give us—me a better life...I lived by myself for a few years and right now I’m living with my brother. But you know I guess, I’m pretty much independent, so I do everything by myself. (Daniel)

You know I—I have friends who knew me before I was injured who were hesitant to meet me and see me again, but once we get back together and talk they—they see me as the exact same person. I don’t get treated different...I couldn’t ask for —it all depends on having the right partner, and my partner is absolutely amazing and we’re on the same track all the time, and I—I view myself extremely lucky. (Evan)

I live in a home that my brother owns. Fortunately I have great accommodations, and—I have caregivers that come and go throughout the day to assist me with uh the normal things I need. (Frank)

The participants also spoke of their current marital status representative of their struggles in initiating and maintaining relationships following SCI.

Single...I'm not like in a relationship so, no I wouldn't say that I am currently sexually active all the time. (Aaron)

Single...not right now. Last time I was, was in June, I was dating a woman for, dating a great, great girl for about—been about six to eight months and things just got really involved really fast and we both kind of freaked out. Still friends, still talk, it was just good person, wrong time. (Brandon)

Single...I find myself trying to date older women because they are a little more understanding and understand life a little more than the younger—girls my age. (Cameron)

Single...I've had some relationships so it's very tough at the beginning, but it takes a person so you find the person that is willing to commit and everything. (Daniel)

Married...I—I think that we have an enviable relationship. (Evan)

Divorced...You don't have a lot to offer a partner...It's not fun, it's a hardship. It was a hardship in my previous marriage and you know...it's just an added stress beyond the physical disability—I'm not the greatest candidate. You'd have to be a real miracle person to choose to put their selves in hot water and partnership. (Frank)

Theme Summary

The theme maintaining relationships exemplifies the importance of personal and sexual relationship to the well-being of personal existence. The men discussed their relationships with sexual partners, friends, and family, as well as struggle to initiate relationships and barriers to maintaining long sustaining relationships following SCI.

Theme: Cautious Exploration

The theme cautious exploration arose as the participants discussed sex education and counseling involved within each participant's individual rehabilitation process.

Despite each participant having attended different rehabilitation facilities, each participant shared similar experiences of having completed rehabilitation unprepared for sexual activity following SCI. As a result the participants speak of figuring out what works best for them in their quest for post-SCI sexual function and satisfaction.

...I took a little tiny class I guess you want to say, on being sexually active with a spinal cord injury. And that's about it...I guess I would say it was a little helpful, but it's been more like—like you know, it's something that you've got to figure out as you go and if you don't have a spinal cord injury you don't really understand fully about every little detail and stuff. You just have like the base knowledge of it, except you don't understand everything else that goes along with it. So they just told me things to watch out for and stuff like that and I had to learn the rest on my own. (Aaron)

...When you're thinking about it—to get you to develop an erection, but when it had to be manipulated, grabbed, yanked, pulled, blown, I mean it had to be something but it was just very, very inconsistent...erection is just so inconsistent until the erection—the erection—the ED meds came out, erectile dysfunction medications came out, especially the Papaverine but it's very difficult asking when you're in the heat of the moment, to asking your partner to do an injection into the base of your penis so you can get an erection, so you can get an erection so you can have sex. Pretty darn uncomfortable. (Brandon)

Later in the interview the participant also added.

...With me I'm still cautious. I'm not going to be with a woman without wearing a condom unless she agrees, and of course I mean I would agree to this also, let's get some blood work. Cause I am not going to get an STD with my care giver over here—I'm not going to say hey how's that oozing, weeping sore on the side of my penis, that's not going to happen. So I have to go into it somewhat cautious regardless if it's going to be penetrating or oral, or anything, you have to have that communication. I have to have that communication before an encounter happens. If she's not comfortable with it—SOL we have to move on. I have to be somewhat cautious. Sure you can kiss and everything else, but when it comes to different fluids and because I have this suprapubic catheter so it's kind of open right there. I need to make sure there's not going to be bodily

fluids that are going to be contaminating, it doesn't matter if it's HPV or HIV or you name it, all of the rreas, yeah definitely don't want any of those. (Brandon)

Other participants also spoke of cautious exploration in sexual function.

I view myself as a student to it all because every time I think—every time I have intercourse or whatever you want to call it with a woman I'm learning something every time. (Cameron)

...You have to find new ways you know to be able to satisfy your partner in other ways. So, and I, you know pretty much that's what I've been doing ever since. Because I've had some relationships so it's very tough at the beginning, but it takes a person so you find the person that is willing to commit and everything. You know somehow it works; sometimes it doesn't so that's the down side of things. (Daniel)

...Everything I learned was pretty much on my own. Like, like—yeah, Talking to the guys or talking to the nurses you know gives you help, but everything I learned I just—was pretty much on my own. (Evan)

Evan also contributed.

...You know when someone becomes a spinal cord injury they are faced with challenges—new challenges and sex is a new challenge, and it's finding out what—what works with you and your partner...(Evan)

The final participant stated.

Uh, there was one [class] that I attended for about one hour in the [hospital] they did have two or three sessions. I was only able to attend one where they talked about sexuality and it not very in depth or you know not very informative, but it did present the possibility that sexual activity would continue to what degree or you know details about how it might continue you know there wasn't much detail given. It was very small amount of information. (Frank)

During this phase of the interviews, several of the participants also discussed how their partners' curiosity of sexuality following SCI has led to further exploration and discovery creating sexual satisfaction for both the participants and their partners alike as exhibited by the following.

They are always curious about it. I mean I've had a woman come up to me and said I've been with a white guy, black guy, Hispanic, Asian, been with tall, been

with short, been with wide, been with thin, with tall with fat with thin, I've been with everybody, but I've never been with a guy in a chair. (Brandon)

Sometimes you're ready for it, but they're not because they don't really know what to expect so sometimes it takes a lot of confidence to get them involved. I think they view me as lacking in all departments because of the—the waist down you know department, well it doesn't work so he must not do anything or he must not enjoy it or he doesn't need to do it anymore... (Cameron)

Others, they wonder, cause I have experience, you know I have been told—I was wondering if you're able to do this and if you're able to do that—so they always see you somehow like you are missing something. (Daniel)

You know I have a partner who's willing to—to try things and, and experiment and, so there's—you know there's no boundaries that—that limit us. (Evan)

Theme Summary

The theme cautious exploration exhibited that that the participants completed rehabilitation having unrealistic understanding and expectations of sexual function and satisfaction following SCI. Through cautious exploration and investigation the participants were able to find methods and techniques that worked best for them allowing for sexuality to occur despite paralysis.

Theme: Whole Body Experience

The core of this research focused on sexual function and satisfaction of adult males following SCI and was explored throughout the duration of the participant interviews. This theme and subsequent subthemes emerged as the participants were asked, “Tell me about your sexual experiences before and since your injury, how long after your injury did this occur,” and followed-up with, “Tell me about your body's response to sexual stimuli before and since your injury?” Each of the participants openly shared intimate detailed accounts of pre and post-injury sexual encounters. Those

personal experiences gave rise to the two subthemes (1) “penisless” sex and (2) mindful orgasm.

Subtheme: “Penisless” Sex. The subtheme “penisless” sex emerged as the participants discussed and described their body’s heightened response to sexual stimuli during post-injury sexual activities. None of the participants spoke of their genitalia being central components or focus of post-injury sexuality. Rather than the penis, the participants have learned to find pleasure, joy, and excitement through other previously unexplored outlets unaffected by SCI and effects of the injury.

Well, now it’s —now it [orgasm] is like coming across as like mild autonomic dysreflexia. (Author Note: Autonomic dysreflexia is an emergent life threatening condition characterized by severe hypertension, bradycardia, profuse sweating, nasal stuffiness, headache, anxiety, and flushing of the skin above the injury level.) Or it will come across as just like a symptom, I guess you could say relief. And that was never there before it was just an orgasm I guess. Yeah, well like for a few seconds or so, I would say that I would like get a really mild headache so it’s not like, it’s not super painful to me, it’s almost like, it’s hard to explain. It’s almost like pleasurable because I know what it’s caused from, and it doesn’t last that long. (Aaron)

But obviously things change—big time. Following injury because there was or there is no sensation. So it’s imperative that a light or something is on—Some sort of glow, some sort of candle, some sort of TV or something in the background so you can see what is going on...Visually stimulated. Visually stimulated and that—I mean that can go even—I’m really not big into pornography on the videos. That doesn’t do it for me. That doesn’t do it for me at all as a matter of fact. Going to—strip joints are fun, but seeing a women naked dancing just doesn’t do it for me. I mean going to a club and seeing a woman—watching a woman who is like beautifully dressed, scantily clad even, and watching her dance, that’s—that’s that is for me, that is the most stimulating part of it. It—it has to be all visual. (Brandon)

Brandon later contributed.

...But my body’s reaction is stimulated. I’m hypersensitive in my neck and my ears—neck, ears, face—totally hypersensitive, so I could

have a woman resting on my penis and wouldn't feel a thing, but when she's up on my chest and like, if her legs are up here, the warmth of her inner thighs, the taste, the—the aroma, the everything just makes it so much more sensual. Near that musk and the smell um it's good.
(Brandon)

Other participants added.

Well, before obviously I had a unit that worked so it was more—I don't know—more about me in those kind of instances...As for now it's—the top half is obviously just as responsive to sensitivity and all that kind of stuff, but obviously the bottom half is lacking there... (Cameron)

...You have to find new ways you know to be able to satisfy your partner in other ways...So in my case I might not be able to use my complete body, but I have the options...So, it's...I seem like I'm—I feel like I am able to satisfy somebody, cause there are so many ways to have sex.
(Daniel)

...Before injury obviously you can feel, and you're—you—you—know before injury it's very physical you know, and you're 22 years old, it's—it's—it's completely different. Post injury where now that my pleasure set areas are—are much different, they're all in your hands, your mouth, anywhere you can feel...and mostly cerebral if that makes sense? (Evan)

Well I function as—I used to function as a normal male. You know with sensation, ejaculation and afterwards, as you know, as a quadriplegic there's no sensation, nor is there ejaculation...From—from the functional point of a male quadriplegic—what can we expect? Is ejaculation possible, how so? Um—um how can we best accommodate our mate? Issues like that are kind of important. (Frank)

Subtheme Summary. The subtheme “penisless” sex contributes to the main theme of whole body experience as the participants spoke of how post-injury sexual activities shifts focus and attention from the penis and genitals to incorporate all other aspects of the male body. Despite removing focus from the penis and genitals post-injury sexuality still provides pleasure, joy, and excitement for the involved participants.

Subtheme: Mindful Orgasm. This theme surfaced as the participants spoke of their body's response to post-injury sexual stimuli. While most measure sexual

fulfillment in relation to climax or orgasm, the participants proved that the psychological orgasm is just as powerful and satisfying as the physical orgasm with the following testimonials.

I would say that my—I would—I would say that my sex life now is almost better than my sex life before my injury. Just because now I feel like things are—like when I have sex with someone it's a lot more meaningful thing now than it was prior—before my injury. It didn't have as much meaning and compassion and—and love. (Aaron)

...Psychologically is far more important than physiological if you feel it with your brain, your eyes and how you feel it—it's much more meaningful. I mean, I can—any guy can sit and just have sex and pump away...So I have never ejaculated since I broke my neck, I maybe ejaculated maybe five times max. But that, like I said, that psych—that can be totally overridden by psychological ejaculation. So when I'm with a woman that's my goal is to please her, that's my main goal, when I am pleasing that woman and she has an orgasm, it's almost psychosomatic, it's like I just had the same one and it feels pretty amazing. But yeah, that's why it's—its intense when there's multiple orgasms on her, it's pretty amazing—yeah. (Brandon)

...You know you go as long as you can go and then you're over it and then, as opposed to now you know you don't have to worry about your climax, you worry about their climax, and you kind of go as long as possible and you're there a lot more for them as opposed to yourself. It's more fulfilling for you to see their reactions to what you are doing to them. So I enjoy—I enjoy it more now in a chair than I did before because I get more of a self-satisfaction from their reactions and it's a lot more drawn out and you go for a lot longer. You can last—can make it last all night if you wanted to depending on the situation, a lot more stimulating mentally as opposed to physically, it's a lot more of a mental game being in this state. (Cameron)

During follow-up communication Cameron also added.

...I can relate to myself, being before I was in the accident of a lot of times I needed it—you know you need that release, you need that energy boost at my age or wherever it is that you needed it—you needed to release that sexual tension you have, and now I don't get that I just get the vibe from them that they have a lot of tension, and so I convince them into letting me help them release the tension and more often than not—more often than not they enjoy it... (Cameron)

Other participants stated.

I've been—I have to say I have been proven that sometimes it matters not being able to have a full complete sex with your partner, and sometimes it doesn't and I have learned that it depends on the other person that you are with. And how I feel about it—I feel like a man regardless of whatever my limitations are. (Daniel)

I'm being complete, I don't feel anything below my upper chest, and you know when you're able bodied you—you do. Now my—what, what I've learned to do is transfer my sexual feelings and enjoyment through my wife. So when she is aroused, I get aroused, when she orgasms I—I—I have—I mentally—start breathing, I—I get excited and that's—that's kind of how I've learned to transfer my sexual relationships, transfer it to that... (Evan)

Evan later contributed.

...What works with you and your partner and one of my biggest things that has helped me is mentally I—I—I'm able to transfer my emotions from my wife to me and so conversely I feel like I am having the orgasm as well as my wife, while I'm having the sexual satisfaction. (Evan)

Subtheme Summary. The subtheme mindful orgasm contributes to the main theme of whole body experience as the participants discussed comparison and contrasts of pre and post-injury orgasm and climax. The post-injury psychological orgasm experienced by many of the participants following SCI became the goal of post-injury sexual activity and contributes to the participants' whole body experience of sex.

Theme Summary

The theme whole body experience and subthemes “penisless” sex and mindful orgasm provides comparison and contrast of pre and post-injury sexual function, climax, and satisfaction. The men sharing these anecdotes provide proof that sexual function and satisfaction does indeed occur following traumatic SCI.

Theme: Regaining Masculinity through Humanity

The final theme regaining masculinity through humanity developed as the participants openly conversed about how they view themselves as individuals following SCI and rehabilitation. The men additionally discussed how they thought others viewed them following their accidents. All of the participants spoke of how the injury defined them as individuals and many of the participants spoke of how they had to regain both humanity and masculinity following SCI and rehabilitation as portrayed by the following statements.

I would say that I have a very high self-esteem since the injury, I think I have learned so much more about myself and who I truly am than what I thought I was before my injury so I think that I am much more of a grounded person than your typical like 22 year old. I think that I am extremely determined and I know what I want with my life and refuse to let a little dilemma stop me from what I really want to go for. (Aaron)

During follow-up communication between the participant and the researcher, the participant emphasized.

I guess just to say that overall I have learned that it's weird to have found that I'm a lot happier person and know who I am way more being in a wheelchair than I ever thought I would ever know before my injury being out of a wheelchair. I am much stronger now and much more determined and know a lot more about myself than I ever did before. So, in a sense I guess you could say that I am a happier person now than I ever was before. (Aaron)

Other participants shared the following anecdotes.

Somebody who uses a wheelchair I look at myself as very fortunate because when I went back to XXX [hospital] recently, I saw all these people coming back for re-evals—as in follow-up appointments, and these people were messes...I'm going to keep pushing in a chair until my shoulders literally fall off...But also when you go back to XXX [hospital] you're around all the new patients, the new injuries, and you realize how fortunate you are. You're a C-4,5—I'm a C-4,5 I live alone, I can drive, I work full-time but seeing a C-2, 13 year old girl asking me what it was like to go to a dance when I was in high school, and having to say it was

probably the last time I danced, really danced, rather than being in my chair, and she said she's never experienced dancing in her—she'll never have a first dance with her father, that's when it's impacting. (Brandon)

Brandon later shared.

I know that I'm described as the guy in the wheelchair...but um, I've been perceived as educated, maybe energetic, compassionate individual, with my job, with my family, with my friends. Through it all just be yourself, just be you. (Brandon)

The remaining participants contributed.

I think I am more than just a man in a wheelchair. I mean I think I could do—I mean I have tons of friends and I am better at things than they are and they're not really much better than me at anything besides, because their attitudes—a lot of their attitudes you know hold them back, and my attitude is [explicit] it, it can't get any worse...I don't hold back and I take 100% of that and keep 100% of strength into and they are still dealing with the 50% of attitude that they can't—they haven't figured out how to use what their emotions get in the way of, a lot of stuff and I think I am stronger than most because I have been through more and I've succeeded more and I've overcome more and I'm still overcoming more every day...Just take life you know with a smile everyday instead of taking it with a frown, and man it just really turns people around when you're around them and makes people think and understand that life is bigger than their own problems and need help staying positive—and that makes your whole life a lot easier and people around you makes them feel a little more confident in knowing that somebody's in a chair, and they can be that confident not because of the chair—it's their mental strength and you can just be strong, you know. (Cameron)

As a man...if there is such a thing as a category of being a man takes—takes this things that you need to have to be able to be a man, if there is such a category, which I don't think there is, I would say I'm a man, because I was born a man, I feel like a man, I've learned to live with my situation...I guess living this way you know is hard, but it's doable and unfortunately not everybody can get over things like that you know...It's not the end of the world. And there's always somebody having a rougher time than you. Yeah, it's tough. (Daniel)

Oh, I'm the happiest person I know. I—I, there's no one I envy...knowing that you could be losing everything, but that was my favorite line I'd tell everybody I'm the happiest person I know, and people who know me would say the same thing...I hope a lot of people see me as being a normal man. (Evan)

...paralysis has not affected or harmed my purpose in life, my sense of purpose is intact, is every bit as strong as ever. Some things inside of us, you know they

don't get affected by the outward. If they're good, you know, they remain good.
(Frank)

Theme Summary

The final theme “regaining masculinity through humanity” portrays how each participant’s injury threatened the men’s sense of humanity and masculinity. This theme personifies how the men overcame difficulties and hindrances that each individual injury caused, and how by doing so the participants redefined and re-identified themselves as men constrained to masculine definitions of society.

Chapter Summary

This chapter provided a thorough discussion and exploration of the lived experiences of sexual function and satisfaction in adult males following traumatic SCI. The exploration was amassed in seven main themes and two subthemes. The interconnected themes and subthemes contributed to the overall essence of the participants’ *Journey to Holistic Pleasure: Mind, Heart, and Body*.

CHAPTER VI

DISCUSSION AND INTERPRETATION

The purpose of this phenomenological inquiry was to explore, expand, and depict a profound understanding of the lived experiences of adult males' sexual function and satisfaction following traumatic spinal cord injury. This research resulted in the recognition of seven main themes and two subthemes extracted from the participant's personal encounters revealing the meaning of these experiences as the essence of male sexual function and satisfaction following traumatic spinal cord injury- -The Journey to Holistic Pleasure; Mind, Heart, and Body.

Common themes emerged linking each individual experience as the men shared emotionally driven anecdotes. While each man's individual story was unique to them, the experiences reveal the common thread in attempts to regain pre-injury sexual function and satisfaction following traumatic SCI. The emergent themes and subthemes were critical to the ultimate understanding of the intimate experiences of men with SCI. The thick, rich descriptions provided by the men provide insight to what it is like to experience a healthy sexual lifestyle following traumatic SCI.

Findings as They Relate to the Current Literature

The focus of the current literature in relation to qualitative research primarily focuses on intimate relationships from a couple's standpoint and difficulties with infertility following SCI. There is a paucity of research that solely concentrates on the individual experiences of male sexual function and satisfaction following traumatic SCI. Keeping this in mind, the findings from this phenomenological research study will be compared to what is available in the current literature.

While the results of this qualitative, phenomenological inquiry may support, expand upon, or hint at similarities found in current literature, it is important to respect that the anecdotes and results in this study are unique to this particular cohort of men.

Participant Demographics

A total of six men were recruited and participated in this study. The age of the participants ranged from 22 to 58 years old with all of the participants suffering traumatic SCI between the ages of 14 and 39 years old. Two participants were injured in diving accidents, one participant was injured in a motor vehicle accident (MVA), one participant was injured in an all-terrain vehicle (ATV) accident, one participant was hit by a drunk driver while walking in a crosswalk, and the final participant was injured while tumbling and performing in competitive cheerleading. All of the participants identified themselves as male and having been born naturally male. Three of the participants identified themselves as Caucasian, one participant identified himself as Hispanic, one participant identified himself having Spanish descent, and the remaining participant identified himself having German descent. The participants in this study mirror the most common demographics of SCI recognized in current literature identifying that most new SCI cases occur in persons younger than 30 years old with 50% to 70% occurring in those aged 15 to 35. Additional data suggests estimated racial and ethnic distribution of SCI is as follows: white 65%, African American 25%, Hispanic 8%, with other accounting for the remaining 2%. Finally, the top four causes of traumatic SCI are identified as: motor vehicle accidents 46%, falls 22%, violence 16%, and sports 12% (Centers for Disease Control and Prevention, 2010; Reeve Foundation, 2013; Schoen & Leahy, 2012).

Main Theme: Accepting Disability

The findings of this study reveal that following SCI men experience an array of sentiment and emotions in their journeys through the acute treatment and rehabilitation phases. The goal of the end result is that of improved physical, mental, and sexual wellbeing despite living with paralysis and other effects of SCI (Hess & Hough, 2012; Hess, Hough, & Tammaro, 2007).

The Americans with Disabilities Act (ADA) (as cited by Wisconsin Department of Health Services, 2013) identifies and defines an individual with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activities. Therefore by definition, SCI constitutes and should be considered a physical impairment and disability. In groundbreaking literature regarding personal acceptance of physical disability, which coincidentally published the same year Munro and associates (1948) completed original research on the sexual function of 84 paraplegic men injured in World War II, identified that, “*Deformed* individuals are commonly vengeful and ill tempered” (p. 28). Barker (1948) further identified deformities and imperfections of those viewed as disabled do not necessarily flaw the affected individual’s personality, but rather lends to improvement. The idea of accepting disability presented itself in this research as the participants discussed their individual experiences of coming to terms with paralysis and the disability caused by the effects of the SCI.

Townend, Tinson, Kwan, and Sharpe (2010) identified the strong correlation between depression and non-acceptance of disability in both quantitative and qualitative studies of individuals with post-stroke disabilities. Participants with post-stroke depression related to non-accepted disabilities were noted to express stronger thoughts

and emotions of sadness and frustration in relationship to feelings of being “trapped” or “helpless” due to their dependence on others (Townend, Tinson, Kwan, and Sharpe, 2010). Bodily impairment has negative influences on the individuals’ psychological experiences, feelings and attitudes toward their own bodies, but evidence suggests that over time individuals gradually adjust to the differences in their bodies accepting their disabilities as the norm (Taleporos & McCabe, 2002). Similarly, participants in this student guided study provided dialogue discussing their SCI’s and the physical and mental effects that the injury had on each of them. Many of the participants spoke of how SCI and the effects of the injury continue to affect them day after day despite the initial injury occurring several years ago. Subsequent discussions portrayed the struggles the men had to overcome with becoming independent and having to rely on others for basic needs, all of which greatly affected their experiences of accepting disability following traumatic SCI.

Main Theme: Rejecting Asexuality

In 1975 the World Health Organization reported, “Sexual health is the integration of the somatic, emotional, intellectual, and social aspects of sexual well-being, in ways that are positively enriching and that enhance personality, communication, and love.” (p. 4). Sexuality is a key characteristic of the human individual which expresses the need for intimacy, love, and relationships with others (Parchomiuk, 2012). Firestone, Firestone, and Catlett (2006) identify that contributing to public and private perceptions of sexuality, are the individual’s feelings, attitudes, and behaviors. Additionally, the natural connection between individuals is what characterizes sexual health and intimacy of the relationship. These same authors speak to the complexity of sexuality despite being “one

of the greatest pleasures in life” (p. 3). Such is true for spinal cord injured men because many individuals underestimate their sexual capacity following SCI (Courtois et al., 1993). Therefore, it is imperative that following traumatic SCI, male patients understand that no injury despite acuity revokes the possibilities to experience relationships, love, and human attraction (Paralyzed Veterans of America, 2011). Simplified judgments, false beliefs, stereotypes, and prejudices are common in society when viewing persons with physical disabilities (Parchomiuk, 2012). Parchomiuk further suggests that people with visible, physical disabilities, are often perceived as asexual; lacking sexual attractiveness and the ability of having sex. Regaining sexual function has been identified as the highest priority for paraplegics, ranking above improving bowel and bladder function, extremity function, independence, and performing activities of daily living (Burns et al., 2009; Hess et al., 2007; Reitz et al., 2004; Sale et al., 2012; Simpson, Eng, Hsieh, & Wolfe, 2012; Sorensen et al., 2008; Sorensen et al., 2012).

In this student guided study, participant Brandon was quoted saying, “Just because somebody uses a wheelchair doesn’t mean that they are asexual.” Several of the anecdotes from the participants in this research mirrors Sakellariou’s (2006) conclusion that those with SCI, and disabled persons are often asexualized by society, but, “it is due time they regain their right to being sexual” (p. 110). While the participants in this study identified that the thought of sex never escaped their mind, it often took various lengths of time before sex occurred following injury because of their partner’s views on post-injury sex.

Main Theme: Resetting Expectations

The theme “resetting expectations” described the participants’ experiences of redefining their personal definitions and expectations of idealistic “normal,” “natural,” and “healthy” sex following SCI. Sexuality is often viewed as universal, automatic, and heterosexual conceptualizing normality (Sakellariou, 2006). Firestone, Firestone, and Catlett (2006) previously identified that the word “normal” refers to the statistical norm and that which most people do, where the terms “natural” and “healthy” are usually used as value judgments in relationship to the moral dimensions of various sexual behaviors or practices. In the broadest sense “normal” is defined by shared beliefs, values, customs, and agreed actions and varies widely amongst individuals and groups. For instance, in Western Society premature ejaculation is generally regarded as poor male sexual performance while in Arab cultures premature ejaculation is viewed as a supreme sign of masculinity and manliness (Phillips, 2013). This example of variances amongst individuals exemplifies the differences in thoughts, opinions, and views toward normalcy amongst individuals worldwide. Therefore, normal post-injury sexuality for males following SCI is purely and entirely defined by individual experiences.

While SCI can greatly impede a man’s sexual arousal, orgasm, erectile functioning, and fertility, his psychological nature of sexual desire remains constant (Burns et al., 2009). “Normal” sexual function and satisfaction following SCI is indeed possible and can be just as pleasurable, joyful, and exciting as pre-injury sex as long as the individual with SCI redefines personal “normal” expectations. According to the Reeve Foundation (2012) it is imperative that following SCI men understand that despite the level or completeness of paralysis, sexual performance and the options for sexual

encounters may be different, but physical desirability and participation in sexual activity are nonetheless realistic expectations. This was evident in this study as the participants shared personal experiences comparing differences with pre and post-injury sexual experiences, and while the participants identified the differences in post-injury sex, the sex still proved exciting and pleasurable.

For individuals living with SCI fears over changes in sexual function and concerns regarding partner satisfaction will likely decrease as the individuals becomes more comfortable with their body and more aware of their own sexuality which is critical to redefining and resetting “normal” expectations (Craig Hospital, 2012). It is, however, important to note that the time which redefining and resetting of sexual expectations occurs widely varying on personal attributes such as partnership status, pre-morbid sexual experiences and attitudes, and openness to sexual experimentation (Hess & Hough, 2012). Additionally, it should be noted that evidence suggests that preserved sexual abilities following SCI has shown no significant correlation to increased sexual satisfaction thereby sustaining that “normal” is based on individual experience (Reitz et al., 2004). Finally, as men with SCI defines and identifies sexual expectations of sexual capacity and potency they are exacerbating their individual adjustments to enhancing the salience of changes for post-injury sexuality (Burns et al., 2008). The men participating in this qualitative study identified common feelings expressing that overtime the effects of their injury affects them less and less, and that as time passes, the men slowly become more accustomed to the “normalness” of post-injury rituals such as intercourse and other sexual behaviors. Additional discussions provided dialogue that confirms that while some of the men remember the emotions and feelings of pre-injury pleasure and orgasm,

post-injury pleasure and orgasm have come to replace the individual's pre-injury conceptions of "normal" pleasure and orgasm.

Main Theme: Maintaining Relationships

Sexuality defines individuals and their roles in various relationships in families and communities. Spinal cord injury dramatically strains all previously invested relationships of the individual affected (Paralyzed Veterans of America, 2011). As a result, following traumatic SCI male patients often struggle with initiating and maintaining sustainable relationships whether they are platonic or sexual in nature. Additional factors affecting initiation and maintenance of relationships for men with SCI result from the taboo label and social disapproval society typically places on intimate relationships between physically or mentally disabled persons and individuals without similar disabilities (Hess et al., 2007; Mendes, Cardoso, & Savall, 2008; Sakellariou, 2006). Physical impairments caused by SCI often cause dissolution of self-esteem, confidence, and social causing significant impact on the individual's physical, emotional, and sexual relationships (Hess et al., 2007). According to Abramson (2008), previous long term and trusted relationships are vital to most individual's getting the most out of their sexual potential following injury. Evidence suggests that maintenance of strong social supports systems buffer the negative effects of the injury and its associated stress and is an important determinant of life satisfaction following SCI (Sale et al., 2012; Simpson et al., 2012). However, Klebine (2008) states, in regards to relationships, there is a higher than normal divorce rate among couples during the first several years following a SCI. Several years following injury, the number of single (never married or divorced) people is higher, with most people remaining single 15 years after injury.

Notably, fewer single individuals with SCI will actually marry. Finally, in speaking of effects of trauma and injury, Beaugard and Noreau (2010) suggest that spouses or partners of those with SCI also experience health problems, anxiety, and stress further leading to difficulties maintaining relationships following SCI. This thereby proves concern for marital stability and relationship preservation in care of the individual post-spinal cord injury (Kreuter, 2000).

Men participating in this study exhibited proof of difficulties maintaining relationships both sexual and platonic in nature following SCI. This was evident by the number of single and divorced individuals participating in this study. Outside of their struggles with romantic and sexual relationships, many of the participants identified their efforts to maintain relationships with friends, family, and caregivers as integral components to their living as individuals in society.

Main Theme: Cautious Exploration

Current literature suggests it is widely accepted that following SCI all individuals who want to be sexually active have the knowledge and resources they need to be comfortable with their post-injury sexuality despite the level or completeness of their injury (Paralyzed Veterans of America, 2011). The key to this is learning what works and feels best for the individual involved. Much like what was stated by the individuals of this study, post-injury sexual response greatly depends on individual attributes including openness to sexual experimentation (Hess & Hough, 2012). Paralyzed Veterans of America (2011) suggests that for the individual involved, sexual well-being is accomplished through a thorough understanding of how the individual's body works after SCI. The understanding of one's body can be achieved through a variety of

methods including formal sex education, informal discussions with doctors or other clinicians, discussions with other people with SCI, experimentation and discovery with a partner or masturbation. In the affected individual's quest for post-injury sexual well-being, it is important that the individual understand the importance of finding safe and comfortable environments to explore new or different sexual practices or positions to enhance post-injury sexual experience and pleasure. Additionally, it is important for the individual to realize it may take time and lots of experimentation to figure out what works best for them and their sexual preferences following SCI (Paralyzed Veterans of America, 2011). Finally, it should be noted that according to the Reeve Foundation (2012) open communication and the willingness of individuals to experiment is essential to successfully define one's sexual identity. The concepts of cautious exploration to redefine sexual identity were clearly identified in this research as the participants shared their experiences with sexual experimentation to enhance post-injury sexual expression. Additionally, it was obvious that those participants in strong relationships with good, established, open communication between the partners found it easier to experiment and often reported more satisfaction with current sexual relationships.

Main Theme: Whole Body Experience

The main theme "whole body experience" with the subthemes "penisless" sex and mindful orgasm explain both the physical and psychological differences the participants spoke of regarding both intercourse and orgasm alike. Following SCI, sexual activities and interest takes on a whole new dimension with individualized goals and expectations for performance and climax of the individuals involved. It is important to remember that sex and sexual expression is not simply defined by penis-vagina intercourse, and

therefore following SCI individuals may need to explore a wider range of sexual activities in seeking sexual fulfillment and pleasure. The physical act of intercourse does not solely define one's sexuality (Craig Hospital, 2012). Limiting sexual activity strictly to traditional penis-vagina intercourse will likely reduce opportunities for sexual satisfaction and pleasure following SCI (Paralyzed Veterans of America, 2011).

Mendes et al. (2008) identified that post-injury sexual satisfaction as being closely linked to functioning of the external genitalia. However, many of the participants interviewed for this study described how following SCI, the focus of sex and sexual activities no longer revolved around them or their penises while still having feelings of sexual satisfaction. Prior studies have identified that for male individuals with SCI, post-injury preference of sexual activity includes kissing, hugging, caressing, and oral sex verses pre-injury preference of penetrative intercourse (Hess et al., 2007; Reitz et al., 2004; Valtonen et al., 2006). According to Craig Hospital (2012), "There are many body parts which can be aroused and provide a pleasant sexual response. These areas of the body are called erogenous zones and are not limited to the genital area" (p. 4). Many individuals with SCI report that the area of their body near the level of their injury to be most sensitive, and often report using the mouth, tongue, or hands to elicit sexual stimulation and pleasure (Craig Hospital, 2012; Paralyzed Veterans of America, 2011). To elicit the most sexual pleasure it is imperative that the male individual with SCI incorporate all his senses including imagination and to take time and experimentation to figure out exactly what elicits the most joy, pleasure, and excitement for him and his partner (Paralyzed Veterans of America, 2011). As a result Burns et al. (2009) contribute

that following SCI men should consider novel ways of viewing sexuality and pleasure without sole focus on the penis.

The subtheme “mindful orgasm” relates to the participants’ difficulties or inabilities to ejaculate following SCI resulting in the experience of psychological or mental orgasms following SCI. Evidence suggests that psychological functions of relationships are more important than the physical aspects of sexual function and pleasure (Valtonen et al., 2006). Additionally, Sakellariou (2006) suggests sexual pleasure is much more related to psychosocial rather than physical factors. Hess and Hough (2012) identified following SCI, priorities and reasons for pursuing sexual activity often changes to the need to experience intimacy and closeness to their partner. While orgasm is medically defined as the climax of sexual excitement usually accompanied by ejaculation of semen in the male and by vaginal contractions in the female (Medline Plus, 2013), Sipski et al. (2006) suggests orgasms are psychological in nature; meaning the mindful orgasm experienced by men following SCI, as expressed by participants in this research, are just as representative of sexual climax accompanied by ejaculation pre-spinal cord injury.

Main Theme: Regaining Masculinity through Humanity

The final theme “regaining masculinity through humanity” expressed the participants’ experiences with regaining feelings of both humanity and masculinity following traumatic SCI. Swain et al. (2004) noted for males with SCI, disability from paralysis often creates emasculation secondary to the weakening and atrophy of the body which threatens the social values of masculinity.

From very early ages boys are taught that manhood is signified by the possession, size, and use of their genitals. Additionally, men are taught that the males should initiate sexual activity, and that males should possess and exhibit insatiable sexual desire. In society powerful, prestigious, and competent men are viewed as sexually achieved and in complete control of their sexual function (Burns et al., 2008; Burns, et al., 2009). Male sexuality is often perceived in an exclusive, phallogentric, and oppressive ways commonly based on physical performance which leads male SCI patients to feelings of castration and emasculation (Sakellariou, 2006). Male individuals with SCI often associate changes in their sexual function to a loss of their masculinity resulting in depression and anxiety as well as feelings of hopelessness, insecurity, shame, humiliation, decreased self-worth, anger, low self-confidence, and poor self-esteem due in part to decreased penetrative capacity (Burns et al., 2008; Burns, et al., 2009).

Mona et al. (2000) previously identified that an intrinsic factor of feeling as complete male or female is the individual's sexual assertiveness and the relationship with communication, enhancing self-esteem, body awareness, and personal desirability in individuals following SCI. Additionally, Burns et al. (2009) suggests adherence to masculine customs may characterize a vital and under researched link between health behaviors and the ability to adjust to a physical disability and chronic/life-threatening conditions. Lastly, it should be noted that following traumatic SCI the male patient's adjustment to SCI and the effects of the injury are likely influenced by a complex interaction of injury-related variables and the individual's constructions of masculinity norm (Burns et al., 2008; Burns et al., 2009).

Many of the participants in this study identified and shared with the researcher how the effects of their SCI threatened their masculinity and identities within society. The participants spoke of how throughout their acute treatment and rehabilitation they were able to piece by piece regain their identities as a human and not just a disease diagnosis, and through perseverance and experimentation the men were able to continue sexual identity and expression allowing them to configure to stereotypical masculine role constraints that they grew accustomed to.

Implications for Nursing

As a novice nurse caring for SCI patients in a Northern Nevada Trauma Center, this nurse failed to recognize the extent of impact of these patients' injuries outside of paralysis itself. Through experience caring for this vulnerable population this nurse began to realize the full extent of the impact SCI has on activities of daily living (ADL) including sexual activity. However, this nurse did not necessarily have and still does not believe most nurses have adequate resources to address such needs when the patients and/or significant others inquire. As a result, in pursuing higher education this nurse chose to research this topic to help better educate nurses and other healthcare providers on the importance of holistic treatment response and restoration in acute injury and illness rehabilitation.

The findings from this research study provide nursing a significant perspective of male sexual function and satisfaction following traumatic SCI. Student nurses are taught that sexuality, "Encompasses our whole being. It includes our sense of femaleness and maleness. Sexuality includes biological, sociological, psychological, spiritual, and cultural dimensions of each person's being...influenced by values, attitudes, behaviors,

relationships with others, and the need to establish emotional closeness with others (Potter & Perry, 2005, p. 523). Additionally, it should be noted that Pioneer nursing theorist Virginia Henderson (1966) identified that the nurse's responsibilities are to assist those in our care with performing activities that contribute to health, recovery, or peaceful death, which would normally be performed without assistance if the individual had the strength, will, or knowledge that allows for regaining independence as soon as reasonably possible. Therefore, by the relationships between shear definition and theory alone; it is absolutely imperative that nurses understand their role to holistically treat all components of the individual patient including sexuality and the importance of human response to sex.

A commonality of the seven main themes and two subthemes identified in this study was lack of education both on part of health care provider and patient alike. The participants spoke of how they were not educated as to what to expect regarding sexual function and satisfaction following SCI and how many practitioners did not adequately know how to address the individual needs. This study has provided foundational knowledge to; 1) educate nurses and other health care providers with a better understanding of the meaning and significance of the lived experience of male sexual function and satisfaction following traumatic SCI and 2) educate male SCI patients regarding the "normalness" of their sexual function and satisfaction following traumatic SCI.

Potter and Perry (2005) identify patient education as one of the nurse's most important roles in any setting of healthcare. Additionally stating reducing length of stays, time constraints, patient acuity and the number of patients being cared for directly affects

the nurse's ability to provide adequate, clear and concise, quality information. Injury, illness, and disease such as traumatic SCI has significant impact on the individual's physical, emotional, and sexual wellbeing, therefore, it is imperative the nurse have the skill, knowledge, and expertise to holistically treat and restore all aspects of life affected by the specific injury, illness, or disease (Hess & Hough, 2012; Hess et al., 2007).

The results of this study suggest that those with SCI desire comforting and supportive healthcare providers knowledgeable of how profoundly their injury will affect every aspect of their life including sexual function and satisfaction. The knowledge regarding sexuality of people with physical or mental disabilities must begin in training for physicians, nurses, therapists, social workers, and other healthcare providers, and must not focus on providing sexual advice but comprehensively understanding sexuality following injury, illness, or disease, and its manifestations (Parchomiuk, 2012). It is the hope of this nurse that this research will inspire future nurse practitioner, nurse educator, and clinical nurse leader students to complete further research to develop in-depth comprehensive patient and client educational programs thoroughly addressing the holistic needs, such as sexual education, for any individual suffering acute injury, illness, or disease because of the impact sexuality has on the definition of the individual being. In doing so the nurse and other practitioners thoroughly understand that, "No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people" (Paralyzed Veterans of America, 2011, p. 3). Lastly, the nurse with full understanding of sexuality and the effects of sexuality on the individual will be able to help the patient understand that coming to acceptance about things that can't be changed leads to the ability to enhance our

recognized attributes (Paralyzed Veterans of America, 2011). Armed with this knowledge nurses and other providers understand the meaning and significance of sexuality and its relationship to personal identity and expression following SCI and other injury, illness, or disease with the hopes that sexual expression will be included early on in acute treatment and rehabilitation to ensure holistic restoration of the affected individual.

Limitations

Findings from this study are limited to one geographical region of the United States. During the recruitment process of this study men began to refer their friends and acquaintances to the researcher ballooning effects of the participants, as a result numerous diversities were not yielded. While it was the researcher's goal to recruit a diverse participant population, the sample predominantly reflects the views of single, heterosexual, Caucasian men. Additionally, because many of the participants self-selected to participate in this study, the participants are primarily representative of those men whom have completed or are near completion of their journey to sexual satisfaction following SCI.

Recommendations for Future Research

According to Chan, Brykczynski, Malone, and Benner (2010) interpretive phenomenology such as those methods guided by Heidegger, "Reveals knowledge embedded in caring, cultural and social practices, engaged skilled actions, embodied know-how, and concrete ways people cope with everyday life events such as health, illness, inquiry, birth, suffering, and dying" (inside cover). Phenomenologist van Manen (1990) suggests that no phenomenological inquiry provide enough individual

interpretation of the phenomenon to forgo the possibilities of future research building a deeper and even richer description of the experience. As a result, it is the hopes of this researcher that the results of this study will spark replication and further inquiry into the experiences of male sexual function and satisfaction following traumatic SCI. While the themes produced in this study are representative of this population alone, it is recommended the resulting themes be tested with other populations for follow-up comparison and validation.

Due to the limited amount of qualitative research regarding male sexuality following traumatic SCI, more research is suggested taking other variables into account. Replication of this study will likely offer new and different variables of individual experiences of male sexuality following traumatic SCI. Studies addressing specific ethnic groups should be considered for future research to explore variances amongst cross-cultural experiences. Comparison studies evaluating female sexuality following SCI and studies evaluating how SCI affects the sexual function and satisfaction of nondisabled significant others would also provide for comparative studies. Additionally, future studies solely evaluating sexual function and satisfaction of homosexual individuals would provide for further comparison and validation of themes yielded in this study. Finally, exploring the patient's psychological reaction to healthcare providers will likely provide more insight for healthcare providers to improve care to vulnerable populations during acute treatment and rehabilitation.

Chapter Summary

This chapter presented discussion and interpretation of the themes identified in this phenomenological inquiry. Much of the produced research findings support and

contribute to the current reviewed literature. In general this research provides new information and insight into the experiences of male sexual function and satisfaction following traumatic SCI. Also included are implications for nursing and recommendations for further research.

CONCLUSION

Six male participants voluntarily participated in this research. The findings from this research yielded seven main themes and two subthemes contributing to a thick, rich description of the experiences of male sexual function and satisfaction following traumatic SCI. Findings were validated through participant review and provide the experiences that contributed to the overall essence of the male sexual function and satisfaction following traumatic spinal cord injury--The Journey to Holistic Pleasure; Mind, Heart, and Body. Understanding the meaning and significance of these experiences has significant implications for individuals with SCI and their families, along with nurses, other health care providers, and future researchers. The research produced supports and contributes to current literature regarding aspects of male sexuality following traumatic SCI. Finally, while this research provides a single interpretation of the phenomena, it ultimately lends opportunity for future investigation regarding a significant component of men's health.

APPENDIX A

LITERATURE REVIEW OF SEXUAL FUNCTION AND SATISFACTION IN
YOUNG MALES FOLLOWING TRAUMATIC SPINAL CORD INJURY

Reference	Description of Study	Results/Conclusions
<u>General Information</u>		
Kendall et al., 2003	Expository	Provides detailed background and overview of the development of a standardized scale to assess the training needs of professionals in providing sexuality rehabilitation following SCI.
Milligan & Neufeldt, 2001	Expository	Explores the social and empirical foundations for the contention that persons with disabilities (PWD) are viewed as asexual, and examines whether there is cause and concern for intervention.
Munro, Horne, & Paull, 1948	Groundbreaking original research analyzing the sexuality of 84 paraplegic men returning home from World War II.	First identification of the effects SCI on sexual potency in males.
Sipski, Alexander, & Gomez-Marin, 2006	Laboratory-based experimental design analyzing the ability of 45 men with SCI and 16 able-bodied subjects to achieve orgasm coupled with detailed neurologic examination, history and physical examination, and administration of the International Index of Erectile Function.	Results suggest men with SCIs are less likely than controls to achieve orgasm. Additionally, a disconnect was noted between the presence of orgasm and the presence of ejaculation.
Sipski-Alexander et al., 2009	Expository	Identifies and describes the instruments most frequently used to measure aspects of sexual function for individuals living with SCI.

Sorensen, Hansen, & Sorensen, 2012	Cross-sectional questionnaire with retrospective and prospective data from medical files to examine sexual function at least 10 years after traumatic SCI.	Identifies sexual dysfunctions secondary to SCI for both males and females. Identifies bowel and bladder management, pressure ulcers, spasticity, and pain correlation to lower sexual satisfaction in both sexes.
Swope Rodante, 2012	Website	Examines and identifies the varying effects of SCI based on the level of the injury.
<u>Anatomy and Physiology Overview</u>		
Craggs, Balasubramaniam, Chung, & Emmanuel, 2006	Systemic literature review of current literature reviewing pathophysiology of SCI.	Provides detailed background and overview of current literature covering anatomy, physiology, and pathophysiology of SCI.
Porth, Gaspard, & Noble, 2011	Textbook	Provides detailed explanation of human body anatomy and physiology with pathophysiology of injury, illness, and disease.
Sarhan, Saif, & Saif, 2012	Expository	Provides detailed background and overview of anatomy, physiology, and pathophysiology of SCI.
<u>Physiological Barriers</u>		
Courtois et al., 2012	Systematic review of the literature on acute or prophylactic treatment of autonomic dysreflexia (AD) in the context of sexual activities.	Identifies sexual activities as potential source of AD, as well as in-depth overview of adequate treatments and prophylaxis of sexually-induced AD.
Hess & Hough, 2012	Systemic literature review focusing on the impact SCI may have on achieving physical and emotional intimacy.	Identifies a positive relationship between sexual education and sexual activity, and suggests that the impact of inadequate sexual counseling and education as part of rehabilitation can be deleterious.

Johnston & Ducharme, 2010	Expository	Provides detailed background and overview of erectile dysfunction (ED) secondary to SCI with details of various treatment options.
Sorensen et al., 2008	Multicenter prospective cohort study analyzing the prevalence and predictors of sexual dysfunction after moderate-to-severe trauma.	Identifies that sexual dysfunction is common and usually severe after major trauma, while injury severity is a significant independent predictor.
Valtonen et al., 2006	Cross-sectional questionnaire analyzing satisfaction with sexual life and self-assessed sufficiency of sexual counseling in persons with traumatic SCI and meningomyelocele (MMC).	Results suggest that the median of satisfaction with sexual life was low among both females and males living with SCI or MMC. Identifies urinary and fecal incontinence and neuropathic pain as causes to sexual dissatisfaction.
<u>Psychological Distress</u>		
Abramson et al., 2008	Systematic literature review of all sexual health outcome measures reporting psychometric properties for a SCI population.	Results suggests that there is no clinically agreed upon SCI measurement tool for sexual health outcomes in a SCI population.
Burns, Hough, Boyd, & Hill, 2009	Hierarchical multiple linear regression analysis of internet-based survey analyzing the role of men's conformity to gender norms for sexual prowess on the relationship between sexual desire and depression following SCI.	Results indicate that men with SCI with strong sexual desire exhibit higher rates of depression when conformed to masculine norms emphasizing sexual prowess.
Ducharme, 2006	Editorial	Provides detailed background and overview of medical and psychosocial aspects of infertility for men with SCI and their partners.
Hess, Hough, & Tamarro, 2007	Qualitative study analyzing males with SCI enrolled in an outpatient SCI sexuality program at an urban Veterans Affairs Medical Center.	Results suggests that availability of continued access to counseling regarding sexually related issues is very important and

		that men with SCI can benefit from an interdisciplinary approach in addressing functional and emotional needs.
Klebine, 2008	Expository	Identifies common myths and clarifies realities of the physical, emotional, and sexual relationships of individuals with SCI.
Reitz, Tobe, Knapp, & Schurch, 2004	Prospective follow-up questionnaire study assessing individuals' sexual activities, abilities, desires, satisfaction, and sexual adjustment following SCI.	Identifies that SCI has major impact on sexual function, relationship to partner, social life, bladder management, physical well-being, and overall quality of life.
Richards, Tepper, Whipple, & Komisaruk, 1997	Qualitative study analyzing the "lived experience" of sexuality and relationships of 15 adult women living with complete SCI between the levels of T6 and L2.	Identifies themes of the sexual "lived experience" following SCI to include; cognitive-genital dissociation, sexual disenfranchisement, sexual exploration, and sexuality reintegration.
Sakellariou, 2006	Qualitative study analyzing Greek males with SCI perspectives on barriers that compromise sexuality following SCI.	Identifies barriers as causes of unsatisfying sexual life for men with SCI that seem to diminish or disappear overtime.
<u>Adjustments and Motivations</u>		
Burns, Mahalik, Hough, & Greenwell, 2008	Systematic literature review and thorough case study example highlighting how men's adherence to gender scripts for sexual potency may contribute to their adjustments following SCI.	Identifies how men with SCI adhere to this gender norm influences the individual's post-injury mental health.
Sale et al., 2012	Prospective follow-up observational study investigating changes and identifying predictors in interpersonal functioning and sexual	Identifies vocational status and car-driving ability as positive predictors of sentimental life. Identifies bowel and bladder continence

	life following traumatic SCI	inconsistently as positive indicators for sexual satisfaction.
Simpson et al., 2012	Systematic review of studies that directly surveyed individuals with SCI to ascertain health priorities and domains of importance.	Identifies priorities and domains of importance for individuals with SCI.
<u>Patient Education/Publication</u>		
Firestone, Firestone, & Catlett, 2006	Textbook	Examines and provides detailed explanation of sex and love in the context of intimate relationships and how such shapes the individual involved.
Medline Plus, 2013	Website	Provides medical definition and detailed explanation of the process of orgasm in the able-bodied individual.
Paralyzed Veterans of America, 2008	Patient Education Publication	Provides patient-focused easy to understand detailed background and explanation of clinical practice guidelines for acute management of SCI.
Paralyzed Veterans of America, 2011	Patient Education	Provides patient-focused easy to understand detailed background and explanation of clinical practice guidelines for sexual counseling and rehabilitation for individuals with SCI.
Swain, French, Barnes, & Thomas, 2004	Textbook	Examines the relationship of individuals living with disabilities and the environments they live in.
University of Miami, 2009	Website	Provides patient-focused easy to understand detailed explanation of sexuality following SCI.

APPENDIX B

IRB APPROVAL, UNIVERSITY OF NEVADA, Reno



University of Nevada, Reno

Office of Human Research Protection
 218 Ross Hall / 331, Reno, Nevada 89557
 775.327.2368 / 775.327.2369 fax
 www.unr.edu/research-integrity

Certification of Approval for New Protocol: Social Behavioral
 Social Behavioral Institutional Review Board
 FWA00002306

Date: May 22, 2013
 To: Stephanie S DeBoor, PhD, MS, RN, CCRN Division of Health Sciences
 Copy: Derek Drake

UNR Protocol Number: 2013S110
 Protocol Title: An Exploration of the Lived Experiences of Sexual Function and
 Satisfaction in Young Males Following Spinal Cord Injury

Sponsor Names:

Type of Review: Expedited 7 Minimal risk

Meeting/Review Date: 05/20/2013
 Approval Period: May 20, 2013 to May 19, 2014

This approval is for:

Approved number of subjects: 10
 Approved documents:
 Protocol dated 05/15/2013
 Consent form dated 05/15/2013
 Recruitment Flyer
 Transcriber Confidentiality Agreement
 Interview Questions

The above-referenced protocol was reviewed and approved by one of UNR's Institutional Review Boards in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46 and 21 CFR 50 and 56).

Problems Researchers Must Report to the Research Integrity Office or IRB Staff
(to be reported as soon as possible, but within 10 business days)

- New or additional risks: Outcomes that the principal investigator believes are unexpected, related to the research, and suggest the research may place

participants or others at greater risk of harm than was previously known or recognized

- Changes to expected harms or benefits: Any report indicating the frequency or magnitude of harms or benefits may be different than initially presented to the IRB
- Privacy: Any invasion of privacy related to an individual's participation in research
- Confidentiality: Any breach of confidentiality involving research data
- FDA Changes: Any change in FDA labeling or approval for a drug, device or biologic used in a research protocol
- Immediate harm: Any change to the protocol to eliminate an apparent immediate hazard to a research participant, prior to seeking IRB review and approval
- Prisoner: Any incarceration of a participant in a protocol not approved to enroll prisoners
- Sponsor: Any event that requires prompt reporting to the sponsor
- Sponsor: Any sponsor-imposed suspension for risk
- Protocol change: Any accidental or unintentional change to the IRB approved protocol that harmed participants or others, indicates participants or others may be at increased risk of harm, or has the potential to recur
- Device: Any unanticipated adverse device effect
- Department of Health: Any non-compliance identified by Department of Health audit or monitoring
- Federal agency: Any investigation or report by federal agency related to the research
- Medical license or practice changes: Any loss of license or hospital privileges by any researcher on the study
- Complaints: Any complaints that suggest participants or others may have been harmed or placed at increased risk of harm

PI Responsibilities

- Maintain an accurate and complete protocol file.
- Submit continuing projects for review and approval prior to the expiration date.
- Submit proposed changes for review and approval prior to initiation, except when necessary to eliminate apparent immediate hazards to subjects. Such exceptions must be reported to the IRB at once.
- Report any unanticipated problems which may increase risks to human subjects or unanticipated adverse events to the IRB within 5 days.
- Submit a closure request 10 days after project completion to the IRB.

Reference the protocol number on all related correspondence with the IRB. If you have any questions, please contact Rebecca Thomas at 775.327.2368.

For Veteran's Administration research only

VA Research: No

Flag VA Medical Record: N/A

NOTE: You are not approved to begin this research until you receive an approval letter from the VASNHCS Associate Chief of Staff for Research stating that your research has been approved by the Research and Development Committee.

APPENDIX C

AMENDED IRB APPROVAL, UNIVERSITY OF NEVADA, Reno



University of Nevada, Reno

Office of Human Research Protection
 218 Ross Hall / 331, Reno, Nevada 89557
 775.327.2368 / 775.327.2369 fax
 www.unr.edu/research-integrity

Certification of Approval for Modifications: Social Behavioral
 Social Behavioral Institutional Review Board
 FWA00002306

Date: October 07, 2013
 To: Stephanie DeBoor, PhD
 Copy:

UNR Protocol Number: 2013S110
 Protocol Title: An Exploration of the Lived Experiences of Sexual
 Function and Satisfaction in Young Males Following
 Spinal Cord Injury
 Sponsor Names: N/A
 Type of Review: Expedited 7, minimal risk
 Meeting/Review Date: 08/28/2013
 Approval Period: April 4, 2013 to April 3, 2014

This approval is for:

Approved number of subjects: 10
 Approved documents:
 Modified Protocol dated 09/19/2013
 Modified Consent Form dated 09/19/2013
 Modified recruitment flyer

The above-referenced protocol was reviewed and approved by one of UNR's Institutional Review Boards in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46 and 21 CFR 50 and 56).

Problems Researchers Must Report to the Research Integrity Office or IRB Staff
(to be reported as soon as possible, but within 10 business days)

- New or additional risks: Outcomes that the principal investigator believes are unexpected, related to the research, and suggest the research may place

participants or others at greater risk of harm than was previously known or recognized

- Changes to expected harms or benefits: Any report indicating the frequency or magnitude of harms or benefits may be different than initially presented to the IRB
- Privacy: Any invasion of privacy related to an individual's participation in research
- Confidentiality: Any breach of confidentiality involving research data
- FDA Changes: Any change in FDA labeling or approval for a drug, device or biologic used in a research protocol
- Immediate harm: Any change to the protocol to eliminate an apparent immediate hazard to a research participant, prior to seeking IRB review and approval
- Prisoner: Any incarceration of a participant in a protocol not approved to enroll prisoners
- Sponsor: Any event that requires prompt reporting to the sponsor
- Sponsor: Any sponsor-imposed suspension for risk
- Protocol change: Any accidental or unintentional change to the IRB approved protocol that harmed participants or others, indicates participants or others may be at increased risk of harm, or has the potential to recur
- Device: Any unanticipated adverse device effect
- Department of Health: Any non-compliance identified by Department of Health audit or monitoring
- Federal agency: Any investigation or report by federal agency related to the research
- Medical license or practice changes: Any loss of license or hospital privileges by any researcher on the study
- Complaints: Any complaints that suggest participants or others may have been harmed or placed at increased risk of harm

PI Responsibilities

- Maintain an accurate and complete protocol file.
- Submit continuing projects for review and approval prior to the expiration date.
- Submit proposed changes for review and approval prior to initiation, except when necessary to eliminate apparent immediate hazards to subjects. Such exceptions must be reported to the IRB at once.
- Report any unanticipated problems which may increase risks to human subjects or unanticipated adverse events to the IRB within 5 days.
- Submit a closure request 10 days after project completion to the IRB.

Reference the protocol number on all related correspondence with the IRB. If you have any questions, please contact Rebecca Thomas at 775.327.2368.

For Veteran's Administration research only

VA Research: N/A

Flag VA Medical Record: No

APPENDIX D

RECRUTIMENT FLIER

Spinal Cord Injury Research Opportunity



Males With Spinal Cord Injury Wanted For Research Study

I hope you consider being part of this research. If you would like to participate or have additional questions, please contact me at:

dereksdrake@hotmail.com

or

775-336-9588

or

Dr. Stephanie DeBoor,

Faculty Chair

deboors2@unr.edu

- My name is Derek Drake. I am a Registered Nurse pursuing a Master's Degree at the University of Nevada, Reno.
- I am researching the experiences of men with spinal cord injuries relating to sexual function and satisfaction.
- The title of my study is *An Exploration of the Lived Experiences of Sexual Function and Satisfaction in Young Males Following Traumatic Spinal Cord Injury*.
- Would you like to share your story with me?
- Inclusion criteria: any man (18 years and older) with traumatic spinal cord injury that occurred more than 1 year ago resulting in paraplegia or tetraplegia (quadriplegia) residing in Northern California or Nevada
- Participants will agree to a face-to-face audio-taped interview to be conducted at a private location of your choice.
- A follow-up interview will be conducted so you can clarify your experience and add any additional remarks.
- All information will be kept strictly confidential and you will be given an alias for the research study results.

APPENDIX E
RECRUITMENT LETTER

Thank you for your interest in my study!

My name is Derek Drake. I am a Registered Nurse and am pursuing my Master's Degree at the University of Nevada, Reno. I am currently conducting research in the area of sexual function and satisfaction in adult men following traumatic spinal cord injury. The study is entitled *An Exploration of the Lived Experiences of Sexual Function and Satisfaction in Adult Males Following Traumatic Spinal Cord Injury*. Men interested in participating must meet the following criteria: 1) male gender, 2) 18 years of age and older, 3) residing in northern California or Nevada, 4) suffered a traumatic mechanism of action, 5) spinal cord injury resulting in paraplegia or quadriplegia, and 6) living with SCI for a minimum of one year. Participants will agree to a face-to-face, audio-taped interview to be conducted at a private location of the participant's choice. Additionally, participants will be asked to agree to meeting for a second time to discuss the transcribed verbatim material, clarify any misinterpretations, and to allow time to add any thoughts to their experiences.

Participation is completely voluntary, confidential, and there is no cost incurred as a result of participating. The interviews will last approximately 60 minutes and will be held in a private mutually agreed upon location. In the first interview we will be discussing your experiences regarding sexual function and satisfaction following spinal cord injury. The second interview will be mainly for clarification purposes and for you to add any other comments.

Due to the emotional nature of the subject matter, you may refuse to answer any question. There will be information for medical referral should you be interested. You may withdraw from the study at any point without penalty. The benefits of participating in this research study, is to describe the meanings and significance of male sexual function and satisfaction following spinal cord injury. These experiences will contribute to the nursing profession's knowledge as well as patients seeking medical advice from primary care practitioners. The goal of this qualitative research is to bring meaning to the experiences of sexual function and satisfaction following spinal cord injury and to better understand the needs of patients seeking medical advice related to sexuality after spinal cord injury. The findings of this study will be presented in a master's thesis and made available to you upon request. It will also be used for article publication, poster, and power point presentations.

All information obtained in this research will remain strictly confidential. Participants will be given a pseudonym and all research materials will be kept in a locked cabinet in the researcher's office. Audiotapes will be destroyed in compliance with specifications of the granting IRB.

I hope you will consider being a participant in this study and look forward to working with you. If you are interested in participation or have any questions please contact me at dereksdrake@hotmail.com or 775-336-9588. Thank you for your consideration.

Sincerely,

Derek S. Drake, RN, BSN

APPENDIX F

INFORMED CONSENT, UNIVERSITY OF NEVADA, RENO

**UNIVERSITY OF NEVADA, RENO SOCIAL BEHAVIORAL INSTITUTIONAL
REVIEW BOARD****CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

TITLE OF STUDY: An Exploration of the Lived Experiences of Sexual Function and Satisfaction in Adult Males Following Traumatic Spinal Cord Injury

INVESTIGATOR(S): Stephanie DeBoor, PhD, RN, CCRN 775-682-7156; Derek S. Drake, RN, BSN 775-336-9588

PROTOCOL #: 2013S110

SPONSOR: N/A

PURPOSE

You are being asked to participate in a research study. The purpose of this study is to achieve a better understanding of what young men with spinal cord injury experience regarding sexual function and satisfaction. Understanding your experiences might help nurses to better support other male spinal cord injury patients with similar experiences.

PARTICIPANTS

You are being asked to participate because you are; 1) male gender, 2) 18 years of age or older, 3) residing in northern California or Nevada, 4) have suffered a traumatic mechanism of action, 5) History of a spinal cord injury resulting in paraplegia or tetraplegia (quadriplegia), and 6) living with SCI for a minimum of one year. Approximately 8 to 10 participants will be enrolled in this study.

PROCEDURES

If you volunteer to participate in this research study, you will be asked to take part in a face-to-face, audio-taped interview, with the student researcher, lasting approximately one hour. The interview will be held at a mutually agreed upon, convenient location. This location will be private to ensure confidentiality of the participant and the information collected. During the interview you will be asked questions related to your sexual experiences following spinal cord injury. Following the initial interview, you will be asked to read the transcript from the interview and the student researcher's interpretation to make sure it is a good description of your experience. Follow-up communication will be conducted either by telephone, post office mail or face-to-face. Review and discussion of the transcript is expected to take no more than one additional hour of your time. It is important for you to remember that your participation in this study is voluntary and all information shared will be kept confidential.

DISCOMFORTS, INCONVENIENCES, AND/OR RISKS

There are risks involved in all research studies. This study may include only minimal risks. There may be some discomfort answering some of the questions related to your spinal cord injury, sexual function and satisfaction. You may take a break, refuse to answer any question that makes you feel uncomfortable, or end the interview. You may withdraw from the study at any time. There are no risks for refusing to participate.

BENEFITS

You may not experience any direct benefits from participating in this study other than the satisfaction of having participated in research. However, we hope that learning about your sexual experiences following spinal cord injury will help health care providers to better understand how to support other men with similar experiences.

CONFIDENTIALITY

All information gathered during this research study will be kept completely confidential. All participants will be given an alias (pseudonym) to keep all material confidential. In field notes, recordings, and transcription, participants will be referred to by their pseudonym to protect anonymity and confidentiality of shared information. Interviews will be audio taped and transcribed by a private, professional transcriptionist who has signed a confidentiality statement. Your identity will be protected to the extent allowed by law. You will not be personally identified in any reports or publications that may result from this study.

The Department of Health and Human Service (HHS), other federal agencies as necessary, the University of Nevada, Reno Social Behavioral Institutional Review Board may inspect your study records. The study records will be securely stored in a locked file cabinet in the researcher's office and destroyed in accordance with the granting IRB specifications. .

COSTS/COMPENSATION

There will be no cost to you nor will you be compensated for participating in this research study.

DISCLOSURE OF FINANCIAL INTERESTS

The researcher has no financial interest in this study.

RIGHT TO REFUSE OR WITHDRAW

You may refuse to participate or withdraw from the study at any time and still receive the care you would normally receive if you were not in the study. If the study design or use of the data is to be changed, you will be so informed and your consent re-obtained. You will be told of any significant new findings developed during the course of this study, which may relate to your willingness to continue participation.

QUESTIONS

If you have questions about this study or wish to report a research-related injury, please contact Derek S. Drake, RN, BSN at 775-336-9588 or Dr. Stephanie DeBoor, PhD, RN, CCRN at 775-742-7732 at any time.

You may ask about your rights as a research subject or you may report (anonymously if you so choose) any comments, concern, or complaints to the University of Nevada, Reno Social Behavioral Institutional Review Board, telephone number (775) 327-2368, or by addressing a letter to the Chair of the Board, c/o UNR Office of Human Research Protection, 205 Ross Hall / 331, University of Nevada, Reno, Reno, Nevada, 89557.

CLOSING STATEMENT

I have read () this consent form or have had it read to me (). [Check one.]

_____ has explained the study to me and all of my questions have been answered. I have been told of the risks or discomforts and possible benefits of the study.

If I do not take part in this study, my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty [or loss of other benefits to which I am entitled].

I have been told my rights as a research subject, and I voluntarily consent to participate in this study. I have been told what the study is about and how and why it is being done. All my questions have been answered.

I will receive a signed and dated copy of this consent form.

Signature of Participant (*or Legally Authorized Representative**) Date

Signature of Person Obtaining Consent Date

Signature of Investigator Date

APPENDIX G

CONFIDENTIALITY STATEMENT SIGNED BY TRANSCRIPTIONIST

Transcriber's Confidentiality Agreement

Title of Study: An Exploration of the Lived Experiences of Sexual Function and Satisfaction in Young Males Following Spinal Cord Injury

Principal Investigator: Stephanie DeBoor, PhD, RN, CCRN

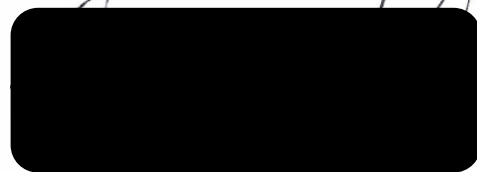
Student Investigator: Derek S. Drake, RN, BSN

Contact Phone Number: 775-742-7732 or 775-336-9588

As a transcribing typist of this research study, I understand that I will be hearing tapes of confidential interviews. The information on these tapes has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement:

I hereby agree not to share any information on these tapes with anyone except the principal investigator and student researcher of this project. Any violation of this agreement would constitute serious breach of ethical standards and I pledge not to do so.

This acknowledgment is governed by HIPAA as well as other applicable Federal, state, university, and local laws and regulations.



9/19/13
Date

Printed Name of Transcribing Typist

APPENDIX H
INTERVIEW QUESTIONS

Demographic Questions:

- 1) What is your age?
- 2) What is your gender?
- 3) Were you born male?
- 4) What is your marital status? (Single, Married, Divorced, Separated, Significant Other, Partner).
- 5) Do you have children? Were he/she/they born before or after your injury?
- 6) What is your ethnic background?
- 7) What is your sexual orientation?

Structured Interview Questions:

- 1) What level is your injury?
- 2) Tell me about your injury.
- 3) Tell me about your rehabilitation process.
- 4) What has been the biggest change, challenge, or difference you've experienced since your injury?
- 5) Tell me about your living situation?
- 6) How sexually active were you prior to your injury?
- 7) Do you remember the first time following your injury that you started thinking of sex and the potential for sex? Can you tell me about that?
- 8) Tell me about any sort of sex education or counseling in your rehabilitation process?
- 9) Tell me about your sexual experiences before and since your injury. How long after your injury did this occur?
- 10) Are you currently involved in sexual relationship(s)?
- 11) Tell me about your body's response to sexual stimuli before and since your injury?
- 12) Overall, how do you view yourself?
- 13) Overall, how do you think others view you?
- 14) Overall, how do you view yourself related to sex?
- 15) Overall, how do you think others view you related to sex?

Potential Cue Questions:

- 1) Can you tell me more about that?
- 2) How does that make you feel?

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