

2019

Relationship Between Doctor-Patient Communication and Sexual Functioning Among Women With Spinal Cord Injury

Melissa Lafferty
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Walden University

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Melissa Lafferty

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Walden University
2019

Abstract

Relationship Between Doctor-Patient Communication and Sexual Functioning Among
Women With Spinal Cord Injury

by

Melissa Lafferty

MS, Walden University, 2013

BA, University of Nebraska at Kearney, 2008

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

February 2019

Abstract

After individuals sustain a spinal cord injury, all aspects of their lifestyle must change for them to manage their new life roles. One important area of recovery that is often not addressed during the rehabilitation process is sexual functioning. The purpose of this quantitative study was to examine how doctor communication about sexual health with women who have sustained spinal cord injuries predicts their levels of sexual functioning and sexual self-esteem. The theoretical framework was the sexual health model. Questionnaires were used to gather data from 45 women who had completed rehabilitation from spinal cord injuries. Level of current sexual functioning was measured using the Female Sexual Function Index. Sexual self-esteem was measured using the Multidimensional Sexual Self-Concept Questionnaire. Satisfaction with doctor-patient communication was measured using the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex. Findings from correlation analysis indicated a positive correlation between general satisfaction with doctor-patient communication and confidence to communicate with the doctor about sexual health. Results also indicated a negative correlation between sexual self-esteem and sexual functioning. Findings may be used to improve communication between doctors and patients about sexual health, which may reduce the stigma of talking about sexuality and may promote more holistic treatment for women recovering from spinal cord injuries.

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Acknowledgments

I would like to thank my committee chair member, Dr. Zamboni, who has been so supportive of me this entire process. He has helped me progress through the dissertation process to make it to the light at the end of the tunnel. I would also like to thank Dr. Dardeck for all of her help, specifically with methodologies. I could not have gotten this done without both of you and all of the input that you provided to me. I would like to thank all my participants for their involvement and support of this research project.

I want to thank my coworkers and supportive supervisors who have stuck by me through this long, treacherous process, and who have been encouraging and helpful along the way.

I especially want to thank my family members who have given me so much support and have been willing to help in any way they could, especially my children, Lily and Haille, who have been my cheerleaders every step of the way, and my partner and rock, Ty Lafferty. I could not have made it through this program and my doctoral degree without you. I hope you know how much your support and love has meant to me! I could never repay you for all that you have given up to make this happen for me.

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Chapter 1: Introduction to the Study

After individuals sustain a traumatic injury such as a spinal cord injury, all aspects of their lifestyle must change for them to manage their life roles. People often have to learn through a rehabilitation program and communication with their doctors how to manage activities of their daily lives that were previously second nature (Leibowitz, 2005). One important area of recovery that is often not fully addressed during the rehabilitation process is the topic of sexuality (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi, Del Popolo, Macchiarella, Mencarini & Celso, 2010). The current study addressed how doctor communication about sexual health information with women who have sustained spinal cord injuries predicts their levels of sexual functioning and sexual self-esteem following injury.

Background and Statement of Problem

Sexual health information is critical in helping women define the status of the relationships in which they are invested in their lives. As explained by Richards, Tepper, Whipple, and Komisaruk (1997), the emotional connection to relationships is key for women “to define themselves in the context of human relationships” (p. 281). When the structure of a romantic relationship changes due to an injury or catastrophic event, quality of life is diminished for women until they are able to better define their current functioning within the relationship (Richards et al., 1997). A medical injury such as a spinal cord injury can damage a women’s sexual self-esteem (Richards et al., 1997). A woman’s ability to be fully engaged in her previous relationships with a significant other may suffer if the woman is not provided with an adequate amount of education (Otero-

Villaverde et al., 2015; Richards et al., 1997). Women who sustain spinal cord injuries often proceed through a rehabilitation process in which they gather education about how to return to activities of daily living, with the goal to return home and be reengaged in their relationships that they formed pre-injury (Richards et al., 1997). However, research indicated that women are not provided with information from their primary care physicians regarding their sexual functioning post-injury, or provided with information to encourage positive sexual adjustment following a spinal cord injury (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi et al., 2010; Parker & Yau, 2012; Richards et al., 1997).

According to Beckwith and Yau (2013), women with spinal cord injuries reported that many of their post-injury experiences with sexual functioning happened through experimentation, but they were not provided with any sexual health information during the rehabilitation process or after their return to home. Additionally, according to Leibowitz (2005), following a spinal cord injury, concepts of sexuality often change for women and include issues such as trust, intimacy, and communication. Women reported having to establish a greater amount of trust and communication about topics of sexuality with their partners post-injury to feel more comfortable during sexual experiences (Leibowitz, 2005). Women also reported that the concept of intimacy changes following a spinal cord injury, as seemingly nonsexual behaviors can become more intimate; examples included hand-holding, cuddling, and kissing (Leibowitz, 2005). These studies demonstrated that post-injury sexuality can consist of a range of topics for women beyond sexual functioning.

Purpose of the Study

Examining the sexuality and relationship experiences of women with spinal cord injuries is needed to create and develop programs that would enhance the sexual quality of life for this underserved population (Otero-Villaverde et al., 2015; Richards et al., 1997). One purpose of the current study was to examine women's level of satisfaction with the communication with their doctor. The hypothesis that guided this study was that communication about sexual health matters would increase women's sexual confidence (overall sexual self-esteem), which in turn would predict better sexual functioning in women. The second purpose of this study was to examine whether there was a relationship between women's positive sexual functioning after they had a spinal cord injury and the level of satisfaction with doctor-patient communication. I hypothesized that good doctor-patient communication would engender positive sexual self-esteem, which would foster good sexual functioning. Sexual self-esteem, as measured by the Multidimensional Sexual Self-Concept Questionnaire, should mediate the relationship between doctor-patient communication, as measured by the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex, and sexual functioning, as measured by the Female Sexual Function Index (Baron & Kenny, 1986). Although a number of variables have been examined with regard to women's sexual health, such as age, age of injury, anxiety, and depression (Beckwith & Yau, 2013; Leibowitz, 2005), it was not clear which variables were related to positive sexual functioning in women after spinal cord injuries. In the current study, I hypothesized that doctor-patient communication, as measured by the Patient Satisfaction Questionnaire and

Perceived Self-Efficacy in Patient-Physician Interactions—Sex, would be the best predictor of female sexual functioning, as measured by the Female Sexual Function Index, following spinal cord injuries when compared to age of injury, time since rehabilitation, and sexual attitudes as predictors. This hypothesis was based on the idea that doctors are individuals in authority who may empower women to engage in healthy sexual functioning and return to relationship experiences after injury.

Research Questions and Hypotheses

The following research questions (RQs) and hypotheses were used to guide the current study:

RQ1: Using the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex, does sexual health communication with one's doctor correlate to sexual functioning in women who have suffered a spinal cord injury as measured by Female Sexual Function Index?

H_01 : Scores on the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex do not predict scores on the Female Sexual Function Index.

H_{a1} : High scores on the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex predict low scores on the Female Sexual Function Index.

RQ2: Using the Multidimensional Sexual Self-Concept Questionnaire as a measure of sexual self-esteem, do higher scores predict a higher degree of sexual

functioning for women with spinal cord injuries as measured by the Female Sexual Function Index?

H₀2: There is no relationship between the scores of the Multidimensional Sexual Self-Concept Questionnaire and the Female Sexual Function Index.

H_a2: High scores on the Multidimensional Sexual Self-Concept Questionnaire predict low scores on the Female Sexual Function Index.

RQ3: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning)?

H₀3: The Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) does not mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning).

H_a3: Scores on the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between Patient Satisfaction Questionnaire (communication with doctor) and Female Sexual Function Index (sexual functioning).

RQ4: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual functioning)?

H₀4: The Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) does not mediate the relationship between the Perceived Self-Efficacy in Patient-

Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual functioning).

H_{a4}: Scores on the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and Female Sexual Function Index (sexual functioning).

RQ5: Is satisfaction with doctor-patient communication about sexual health the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem?

H₀₅: Satisfaction with doctor-patient communication is not the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem.

H_{a5}: Satisfaction with doctor-patient communication about sexual health information is the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem.

Theoretical Framework

The theoretical framework used for this study was the sexual health model (SHM), which states that sexual health is defined by attitudes, beliefs, and behaviors surrounding the topic of sexuality (Robinson, Bockting, Rosser, Miner, & Coleman, 2002). This theory indicates the importance of obtaining sexual knowledge from medical professionals as well as knowledge from the self, including beliefs and attitudes about sexual intimacy (Robinson et al., 2002). The purpose of the SHM is to provide a clear

definition of what sexual health means to help individuals obtain knowledge that may influence their sexual activities through the exploration of 10 different categories, which include talking about sex, culture and sexual identity, sexual anatomy and functioning, sexual health care and safe sex, challenges in obtaining sexual health information, body image, masturbation and fantasy, positive sexuality, intimacy and relationships, and spirituality (Robinson et al., 2002). For this study, the following categories of the SHM were examined through the questionnaires: talking about sex, culture and sexual identity, sexual anatomy and functioning, sexual health care and safe sex, challenges in obtaining sexual health information, body image, and intimacy and relationships.

Nature of the Study

The study was quantitative with questionnaires completed by women who had completed rehabilitation and recovery from spinal cord injuries. There were two dependent variables in this study. The first was the level of current sexual functioning following a spinal cord injury, as measured by the Female Sexual Function Index. The second was sexual self-esteem following a spinal cord injury, as measured by the Multidimensional Sexual Self-Concept Questionnaire. The independent variable was satisfaction with doctor-patient communication about sexual health information received by women with spinal cord injuries, as measured by the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex. The women were recruited from Ms. Wheelchair America via two Facebook groups and e-mail. To invite participants from the online communities, I established an online informed consent form in which the purpose of the study and the use of data were

explained. I also included the questionnaires online for consenting participants to complete the study. The questionnaires were used to gather information regarding women's attitudes toward as well as engagement in sexual activities post medical injury. Women were asked a variety of questions regarding their current sexual practices as well as current and previous sexual relationships in the Multidimensional Sexual Self-Concept Questionnaire. Women were asked to define how their sexual activities had changed and been reconstructed following their spinal cord injuries in the Female Sexual Functioning Index. I hypothesized that when women are provided with accurate information from their doctors, as measured by the Patient Satisfaction Questionnaire and the Perceived Self-Efficacy in Patient-Physician Interactions—Sex, women are able to return to previous sexual relationships with possible modifications. Women were asked to provide information regarding their medical injury, their sexual health practices, their sexual attitudes and beliefs, and demographic information.

Definitions

The following definitions are provided for clarification of terms used throughout the study:

Complete spinal cord injury: The ability of the spinal cord to convey messages to and from the brain is completely lost or damaged (Marini, Glover-Graf, & Millington, 2012).

Incomplete spinal cord injury: The ability of the spinal cord to convey messages to and from the brain is not completely lost (Marini et al., 2012).

Sexual dysfunction: A difficulty experienced by an individual or a couple during any stage of sexual response, including desire, arousal, or orgasm (Marini et al., 2012).

Sexual functioning: How the body reacts in different stages of the sexual response cycle (Marini et al., 2012).

Sexual self-esteem: How a person views his or her sense of self as a sexual being (Marini et al., 2012).

Spinal cord injury: Damage to any part of the spinal cord or nerves at the end of the spinal canal, which often causes permanent changes in strength, sensation, and other body functions below the site of the injury (Marini et al., 2012).

Assumptions

I assumed that participants with spinal cord injuries had been able to return to their activities of daily living with appropriate modifications to their lives. This assumption was necessary to obtain an accurate measure of female sexual functioning.

Scope and Delimitations

The focus of this study was sexual functioning for women with spinal cord injuries following the rehabilitation process. Addressing all of the possible topics for rehabilitation therapy would have been too cumbersome. There are many other topics covered during rehabilitation therapy; however, I chose to examine the relationship between female sexual functioning and the amount of communication women received from doctors.

Limitations

Many different factors impact female sexual functioning following spinal cord injuries. I was not able to address all of the factors that women with spinal cord injuries may have experienced in their lifetime. I examined only their personal medical experiences related to doctor communication, and how this may have impacted their sexual functioning and sexual self-esteem following spinal cord injuries. This study was limited to a self-selecting sample; therefore, the results of this study are not generalizable to the all women. This study was also limited to those literate in English who had access to the Internet.

Significance

This study was unique because during the rehabilitation process, the topic of sexuality and the recovery of sexual functioning are often presented to men who sustain spinal cord injuries, but often not to women (Lombardi et al., 2010). Previous research indicated that women with spinal cord injuries report negative sexual experiences after spinal cord injury (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi et al., 2010) possibly due to the lack of education received during rehabilitation therapy. Research indicated that women with spinal cord injuries reported a lack of education and supportive information about sexual health information provided during the rehabilitation process (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi et al., 2010).

The current study was conducted to measure the current sexual functioning of women who had sustained spinal cord injuries, and the sexual health information and support they received during their rehabilitation process to help them be successful in

their return to sexual life roles and to improve their sexual self-esteem. Through examination of the satisfaction of doctor-patient communication about sexual health issues among women with spinal cord injuries, the current study may promote social change through the analysis of current sexual health information available to women with spinal cord injuries. Results may contribute to social change by (a) highlighting possible doctor communication practices and how they can be improved with this population and (b) filling the gap in scholarly literature regarding sexuality for women with spinal cord injuries.

Summary

This chapter provided the focus of this study. One important area of recovery that has not been fully addressed during the rehabilitation process is the topic of sexuality (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi et al., 2010). This study was unique for two reasons. First, the study addressed the following variables: sexual self-esteem, sexual functioning, and doctor-patient communication regarding sexual health information. Previous studies indicated that women with spinal cord injuries had completed assessments that measured sexual functioning and sexual self-esteem. Second, through the measurement of doctor-patient communication, I examined why some women are more successful in sexual adjustment after a spinal cord injury. Previous researchers did not measure or discuss this variable. The purpose of this study was to determine whether access to sexual health information was related to sexual functioning and sexual self-esteem for women with spinal cord injuries following their rehabilitation.

In Chapter 2, I review the literature on the topic of sexuality for men and women with spinal cord injuries.

Chapter 2: Literature Review

Research indicated a lack of sexual health information provided to women with spinal cord injuries by their doctors (Beckwith & Yau, 2013). If women have more access to sexual health information from their doctors, they may experience improved sexual functioning following injury. An exploration of sexual health information provided to women with spinal cord injuries is important to determine whether it may be impacting their level of sexual functioning and sexual self-esteem.

Specific variables such as satisfaction with doctor-patient communication, sexual self-esteem in relationships, adjustment to sexual experiences following injury, and predictions of positive sexual functioning are discussed in this chapter. Previous literature on these variables is reviewed in this chapter. Review of the literature indicated a need for the current study addressing variables influencing the return to sexual functioning for women with spinal cord injuries.

Literature Search Strategy

The literature search for this study focused on women with spinal cord injuries, sexual functioning of women with spinal cord injuries, sexual education of women with spinal cord injuries, and training programs for professionals who work with individuals who sustain spinal cord injuries. Additional searches were completed to obtain information on sexual functioning and experiences with men who sustain spinal cord injuries. All studies that addressed the sexual functioning for women with spinal cord injuries were qualitative in nature and had very limited numbers of participants.

There were 17,130 articles in the psychological databases including Academic Search Complete, Health and Psychosocial Instruments, Medline with full text, Primary Search, PsycArticles, PsycBooks, PsycCritiques, PsycExtra, PsycInfo, and PsycTests that contained the search words *spinal cord injury*. Of the 17,130 articles, 2,031 were about women and spinal cord injury, and most of the articles addressed the medical complications due to traumatic spinal cord injuries. Of the 2,031 articles, 755 that addressed women with spinal cord injury were published in or after 2010. Of these 755 articles, only 48 addressed sexual health information. A total of 67 articles were included in this literature review. The relative lack of literature in this area supported the need for research on sexuality as it concerns women with spinal cord injuries.

Theoretical Foundation

The theoretical foundation for the current study was the sexual health model (SHM). According to Robinson et al. (2002), talking about sex is “the cornerstone of the Sexual Health Model” (p. 47) in that individuals must be able to explain their sexual preferences, beliefs, and attitudes to engage in safe sex practices. The purpose of this study was to determine how doctor communication about sexual health information for women with spinal cord injuries affects overall sexual functioning and sexual self-esteem following injuries. The hypothesis guiding this study was that if doctors communicate more openly about sexual health information, women with spinal cord injuries will report more satisfaction with their sexual functioning and will report higher levels of sexual self-esteem. This hypothesis was driven by the SHM because Robinson et al. (2002) explained that minority populations, such as individuals with spinal cord injuries, have a

difficult time gaining access to appropriate sexual health information. Because information is not readily available, individuals have a difficult time navigating the sexuality as it applies to their cultural and sexual identity, engaging in safe sex practices with partners, having a positive body image, and engaging in lasting and positive relationships (Beckwith & Yau, 2013). The current study was unique because the questionnaires addressed sexual health information and shed light on the sexual functioning and self-esteem of women with spinal cord injuries.

Literature Review

Sexuality is “a personal view of the sexual self and how sexuality is expressed” (Beckwith & Yau, 2013, p. 314). Sexuality includes thoughts, feelings, and behaviors within relationships, and is a central aspect of being human (Beckwith & Yau, 2013). After a traumatic incident such as a spinal cord injury, individuals have a difficult time rediscovering their sexuality and coming to grips with what that means within their relationships.

Limited research was available on the sexuality of women who have sustained spinal cord injuries. More research was available on the sexuality of men who sustained spinal cord injuries, possibly because men are more likely to sustain a spinal cord injury compared to women (Leibowitz, 2005). The following section addresses the literature available on sexual experiences of males with spinal cord injuries to determine whether the information can inform research on sexual functioning among women with spinal cord injuries.

Male Sexual Experiences Following Spinal Cord Injury

After people sustain a spinal cord injury, there is often a misunderstanding as to what functions the body will be able to continue to perform. The purpose of rehabilitation is to improve general activities of daily living; however, the topic of sexual functioning is often overlooked with patients (DeForge et al., 2006). Hess, Hough, and Tammaro (2007) reported that 65% of persons with spinal cord injury do not bring up their sexual health concerns with their doctors during the rehabilitation process. The lack of communication between doctors and male patients can lead to patients having misunderstanding of body sexual functions, including what sexual activities they can perform, how long an erection will last, and what achieving an erection after injury will involve for them.

The recent literature suggested that for males who sustain spinal cord injuries, there are resources such as medications to improve sexual functioning. In research conducted by Choi, Kang, and Shin (2015), male individuals with spinal cord injuries in Korea participated in face-to-face interviews about the return to sexual functioning following in-patient rehabilitation stays. Choi et al. found that 65% of their participants engaged in sexual activity following their injuries, and were using medications or intravenous injections of alprostadil to achieve an erection during sexual activity. Further support for the use of medications to return to sexual functioning for males with spinal cord injuries can be found in a systematic review of the literature. There was evidence in 49 studies that addressed the use of medications to help males return to sexual functioning after spinal cord injuries; forty-one were examined in detail for the current research (Alexander et al., 1993; Beretta et al., 1993; Beretta et al., 1986; Bodner

et al., 1998; Chancellor et al., 1994; Clontz et al., 1999; Costa et al., 1992; Costa et al., 1993; Courtois et al., 2001; Derry et al., 1998; Earle et al., 1992; Fisher et al., 2002; Gans et al., 2001; Giuliano et al., 1999; Giuliano et al., 1999; Golji, 1979; Green & Sloan, 1986; Gross et al., 1996; Heller et al., 1992; Hirsch et al., 1994; Hultling et al., 2000; Iwatsubo et al., 1986; Kapoor et al., 1993; Kier et al., 1999; Kim & McVary, 1995; Kim et al., 1995; Laschke et al., 2002; Maytom et al., 1999; Montague, 1994; Raviv et al., 2000; Renganathan et al., 1997; Sanchez et al., 2001; Schmid et al., 2000; Shenot et al., 1999; Sidi et al., 1987; Sonsken & Biering-Sorenson, 1992; Takeda et al., 2000; Tang et al., 1995; Waldbaum et al., 1998; Zaslau et al., 1999; Zasler et al., 1989 from DeForge et al., 2006). The articles did not include single case-studies. The evidence suggested that for men the return to sexual functioning may be possible with the help of interventions such as behavioral therapy, topical agents, intraurethral alprostadil, intracavernous injections, vacuum tumescence devices, penile implants, sacral stimulators, and oral medications (DeForge et al., 2006). However, the primary findings indicated that the research on sexuality for men who sustain spinal cord injuries addressed their ability to keep and maintain an erection. DeForge et al. demonstrated that penile injections, sildenafil, and vacuum devices are the most useful medical interventions for males with spinal cord injuries to keep and maintain erections during sexual activity.

Studies indicated that therapy, including psychotherapy and sex therapy, had a positive influence on return to sexual functioning for men with spinal cord injuries (DeForge et al., 2006). Furthermore, DeForge et al. (2006) discovered that sexual health information for men with spinal cord injuries was available during in-patient

rehabilitation stays. The immediate availability of sexual health information may contribute to positive outcomes following spinal cord injury in males. Not all men regain adequate sexual functioning after their spinal cord injury. According to Phelps et al. (as cited in Hess et al., 2007)) 42% of men with spinal cord injuries reported being dissatisfied with their sexual life and 50% had a weak sense of sexual adequacy.

A variety of research methods were used to examine the return to sexuality for males with spinal cord injuries. Courtois, Mathieu, and Charvier (2001) used a case-series to examine the sexual functioning of 10 males with spinal cord injuries. The men were provided with perineal muscle training exercises during their in-patient rehabilitation stay. Then the individuals were asked to return to the hospital for a series of biofeedback sessions to determine whether there was improvement in sexual functioning (Courtois et al., 2001). Results indicated that the men were more successful with their sexual adjustment following their biofeedback sessions than they were prior to treatment (Courtois et al., 2001). Courtois et al. did not measure the level of doctor-patient communication or the mean level of sexual functioning on a standardized measure.

Other studies were designed as comparative case-series in which males with spinal cord injuries were studied to examine the influence of vacuum-pump devices with papaverine injections as a means of sustaining an erection during sexual activity. The results indicated no significant differences between groups and their abilities to sustain an erection during sexual activities (Beretta et al., 1986; Beretta et al., 1993; Bodner et al., 1999; Earle et al., 1992; Hirsch et al., 1994; Kapoor et al., 1993; Kim & McVary, 1995; Kim et al., 1995; Renganathan et al., 1997; Sidi et al., 1987; Sosken & Biering-Sorenson,

1992; Tang et al., 1995; Walddbaum et al., 1998; & Zaslau et al., 1999). No standardized measures were used to measure communication between doctor-patient or level of sexual functioning.

Several studies were randomized control trials addressing the effects of sildenafil on males with spinal cord injuries. The results indicated that there were many physical side effects of sildenafil including headaches, visual blurring, dizziness, and facial flushing (Clontz et al., 1999; Derry et al., 1998; Giuliano et al., 1999; Kier et al., 1999; Laschke et al., 2002; Sanchez et al., 2001; Schmid et al., 2000; Shenot et al., 1999; Takeda et al., 2000). There were no standardized measures used in these studies to measure doctor-patient communication or level of sexual functioning. Five studies addressed the use of penile implants for sustaining an erection during sexual activities (Golii, 1979; Green & Sloan, 1986; Gross, 1996; Iwatsubo, 1986; Montague, 1994). The researchers found that different prostheses (including inflatable, semirigid, semiflexible and flexible devices) were successful in maintaining erections during sexual activities. There were no standardized measures used in these studies to measure doctor-patient communication or level of sexual functioning.

Some researchers set out to measure the level of erectile function for sexual intercourse at home by using the The International Index of Erectile Function. In the systematic review of the literature, the following researchers Goldstein (1998), Montorsi et al., (1999), Meuleman et al., (2001), Tan et al., (2000), Chen et al., (2001), Dinsmore et al., (1999), Rendell, Rajfer, Wicker, and Smith, (1999), Giuliano et al., (1999), Conti, Pepine, and Sweeney, (1999), Olsson and Persson, (2001), Seidman et al., (2001) found

that males with spinal cord injuries were able to achieve an estimate 79% successful erectile function utilizing this measure. The International Index of Erectile Function is a multidimensional measure of male sexual functioning that was developed and validated in 1996–1997 (Rosen, Cappelleri, & Gendrano, 2002). The International Index of Erectile Function has 15 items that are divided into five domains of sexual function: erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction (Rosen et al., 2002). These 12 studies included a standardized measure of sexual functioning for males with spinal cord injuries; however, none of the researchers measured levels of doctor-patient communication or levels of sexual self-concept in males with spinal cord injuries.

Overall a review of literature has found that when men sustain spinal cord injuries, there is just as much concern about resuming sexual activity as there is for women who sustain spinal cord injuries as many individuals with spinal cord injuries report being dissatisfied with their sex lives (Hess et al., 2007). Furthermore there is evidence from the literature review that males with spinal cord injuries are offered many medical interventions to assist with the return to sexual functioning. However, there is little evidence to suggest that there is follow-up communication from medical professionals about the quality of the sexual health information received, or their quality of sexual functioning after returning to their homes. Therefore, there may be a lack of communication about sexuality and sexual health information received from medical professionals (Hess et al., 2007). This is a common theme that appears in the literature for both males and females who sustain spinal cord injuries. Furthermore, the previous

research does not use any standardized assessments to measure doctor-patient communication or sexual self-concept in males with spinal cord injuries.

Female Sexual Experiences Following Spinal Cord Injury

After sustaining a traumatic injury, women can struggle with companionship in their relationships which in turn can threaten one's self-esteem and communication with their partner post-injury (Beckwith & Yau, 2013). The current study will focus on the following concepts of sexuality following spinal cord injury: doctor-patient communication, sexual self-esteem in relationships, adjustment to sexual experiences following injury, and predictions of positive sexual functioning.

Doctor-Patient Communication

Seven articles, out of sixty-seven articles, examined the influence of sexual health information provided to women during the rehabilitation process by their medical providers (Alexander et al., 2007; Khoei et al., 2013; Forsythe & Horsewell, 2006; Gianotten et al., 2006; Leibowitz, 2005; Robinson et al., 2011; White et al., 2010). The studies found that the use of a common language between providers is helpful when discussing information with patients. This means that when all medical professionals are using the same terms to help clients understand their injuries, they are more successful. Gianotten et al. (2006) provided an outlook on two different training programs to provide sexology training for medical professionals working with patients with various disabilities, including spinal cord injury. Additionally, Robinson et al. (2011) provided a pilot study for adding sexual health information to women recovering from a spinal cord injury into their rehabilitation program. A qualitative phenomenological research design

was used to gain information from women with spinal cord injuries about their experiences with rehabilitation process, and the education they were provided (Robinson et al., 2011). The researchers found that women were not provided with information regarding their sexual health during the rehabilitation process, and as a result many women suffered from lower levels of sexual functioning and lower levels of sexual self-esteem (Robinson et al., 2011). This study further supports the hypothesis and research questions presented in the current study, and the need for this research. Khoei et al. (2013) utilized the following standardized measures in their study: Emotional Quality of the Relationship Scale (EQR), Sexual Activity and Satisfaction scale (SAS), Sexual Attitude and Information Questionnaire (SAIQ), and the Sexual Interest and Satisfaction scale (SIS). No other standardized measures were utilized by the other studies.

In a more thorough study of doctor-patient communication, Leibowitz (2005) conducted a series of semi-structured interviews with twenty-four women with spinal cord injuries. The interview topics focused on concerns regarding the amount of sexual rehabilitation services and counseling received, sexual issues following return to home, and input regarding improvement of sexuality services during in-patient rehabilitation. The goal of this study was to assess the sexuality services covered during in-patient treatment for women with spinal cord injuries. Upon analysis of the results of the study, two major themes were explored during the semi-structured interviews: the importance of timing conversations about sexuality and honoring individual differences of sexual recovery.

The in-patient rehabilitation process for women with spinal cord injuries tends to focus on the recovery and rediscovery of how to complete daily living activities (Robinson et al., 2011). However, women in this study reported that timing the conversation about sexuality is an important topic that should be covered but is often neglected. Women in the study reported that they were not prepared to discuss sexual health information during their in-patient stay, as they were concerned about returned to daily living activities (Leibowitz, 2005). However, the majority of the women reported they believed they should have been provided with resources that they could use after their in-patient rehabilitation stay (Leibowitz, 2005). Thus women with spinal cord injuries are not offered adequate services or resources following in-patient rehabilitation as their lives readjust and sexuality becomes important to discuss. Furthermore, sexuality does not simply imply a genital-focus for women. According to Leibowitz (2005), “for most women sexuality was tied to issues of relationship, intimacy, trust, and other constructs that were not solely body-oriented” (p. 103). Honoring these individual differences presented by women with spinal cord injuries demonstrates ways that help professionals understand and utilize patient-centered care services. Understanding how women with spinal cord injuries define sexuality within their relationships may help providers to better understand ways to help them cope and adjust to their medical conditions.

Gianotten, Bender, Post, and Hoing (2006) examined the training of medical professionals (doctors, nurses, physical therapists, occupational therapists, mental health therapists and speech therapists) when dealing with sexuality of their patients after

traumatic injuries. The goals of this study were to explore two different training programs, and their effectiveness in addressing issues of sexuality post-injuries.

Their findings indicate that medical professionals have a difficult time addressing issues of sexuality with their patients following traumatic injuries. According to Gianotten et al. (2006), the rehabilitation process aims to minimize impairments following an injury, and as this can be a long process, “the patient is confronted with the physical disruption and direct consequences of disease or trauma” (p. 304). As the patient is focusing on improving her activities of daily living, it can cause sexual relationship issues to be left unaddressed. These interpersonal issues can cause stress and strain in romantic relationships and exacerbate issues of sexuality. Additionally, medical professionals feel they are not properly trained to handle issues of sexuality post traumatic injuries (Gianotten et al., 2006). Due to the lack of training by medical professionals, many issues of sexuality go unaddressed with both the patient and her partner’s. While many professionals will argue that the topic of sexuality is important to patients (Gianotten et al., 2006), this review of the literature reveals that it remains neglected during the rehabilitation process.

Twenty of the articles examined the experiences of women with spinal cord injuries on childbearing, pregnancy, and fertility issues (Asci et al., 2012; Aune, 2013; Bertschy et al., 2015; Bertschy et al., 2016; Camune, 2013; Chilkoti et al., 2016; Cowley, 2014; Dawood et al., 2014; Dillaway et al., 2015; Gilad & Lavee, 2010; Iezzini et al., 2015; Lui & Krassioukov, 2014; McLain et al., 2016; Nor Azlin et al., 2013; Pebdani et al., 2014; Rasul & Bering-Sorensen, 2016; Signore, 2012; Sterling et al., 2013; Tarasoff,

2011; Ward & Walker, 2011). A common theme among these articles is the lack of training among medical professionals to assist women with spinal cord injuries, and the lack of education received during the rehabilitation process on how to embrace childbearing with their physicians (Asci et al., 2012; Aune, 2013; Bertschy et al., 2015; Bertschy et al., 2016; Camune, 2013; Chilkoti et al., 2016; Cowley, 2014; Dawood et al., 2014; Dillaway et al., 2015; Gilad & Lavee, 2010; Iezzini et al., 2015; Lui & Krassioukov, 2014; McLain et al., 2016; Nor Azlin et al., 2013; Pebdani et al., 2014; Rasul & Bering-Sorensen, 2016; Signore, 2012; Sterling et al., 2013; Tarasoff, 2011; Ward & Walker, 2011). The lack of education for women with spinal cord injuries is evident in multiple areas of their sexual health, and building their positive sexual adjustment after the injury.

Sexual Self-Esteem in Relationships

Ten of the articles were semi-structured interviews that included some standardized questionnaires that examined sexual self-esteem in women with spinal cord injuries. The results of these studies indicated that post-injury women with spinal cord injuries remained interested in sexual activity with their partners, but their body image, sexual self-esteem, sexual satisfaction, and life satisfaction were significantly lower compared to pre-injury (Julia & Othman, 2011; Moin et al., 2009; Li & Yau, 2006; Beckwith & Yau, 2013; Richards et al., 1997; Cramp et al., 2015; Lombardi et al., 2008; Komisaruk, 2001; Lombardi et al., 2010; Torregrosa-Ruiz et al., 2017). Moin et al. (2009) had their participants complete the following standardized measures of sexual self-esteem: Sexuality Scale, Body Image Scale, and Quality of Life Questionnaire. The

other studies did not use any standardized measures to examine doctor-patient communication or level of sexual functioning.

Beckwith and Yau (2013) completed a series of semi-structured interviews with seven women with spinal cord injuries in order to discover how they were able to reconstruct their sexual identity post-injury, and to help identify the barriers to receiving information regarding sexual reconstruction during the rehabilitation process. Upon analysis of the results of the study, four major themes were explored during the semi-structured interviews: loss, sexual rehabilitation and information gathering, external factors, and sexual recovery/discovery” (Beckwith & Yau, 2013, p. 313).

According to Beckwith and Yau (2013), women completing rehabilitation following a spinal cord injury reported a lack of resources provided to them regarding the topic of sexuality. In this particular study, “all participants reported a negative view of the information they received from health professionals” (Beckwith & Yau, 2013, p. 318). This negative view stemmed from many factors, including health professionals’ reactions to questions and lack of advice provided, which left many women feeling alone regarding their sexual lives. The lonely feeling caused many women to discard the idea of participating in their sexual lives. According to Beckwith and Yau (2013), participants in this study, on average, took over a year to return to sexual functioning. Participants had to learn to love their own bodies as they are, and appreciate the ability they have now; they were not focusing on the loss of mobility and function.

With regard to loss, women with spinal cord injuries reported the largest barrier post-injury is a lack of confidence in their body image (Beckwith & Yau, 2013).

“Concerns included muscle wastage, excess weight, and the belly region which is perceived as fat due to paralysis of the abdominal muscles” (Beckwith & Yau, 2013, p. 317). It is evident from the interviews that women with spinal cord injuries do not feel like they have the body that they once had, and that creates a vast sense of loss (Beckwith & Yau, 2013, p. 318 – 321). Women with spinal cord injuries express other losses as well. These other losses sometimes include a loss of employment, the loss of mobility, the loss of independence, the loss of feelings and sensations, and the loss of relationships. These losses may have an isolating effect on women with spinal cord injuries, which further harms their self-esteem. The sense of loss can also prolong the sexual recovery process for many women with spinal cord injury. Similar themes were discovered and supported throughout the literature (Beckwith & Yau, 2013).

In a seminal study conducted by Richards et al. (1997), fifteen women with complete spinal cord injuries took part in semi-structured interviews. The goal of this study was to explore the experiences of rediscovering sexuality post-injury for women with complete spinal cord injuries. After analysis of their answers, the following themes emerged: “cognitive-genital dissociation, sexual disenfranchisement, sexual exploration, and sexuality reintegration” (Richards et al., 1997, p. 271).

Their findings indicate that women with complete spinal cord injuries have a difficult time accepting their bodies as they are post-injury. According to Richards et al. (1997), many women had a difficult time returning to sexual activities following their injuries due to beliefs that sexual acts would be unsatisfying. Many women reported distancing themselves from their own bodies as a defense mechanism. As women have a

loss of self after a traumatic injury, is it easier to shut out the ideas of sexuality as being a satisfying activity. Also, according to Richards et al. (1997), the loss of self after an injury can also contribute to the loss of relationships. After an injury, many women reported having to re-discover what a positive sexual relationship is like, and discover new partners (Richards et al., 1997). Finding these positives after injury is not an easy task, and can be complicated by the recovery for an injury.

Adjustment to Sexual Experiences Following Injury

Fourteen of the articles used semi-structured interviews that examined adjustment to sexual experience post-injury in women with spinal cord injuries. The results of these studies indicated that post-injury women with spinal cord injuries have several barriers to remaining sexually active including physical as well as psychological barriers (Cramp et al., 2014; Fritz et al., 2015; Hocaloski et al., 2016; Kalpakijan et al., 2011; Merghati-Khoei et al., 2015; Miller & Marini, 2004; Mona et al., 2000; Otero-Villaverde et al., 2015; Parker & Yau, 2012; Sale et al., 2012; Singh & Sharma, 2005; Westgren & Levi, 1999; Whipple & Komisaruk, 1997; Whipple & Komisaruk, 2002). None of the studies utilized standardized measures to examine doctor-patient communication, sexual self-concept, or level of sexual functioning.

Parker and Yau (2012) conducted research with four women with spinal cord injuries through semi-structured interviews in order to explore the experiences and perceptions of sexuality post-injury for women with spinal cord injuries. After analysis of their answers, the following themes emerged: “factors facilitating positive sexual

adjustment, barriers to sexuality post-injury and lack of sexual education in the rehabilitation process” (Parker & Yau, 2012, p. 15).

Discovering sexuality after a traumatic injury takes many steps. According to Parker and Yau (2012), women reported that positive sexual adjustment included the following factors: having good social support, a partner who is willing to explore sexuality after injury, and a partner to develop personal strategies in the bedroom. These findings indicate that positive sexual adjustment after injury is possible, but it takes flexibility and patience. However, there are factors that contribute to challenges to positive sexual adjustment. According to Parker and Yau (2012), the factors that contribute to difficulties in positive sexual adjustment include altered body image and negative social perceptions of individuals in wheelchairs. These factors could lead to difficulties developing interpersonal relationships, and finally medical complications during sexual activities. Finding a way to overcome these challenges can be difficult as there are limited resources for women with spinal cord injuries post in-patient rehabilitation. Women with spinal cord injuries further report that having counseling or other services that discuss sexuality post in-patient stay is vital as these issues develop over time (Parker & Yau, 2012). Finding a way to add more out-patient services in sexual health for women with spinal cord injuries is essential.

In a study conducted by Singh and Sharma (2005), forty women with spinal cord injuries completed an author-constructed standardized questionnaire. The questionnaire covered concerns related to sexual activities, especially medical challenges that interfere with sexual activity as well as an examination of menstruation, pregnancy, and

childbearing following spinal cord injuries, and an examination of interpersonal relationships after injury. The goals of this study were to discover the amount of information women with spinal cord injuries receive regarding sexuality after spinal cord injury from health care professionals.

Results of the study indicated that women with spinal cord injuries show an interest in sexual activity following injury, but few individuals participate in sexual activities. According to Singh and Sharma (2005), “a substantial portion of participants indicated that they had interest in sex (72.5%) and understood the importance of sex in life (87.5%) after injury” (p. 23). These results indicate that simply sustaining an injury does not mean that sexuality stops. The participants in the study indicated that many have a difficult time performing due to medical challenges, and a little over half (55%) were satisfied with their sexual experiences post-injury (Singh & Sharma, 2005). Furthermore, Singh and Sharma (2005) reported, “Women’s sexuality is multifaceted, involving relationship, sharing feelings, attractiveness, self-confidence and self-worth, as well as pregnancy and child rearing” (p. 28). Thus, women’s sexuality goes beyond just participating in sexual activities with a partner or child-bearing. Additionally, the research shows that to improve sexual satisfaction among women with spinal cord injuries, information and specific programs during the rehabilitation process can help women to discover new possibilities of their sexual health, thus improving their sexual self-esteem and social relationships (Otero-Villaverde et al., 2015). Women’s sexuality involves issues or concerns of body image, self-worth in the relationship, as well as

challenges of self-esteem and feeling like a woman. The complexity of sexuality encompasses these traits for women, and can be greatly impacted by a traumatic injury.

Predictions of Positive Sexual Functioning

Finally, sixteen of the articles used semi-structured interviews as well as standardized questionnaires that examined sexual functioning post-injury in women with spinal cord injuries. The results of these studies indicated that the frequency of sexual activity and desire are lower among women with spinal cord injuries, and overall sexual functioning is lower for women with spinal cord injuries when there is a lack of communication (Alexander et al., 2011; Celik et al., 2014; Hajiaghababaei et al., 2014; Kreuter et al., 2011; Lombardi et al., 2010; Lombardi et al., 2015; Lubbers et al., 2012; Milicevic et al., 2012; Moreno-Lozano et al., 2016; New, 2016; Nikoobakht et al., 2014; Othman & Engkasan, 2011; Rees et al., 2007; Salonia et al., 2004; Worsley & Kulkarni, 2012; Wyndaele, 2010). Three articles utilized the Female Sexual Function Index to examine positive effects of sexual functioning for women with spinal cord injury (Celik et al., 2014; Hajiaghababaei et al., 2014; Othman & Engkasan, 2011). All these study results indicated that women with spinal cord injuries did not receive resources during their rehabilitation, which may have resulted in patients having higher levels of sexual dysfunction. Specifically it was discovered by Hajiaghababaei et al (2014) that 88% of women with spinal cord injuries reported at least one sexual dysfunction, as compared to 37% of health controls. The other studies did not use measures to examine doctor-patient communication or level of sexual self-concept.

Lombardi et al. (2010) conducted longitudinal research on women from the time of injury to long-term follow up in order to discover the full recovery process. The overall purpose of the longitudinal study was to gain feedback on the return to sexual functioning following in-patient stay and discover if the sexual health information provided assisted in this process (Lombardi et al., 2010). Overall, the results of their study found that there were many psychological factors that contributed to the recovery of women with spinal cord injuries. The most important finding was the grieving process many women with spinal cord injuries reported they went through in order to move forward with their lives. Specifically, there was a great sense of loss when it came to their sexuality, body image, and understanding of what it means to be a woman. “The process of mourning the losses brought on by injury requires psychological support because most women feel their bodies are less attractive after the spinal cord lesion” (Lombardi et al., 2010, p. 843). Support from a partner or a loved one can have a substantial impact on the psychological adjustment to one’s body after a traumatic injury. Additionally, providing education to partner and other loved ones can help build the lines of communication to nurture and grow this aspect of sexuality following spinal cord injury.

Summary and Conclusions

The current study aimed to explore the communication of sexual health information made available by their doctors to women who sustain spinal cord injuries, and how this impacted their sexual functioning and sexual self-esteem following a traumatic injury. From the current literature review, it is clear that previous studies have looked at sexual functioning and sexual self-esteem following spinal cord injuries. This

study aimed to discover if women who had higher levels of sexual self-esteem following a spinal cord injury, would indicate they have lower levels of sexual dysfunction and greater levels of positive sexual adjustment. As previous research demonstrates, there have been qualitative studies (Alexander et al., 2007; Forsythe & Horsewell, 2006; Gianotten et al., 2006; Leibowitz, 2005; Robinson et al., 2011; White et al., 2010; Asci et al., 2012; Aune, 2013; Bertschy et al., 2015; Bertschy et al., 2016; Camune, 2013; Chilkoti et al., 2016; Cowley, 2014; Dawood et al., 2014; Dillaway et al., 2015; Gilad & Lavee, 2010; Iezzini et al., 2015; Lui & Krassioukov, 2014; McLain et al., 2016; Nor Azlin et al., 2013; Pebdani et al., 2014; Rasul & Bering-Sorensen, 2016; Signore, 2012; Sterling et al., 2013; Tarasoff, 2011; Ward & Walker, 2011; Julia & Othman, 2011; Li & Yau, 2006; Beckwith & Yau, 2013; Richards et al., 1997; Cramp et al., 2015; Lombardi et al., 2008; Komisaruk, 2001; Lombardi et al., 2010; Torregrosa-Ruiz et al., 2017; Cramp et al., 2014; Fritz et al., 2015; Hocaloski et al., 2016; Kalpakijan et al., 2011; Merghati-Khoei et al., 2015; Miller & Marini, 2004; Mona et al., 2000; Otero-Villaverde et al., 2015; Parker & Yau, 2012; Sale et al., 2012; Westgren & Levi, 1999; Whipple & Komisaruk, 1997; Whipple & Komisaruk, 2002; Alexander et al., 2011; Kreuter et al., 2011; Lombardi et al., 2010; Lombardi et al., 2015; Lubbers et al., 2012; Milicevic et al., 2012; Moreno-Lozano et al., 2016; New, 2016; Nikoobakht et al., 2014; Rees et al., 2007; Salonia et al., 2004; Worsley & Kulkarni, 2012; Wyndaele, 2010) conducted that discuss the lived experiences of women with spinal cord injuries and their subjective level of sexual self-esteem. There have been limited quantitative studies (Khoei et al., 2013; Moin et al., 2009; Singh & Sharma, 2005; Celik et al., 2014; Hajiaghababaei et al.,

2014; Othman & Engkasan, 2011) with standardized measures of female sexual self-esteem after spinal cord injuries, which is an advantage of the current study. Additionally, what is not clear from the previous research is the amount of sexual health information that was available to women during the rehabilitation process, and how this information has contributed to sexual functioning and sexual self-esteem. Therefore, this study aimed to measure the effectiveness of doctor communication with patients about their sexuality following a spinal cord injury. The prediction was that women would have a more positive sexual self-concept, which would in turn lead to higher levels of sexual functioning following a spinal cord injury. As previous literature demonstrates, there have not been previous studies conducted that provide a standardized measure of the level of communication between doctors and women that have sustained spinal cord injuries, which provided an advantage to the current study and made the study unique to previous literature on the topic. Other factors such as age, gender, ethnicity, region of the United States, and years since injury were also examined to determine the relationship they may have to their sexual functioning and sexual self-esteem. This is the beginning of the process in order to determine the appropriate actions to take to improve the current programming for in-patient rehabilitation centers on the education provided to women with spinal cord injuries. Chapter 3 will discuss the research design and rationale of this study, the methodology, threats to validity and will provide a summary of the method of inquiry.

Chapter 3: Research Method

This chapter focuses on the research design and methods used to obtain the data for this study. The population that was targeted and how the sample population was obtained are outlined in this chapter. Threats to the validity of this study are identified and explained as well as ethical concerns for the completion of this study. I conclude this chapter with a summary.

Research Design and Rationale

This study was quantitative including questionnaires that were completed by women who had sustained spinal cord injuries. The questionnaires addressed the satisfaction of sexual health information received from the doctor, the women's current level of sexual functioning, and their current level of sexual self-esteem. Women with spinal cord injuries were also asked to provide information regarding the number of years since the injury, their age and ethnicity, and their level of education.

The dependent variables were the current level of sexual functioning and the current level of sexual self-esteem, which were measured using the Female Sexual Function Index (FSFI) and the Multidimensional Sexual Self-Concept Questionnaire (MSSCQ), respectively. The independent variable was the sexual health information obtained from the primary care physician, which was measured using the Patient Satisfaction Questionnaire (PSQ) and Perceived Self-Efficacy in Patient-Physician Interactions—Sex (PEPPI-S).

For this study, multiple regression analysis was used to determine whether there was any relationship between each criterion variable and the independent variable. The research questions and hypotheses for this study were as follows:

RQ1: Using the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex, does sexual health communication with one's doctor correlate to sexual functioning in women who have suffered a spinal cord injury as measured by Female Sexual Function Index?

H_01 : Scores on the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex do not predict scores on the Female Sexual Function Index.

H_a1 : High scores on the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex predict low scores on the Female Sexual Function Index.

RQ2: Using the Multidimensional Sexual Self-Concept Questionnaire as a measure of sexual self-esteem, do higher scores predict a higher degree of sexual functioning for women with spinal cord injuries as measured by the Female Sexual Function Index?

H_02 : There is no relationship between the scores of the Multidimensional Sexual Self-Concept Questionnaire and the Female Sexual Function Index.

H_a2 : High scores on the Multidimensional Sexual Self-Concept Questionnaire predict low scores on the Female Sexual Function Index.

RQ3: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning)?

H₀3: The Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) does not mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning).

H_a3: Scores on the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between Patient Satisfaction Questionnaire (communication with doctor) and Female Sexual Function Index (sexual functioning).

RQ4: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual functioning)?

H₀4: The Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) does not mediate the relationship between the Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual functioning).

H_a4: Scores on the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and Female Sexual Function Index (sexual functioning).

RQ5: Is satisfaction with doctor-patient communication about sexual health the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem?

H₀₅: Satisfaction with doctor-patient communication is not the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem.

H_{a5}: Satisfaction with doctor-patient communication about sexual health information is the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem.

Methodology

Population

The population for the study was women over the age of 18 who had been rehabilitated from complete or incomplete spinal cord injuries. The self-selecting convenience sample was drawn from participants in Ms. Wheelchair America. Participation was anonymous. The women were provided a link to the survey and questionnaires through KwikSurveys, and completed questionnaires were analyzed after I confirmed that participants met the inclusion criteria.

Sampling and Sampling Procedures

The sampling strategy for this study was nonprobability sampling. The inclusion criteria were that participants must be women who had been rehabilitated from spinal cord injuries. Inclusion criteria were necessary to answer the research question addressing the sexual experiences of women with spinal cord injuries.

Sample Size

An a priori sample size for multiple regression analysis was calculated using Statistics Calculators (Soper, 2019). This calculator indicated that for an anticipated medium effect size (0.15), a desired statistical power level of 0.8, an alpha level of 0.05, and three variables, the minimum sample size would be 76. However, I attempted to recruit more participants to ensure a representative sample.

Procedures for Recruitment, Participation, and Data Collection

For the recruitment with Ms. Wheelchair America, two different procedures occurred. For the first one, the participants were recruited through two Facebook groups, one entitled “Ms. Wheelchair America” which has over 3,000 members and the second one titled “Wheel Mommies” which has over 700 members. As the groups are private, I created an online consent form which was then posted onto their Facebook group by the leader of the group. Shelley Loose, the President of Ms. Wheelchair America agreed to participate in this research following a verbal conversation and continued follow-up conversations with me. The online message included the informed consent and a link to participate in the survey along with my contact information. The second procedure was a direct e-mail with the same informed consent, which was sent by the president of Ms. Wheelchair America, to the last 11 years of participants of Ms. Wheelchair America, which is estimated to be 150 members. These participants were also provided the informed consent and a link to participate in the survey along with my contact information. Demographic information that was asked of the participants included their gender, ethnicity, and number of years since injury, where they are from regionally and

years of education. This was included in the survey link they will be provided with the email. The information in the informed consent included the purpose of the study, information regarding exiting the study, my contact information and my committee members' information in case there are any questions regarding the research.

Data collection was through KwikSurveys (<https://kwiksurveys.com>), in which the link was provided to each individual through email or through access to the Facebook groups. Once they have clicked the link, they agreed to be part of the study. The link took the participants to KwikSurveys (<https://kwiksurveys.com>), where they could proceed to answer the questionnaires online. Once they have completed their questionnaires, I was alerted by KwikSurveys (<https://kwiksurveys.com>) that the questionnaire was completed, and then I transferred the data to SPSS for analysis.

Instrumentation and Operationalization of Constructs

The Patient Satisfaction Questionnaire (PSQ) was used to measure the variable doctor-patient communication. This 18-item measure was developed by Marshall and Hays (1994) to have a standardized measure for understanding the attitudes of patients about the communication they are receiving from their doctor. The assessment has seven domain measures: general satisfactions (two items), technical quality (four items), interpersonal manner (two items), communication (two items), financial aspects (two items), time spent with doctor (two items), and accessibility and convenience (four items) (Marshall & Hays, 1994). According to Marshall and Hays (1994), the Patient Satisfaction Questionnaire has a high internal reliability for all seven domains (Cronbach's alpha values of 0.70 to 0.92) as well as high levels of face validity. For each

question, participants were asked to rate their answer on a Likert scale of 1 to 5, with 1 indicating strongly agree and 5 indicating strongly disagree. An example item is “Doctors sometimes ignore what I tell them.” The total score was used to measure the doctor’s ability to communicate with his or her patients. High scores would indicate that patients were not having successful interactions with their doctors, and would indicate that women with spinal cord injury were not obtaining the information they were looking for during their doctor’s appointments.

The Perceived Self-Efficacy in Patient-Physician Interactions—Sex (PEPPI-S) was used for this study. This 5-item measure was modified from the Perceived Self-Efficacy in Patient-Physician Interactions by Stepleman et al. (2016) to have a standardized measure for understanding the attitudes of patients about the communication they are receiving from their doctor regarding obtaining sexual health information. According to Stepleman et al. (2016), the Perceived Self-Efficacy in Patient-Physician Interactions—Sex has high internal consistency (Cronbach’s alpha values of 0.97) and strong reliability for the this modified version ($\alpha = 0.93$), as well as high levels of face validity. For each question, participants were asked to rate their level of confidence on a Likert scale of 1 to 10 with 1 indicating they are not confident and 10 indicating high confidence. An example item is “Get the doctor to do something about my sexual health concerns.” The total score was used to measure participants’ abilities to communicate their sexual health concerns with their doctors. High scores would indicate that patients were having successful interactions with their doctors, and would indicate that women

with spinal cord injury were obtaining the sexual health information they were looking for during the doctor's appointments.

The Female Sexual Function Index (FSFI) was used to measure the variable of sexual functioning. This 19-item measure was developed by Rosen et al. (2000) to have a brief multidimensional standardized measure of sexual functioning for women. The assessment has five domain measures: desire, arousal, lubrication, orgasm, global satisfaction, and pain (Rosen et al., 2000). Updating this scale has increased the reliability and validity by reducing the number of questions and by providing consistency in the items that assess norms and perceived behaviors related to positive sexual functioning (Rosen et al. 2000). According to Rosen et al. (2000), the FSFI has high internal reliability for all five domains (Cronbach's alpha values of 0.82 and higher). Additionally, the test-retest reliability is high for all domains ($r = 0.79 - 0.86$). According to Rosen et al. (2000), the FSFI full scale divergent validity is $r = 0.41$ ($p = 0.001$). For each question, participants were asked to answer the multiple-choice questions. An example item is "Over the past 4 weeks, how satisfied have you been with the amount of emotional closeness during sexual activity between you and your partner?" On the FSFI, a total standard score of 26.55 (Mean = 4.43) with all six domains indicate female sexual dysfunction (Rosen et al., 2000). The total score was used to measure women's level of sexual functioning in their lives after their spinal cord injury. High scores would indicate greater levels of sexual dysfunction.

The Multidimensional Sexual Self-Concept Questionnaire (MSSCQ) was used to measure the variable of sexual self-esteem. This 101-item measure was developed by

Snell (1998) to have a standardized measure for psychological concepts related to human sexuality. The assessment has 20 domain measures: sexual anxiety, sexual self-efficacy, sexual consciousness, motivation to avoid risky sex, chance/luck sexual control, sexual preoccupation, sexual assertiveness, sexual optimism, sexual problem self-blame, sexual monitoring, sexual motivation, sexual problem management, sexual esteem, sexual satisfaction, power-other sexual control, sexual self-schemata, fear of sex, sexual problem prevention, sexual depression, and internal sexual control (Snell, 1998). For this study, 45 questions were used related to the following subscales on the assessment: sexual anxiety, sexual self-efficacy, sexual consciousness, sexual optimism, sexual problem self-blame, sexual-esteem, sexual satisfaction, sexual self-schemata, and internal sexual control.

These subscales scores were utilized in this study as they are all correlated to measure aspects of sexual self-esteem, which was one of the main variables of this study.

Updating this scale also increased the reliability and validity by providing consistency in the items to the scale that assess norms and perceived behaviors related to psychological concepts of human sexuality. According to Snell (1998), MSSCQ has a high internal item correlations observed for all twenty subscales (Cronbach's alpha values ranging between 0.72 – 0.94) and high validity ($r = 0.31$, $p = 0.008$). For each question individuals were asked to rate their answer on a Likert scale of A - E, with A indicated the question is not related to them and E indicated the answer was very characteristic of them. An example item is “, I worry about the sexual aspects of my life.” On the MSSCQ, scores are totaled all together (A = 1, B = 2, C = 3, D = 4, and E = 5) with higher scores indicating higher levels of sexual self-esteem (Snell, 1998). The overall total score was utilized to measure

women's level of sexual self-esteem in their lives after their spinal cord injury. In the scoring process, letter scores are provided numerical values; high scores indicated great levels of sexual self-esteem, where low scores indicated lower levels of sexual self-esteem.

Threats to Validity

With data collection conducted through an online survey method, the women provided this information anonymously. When using self-report forms, such as the tool being used for this study, there are always the concerns related to a person rating themselves in a better light, or based on what they believe they are supposed to answer. The tool being used for this study has been shown to be valid in measuring personal attitudes of sexual health. This threat is addressed through the information provided on the instruments reliability and validity.

Additionally, the sample in this study may not be a full representation of women with spinal cord injury as not every woman with a spinal cord injury had access to internet or may use the internet very much. As the recruitment method was online, and participation in the study was online, it may limit the amount of women available to participate in this research. Thus, the results of this study may not be generalizable to represent the experiences of all women with spinal cord injury.

Ethical Procedures

Information related to all participant names were not be known to the researcher, and remained confidential throughout the study. When participants completed the study through KwikSurveys, they were only assigned a participant number with no identifying

information linked to their information. This ensured that all names of participants remain anonymous and confidential.

All surveys were completed through KwikSurveys. Once the data was submitted for all needed participants, the data was reviewed prior to analysis and transferred into SPSS by myself. This ensured that the information was correct and that participants completed the questionnaires correctly. Participants were not asked their names, and this also ensured that participant information was confidential and no chance of data privacy being released.

Once the data was uploaded into SPSS, the data set is being kept on a flash drive, which is also stored in a locked file cabinet at my home when not being analyzed. I have the only key to the file cabinet, which ensured that the data was not changed or manipulated to keep the data pure and free from error. This is preserving the original information from the participants in this study. Recruitment was nonprobability sampling based on the inclusion criteria for the participants in this study. Women with spinal cord injuries, complete or incomplete, was the required criteria for inclusion in this study.

Summary

The design for this study was the use of a survey with a nonprobability sampling for the population. The target population came from online communities in Ms. Wheelchair America and they needed to accurately respond to the inclusion criteria of being a woman with a spinal cord injury. This population was from within the United States. This approach was the best way to gain information from women with spinal cord injury regarding their personal attitudes toward sexual health information received during

rehabilitation services and how this has impacted their sexual self-esteem and sexual functioning.

The data obtained was anonymous and has been kept private in order to ensure data integrity. I am the only one to access and analyze the data obtained for this study. Ensuring confidentiality and data integrity has produced the most reliable outcome data for analysis and research conclusions.

Chapter 4: Results

This chapter includes the statistical results of this quantitative study using questionnaires that were completed by women who had sustained spinal cord injuries. The questionnaires were used to gather data regarding the satisfaction of sexual health information received from the doctor, participants' current level of sexual functioning, and their current level of sexual self-esteem. Women with spinal cord injuries were also asked to provide information regarding the number of years since their injury, their age and ethnicity, and their level of education.

The dependent variables included the current level of sexual functioning and the current level of sexual self-esteem, which were measured using the Female Sexual Function Index and the Multidimensional Sexual Self-Concept Questionnaire. The independent variable was the sexual health information self-reported about the primary care physician, which was measured through the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex.

The research questions and the hypotheses for this study were as follows:

RQ1: Using the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex, does sexual health communication with one's doctor correlate to sexual functioning in women who have suffered a spinal cord injury as measured by Female Sexual Function Index?

*H*₀1: Scores on the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex do not predict scores on the Female Sexual Function Index.

H_{a1}: High scores on the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex predict low scores on the Female Sexual Function Index.

RQ2: Using the Multidimensional Sexual Self-Concept Questionnaire as a measure of sexual self-esteem, do higher scores predict a higher degree of sexual functioning for women with spinal cord injuries as measured by the Female Sexual Function Index?

H₀₂: There is no relationship between the scores of the Multidimensional Sexual Self-Concept Questionnaire and the Female Sexual Function Index.

H_{a2}: High scores on the Multidimensional Sexual Self-Concept Questionnaire predict low scores on the Female Sexual Function Index.

RQ3: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning)?

H₀₃: The Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) does not mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning).

H_{a3}: Scores on the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between Patient Satisfaction Questionnaire (communication with doctor) and Female Sexual Function Index (sexual functioning).

RQ4: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual functioning)?

H₀4: The Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) does not mediate the relationship between the Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual functioning).

H_a4: Scores on the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and Female Sexual Function Index (sexual functioning).

RQ5: Is satisfaction with doctor-patient communication about sexual health the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem?

H₀5: Satisfaction with doctor-patient communication is not the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem.

H_a5: Satisfaction with doctor-patient communication about sexual health information is the best predictor of female sexual functioning among the following variables: amount of time since injury or sexual self-esteem.

This chapter focuses on the statistical results the data analysis for this study. The statistical analysis along with tables of results are included in this chapter. This chapter also includes a summary in which all major components of this study are described.

Data Collection

The data collection period began on May 20, 2018, and was open for 2 months. Recruitment was conducted with Ms. Wheelchair America's president, Shelly Loose, and two different procedures occurred during the data collection process. In the first procedure, the participants were recruited through two Facebook groups, both administered by Shelly Loose. One was Ms. Wheelchair America, which has over 3,000 members, and the second was Wheel Mommies, which has over 700 members. Because the groups are private, I created an online message, which was posted onto the Facebook groups by the leader of the group, Shelley Loose. The President of Ms. Wheelchair America agreed to participate in this study following a verbal conversation and continued follow-up conversations with me. The online message included the informed consent and a link to participate in the survey along with my contact information.

The second procedure was a direct e-mail with the same informed consent, which was sent by the president of Ms. Wheelchair America to participants of Ms. Wheelchair America from the last 11 years, which were estimated to be 150 members. The participants were provided the informed consent and a link to participate in the survey along with my contact information. Demographic information included participants' gender, ethnicity, number of years since injury, U.S. region, and years of education, as shown in Table 1. The average age of the participants was 33.5 years ($SD = 7$). The

average number of years since injury was 13.4 ($SD = 5$). The information in the informed consent included the purpose of the study, information regarding exiting the study, my contact information, and my committee members' information in case there were any questions regarding the study. The informed consent also included a link to a website that could provide participants with a sexual health therapist in their area in case they became distressed during the completion of the questions.

Data were collected through KwikSurveys, and the link was provided to each individual through e-mail or through access to the Facebook groups. Once participants clicked the link, they agreed to be part of the study. The link took the participants to KwikSurveys, where they proceeded to complete the questionnaires. Once they completed their questionnaires, this researcher was alerted by KwikSurveys (<https://kwiksurveys.com>) that the questionnaire is completed, and then transferred the data to SPSS for analysis.

Table 1

Demographic Information

	Number of Participants	Percentage
Highest Level of Education		
High School Diploma	9	13%
Some College	26	38%
Bachelor's	25	37%
Graduate	10	15%
Household Income		
\$0 – 24,999	15	22%
\$25,000 – 49,999	29	43%
\$50,000 – 74,999	11	16%
\$75,000 – 99,999	3	4%
\$100,000 – 149,999	8	12%
\$150,000 +	2	3%
Ethnicity		
American Indian/Native	2	3%
Asian	0	0%
Black/African American	12	18%
Hispanic/Latino	2	3%

Pacific Islander	0	0%
White/Caucasian	53	78%
Region of U.S.		
New England	6	9%
Mid-Atlantic	9	13%
East North Central	14	21%
West North Central	5	7%
South Atlantic	3	4%
East South Central	16	24%
West South Central	4	6%
Mountain	7	10%
Pacific	3	4%

Data Analysis

Table 2 provides the descriptive statistics of the variables from the study. The Patient Satisfaction Questionnaire was measured on a Likert scale ranging from 1 – 5, with one being strongly agree and five being strongly disagree. Statistically, the questions were reversed scored to demonstrate that higher scores indicate more positive communication with their doctor. The Perceived Self-Efficacy in Patient-Physician Interactions – Sex was also measured on a Likert scale ranging from 1 – 10, with one being not confident in their abilities to speak to their doctor and 10 being most confident in their abilities to speak with their doctor. Higher scores on the PSQ indicate that women

are having successful interactions with their doctors, and are obtaining the information they are looking for during the doctor's appointments. Additionally, higher scores on the PEPPI-S indicate higher confidence in women to communicate their sexual health concerns with their doctors. The mean scores 3.43 on the PSQ and 7.07 on the PEPPI-S demonstrate that overall, higher levels of general doctor-patient communication satisfaction were associated with higher levels of confidence in one's ability to talk to their doctor about sexual health matters. On the PSQ, the standard score for general doctor-patient communication satisfaction is Mean = 3.58, SD = 0.94 (Marshall & Hays, 1994). The mean score obtained from this study are within the standard deviation of the standard score and demonstrate higher levels of general doctor-patient communication satisfaction. On the PEPPI-S, there are no standard scores; however, higher scores indicate higher levels of patient confidence in communication with their doctors (Stempleman et al., 2016). On a scale of 1 – 10, a general average would be 5; therefore, obtaining a mean of 7.07 demonstrates higher than average scores women's confidence in being able to communicate with their doctor about sexual health information.

The Female Sexual Function Index was measured from 1 – 6, with lower scores indicating lower levels of sexual dysfunction. On the FSFI, a total standard score of 26.55 (Mean = 4.43) with all six domains indicate female sexual dysfunction (Rosen et al., 2000). In this study, the mean obtained was 3.13 (SD = 0.82) which demonstrated lower levels of sexual dysfunction reported from women with spinal cord injuries. Finally, the Multidimensional Sexual Self-Concept Questionnaire was measured from 1 – 5, with higher scores indicating higher levels of sexual self-esteem. On the MSSCQ, there are no

standard scores; however, higher scores indicate higher levels of sexual self-esteem (Snell, 1998). On a scale of 1 – 5, a general average would be 2.5; therefore, obtaining a mean of 3.85 demonstrates higher than average scores women’s sexual self-esteem for the women who participated in this research.

Table 2

Descriptive Statistics of Variables

	<i>M</i>	<i>SD</i>	<i>range</i>
Patient Satisfaction Questionnaire	3.43	0.50	1 - 5
Perceived Self-Efficacy in Patient-Physician Interactions – Sex (PEPPI-S)	7.07	2.08	1 - 10
Female Sexual Function Index	3.13	0.82	1 - 6
Multidimensional Sexual Self-Concept Questionnaire	3.85	0.66	1 - 5

Note = for all descriptive measures $n = 45$, except for PEPPI-S $n = 44$

High scores = positive patient-doctor communication, lower sexual dysfunction, and positive sexual self-esteem

Table 3 provides the correlation analysis outlined in the research questions.

Table 3

Correlation Statistics of Variables

	PEPPI-S	FSFI	MSSCQ	Time past injury	Age
PSQ	.421**	.121	.232	.037	.114
PEPPI-S		-.151	.202	-.211	.000
FSFI			-.359*	-.111	.105
MSSCQ				.170	-.072
Time past Injury					.527**

Note. For all descriptive measures $N = 45$, except for PEPPI-S $N = 44$

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Patient Satisfaction Questionnaire = PSQ; Perceived Self-Efficacy in Patient-Physician Interactions – Sex = PEPPI-S; Female Sexual Function Index = FSFI; and Multidimensional Sexual Self-Concept Questionnaire = MSSCQ

Results

The first research question was answered through a correlation analysis. The first research question was the following: Using the Patient Satisfaction Questionnaire and Perceived Self-Efficacy in Patient-Physician Interactions—Sex, does sexual health communication with one's doctor correlate to sexual functioning in women who have suffered a spinal cord injury as measured by Female Sexual Function Index? The correlation analysis indicated a statistically significant positive correlation between the Patient Satisfaction Questionnaire and the Perceived Self-Efficacy in Patient-Physician Interactions—Sex; however, it did not show a correlation to sexual functioning as measured by the Female Sexual Function Index. Higher scores on the PSQ indicated that women were having successful interactions with their doctors and were obtaining the

information they were looking for during their doctor's appointments. Higher scores on the PEPPI-S indicated higher confidence in women to communicate their sexual health concerns with their doctors. Overall, higher levels of general doctor-patient communication satisfaction were associated with higher levels of confidence in the ability to talk to the doctor about sexual health matters.

The second research question was examined through a correlation analysis. The second research question was the following: Using the Multidimensional Sexual Self-Concept Questionnaire as a measure of sexual self-esteem, do higher scores predict a higher degree of sexual functioning for women with spinal cord injuries as measured by the Female Sexual Function Index? The correlation analysis indicated a statistically significant negative correlation between sexual self-esteem and sexual functioning. Higher scores on the MSSCQ were significantly associated with lower scores on the FSFI. Because higher scores on the MSSCQ reflected higher levels of sexual self-esteem, this meant that higher sexual self-esteem levels were associated with lower levels of sexual dysfunction.

The third research question was as follows: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Patient Satisfaction Questionnaire (communication with doctor) and the Female Sexual Function Index (sexual functioning)? The fourth research question was as follows: Does the Multidimensional Sexual Self-Concept Questionnaire (sexual self-esteem) mediate the relationship between the Perceived Self-Efficacy in Patient-Physician Interactions—Sex (communication with doctor) and the Female Sexual Function Index (sexual

functioning)? The correlation analysis demonstrated no relationship between these measures, which violated the prerequisites of a mediation analysis (see Baron & Kenny, 1986). The Multidimensional Sexual Self-Concept Questionnaire was not evidenced to mediate the relationship between the Patient Satisfaction Questionnaire or the Perceived Self-Efficacy in Patient-Physician Interactions—Sex and the Female Sexual Function Index. No further analysis was warranted for these research questions.

Summary

There were strong relationships between some of the variables in this study including doctor-patient communication and time passed since injury, and between higher sexual self-esteem and positive sexual functioning. There were two statistically significant correlations found from this study. The first was the positive correlation between the PSQ and the PEPPI-S, which showed the association between general satisfaction with doctor-patient communication and confidence in communicating with the doctor about sexual health information. The second was the negative correlation between the MSSCQ, a measure of sexual self-esteem, and the FSFI, a measure of sexual functioning. Higher scores on the MSSCQ correlated with lower scores on the FSFI, indicating that higher sexual self-esteem was associated with lower sexual dysfunction reported within the relationship. The mediation analyses could not be completed because the correlation analysis demonstrated that there was no relationship between these measures, which violated the prerequisites of a mediation analysis. Further discussion, conclusions, and recommendations are presented in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

In Chapter 5 I discuss the statistical results of this quantitative study in which the sexuality and relationship experiences of women with spinal cord injuries were examined to provide information for programs that would enhance the sexual quality of life for this underserved population (Otero-Villaverde et al., 2015; Richards et al., 1997). The first purpose of the study was to examine the level of satisfaction with participants' communication with their doctor. The hypothesis that guided this study was that communication about sexual health matters would increase women's sexual confidence (overall sexual self-esteem), which would predict better sexual functioning in women. The second purpose of the study involved examining whether there was a relationship between women's positive sexual functioning after they had a spinal cord injury and the level of satisfaction with doctor-patient communication. I hypothesized that good doctor-patient communication would engender positive sexual self-esteem, which foster good sexual functioning.

Interpretation of the Findings

The findings of the study indicated fairly strong relationships between doctor-patient communication scales with one another. Additionally, the findings demonstrated a statistically significant correlation between sexual self-esteem subscales of the MSSCQ and higher levels of sexual functioning. The correlation between sexual self-esteem and higher levels of sexual functioning was consistent with findings from previous research. Robinson et al. (2011) found that when women were not provided with information regarding their sexual health from their health providers during the rehabilitation process,

women suffered from lower levels of sexual functioning and lower levels of sexual self-esteem.

Findings from the current study were also consistent with previous studies about the difficulties women with spinal cord injuries face with their sexual functioning and with their sexual self-esteem after injury. Previous studies indicated that women with spinal cord injuries have several barriers to remaining sexually active including physical as well as psychological barriers (Cramp et al., 2014; Fritz et al., 2015; Hocaloski et al., 2016; Kalpakijan et al., 2011; Merghati-Khoei et al., 2015; Miller & Marini, 2004; Mona et al., 2000; Otero-Villaverde et al., 2015; Parker & Yau, 2012; Sale et al., 2012; Singh & Sharma, 2005; Westgren & Levi, 1999; Whipple & Komisaruk, 1997; Whipple & Komisaruk, 2002). An additional significant correlation was found was between the variable of age and the number of years that had passed since the injury, which was not a primary focus of this study. This finding implied that as the number of years since injury increases, women with spinal cord injuries become more confident in their sexual functioning and their sexual self-esteem. This finding was consistent with previous studies that indicated that as years increased from injury, women with spinal cord injuries reported being more comfortable exploring their sexuality, seeking additional support services such as counseling or other services, and recognizing that confidence can develop over time (Parker & Yau, 2012).

One of the primary purposes of this research study was to examine whether positive sexual self-esteem mediated the relationship between doctor-patient communication and higher levels of sexual functioning. I hypothesized that when women

with spinal cord injuries received helpful sexual health information from their doctor, they would have higher levels of sexual self-esteem, which would lead to lower levels of sexual dysfunction. This hypothesis was based on the assumption that if more information is available about sexual health after an injury, women will feel more confident in their ability to engage in sexual activities and will report less sexual dysfunction. In other words, if medical doctors take the time to communicate with women about sexual health during their recovery from a spinal cord injury, this communication would affirm their sexuality and give women with spinal cord injuries permission to be sexual beings. This communication would provide a holistic approach to treatment for women with spinal cord injuries. This hypothesis was not supported through findings in the study. One potential reason why this hypothesis was not supported was too many of the participants were too far removed from their injury and were less engaged with their primary care providers to be able to identify with the key variables in the study. Additionally, other sources of sexual health information may have influenced participants in better managing their sexual functioning after injury.

Limitations of the Study

There are many different factors and characteristics that can impact female sexual functioning following spinal cord injuries. This study did not address all of the factors and characteristics that females with spinal cord injuries have experienced in their lifetime. This study addressed only their personal medical experience related to doctor communication, and how this impacted their sexual functioning and sexual self-esteem following spinal cord injuries. This study was limited to a self-selecting sample. The a

priori sample size analysis indicated that the minimum sample size needed was 76 participants; however, only 45 women with spinal cord injuries completed the study. Having a limited number of participants affected the results of this study because it reduced the ability to confirm all hypotheses presented in this study. Statistically, as the sample size increases, the confidence in the estimate increases and the uncertainty of the results decreases as there is now greater precision in our results. Specifically in examining the results of the correlations between sexual self-esteem subscales of the MSSCQ and the doctor-patient communication measures the PSQ and the PEPPI-S, more participants might have resulted in those correlations being statistically significant. Overall, the results of this study must be interpreted with caution due to the low power in the study. One reason that the participants may not have volunteered for this study was because the topic of sexuality can be viewed as taboo or controversial. Another reason that participants may not have volunteered is the study being conducted online. Early in the recruitment process, participants expressed concerns to the president of Ms. Wheelchair America about the legitimacy of the study. Participants were concerned that I was not a real person and that they were being exploited through their participation in the survey. I hoped that through the development of a social media page in which volunteers could see me as a person and confirm the study as legitimate, more people would volunteer. Additionally, my contact person with Ms. Wheelchair America agreed to send out a second reminder to participate; when I requested one more reminder, it was denied. Because of these limitations, the results of the study are not generalizable to the all

women, and are not generalizable to all women with spinal cord injuries. Finally, this study was limited to those literate in English who had access to the Internet.

Recommendations

One strength of this study was that it was included at a nationwide sample. The access to women with spinal cord injuries exceeded previous studies that were conducted through hospitals, rehabilitation centers, or physical or occupational therapy clinics. Sampling in the current study provided a basis for the findings to be representative of the U.S. population of women with spinal cord injuries. Future studies would benefit from taking a similar approach to connecting with rehabilitation hospitals that can provide broader access to women with spinal cord injuries. An additional strength of this study was that it addressed an aspect of sexual health information that had not been previously examined: the relationship between sexual health information presented to women with spinal cord injuries and their current level of sexual functioning and sexual self-esteem. The benefits of examining this relationship include developing programs for doctors or physicians treating women with spinal cord injuries in a more productive way, and ensuring that sexual health information is communicated at every visit to the doctor.

Implications

The findings from this study may be used to improve training programs for doctors and physicians working with women with spinal cord injuries. Training program developers may use results from this study to teach doctors to ask questions about sexual health when working with women with spinal cord injuries. Findings may also be used to help women with spinal cord injuries take charge of their sexual health by asking

questions of their doctors during visits and bringing up concerns regarding their sexual health when they are unsure of the information.

The theoretical framework for this study was the sexual health model (SHM), which states that sexual health is defined by attitudes, beliefs, and behaviors surrounding the topic of sexuality (Robinson et al., 2002). This theory indicates the importance of obtaining sexual knowledge from medical professionals as well as knowledge of the self, including beliefs and attitudes about sexual intimacy (Robinson et al., 2002). The purpose of the SHM is to provide a clear definition of what sexual health means to help individuals obtain knowledge that may influence their sexual activities through the exploration of 10 categories, which include talking about sex, culture and sexual identity, sexual anatomy and functioning, sexual health care and safe sex, challenges in obtaining sexual health information, body image, masturbation and fantasy, positive sexuality, intimacy and relationships, and spirituality (Robinson et al., 2002). This framework was appropriate for the study as the results demonstrated that continued education regarding sexual health continues to be an area of need in the health care field.

Conclusion

Recognizing that sexuality is a part of people's identities and generating more positive conversation about sexual functioning and sexual self-esteem is important for the development of interpersonal relationships and connections with others (Robinson et al., 2002). This is especially true following a traumatic injury that may change a person's physical functioning. Research that the topic of sexuality and the recovery of sexual functioning has focused on men who have sustained spinal cord injuries, but not often on

women (Lombardi et al., 2010). Previous studies demonstrated that women with spinal cord injuries report negative sexual experiences after spinal cord injury (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi et al., 2010) possibly due to a lack of education and supportive information about sexual health information provided to them during the rehabilitation process (Beckwith & Yau, 2013; Leibowitz, 2005; Lombardi et al., 2010). Further research about women's sexuality after spinal cord injuries is needed. Improved communication between doctors and patients may decrease the stigma of talking about sexuality and foster a more holistic approach to recovery for women with spinal cord injuries.

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Appendix A: Demographic Form

What is your gender?

1. Female
2. Male

Do you have a Spinal Cord Injury?

1. Yes
2. No

If no, please describe your injury?

1. _____

What is your age?

1. _____

What is the highest level of education you have completed?

1. Less than HS diploma
2. High School
3. Some College
4. Bachelor's degree
5. Graduate degree

What is your current household income?

1. \$0 – \$24,999
2. \$25,000 – \$49,999
3. \$50,000 – \$74,999
4. \$75,000 – \$99,999
5. \$100,000 – \$149,999
6. \$150,000 or more

What is your ethnicity? Check all that apply.

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Hispanic or Latino
5. Native Hawaiian or Other Pacific Islander
6. White or Caucasian

What region of the United States do you currently live in?

1. New England
2. Mid-Atlantic
3. East North Central

4. West North Central
5. South Atlantic
6. East South Central
7. West South Central
8. Mountain
9. Pacific

How many years have passed since your injury?

1. 0 – 10
2. 11 – 20
3. 21 – 30
4. 31 – 40
5. 41 – 50
6. 50 or more

Appendix B: Patient Satisfaction Questionnaire Short-Form (PSQ-18)

On the following pages are some things people say about medical care. Please read each one carefully, keep in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received. Rate how strongly you AGREE or DISAGREE with each of the following statements on a 5-point-scale with 1 = Strongly agree, 2 = Agree, 3 = Uncertain, 4 = Disagree and 5 = Strongly disagree.

1. Doctors are good about explaining the reason for medical tests.....[1 2
3 4 5]
2. I think my doctor's office has everything needed to provide complete medical care .[1 2
3 4 5]
3. The medical care I have been receiving is just about perfect.....[1 2
3 4 5]
4. Sometimes doctors make me wonder if their diagnosis is correct.....[1 2
3 4 5]
5. I feel confident that I can get the medical care I need without being set back
financially..... [1 2 3 4 5]
6. When I go for medical care, they are careful to check everything when treating and
examining me...[1 2 3 4 5]
7. I have to pay for more of my medical care than I can afford[1 2
3 4 5]
8. I have easy access to medical specialists I need[1 2
3 4 5]
9. Where I get medical care, people have to wait too long for emergency treatment[1 2
3 4 5]
10. Doctors act too businesslike and impersonal toward me[1 2
3 4 5]

11. My doctors treat me in a very friendly and courteous manner[1 2
3 4 5]
12. Those who provide my medical care sometimes hurry too much when they treat me.[1 2
3 4 5]
13. Doctors sometimes ignore what I tell them[1 2
3 4 5]
14. I have some doubts about the ability of the doctors who treat me.[1 2
3 4 5]
15. Doctors usually spend plenty of time with me.[1 2
3 4 5]
16. I find it hard to get an appointment for medical care right away.[1 2
3 4 5]
17. I am dissatisfied with some things about the medical care I receive.[1 2
3 4 5]
18. I am able to get medical care whenever I need it.[1 2
3 4 5]

Appendix C: Perceived Self-Efficacy in Patient-Physician Interactions - Sex (PEPPI-S)

On the following page are some things people say about medical care. Please read each one carefully, and then rate your self-confidence on a scale of 1 = Not Confident to 10 = Most Confident on your ability to interact with your physician.

1. Know which questions to ask your doctor about sexual health concerns...[1 2 3 4 5 6 7 8
9 10]
2. Get the doctor to answer all my questions about sexual health concerns...[1 2 3 4 5 6 7 8
9 10]
3. Make the most of your visit discussing sexual health concerns.....[1 2 3 4 5 6 7 8
9 10]
4. Get the doctor to take your sexual health concerns seriously.....[1 2 3 4 5 6 7 8
9 10]
5. Get the doctor to do something about my sexual health concerns.....[1 2 3 4 5 6 7 8
9 10]

Appendix D: Female Sexual Function Index

Subject Identifier _____ Date _____

INSTRUCTIONS: These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Your responses will be kept completely confidential. In answering these questions the following definitions apply:

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.

Sexual intercourse is defined as penile penetration (entry) of the vagina.

Sexual stimulation includes situations like foreplay with a partner, self-stimulation (masturbation), or sexual fantasy.

CHECK ONLY ONE BOX PER QUESTION.

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to a partner's sexual initiation, and thinking or fantasizing about having sex.

1. Over the past 4 weeks, how **often** did you feel sexual desire or interest?
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never

2. Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?
 - Very high
 - High
 - Moderate
 - Low
 - Very low or none at all

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

3. Over the past 4 weeks, how **often** did you feel sexually aroused ("turned on") during sexual activity or intercourse?
 - No sexual activity
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never

4. Over the past 4 weeks, how would you rate your **level** of sexual arousal ("turn on") during sexual activity or intercourse?
 - No sexual activity

- Very high
 - High
 - Moderate
 - Low
 - Very low or none at all
5. Over the past 4 weeks, how **confident** were you about becoming sexually aroused during sexual activity or intercourse?
- No sexual activity
 - Very high confidence
 - High confidence
 - Moderate confidence
 - Low confidence
 - Very low or no confidence
6. Over the past 4 weeks, how **often** have you been satisfied with your arousal (excitement) during sexual activity or intercourse?
- No sexual activity
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never
7. Over the past 4 weeks, how **often** did you become lubricated (“wet”) during sexual activity or intercourse?
- No sexual activity
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never
8. Over the past 4 weeks, how **difficult** was it to become lubricated (“wet”) during sexual activity or intercourse?
- No sexual activity
 - Extremely difficult or impossible
 - Very difficult
 - Difficult
 - Slightly difficult
 - Not difficult

9. Over the past 4 weeks, how often did you **maintain** your lubrication (“wetness”) until completion of sexual activity or intercourse?
- No sexual activity
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never
10. Over the past 4 weeks, how **difficult** was it to maintain your lubrication (“wetness”) until completion of sexual activity or intercourse?
- No sexual activity
 - Extremely difficult or impossible
 - Very difficult
 - Difficult
 - Slightly difficult
 - Not difficult
11. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **often** did you reach orgasm (climax)?
- No sexual activity
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never
12. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **difficult** was it for you to reach orgasm (climax)?
- No sexual activity
 - Extremely difficult or impossible
 - Very difficult
 - Difficult
 - Slightly difficult
 - Not difficult
13. Over the past 4 weeks, how **satisfied** were you with your ability to reach orgasm (climax) during sexual activity or intercourse?
- No sexual activity
 - Very satisfied
 - Moderately satisfied
 - About equally satisfied and dissatisfied

- Moderately dissatisfied
 - Very dissatisfied
14. Over the past 4 weeks, how **satisfied** have you been with the amount of emotional closeness during sexual activity between you and your partner?
- No sexual activity
 - Very satisfied
 - Moderately satisfied
 - About equally satisfied and dissatisfied
 - Moderately dissatisfied
 - Very dissatisfied
15. Over the past 4 weeks, how **satisfied** have you been with your sexual relationship with your partner?
- Very satisfied
 - Moderately satisfied
 - About equally satisfied and dissatisfied
 - Moderately dissatisfied
 - Very dissatisfied
16. Over the past 4 weeks, how **satisfied** have you been with your overall sexual life?
- Very satisfied
 - Moderately satisfied
 - About equally satisfied and dissatisfied
 - Moderately dissatisfied
 - Very dissatisfied
17. Over the past 4 weeks, how **often** did you experience discomfort or pain during vaginal penetration?
- Did not attempt intercourse
 - Almost always or always
 - Most times (more than half the time)
 - Sometimes (about half the time)
 - A few times (less than half the time)
 - Almost never or never
18. Over the past 4 weeks, how **often** did you experience discomfort or pain following vaginal penetration?
- Did not attempt intercourse
 - Almost always or always
 - Most time (more than half the time)
 - Sometimes (about half the time)

- A few times (less than half the time)
- Almost never or never

19. Over the past 4 weeks, how would you rate your **level** (degree) of discomfort or pain during or following vaginal penetration?

- Did not attempt intercourse
- Very High
- High
- Moderate
- Low
- Very Low or None at all

Appendix E: Multidimensional Sexual Self-Concept Questionnaire (MSSCQ)

INSTRUCTIONS: The items in this questionnaire refer to people's sexuality. Please read each item carefully and decide to what extent it is characteristic of you. Give each item a rating of how much it applies to you by using the following scale:

- A = Not at all characteristic of me
- B = Slightly characteristic of me.
- C = Somewhat characteristic of me.
- D = Moderately characteristic of me.
- E = Very characteristics of me.

Note: Remember to respond to all items, even if you are not completely sure. Your answers will be kept in the strictest confidence. Also, please be honest in responding to these statements.

1. I feel anxious when I think about the sexual aspects of my life.
2. I have the ability to take care of any sexual needs and desires that I may have.
3. I am very aware of my sexual feelings and needs.
4. I expect that the sexual aspects of my life will be positive and rewarding in the future.
5. I would be to blame, if the sexual aspects of my life were not going very well.
6. I derive a sense of self-pride from the way I handle my own sexual needs and desires.
7. I am satisfied with the way my sexual needs are currently being met.
8. Not only would I be a good sexual partner, but it's quite important to me that I be a good sexual partner.
9. My sexuality is something that I am largely responsible for.
10. I worry about the sexual aspects of my life.
11. I am competent enough to make sure that my sexual needs are fulfilled.
12. I am very aware of my sexual motivations and desires.
13. I believe that in the future the sexual aspects of my life will be healthy and positive.
14. If the sexual aspects of my life were to go wrong, I would be the person to blame.
15. I am proud of the way I deal with and handle my own sexual desires and needs.
16. I am satisfied with the status of my own sexual fulfillment.
17. Not only would I be a skilled sexual partner, but it's very important to me that I be a skilled sexual partner.
18. The sexual aspects of my life are determined in large part by my own behavior.
19. Thinking about the sexual aspects of my life often leaves me with an uneasy feeling.
20. I have the skills and ability to ensure rewarding sexual behaviors for myself.
21. I tend to think about my own sexual beliefs and attitudes.
22. I do not expect to suffer any sexual problems or frustrations in the future.
23. If I were to develop a sexual disorder, then I would be to blame for not taking good care of myself.
24. I am pleased with how I handle my own sexual tendencies and behaviors.
25. The sexual aspects of my life are personally gratifying to me.

26. Not only could I relate well to a sexual partner, but it's important to me that I be able to do so.
27. I am in control of and am responsible for the sexual aspects of my life.
28. I worry about the sexual aspects of my life.
29. I am able to cope with and to handle my own sexual needs and wants.
30. I'm very alert to changes in my sexual thoughts, feelings, and desires.
31. I will probably experience some sexual problems in the future.
32. If I were to develop a sexual problem, then it would be my own fault for letting it happen.
33. I have positive feelings about the way I approach my own sexual needs and desires.
34. The sexual aspects of my life are satisfactory, compared to most people.
35. I feel unhappy about my sexual experiences.
36. The main thing which affects the sexual aspect of my life is what I myself do.
37. I feel nervous when I think about the sexual aspects of my life.
38. I have the capability to take care of my own sexual needs and desires.
39. I am very aware of the sexual aspects of myself (e.g., habits, thoughts, beliefs).
40. I anticipate that in the future the sexual aspects of my life will be frustrating.
41. If something went wrong with my own sexuality, then it would be my own fault.
42. I feel good about the way I express my own sexual needs and desires.
43. I am satisfied with the sexual aspects of my life.
44. Not only am I capable of relating to a sexual partner, but it is important to me that I relate very well.
45. My sexuality is something that I myself am in charge of.