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THE LIVED EXPERIENCES AND OCCUPATIONS OF INITIMATE PARTNERS OF
INDIVIDUALS WITH SPINAL CORD INJURY RELATED TO SEXUAL WELL-BEING

by

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ABSTRACT

The Lived Experiences and Occupations of Intimate Partners of Individuals with Spinal Cord Injury Related to Sexual Well-Being

Kate Eglseder MS, OTR/L, CLT

The onset of spinal cord injury (SCI) results in physical and psychological changes which impact participation in occupations related to sexual well-being. Although education and resources are often provided to the injured individual, frequently the intimate partners of individuals with SCI are not included in this training. The purpose of the research for this dissertation was twofold. One purpose was to describe the lived experience of intimate partners of individuals with SCI related to sexuality. The second was to identify education and resource needs related to sexuality for these individuals. It is believed that information gained from this study can be utilized to inform future development of educational resources for this population. A collective case study design was chosen for this project. For the purpose of this project, four participants were selected utilizing purposeful sampling and participated in in-depth interviews relating to the lived experiences and perceived educational needs of the participants.

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Chapter 1

Introduction

Sexuality is an important part of the human experience and has been identified as a contributing factor of quality of life, satisfaction, and overall health (Crooks & Baur, 2008). A healthy sex life contributes to overall health and happiness, as sex is an important aspect of intimate relationships and is important to physical and emotional well-being (Bridges, Lease, & Ellison, 2004; Hook, Gerstein, Detterich, & Gridely, 2003). Additionally, a review of current literature reveals that sexual satisfaction is a significant predictor of overall relationship satisfaction (Litzinger & Gordon, 2005; Smith et al., 2011). The World Health Organization (WHO) reports that an integral part of being human encompasses sex, pleasure, and intimacy; and that sexual health is “a state of physical, emotional, mental and social well-being in relation to sexuality” (WHO, 2013a, Sexual Health section, para. 3). In the first chapter of this dissertation, additional background, the significance to occupational science, the purpose of the study, the research questions, and definitions of relevant terms are described.

Addressing the needs of individuals with disabilities and their intimate partners is important to the overall health and well-being of both individuals. This is supported by the U.S. Department of Health and Human Services (USDHHS) and is consistent with an overarching goal in *Healthy People 2020*. One of the main goals in *Healthy People 2020* is to “promote quality of life, healthy development and healthy behaviors across all life stages” (USDHHS, 2013, para. 4). While the USDHHS has not identified specific goals to address the sexual needs of individuals with disabilities or their intimate partners, several new objectives have been identified which relate to the overriding issues within this topic (see Table 1). One such goal is to increase the number of individuals with disabilities who participate in social activities to the

extent that they wish (USDHHS, 2014, Disability and Health-13). The USDHHS (2013) also has identified new goals related to providing health promotion programs aimed at increasing well-being for caregivers of individuals with disabilities. Lastly, a new topic for *Healthy People 2020* focuses on health related quality of life and well-being (USDHHS). Because healthy sexual relationships have been linked to quality of life and well-being, addressing the needs of intimate partners of individuals with SCI could be one avenue to address these goals. Although limited research has been conducted related to sexuality from an intimate partners' perspective, partnered sexual activity requires interest and participation from both the injured person and their partner. It is therefore believed that addressing the needs of intimate partners related to sexuality could enhance the progression toward this goal.

Table 1

Healthy People 2020 Goals and Objectives Related to Sexual Well-Being

| Goals | Objectives |
|---|---|
| Promote quality of life, healthy development, and healthy behaviors across all life stages. | Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community and civic activities to the degree that they wish |
| Improve health-related quality of life and well-being for all individuals. | Increase the number of State and the District of Columbia health departments that conduct health surveillance of caregivers for people with disabilities |
| | Increase the number of State and the District of Columbia health departments that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities |
| | Increase the number of Tribes that have at least one health promotion program aimed at improving the health and well-being of people with disabilities |
| | Increase the number of Tribes that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities |

World Health Organization. (2013b). *2020 Topics and Objectives*. Retrieved from <http://www.healthypeople.gov/2020/topics-objectives>

The onset of SCI can have a devastating impact on sexual relationships and functioning, resulting in impairments in sexual health. This is not only due to the significant physical limitations resulting from injury, but also due to the complexity of sexual relationships and the need for both partners to adapt to the changes resulting from the disability (Crooks & Baur, 2008).

Rehabilitation services for persons with SCI often include sexuality education. This education is based on the belief that all individuals have the right to sexual education, intimacy, and meaningful relationships (Parker, 2007; WHO, 2013a). The WHO supports this belief and identifies sexual rights as the rights of all people to attain the highest level of sexual health including access to sexual health services. The American Occupational Therapy Association (AOTA) supports the belief that “sexuality is a core characteristic and formative factor for human beings” (MacRae, 2013, para. 1). Additionally, the AOTA, via *the Occupational Therapy Practice Framework (OTPF)* has identified sexual activity as an activity of daily living (ADL) indicating that this is an important area to consider in addressing individual’s physical, psychological, and emotional needs (AOTA, 2014). For individuals with SCI within the United States, the standards for Certification of Acute Rehabilitation Facilities require such education in order to meet and maintain certification (Commission on Accreditation of Rehabilitation Facilities [CARF], 2012).

The CARF (2012), through its standards, mandates education for the individual with SCI, but does not suggest the inclusion of the partners of these individuals. Because sex is multifaceted, and in many cases includes the dynamics of an intimate relationship, it could be argued that sexual partners of those with SCI should be included in the educational process. Often, partners of those with disabilities also are faced with the challenges of adapting to

changes in their existing life roles and their relationships, including sexuality (Hawkins et al., 2009). Several authors have reviewed the impact of SCI on sexual functioning for the individual with the disability, and have addressed educational needs to improve the sexual experience (Booth, Kendall, Fronek, Miller, & Geraghty, 2003; Hess, Hough, & Tammara, 2007; Krueter, Taft, Siosteen, & Biering-Sorenson, 2011; Mendes, Cardoso, & Savall, 2008; Sakellariou & Sawada, 2006; Singh & Sharma, 2005; Valtonen, Karlsson, Siosteen, Dahlof, & Vikari-Juntura, 2006; Westgreen & Levi, 1999).

Partnered sexual relationships are complex and require an alignment of both individuals' emotional, physical, and mental needs. When individuals sustain a traumatic injury resulting in significant physical and emotional changes, it is imperative that their sexual partner also is given the tools to assist in redefining the intimate relationship within the context of these changes. However, there is little literature that addresses the educational and resource needs of partners of individuals with SCI in relation to sexuality. These issues are explored in this research study.

Background

According to the 2012 report published by the National Spinal Cord Injury Statistical Center (NSCISC), it is estimated that the annual incidence of new onset SCI is 40 cases per million in the United States or approximately 12,000 new cases each year. It also is estimated that in 2013, approximately 273,000 people in the United States are living with SCI (NSCISC, 2012).

Information from the same NSCISC report indicates that out of 29,096 persons with SCIs in the database, 9,394 or 32.3% were married at the time of injury, and 14 were living with a significant other. It should be noted that the category of "living with a significant other" was not added to the database until 2011 (NSCISC, 2012). These statistics do not include individuals

who were involved in intimate relationships with sexual partners who were not married or living with their partners at the time of injury. As a result, the number of individuals who might benefit from sexuality education may be under represented by this data. Regardless, the number of individuals identified in this database is vast.

A review of the NSCISC 2012 data indicates that, of the nearly 10,000 individuals who were married or living with a partner at the time of their injury, 2,477 or 25% reported a change in marital status with 1,168 or 47% of those individuals reporting divorce. Because the data does not reflect the reasons for the change in marital status, it is impossible to say that these are a result of a change in intimate sexual contact; however, it has been reported that a decline in sexual satisfaction occurs status post SCI (Mendes et al., 2008; Valtonen et al., 2006). Although the exact incidence and prevalence of SCI is difficult to identify, the NSCISC database estimates that there are approximately 12,000 new cases of SCI each year (NSCISC, 2012). Due to the high numbers of individuals impacted by SCI, it is believed that proactive education and support for both the individual with SCI and their partner would be beneficial in maintaining the integrity of the intimate relationship.

There were two purposes of this study. The first purpose was to identify themes related to the lived experience of intimate partners of individuals with SCI during sexual encounters. The second purpose was to identify educational and resource needs related to successful transition to a healthy sexual relationship for partners of individuals with new onset SCI.

While a vast amount of data is available which reflects the impact of SCI on sexuality for individuals with the injury, little research has been published on the impact of SCI on sexuality from the perspective of the partner (Krueter et al., 2011; Mendes et. al, 2008; Valtonen et. al., 2006; Westgreen & Levi, 1999). Because partnered intimate sexual relationships require

involvement from both individuals, an appreciation for the impact of SCI on sexuality should include education of both partners.

Similarly, current data is available to aide in determining education and resource needs for individuals with SCI, while no data is available to address these needs for the partners of individuals with SCI (Booth et. al., 2003; Fisher et al., 2002; Forsythe & Horsewell, 2006; Fronek, Kendall, Booth, Eugarde, & Geraghty, 2011; Hess et al., 2007). Unless the needs of partners of individuals with SCI are identified, the issues related to partner intimacy and sexual relationships cannot be adequately addressed.

Significance to Occupational Science

This study contributes to occupational science by exploring the supports required for sexual partners of individuals with SCI to return to occupations related to sexual well-being. Within the discipline of occupational science, it is believed that the constructs of health, well-being, and quality of life are directly related to an individual's ability to engage in purposeful and meaningful occupations. This field of study emphasizes the importance of the meaning and contexts in which occupations occur (Clark et al., 1991; Hocking, 2009). For occupational scientists, the environment plays an important role in the unfolding of occupations. The external environment can be viewed as the time and space in which occupations occur. The meaning of occupation is individualized by persons' past experiences, internal perception and value of time, and their analysis of the constraints and opportunities afforded by space. It is the relationship of both the external environment and the internal meaning which truly defines occupation (Zemke, 2004).

Occupational scientists strive to produce knowledge about humans interacting with the environment through the use of occupations (Yerxa, 2000). From an occupational science

perspective, this study was conducted to investigate the occupation of sexual activity and participation post-SCI from the partners' points of view. Insight in this area can inform practice by providing a framework for the development of sexuality education programs which address the needs of partners of individuals with SCI.

In order to evaluate the potential contribution of this research to occupational science, a document analysis was performed. A review of the content of the *Journal of Occupational Science* (JOS) from 2007 through 2013 was performed. Additionally, conference programs from Society for the Study of Occupations: USA (SSO-USA) annual research conference from 2011-2013 were reviewed. Although the three year time frame may appear to be short, in the history of the JOS and SSO-USA conferences this is considered exhaustive. No content related to the occupation of sex was revealed through the document analysis during those time frames.

Problem Statement

The onset of SCI produces both physical and emotional changes which impact all areas of occupation. Although much time and attention is given to the individual sustaining the injury, little time and attention is given to the impact of these changes on the individual's partner. These injuries often result in role changes for intimate partners which are due, in part, to the loss of the sexual relationship (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010) and increased caregiving (Dickson et al., 2010; Gajraj-Singh, 2011). The role changes for intimate partners which take place after SCI, including the loss of sexual relationships, can result in a decrease in overall well-being (Dickson et al., 2010). There is a need to more fully understand the impact on the partners of those with SCI and the relation to identity, self-concept, self-esteem, and competency for the partner.

There is an existing body of literature that identifies education and resource needs of individuals with SCI related to sexuality, as well as the impact of the injury on the individual with SCI (Booth et. al., 2003; Fisher et al., 2002; Forsythe & Horsewell, 2006; Fronck et. al., 2011; Hess et. al., 2007; Krueter et al., 2011; Mendes et.al., 2008; Valtonen et. al., 2006; Westgreen & Levi, 1999;). The impact of SCI on sexual partners has yet to be evaluated.

It is important for health care providers and physicians to discover and understand the complex roles of partners of individuals with SCI in order to assist in creating success with sexual activity. Identification of education and resource needs in the early stages of rehabilitation can offer the patient, the partner, the physician and other health care providers the ability to jointly create strategies for successful resumption of joint sexual activity.

Purpose of the Study

The purpose of this phenomenological collective case study is to illustrate the lived experiences of intimate partners of individuals with SCI, discover the education and resource needs related to sexuality for intimate partners of individuals with SCI, and inform future development of educational resources. For the purpose of this study, education and resource needs are generally defined as tailored learning activities to convey knowledge needed to improve participation in sexual activity and any materials which supplement these activities.

The collective case study design allows the researcher to gain an in-depth understanding of the issues from the perspective of each participant (Creswell, 2013). The advantage of this design is that it allows the researcher to view the topic from varying perspectives before arriving at themes that best describe the experiences of the partners of those with SCI.

Qualitative data from one interview per participant was used to identify education and resource needs related to sexuality as perceived by the participants. Within case analysis was

used to identify themes for each participant related to sexual participation, followed by cross-case analysis to identify common themes among the group of four participants.

Despite the evidence that SCI can have a devastating impact on the intimate partner, there is a conspicuous lack of published research that has investigated the impact of SCI on partners of individuals with the injury. Similarly, there is no current available research which specifically focuses on the impact of SCI on sexuality from the intimate caregiver's perspective. Through this exploratory study, the researcher will identify themes related to sexual encounters post SCI from the perspective of the intimate caregivers/partners.

Research Questions

1. What are the lived experiences of intimate partners of individuals with SCI related to sexual encounters?

Figure 1 represents the theoretical framework that was used to create the interview protocol and displays a sampling of the interview questions related to the research. The theoretical model will be explained further in Chapter 2.

Figure 1: Theoretical Conceptual Model for Research Question 1:

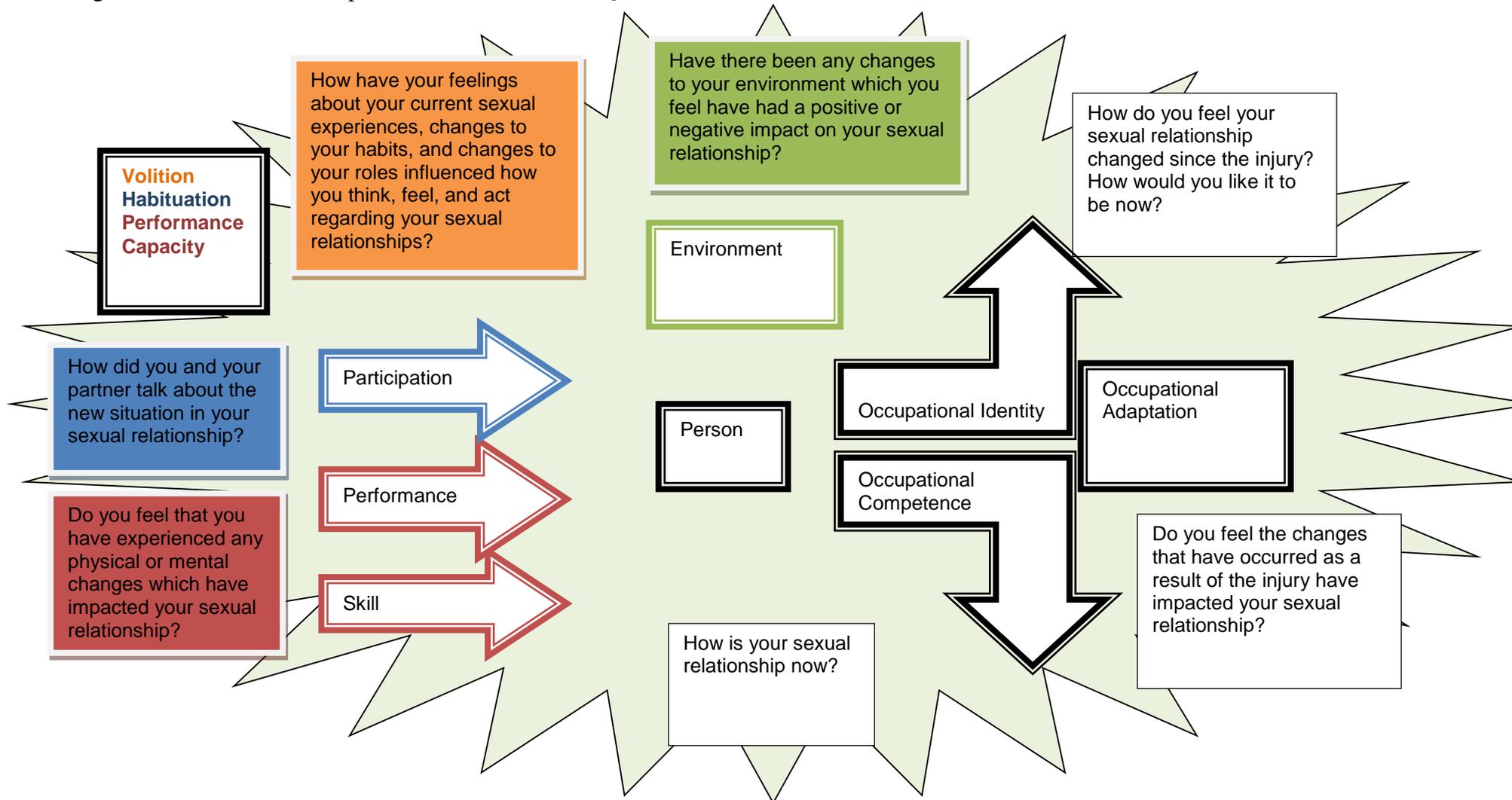


Figure 1. Model of Human Occupation for sexual relationships. Adapted from Model of human occupation: Theory and application 3rd ed.

(p. 169), by G. Keilhofner, 2002, Chicago, Lippincott. Copyright 2002, Lippincott, Williams and Wilkins. Adapted under the fair use provision of U.S. Copyright law.

2. What are the education and resource needs of intimate partners of individuals with SCI related to sexuality?

Figure 2: Theoretical Conceptual Model for Research Question 2 based on constructs from the model of human occupation (MOHO) (Keilhofner, 2008).

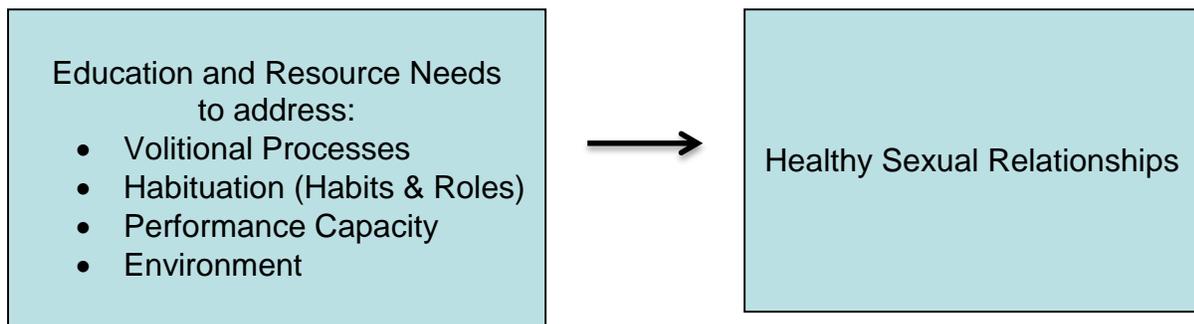


Figure 2 demonstrates the importance of volition, habits, roles, performance ability and environment to healthy sexual relationships. Each of these components can facilitate or limit positive sexual well-being.

The chosen study design was based upon a pilot study which was previously performed with this population. Pilot data was collected from 8 intimate caregivers of individuals with SCI to formulate the interview questions for this project (Eglseder, 2012). Pilot data collected from the partners/caregivers indicate that no formal or informal training was provided to partners of individuals with SCI during the patients' in-patient rehabilitation. All participants shared that they faced issues related to sexuality upon returning home, and all reported that they would have liked to have received education and resources. Based on the limited number of responses in the pilot a collective case study design was used to obtain data to answer both research questions.

Because many of the terms included in this research can be defined in varying ways, the following section has been included. For the purpose of this study, the definitions outlined below will be the working definitions for this dissertation.

Definition of Terms

Education

The WHO defines education as “any combination of learning experiences designed to help individuals and communities improve their health, by increasing their knowledge or influencing their attitudes” (2013c, Health Education section, para. 1). Education, in this study, is defined as tailored learning activities to convey knowledge needed to improve participation in sexual activity as an occupation for caregivers and their partners with SCI.

Intimate Partner

For the purpose of this study, intimate partner is defined as an individual who has been in a social relationship of a romantic or sexual nature.

Intimacy

As defined by Crooks and Baur (2008), intimacy is defined as “the emotional component of love that encompasses the sense of being bonded with another person” and includes “feelings of warmth, sharing, and emotional closeness” (p. 169). Additionally, the University of Florida Counseling and Wellness Center defines sexual intimacy as any “form of sensual expression” (University of Florida, 2015, para. 5).

Occupation

According to Zemke and Clark (1996) occupations are the meaningful activities in which humans engage with the emphasis on the meaning of the occupation. Occupations are defined as “daily activities that reflect cultural values, provide structure to living, and meaning to individuals” (Crepeau, Cohn, & Schell, 2003, p.1031). For the purposes of this study, the occupation of sexual well-being will be explored.

Occupational Adaptation

According to Schkade and Schultz (1992), occupational adaptation is the internal process in which an individual's desire to be engaged in meaningful occupations is integrated with striving for and achieving mastery in desired occupations.

Paraplegia

Paraplegia is defined as impairment in function in the legs, trunk and potentially pelvic organs (American Spinal Injury Association [ASIA], 2000).

Resources

For the purpose of this study, resources are defined as materials or information which are referred to, in addition to formal patient education. These could include but are not limited to handouts on sexual positions, information of how to obtain adaptive devices and information on sex counselors.

Sexual Activity

Sexual activity is defined by AOTA in the *Occupational Therapy Practice Framework* as “engagement in activities which result in sexual satisfaction” (AOTA, 2014, p. S19).

Sexual Health

Sexual health, as defined by the WHO (2013a), is a state of physical, emotional, mental and social well-being in relation to sexuality. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled. (Sexual Health section, para. 3)

Self-Perceived Deviance

Kaplan, Gostjev, and Johnson (2013) define deviance as “behavior that deviates from the normative standards of their own membership groups” (p. 564). For the purpose of this paper, self-perceived deviance is defined as behaviors that the participants’ perceive as being abnormal within their social context. Due to the differing backgrounds of the participants, it should be noted that this perception will differ greatly from one person to another.

Sexual Well-Being

Sexual well-being is defined as the “perceived quality of an individual’s sexuality, sexual life and sexual relationship” (Laumann et al., 2005, p. 146).

Tetraplegia

Tetraplegia is defined as impairment of function in legs, arms, trunk and pelvic organs (ASIA, 2000).

Chapter 2

Literature Review

A review of the literature related to the impact of spinal cord injury (SCI) on sexuality and relationships was conducted in order to guide the research process and the selection of the methodology. The literature review involved examining publications related to the impact of SCIs on functional capabilities, the impact of SCI on sexual well-being for the injured individual, the impact of disability on the sexual well-being and quality of life of the non-injured partner, current trends in sexuality education and well-being, and occupational therapy theoretical models that seek to explain decision-making and provide a foundation for future program planning related to occupational engagement. These publications include both research articles and supporting texts.

This literature review is separated into five sections. The impact of SCI on functional capabilities by level of injury is first discussed. Literature outlined in this section describes how SCIs have impacted the sexual well-being of injured individuals. Next, the impact of SCI on sexuality for the injured individual is presented. Literature related to the impact of disability and sexual participation on partners of individuals with a variety of injuries is included next. Because there is limited research on this topic specific to partners of individuals with SCI, the literature search was extended to include a variety of disabilities and injuries. The research in this section focuses primarily on quality of life, as literature specific to sexuality is limited. In addition, this section is utilized to review current trends in research methodology related to the caregiver experience. The fourth section addresses current trends and findings in education related to disability and sexuality for both the injured individual and their partners. The MOHO

and occupational adaptation (OA) will be introduced in the fifth section. These theories will be used to examine the process of occupational adaptation related to sexuality.

Impact of SCI on Functional Capabilities by Level of Injury

The onset of SCI can have a devastating impact on the motor and sensory functioning of the injured individual. The level and severity of injury are outlined by the International Standards for Neurological and Functional Classification of Spinal Cord Injury (American Spinal Injury Association [ASIA], 2008). SCIs can be generally described as tetraplegia or paraplegia. The term tetraplegia indicates that the individual sustained an injury to their cervical region resulting in partial or total motor and sensory loss to all four extremities. Individuals who sustain an injury below the cervical region present with paraplegia resulting in partial or total motor and sensory loss to their lower extremities. SCIs can also be classified as complete or incomplete. This is determined by whether or not there is preservation of voluntary rectal contractions or anal sensation, as this area is controlled by the lowest level on the spinal cord (ASIA, 2008).

The International Standards for Neurological and Functional Classification of Spinal Cord Injury identifies key muscles controlled by each level of the spinal cord and utilizes dermatomal testing to assess the sensory impact of the injury (ASIA, 2008). Functional capabilities can be determined based upon the motor and sensory impacts of the injury (see Table 2). Although individual injuries will have unique presentations, general impacts can include bowel and bladder incontinence, spasticity, and chronic neurogenic pain (Sipski & Alexander, 1997).

Table 2

Functional Impact of SCI by Level of Injury

| Level of Injury | Motor Function | Functional Abilities |
|------------------------|--|--|
| C1 –C4 | <ul style="list-style-type: none"> • Head and neck movement possible • May be able to shrug shoulders • Weak to paralyzed diaphragm – may require ventilation | <ul style="list-style-type: none"> • Total care required • Power wheelchair mobility |
| C5 | <ul style="list-style-type: none"> • Head and neck movement • Shoulder flexion, abduction, horizontal ab/adduction • Elbow flexion • Supination | <ul style="list-style-type: none"> • Modified independent self-feeding • Modified independent light grooming • Total care for all other self-care • Power wheelchair mobility |
| C6 | <ul style="list-style-type: none"> • Head and neck movement • Shoulder flexion, abduction, horizontal ab/adduction • Elbow flexion • Supination • Wrist extension • Tenodesis Grasp | <ul style="list-style-type: none"> • Can complete most or all self-care with modified independence • Can manage bladder with modifications • Possible for independent transfers • May require assistance for bowel management • Power or lightweight manual wheelchair mobility |
| C7 | <ul style="list-style-type: none"> • Head and neck movement • Shoulder flexion, abduction, horizontal ab/adduction • Elbow flexion • Supination • Wrist extension • Tenodesis Grasp • Elbow extension | <ul style="list-style-type: none"> • Can complete most or all self-care with modified independence • Can manage bladder with modifications • Independent transfers • Lightweight manual wheelchair mobility • May drive adaptive vehicle |
| C8 | <ul style="list-style-type: none"> • Head and neck movement • Shoulder flexion, abduction, horizontal ab/adduction • Elbow flexion • Supination • Wrist extension • Elbow extension • Finger flexion | <ul style="list-style-type: none"> • Can complete all self-care with modified independence • Can manage bladder and bowel with modifications • Independent transfers • Lightweight manual wheelchair mobility • May drive adaptive vehicle |

| | | |
|----------------------------|--|---|
| Thoracic Paraplegia | <ul style="list-style-type: none"> • All upper extremity function present • Varying degrees of trunk control | <ul style="list-style-type: none"> • Independent all self care and instrumental activities of daily living with modifications • T2 – T9 may be able to stand with long leg braces and walker • T10-T12 may be able to walk household distances with long leg braces and walker or crutches |
| Lumbar Paraplegia | <ul style="list-style-type: none"> • All upper extremity function present • Trunk control present • Some lower extremity motor return | <ul style="list-style-type: none"> • Independent all self-care and instrumental activities of daily living with modifications • Can achieve independence with community mobility with or without assistive devices |

Adapted from “Spinal cord injury patient – family teaching manual” by Thomas Jefferson University, 2009.

Impact of SCI on Sexual Well-Being for Injured Individuals

A review of the literature on the impact of SCI on sexual functioning and satisfaction for the individual with the disability provided information related to the complexities of sexual relationships after injury. The authors of these publications outline the vast array of issues related to full participation in intimate sexual relationships after traumatic injury (see Table 3).

One of these studies included both men and women. Valtonen et al. (2006) utilized a postal questionnaire aimed at identifying sexual satisfaction among 190 individuals with traumatic SCI. The questionnaire was developed by the authors, and pilot tested prior to use in this study. Although items were included to assess other independent variables including presence of pressure ulcers, fecal and urinary incontinence, and spasticity, the main outcome variable was satisfaction with sexual life. This item was rated utilizing a numerical scale with 0 being dissatisfied and 10 being satisfied. Upon completion of data collection, the Kolmogorov-Smirnov normality test was utilized to ensure the data set modeled normal distribution.

Table 3

Summary of Literature

| Authors / Date | Methods | Major Findings |
|---|---|---|
| Anderson, Borisoff, Johnson, Steins, & Elliott (2007) | Quantitative Study Design Web based survey 87 women with SCI Two questionnaires: one for demographic info, one for sexual issues. | The greater number of years after SCI, the greater the likelihood of having a sexual relationship. |
| Krueter, Taft, Siosteen, & Biering-Sorenson (2011) | Quantitative Study Design Questionnaire 392 community dwelling women with SCI | 87% of women reported that SCI negatively impacted sexuality |
| Mendes, Cardoso, & Savall (2008) | Mixed Method Design Questionnaires available in written and interview formats 40 men with SCI, 50 able bodied men. | Sharp decline in sexual satisfaction post injury for men. Significant difference in satisfaction between men with SCI and non-injured counterparts. |
| Sakellariou & Sawada (2006) | Qualitative Study Design Phenomenological – unstructured interviews Six Greek males with SCI | Initial drop in sexual satisfaction with increasing adaptation over time for men with SCI. |
| Singh & Sharma (2005) | Quantitative Study Design Questionnaire based interviews 40 women with SCI | 87% of women believed that sex was important. 45% of women reported decreased sexual satisfaction |
| Tepper, Whipple, Richards, & Komisaruk (2001) | Qualitative Study Design Semi-structured interviews 15 women with SCI Reviewing sexual changes over time. | Trends in participants related to sexuality including sexual disenfranchisement, cognitive genital dissociation for women with SCI. |
| Valtonen, Karlsson, Siosteen, Dahlof, & Vikari-Juntura (2006) | Quantitative Study Design Postal questionnaire 190 individuals with traumatic SCI Assessed sexual satisfaction and independent variables | Decreased self- reported sexual satisfaction status post spinal cord injury for both men and women. |
| Westgreen & Levi (1999) | Qualitative Study Design Semi-structured interviews 8 women with SCI | Better communication skills correlated with increased satisfaction. Indication that sexual counseling to assist with communication and coping was needed for women with SCI. |

The results from this study demonstrated relatively low sexual satisfaction for individuals with SCI, with a median satisfaction rating of 3. In male participants, increased age and higher age at injury correlated with decreased satisfaction ($p = 0.001$), whereas with women there did not seem to be any such correlation ($p = 0.474$ and $p = 0.949$ respectively). Additionally, there was no correlation between neurologic level and time since the onset of injury and sexual satisfaction for either gender. Bowel and bladder incontinence and neuropathic pain were shown to contribute to a decrease in sexual satisfaction. Most studies found on sexual function post SCI are separated by gender. This is due in part to the differences in sexual functioning between men and women. Although both genders can experience bowel and bladder issues, neurogenic pain, decreased mobility, and decreased sensation, they differ in the response of their genitalia. Men with SCI can experience varying levels of erectile dysfunction, while women with SCI can experience issues related to lubrication. Because of these differences, the results of the other studies will be discussed separately for women and men.

Impact on sexual well-being for women with SCI. Because men and women have differing impacts on their physiology related to sexuality after sustaining a SCI, several authors have narrowed their research by gender. Current research has indicated that women who sustain SCIs have a substantial decrease in their sexual well-being (Krueter et al., 2011; Singh & Sharma, 2005).

One such study was conducted by Singh and Sharma (2005), in which they recruited 40 women to participate in a questionnaire based interview to assess sexuality in women with SCI. The findings indicated that 72.5% of the participants continued to have interest in sex after injury, and 87.5% reported that they believed that sex was important. Despite this, 45% of the

participants reported dissatisfaction with sexual activity, and 47.5% report a decrease in satisfaction from pre-injury sexual activity.

Similarly, in 2011, Krueter et al. published a study including 392 community dwelling females with SCI. Each participant completed a questionnaire designed specifically for this study entitled the *SCI Women Questionnaire*. Utilizing the Kruskal-Wallis test for continuous variables, and the Mantel Haenszel's test for dichotomous variables, the study results indicated that 87% of women reported that their sex life had been negatively impacted by their SCIs. Both physiologic and psychological changes were reported as reasons for the change in sexual satisfaction. Physiologic changes included changes in sensation, changes in orgasm, and difficulty with mobility and positioning. Psychological changes included feeling less attractive, loss of self-confidence, and feelings that they are unable to meet their partners' needs (Krueter et al., 2011).

Although the women in these studies indicate a decrease in sexual satisfaction, there is some indication that education and counseling can aide in better sexual adaptation after injury. Westgreen and Levi (1999) interviewed eight women who had sustained SCIs. Each interview was performed by one of the authors, and all were taped and transcribed. The authors of this study identified a correlation between pre-injury sexual behavior and post-injury satisfaction indicating that those with positive sexual expression prior to injury had better adaptation after injury. Additionally, individuals with good communication skills tended to have better sexual experiences. The authors of this study indicated a need for sexual counseling to aide individuals in communication and coping with the losses after SCI (Westgreen & Levi, 1999).

In addition to education, several authors have researched the correlation between time since injury and sexual well-being. In 2001, Tepper, Whipple, Richards, and Komisaruk

published a phenomenological study of the sexual experiences of women with SCI. A qualitative approach was utilized to investigate the unique human experiences of the participants. Fifteen women were chosen to participate in semi-structured interviews which were structured chronologically in order to obtain descriptions of the changes in sexuality over time. These interviews were then transcribed and analysis completed utilizing ethnographic computer software from Qualis Research Associates, Corvallis.

Three themes emerged from the interviews. The first of these was cognitive genital dissociation in which the participants reported a belief that sexual satisfaction was no longer possible. This was primarily a result of decreased sensation in the genital region. The second theme was sexual disenfranchisement. This was found to be the result of inadequate sexual education post injury, societal views of disabled individuals, issues with body image, and negative feedback from healthcare providers and partners. The last theme identified was sexual re-discovery. It was discovered that over time, 2 – 15 years, the participants began to feel more comfortable and adapt to their physical limitations. This led to increased self-esteem and eventually, increased sexual self-esteem (Tepper et al., 2001).

Anderson et al. (2007) conducted a secure web based interview on the impact of SCI on sexual function. Participants included 87 women with SCI with an average time post injury of 14.5 years. The authors of this study found that the number of years post injury positively impacted the participants' engagement in sexual activity. It was found that women were more likely to engage in sexual activity as time passed. This supports the position that, over time, women can adapt to their physical limitations and more fully participate in sexual relationships.

The review of the literature pertaining to sexual well-being for women with SCI reveals several important considerations. Through the review, it is evident that women who sustain SCIs

report a decreased level of sexual satisfaction. More importantly, the literature review revealed that education, counseling, and increased time since injury can improve the sexual well-being of women with SCI.

Impact on sexual well-being for men with SCI. As with women, men with SCI demonstrate a negative impact on their sexual well-being as a result of SCI. Similar to the research findings for women with SCI, men also demonstrate a decrease in sexual satisfaction after SCI (Mendes et al., 2008). Additionally, time since injury is strongly correlated to the level of sexual satisfaction reported (Sakellariou & Sawada, 2006).

Mendes et al. (2008), found similar results in their study related to sexual satisfaction in men with SCI. Ninety men, forty of which had SCIs, and fifty of which had no disability, participated. Of the individuals with SCI, twenty nine had paraplegia and eleven had tetraplegia. For the purpose of this study, a questionnaire was utilized with a focus on the participants' sexuality prior to injury and after one year of rehabilitation. The questionnaire was available in both written and interview formats and contained both open and closed end questions related to sexual satisfaction, number of partners, educational level, and buying power. The participants could decide upon their preferred method of administration. The themes reported from this study included desire, satisfaction, and sexual behavior (Mendes et al., 2008). The participants in this study reported a decrease in desire to participate in sexual activity, a decrease in the frequency of sexual behaviors, and a decrease in satisfaction with their sexual experiences (Mendes et al., 2008).

The results of this study demonstrated a sharp decline in sexual satisfaction post SCI and a significant difference in satisfaction between the control group and the SCI group. Of the participants in this study, 80% rated their pre-injury sexual life as very satisfying. This dropped

to 47% after sustaining the SCI. When compared to their non-injured counterparts, individuals with SCI were significantly less satisfied, with 72% of the control group being very satisfied (Mendes et al., 2008).

Mendes et al. (2008) found several contributing factors to the decline in sexual satisfaction after the onset of SCI. As a result of an SCI, participants' indicated issues which included problems with sexual adjustment, sexual arousal, achieving orgasm, achieving penetration, finding sex possible without penetration, the decrease in number of sexual partners post injury, and erectile dysfunction. These participant concerns resulted in a report of decreased sexual satisfaction. The most important finding, however, was that increased time since injury resulted in higher sexual satisfaction. This could indicate that over time men learn adaptive strategies to manage the limitations of their injuries. The information can be useful in supporting the need for early education and resource dissemination to improve the timeliness of the adaptive response.

Similarly, Sakellariou, and Sawada (2006) utilized a phenomenological approach to identify themes in the lived experience of Greek males with SCI. Six participants were selected to participate in unstructured interviews in their homes. Thematic analysis was then utilized to identify themes and peer review was utilized to ensure credibility. The results of this study indicate that although dissatisfaction with sexual encounters occurs initially, men with SCI are able to adapt to their injuries over time. Barriers to effective adaptation included loss of independence and social disapproval.

While these studies indicate a decrease in sexual satisfaction for men with SCI, the evidence also demonstrates that occupational adaptation does take place in many of these individuals, however this adaptation takes time. Throughout the literature for both men and

women, distinct trends related to sexual satisfaction and the ability for adaptation were noted (see Table 2). This research informed the current research study by acknowledging that adaptation does take place in relation to sexual well-being. It is proposed that gaining a thorough understanding of the barriers could inform future programming to enhance the speed at which adaptation occurs and increase the number of individuals who achieve occupational adaptation.

Impact of Disability on Non- Injured Partners' Quality of Life

Although sexuality issues related to the individual with SCI has been extensively studied, little information is available as it relates to the impact of SCI on the non-injured sexual partner. Two studies, however, have described the impact of caregiving on quality of life for partners of individuals with SCI (Boschen, Tonack, & Gargaro, 2005; Post, Bloemen, & de Witte, 2005). Additionally, some research has focused on the impact of caregiving with and physical disabilities. Blieszner and Roberto, (2009) reviewed the impact of caregiving for individuals with mild cognitive impairment, while Waldron-Perrine, Rapport, Ryan, and Harper (2009) looked at caregiver impact for those providing care to individuals with multiple sclerosis. The occupation of caregiving is multifaceted and can include such areas as personal care, financial responsibility and home and community management to name a few. The impacts of this occupation on quality of life for the care provider are also multifaceted and can be impacted by a multitude of factors.

Several researchers have examined the impact of social support on the quality of life of caregivers. Rodakowski, Skidmore, Rogers, and Shultz (2012), investigated the impact of social support on depressive symptoms in caregivers of individuals with SCI. For the purposes of this study, the researchers recruited 173 dyads of care providers and care recipients through a variety of announcements and advertisements. Several scales were utilized to gather data including the Center for Epidemiological Studies Depression Scale, the Instrumental Activities of Daily Living

Scale, Katz Index of ADLs, and the Lubben Social Network Index. Additionally, informal measures for health status, formal care service usage, and positive aspects of caregiving were utilized. The authors utilized regression analysis to analyze demographics independently, demographics and caregiver characteristics, and the combination of demographics, caregiver characteristics, and social support. While the first two analyses indicated that caregiver perceived health status and stress had a negative impact on depressive symptoms, the final analysis indicated that social integration and negative social interactions were high predictors of depressive symptoms and quality of life.

Waldron-Perrine et al. (2009) evaluated predictors of life satisfaction for caregivers of individuals with multiple sclerosis. Several quantitative measures including the Kurtzke Expanded Disability Status Scale, the Mishel Uncertainty in Illness Scale-Community Form, the Awareness Questionnaire, and the Social Provision Scale were utilized to investigate potential predictors. The outcome measure utilized was the Satisfaction with Life Scale. This study indicated a strong correlation between awareness of deficits and caregiver quality of life. The results of regression analyses lead the researchers to conclude that those with lower social support, especially female caregivers, were negatively impacted in the area of quality of life. Additionally, it was found that uncertainty regarding the illness situation also predicts a decrease in quality of life for caregivers.

Consistent with these findings, other authors have identified the impact caregivers' perceived burden of support has on their quality of life. Post et al. (2005) found that caregivers who perceived high levels of burden in supporting activities of daily living, emotional support and other practical support demonstrated a decrease in their quality of life. Similarly, Hui, Elliott, Shewchuk, and Rivera (2007) found that family caregivers, despite the communal bond

that they have with the injured individual, report an overall decrease in quality of life and life satisfaction.

These studies indicate the importance of social support and positive social interactions in the quality of life of caregivers. Because the onset of disability often results in significant changes in the lives of the disabled individual and their care providers, changes to social structure can easily occur resulting in a decrease in the social support systems of both individuals.

Despite the lack of research examining non-injured sexual partners of people with SCI, much has been done to evaluate the impact of SCI and other disabilities and changing life roles on the partner / care provider's quality of life (Blieszner & Roberto, 2009; Boschen et al., 2005; McPherson, Wilson, Chyurlia, & Leclerc, 2011). Boschen et al. (2005) evaluated the impact of being a care provider for community dwelling individuals with SCI. For the purpose of this study, the authors utilized questionnaires including an adapted version of Flannagan's Quality of Life Scale, the Measure of Quality of the Environment (Fougeyrollas, Noreau, & Boschen, 2002), the deJong Productivity Status Chart, the Reintegration to Normal Living Index, and a focus group. A total of 100 participants completed the questionnaire, while 46 individuals participated in the focus group. This study found that being a care provider resulted in a decrease in productivity and community integration for the caregiver, which resulted in a decreased reported quality of life.

Blieszner and Roberto (2009) completed a study of caregiver quality of life for those with mild cognitive impairment. For the purpose of this study, several scales were used including the Revised Memory and Behavior Problems Checklist (Teri et al., 1992), Environmental Mastery Scale, the Social Provisions Scale, the Center for Epidemiological Studies-Depression Scale

(Blazer, Burchett, Service, & George, 1991), and open ended questions in the form of interviews. Participants included 106 care providers of community dwelling individuals with mild cognitive impairment. The results of this study indicated that care providers who felt a loss of environmental mastery, or the inability to control activities within their environment, demonstrated higher levels of depressive symptoms resulting in a decrease in overall well-being and quality of life.

In 2011, McPherson et al. published a study on the impact of the caregiving relationship on quality of life for partners of stroke survivors. For the purpose of this study, 56 partner caregivers completed a survey that included the Health Related Quality of Life scale (HRQL), the Caregiver Reaction Assessment, the Caregiver Reciprocity Scale II, the Hatfield Global Measure, and the Quality of Marriage Index. The data was analyzed using descriptive statistics. The results of this study indicated that caregiver quality of life was substantially lower than that of the general population. These authors also found that the negative aspects of caregiving were identified as disrupted schedule, financial problems, lack of family support, and caregiver ill health. Another finding indicated that the caregiving participants perceived inequities in their relationships since the onset of their partners' stroke. The results from this study correspond to previous research in the area of quality of life for caregivers of individuals with stroke (Forsberg-Warleby, Moller, & Blomstrand, 2004; Parag et al., 2008; Visser-Meily, Post, Schepers, & Lindeman, 2005).

These studies indicate the importance of role change on the caregivers' quality of life. With the dramatic changes that occur with the onset of disability, changes in life roles frequently occur. The results of these studies indicate that this can have a significant impact on the quality of life for the person providing ongoing care.

Impact of Disability of Partner on other Partners' Sexual Well-Being

Because sexuality and intimacy are integral parts of many relationships, changing life roles after the onset of any disability can impact the quality of life for the care provider (Sipski, & Alexander, 1997). Although the impact of sexuality on care providers has not been widely studied across any disability, there is some evidence that caregivers experience issues related to quality of life as a result of changes in their roles related to sexuality. Researchers have identified that caregivers can develop an altered view of their intimate partners with changes shifting from that of partner to patient (Gilbert, Ussher, & Hawkins, 2009; Hawkins et al., 2009). This change in view was a direct result of the role changes that occurred at the onset of disability and resulted in a decrease or loss of sexual intimacy. Other factors which impacted sexual intimacy were fatigue from the caregiving experience and a decrease in desire on the part of the care recipient (Gilbert et al.; Hawkins et al.). Additionally, the caregivers reported feelings of disappointment, anger, and sadness about the loss of sexuality and intimacy with their partners (Gilbert et al.).

After an extensive literature search utilizing all databases at Towson University and the University of Maryland Medical System, and after consultation with a Towson University library representative, only three articles were found that discussed issues in sexuality from the perspective of the partners of individuals with SCI. The first of these articles was a description of a sexual education and counseling program for individuals with SCI and their partners. Although the authors of this article discussed inclusion of partners in the education and counseling process, no description of outcomes or effectiveness was provided (Eisenberg & Rustad, 1976).

Another study, performed by Kreuter, Sullivan, and Siosteen (1994) focused on sexual adjustment after SCI from the perspective of the intimate partner. For the purpose of this study, the authors utilized a relationship questionnaire and a quality of life questionnaire, both of which were designed specifically for this study. Forty-nine couples participated in the study, and the results indicated that 59% of partners of individuals with SCI have a decrease in sexual interest, 61% reported satisfaction with their current sex life, and 45% felt their sex life was as good as or better than before the onset of SCI. The participants in this study identified relationship factors such as honesty, trust, closeness, respect, and communication as important to maintaining a sexual relationship.

Most recently, a study was performed to evaluate the spousal experiences of becoming a caregiver of an individual with SCI. The authors of this study performed individual in-depth interviews with eleven individuals who were both the primary care providers and spouses of individuals with SCI. The results of this study indicated that all participants reported a post-injury shift in their relationships with several reporting that the loss of the sexual intimacy was a contributing factor. Additionally, most participants reported a significant role shift from that of partner to a more maternal or paternal role (Dickson et al., 2010).

Although each of these articles addressed sexuality from the perspective of the intimate partner of individuals with SCI, no literature was found which addresses the sexual needs of these partners. This demonstrates a gap in current knowledge about what, if anything, contributes to sexual adaptation for this population.

Current Trends in Education Regarding Disability and Sexual Well-Being

Because of the negative impact of disability on sexuality, much emphasis has been given to the importance of education, resource distribution, and counseling for individuals with SCI

related to sexual function. Booth et al. (2003) performed a needs assessment for the interdisciplinary team of a SCI unit in Australia related to sexuality knowledge and comfort. The results of this needs assessment found that most members of the interdisciplinary team required increased knowledge in the areas of counseling, boundary setting, fertility, and assistive devices (Booth et al.).

Fronek et al. (2005) utilized this needs assessment to develop an interdisciplinary training program for this same SCI team in Australia. The results of the study indicated a significant increase in knowledge both after the training and at three months post training (Fronek et al., 2005). Finally, a follow up to this study was completed to review the knowledge of the interdisciplinary team at five years post training. The results of this study indicated that the knowledge level was maintained suggesting that interdisciplinary training in sexuality could enhance education for individuals with spinal cord injury (Fronek et al., 2011).

Another study was performed to evaluate the effectiveness of an outpatient sexuality program for individuals with SCI. This program consisted of nursing staff, medical staff, and psychology staff. Four participants completed the study which included medical management of physical limitations, psycho educational counseling, as well as psychotherapy, and sex therapy as needed. The results of this study indicate that the participants believed that the experience in the sexuality clinic was positive and improved their overall feelings of satisfaction with their sexuality (Hess et al., 2007).

Forsythe and Horsewell discussed thoughts on sexuality education related to SCI with 70 women with SCI during workshops in Sweden and Denmark. The authors identified themes in participants' feelings regarding their experiences. The participants in this study believed that more education was required during the initial inpatient rehabilitation phase. Additionally, they

reported that continued opportunity for sexual counseling and peer counseling would have been beneficial in increasing their sexual satisfaction post discharge (Forsythe & Horsewell, 2006).

Lastly, one study was identified which aimed to clarify sexuality issues after SCI and identify the appropriate timing for sexuality interventions. Fisher et al. asked forty volunteer participants to complete a response to sexual health needs survey (i.e., sexual activity, sexual concerns, sexual interest, partner sexual factors, educational needs, and sexual adjustment) at four intervals including during inpatient rehabilitation, and at 6, 12, and 18 months post discharge. The results of this study suggest that interest in education regarding sexuality was higher at six months post discharge than during the initial inpatient rehabilitation phase. This is thought to be the result of the individual developing a more realistic view of decline in sexual function from initial post injury levels (Fisher et al., 2002), but also could be a result of increased privacy and time.

Some studies have indicated that interventions for caregivers are effective in improving the caregivers' quality of life throughout the caregiving process. One such study evaluated the impact of problem solving training for caregivers of individuals with SCI. The authors of this study performed a randomized controlled trial in which one group of family caregivers received the standard interventions, and another group received three face to face problem solving training sessions, educational materials, and phone support for the first year of caregiving. The results of this study indicated that the intervention group demonstrated lower dysfunctional problem solving styles over time (Elliott & Berry, 2009). In 2006, Belle et al. published a study indicating that caregivers who received cognitive behavioral therapy demonstrated an increased quality of life over individuals who received only routine follow up. Similarly, Schultz et al. (2009) found that cognitive behavioral training combined with knowledge based training resulted

in increased quality of life, decreased depression scores, and fewer medical problems for caregivers than those individuals who received only one of those interventions. These studies support the hypothesis that focused interventions for care providers can increase the likelihood of successful adaptation.

In summary, the above literature identified the complex issues surrounding the topic of sexuality for both individuals with disabilities and their sexual partners. Making the transition from two able bodied individuals involved in a sexual relationship to one of the individuals having a disability involves change. The process of transition is impacted by both the physical, emotional and mental changes in both partners. Some of the issues that were identified from the disabled individuals were changes in self-image and self-esteem, physical limitations, and societal beliefs regarding individuals with disabilities with regards to sexuality. Some of the limitations identified from the partners of individuals with disabilities include loss of environmental mastery, increased stress and increased fatigue, all resulting from changes in life roles. Despite the complexity of the issue of sexuality and disability, the above research demonstrate that appropriate education and resource allocation can ease the difficult transitions related to this topic.

Theoretical Perspective

Two theoretical perspectives that can be used to facilitate an individual's or couple's adaptive response to change are reviewed in the next section of this literature review. These models include the Model of Human Occupation and the Occupational Adaptation theory. The Model of Human Occupation was utilized to frame the interview questions and guide the research process by explaining the areas of dysfunction which could prevent occupational adaptation related to sexual well-being (see Figure 3). The Occupational Adaptation theory was

utilized to support and frame the process of adaptive responses and to outline how adaptive responses can be influenced through the use of appropriate interventions to enhance sexual well-being. These models are complimentary as they are both systems models, and both view the press for mastery as a motivational factor in influencing behaviors, in this case the press for mastery involves optimum sexual participation. The MOHO was utilized to identify where breakdowns in participation occur, while occupational adaptation was used to identify areas of intervention related to mastering the behaviors associated with sexual well-being.

Model of human occupation. The theory which was used to inform the instrument development for this research is the model of human occupation (MOHO). The MOHO was first developed in 1980 by Gary Keilhofner and Janice Burke (Keilhofner, 2008). This model grew from the occupational behavior tradition of the 1950s and was developed as a description of constructs and principles to guide occupational therapy practice (Keilhofner, 2000). The MOHO views the human being as a complex dynamic system which interacts within the environment in order to make the performance of occupation possible (Keilhofner).

Several principles and constructs that are used to describe the interaction between the individual and the environment are presented in the MOHO. The principles outlined in the MOHO describe how human behavior and interaction with others and the environment occurs. These principles set the stage for understanding and altering participation in occupation.

Figure 3: Occupational Adaptation as Outcome

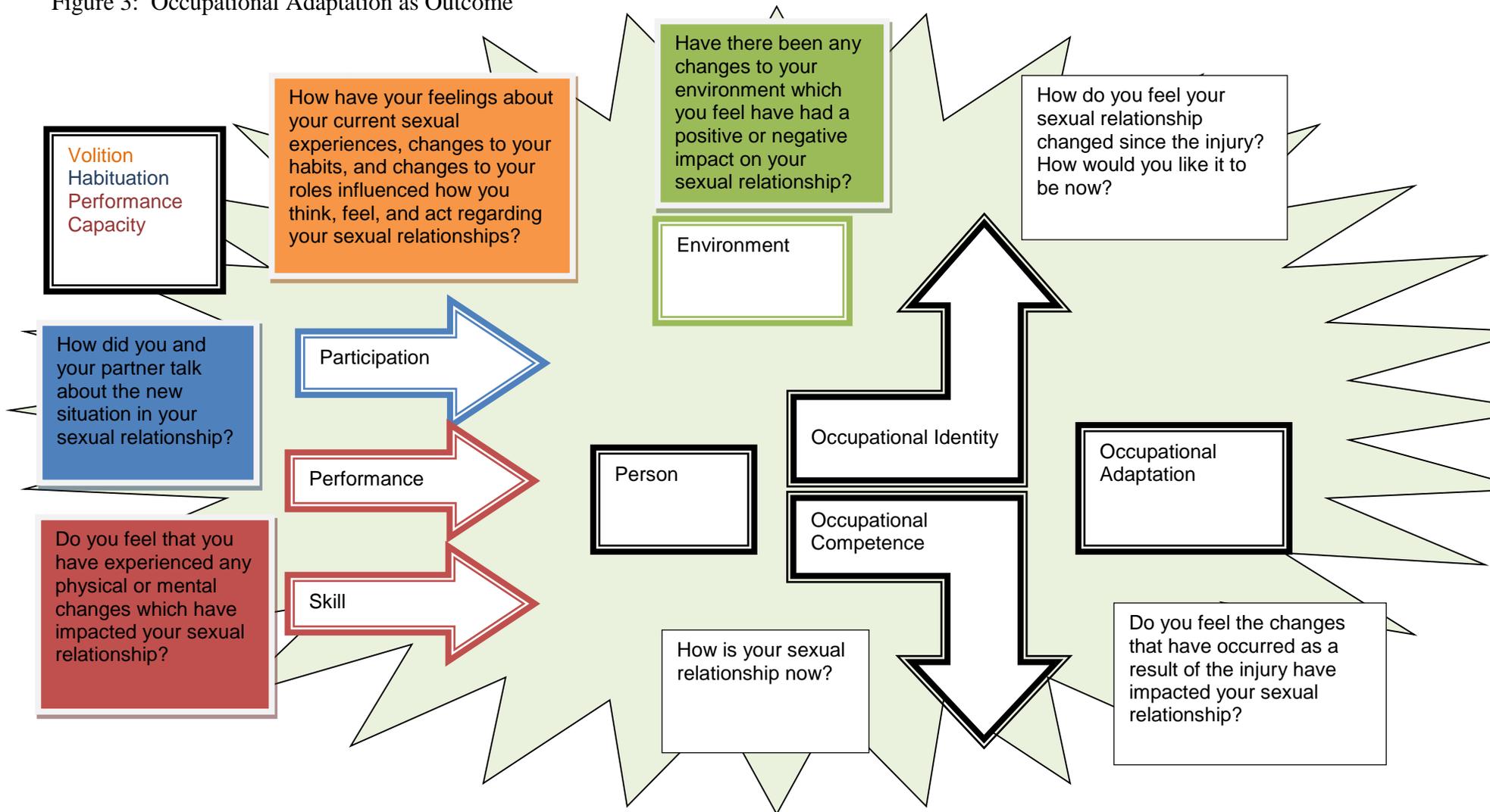


Figure 3. Model of Human Occupation for sexual relationships. Adapted from Model of human occupation: Theory and application 3rd ed. (p. 169), by G. Keilhofner, 2002, Chicago, Lippincott. Copyright 2002, Lippincott, Williams and Wilkins. Adapted under the fair use provision of U.S. Copyright law.

Constructs. The authors of the MOHO have identified key constructs which assist in framing the complexity of human behaviors as they relate to occupation. These ideas are utilized to describe the many aspects of human behavior and their relationships to one another.

Volition. Volition is the process by which individuals are motivated toward and choose what occupations they perform. The core of the volitional process is personal causation, values, and interests. Personal causation refers to an individual's capacities and effectiveness. An individual's sense of personal capacity refers to their assessment of their physical, intellectual, and social abilities. An individual's self-efficacy refers to their sense of effectiveness in utilizing their capacities. These are important constructs in that individuals who feel capable are more likely to seek out opportunities and feedback, and correct their performance to attain their goals. Likewise, individuals who lack self-efficacy, are less likely to seek out opportunities and feedback, and therefore, are less likely to correct performance to attain their goals (Keilhofner, 2000, 2008; Keilhofner, Forsyth, & Barrett, 2003).

Another aspect of volition is values. Values are defined as a set of beliefs that define what is good, right, and important. These values are developed through an individual's culture and influence a sense of worth from participation in certain occupations. Values guide decisions as to what occupations are worth doing and which goals deserve commitment. Because of the cultural link with values, they often arouse strong emotions (Keilhofner, 2000, 2008; Keilhofner et al., 2003).

The last aspect of volition is interests. Interests often begin with natural tendencies toward certain activities. These tendencies are strengthened through the experience of pleasure and satisfaction during occupational performance. An interest in a chosen occupation is derived from an anticipation of positive experiences (Keilhofner, 2000, 2008; Keilhofner et al., 2003). In

relation to sexual health among individuals with SCI and their partners, decreased physical functioning, issues related to bowel and bladder, and decreased mobility can result in a decrease in sexual pleasure and satisfaction eventually impacting interest in participating in sexual activities.

Habituation. Habituation organizes behaviors into patterns that are integrated into the physical, temporal, and social contexts in which an individual or couple resides. When actions are repeated within specific contexts, habituated patterns of behavior are created. Continued use of these patterns strengthens the patterns even further. These habituated patterns are comprised of habits and roles (Keilhofner, 2000, 2008; Keilhofner et al., 2003).

Habits are learned patterns of behavior that take place automatically and within certain contexts. Habits influence routine behaviors and use of time. Roles define an individual's identity through internal and external expectations for each given role. Through interaction with others, individuals internalize an identity and a method of behaving that matches the identified role. Roles and habits allow most daily routines to happen automatically and predictably (Keilhofner, 2000, 2008; Keilhofner et al., 2003).

Performance Capacity. Performance capacity refers to the ability to perform occupations provided by the physical and mental components and the subjective experience of an individual. Proponents of the MOHO view capacity from both the objective, physical approach and from the subjective experiential focus (Keilhofner, 2008). In relation to sexual health, a decrease in an individual's physical capacity can result in a decrease in their subjective experience of the sexual activities.

It was believed that the MOHO was an appropriate model to inform this research project as it views humans as dynamic systems in which each component of a system can influence the other components. Although no literature has been identified that specifically links the MOHO to sexuality and SCI, several articles have been identified which demonstrate the effectiveness of the MOHO in aiding occupational adaptation for complex issues such as fatigue management and activity competency (Finalyson, Preissner, & Cho, 2012; Levine & Gitlin, 1990; Taylor & McGruder, 1996). Because the topic of SCI and sexuality involves all components of an individual's being this model could be utilized as a framework for understanding the interrelated components that contribute to occupational function and dysfunction.

Principles. The MOHO has six identified principles which frame the model. The first principle is that the human being is a complex system made up of three subsystems which motivate, organize, and make participation in occupations possible. These subsystems include volition, habituation, and mind-brain-body performance. According to the authors of this model, volition is utilized to choose occupational behaviors, habituation is utilized to organize behaviors into patterns appropriate to an individual's lifestyle, and the mind-brain, body subsystem is utilized to support occupational performance (Keilhofner, 2008).

The second principle of the MOHO is that occupational behavior arises from environmental interaction. According to this model, human beings are viewed as dynamic, self-organizing systems whose behavior is shaped by real time events within environmental contexts. It is believed that during the performance of occupation, individuals alter their own capacities, beliefs, and dispositions. Thus, occupational adaptation shapes future organization of the human system (Keilhofner, 2008).

The third stated principle is that the volitional subsystem arises from human beings' innate need to act. It is believed that these actions are driven by motivation which includes an individual's thoughts and feelings regarding personal capacity and effectiveness, importance and worth in one's actions, and enjoyment or satisfaction in performing occupations. According to the authors of this model, while individuals are driven toward action, there also is a desire to perform occupations which are perceived as valuable and satisfying. Therefore, this subsystem is responsible for anticipating, choosing, experiencing, and interpreting occupational behavior (Keilhofner, 2000, 2008).

Another principle of MOHO is that choices in occupational engagement are shaped by, but not constrained by habits and roles. The habituation subsystem is made up of habits and internalized roles. Habits are defined as the acquired ways in which individuals respond and perform in familiar situations or contexts. This requires an individual to repeat an action sufficiently enough to establish a pattern of behavior within a consistent context. Internalized roles refer to the patterns of action associated with an individual's social identity (Keilhofner, 2000, 2008).

The fifth principle of MOHO is that occupational performance is comprised of motor, process, communication, and interaction skills. It is believed that occupational performance results from complex interactions from all aspects of the mind-brain-body subsystem as they interact within the environment (Keilhofner, 2000, 2008). Because occupational performance is dependent on the mind-brain-body connection as it interacts within the environment, a change or disruption to any of these components can result in a decrease in occupational performance or desire for enhanced performance. When the outcome of an occupational performance is not the desired outcome, occupational adaptation must occur. According to the MOHO, occupational

adaptation requires the “rebuilding of occupational identity and competence” (Keilhofner, 2002, p. 122).

The last identified principle is that an individual’s social and physical environment provides opportunities and constraints which can shape occupational behavior. According to the authors of this model, this can be done in two ways. The environment can provide opportunities for performance, or it can constrain opportunities, thus shaping occupational behavior (Keilhofner, 2000, 2008).

The onset of SCI has a significant impact on a couple’s occupational performance. This alteration in the performance skills can, in turn, alter the individual’s habits and roles related to sexual engagement. Additionally, changes in the physical environment, including the addition of equipment or relocation of sleeping quarters can constrain participation in sexual activities (see Figure 4).

Figure 4: MOHO for Partnered Sexual Activity

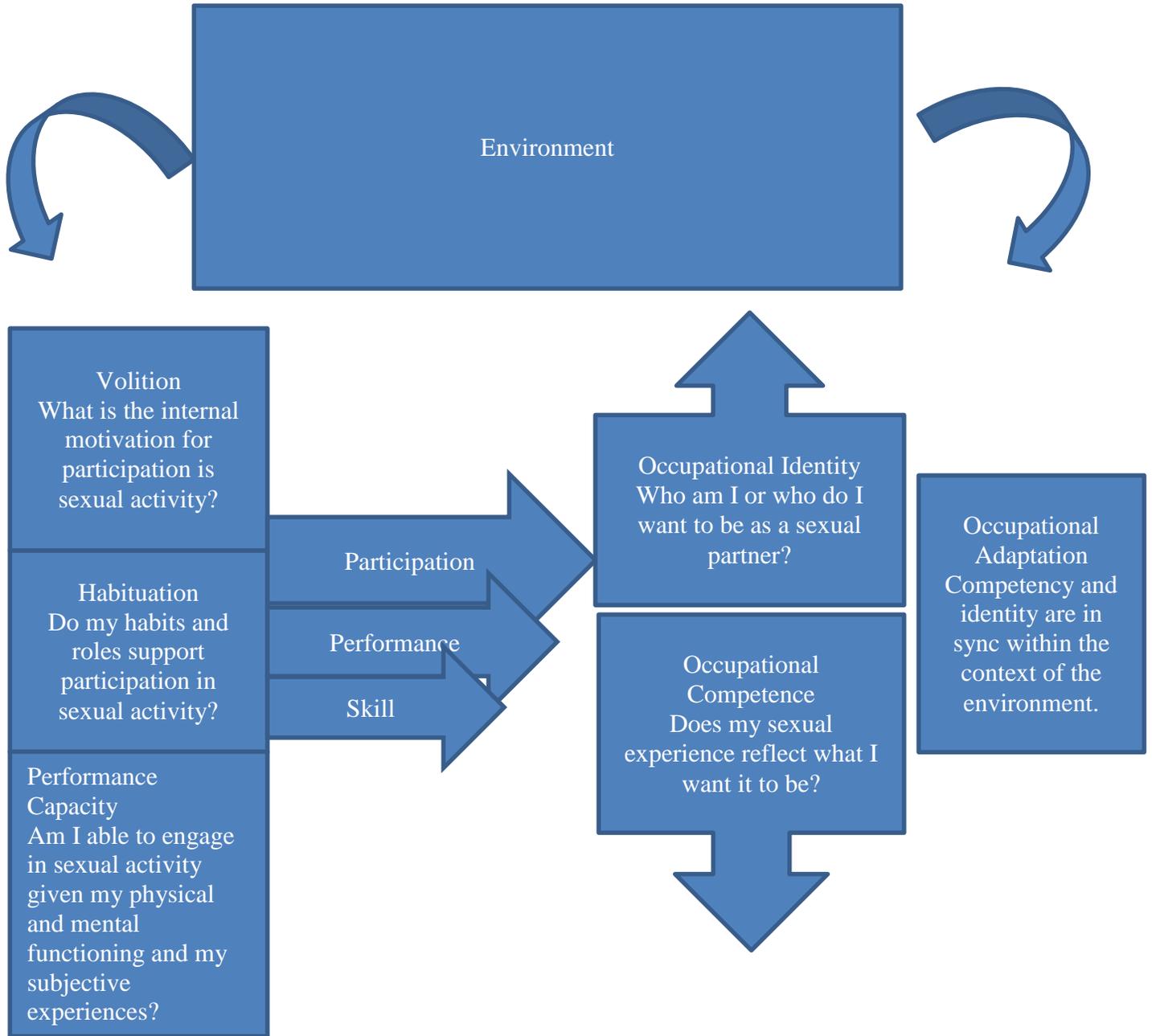


Figure 4. MOHO for sexual relationships Adapted from “Model of human occupation: Theory and application, Keilhofner, 2002, p. 121. Copyright 2002, Lippincott. Adapted under the fair use provision of U. S. Copyright law.

Occupational adaptation theory. The occupational adaptation theory was developed as a holistic approach to intervention and research in the discipline of occupational therapy.

Published in 1992 by Schkade and Shultz, occupational adaptation is a systems model which focuses on two key constructs of occupational therapy: occupation and adaptation. The traditions of this theory were established based on the writings of Adolph Meyer (Schultz, 2013).

The occupational adaptation theory differs from its predecessors in that it views occupation and adaptation as inter-related entities which are present in individuals regardless of the presence of function or dysfunction. According to this theory, adaptation is an automatic response to a lack of occupational mastery. Occupational adaptation can be used to guide the interaction between adaptation and occupation (Schkade & Schultz, 1992). Occupational adaptation views the adaptation process from a system's perspective, meaning that in order to study the adaptive response one must understand the network of relationships making up this process. In the adaptation process, the person, the occupational environment, and the interaction of the two, are equally important (see Figure 5).

Occupational adaptation focuses on three elements. These are the person, the occupational environment, and the interaction of the two as they relate to occupation. A key construct in this relationship is mastery. According to the occupational adaptation model, as well as the MOHO, each person has a desire for mastery which is present at birth. This is the internal motivation for adaptation. Additionally, the environment produces the demand for mastery through barriers or facilitators within the environment. Lastly, the interaction of these two constructs is titled the press for mastery. In this model, the desire for mastery, the demand for

mastery, and the press for mastery are constants, even when circumstances change (Schkade & McClung, 2001; Schultz, 2013).

Figure 5: Occupational Adaptation

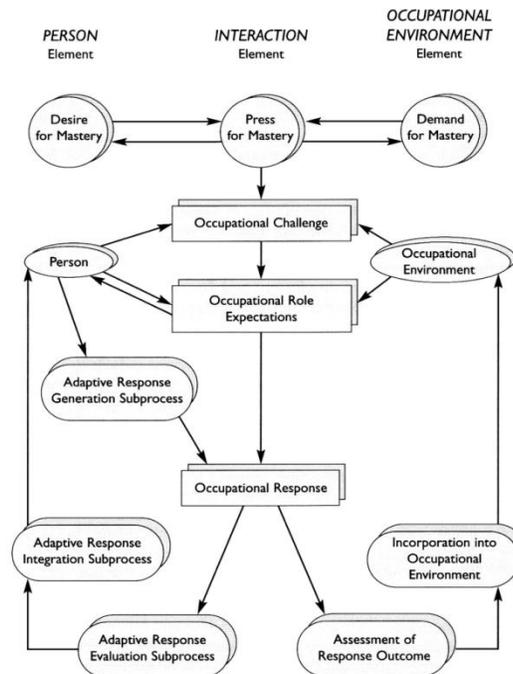


Figure 5. “Occupational Adaptation,” by J. Schkade & M. McClung, 2001, *Occupational adaptation in practice: Concepts and cases*, p. 5. Reprinted with permission, Copyright 2001 by SLACK.

The occupational adaptation model is focused upon the use of the adaptive response process in order to attain mastery. During times of change or challenge, each individual must adapt his or her behaviors to meet the demands of the environment. During this time, the person is believed to initiate the adaptive response mechanism. This mechanism consists of adaptive energy, which is the amount of energy required to adapt to life situations, adaptive response modes and adaptive response behaviors (Schkade & McClung, 2001; Schultz, 2013).

The adaptive energy is believed, by this model, to exist on two levels. The authors of this model propose that each individual has a set amount of adaptive energy that does not increase or

decrease. It is believed that people can use primary or secondary adaptive energy, with the latter expending less energy than the former. Primary adaptive energy involves actively thinking about an issue in an effort to identify a response. The secondary energy happens on a less conscious level, and is thought to be more sophisticated and creative (Schkade & Schultz, 1992). In solving problems individuals utilize either primary or secondary adaptive energy.

Adaptive response modes are another component of the adaptive response mechanism. These modes are identified as existing, modified, and new. Existing modes are methods with which people are already familiar and comfortable (Schkade & Schultz, 1992). This is described by Spencer, Davidson, and White (1996) as a cumulative development of adaptive responses that allow a person to perform competently. Each time a challenge is overcome, the adaptive response used becomes an existing mode (Schkade & McClung, 2001). Modified modes are slight variations of existing modes, and require a little more adaptive energy than those that are already in the repertoire. New modes are modes of adaptation that need to be created from scratch. These modes require the most energy, and are the last resort for problem solving (Schkade & McClung, 2001).

The last portion of the adaptive response mechanism is adaptive response behaviors. These are the types of behaviors used when attempting to adapt. These are classified by primitive, transitional, and mature adaptive responses. The primitive responses are the behaviors most frequently used when faced with challenges that are beyond the individual's abilities to adapt. These are characterized as "hyperstable" (Schkade & McClung, 2001) and can present as the person being "stuck" in that behavior. This is considered a normal response to stress (Schkade & McClung, 2001).

Transitional adaptive response behaviors are viewed as “hypermobility” (Schkade & Schultz, 1992, p. 834). Often the behaviors in this stage are variable, random, and not goal directed. This stage results in a variety of potential solutions to the challenge. Lastly, the mature stage provides a balance between hyperstability and hypermobility, resulting in an adaptive gestalt.

The adaptive gestalt is the plan which arises from the adaptive response mechanism. This plan consists of all three person factors including cognitive, psychosocial, and sensorimotor components. The gestalt will change from situation to situation, as no gestalt is universal and varies for each individual and each situation (Schkade & McClung, 2001; Schultz, 2013).

Another important construct in the occupational adaptation model is the adaptive response evaluation sub process. After the adaptive response has been performed, each person must self-evaluate his or her response. The authors of this model propose that the tool utilized for self-evaluation is the experience of “relative mastery” (Schkade & Schultz, 1992, p. 834). Relative mastery consists of efficiency (i.e., wise use of time, energy, and resources), effectiveness (i.e., obtainment of desired goal), and satisfaction to self and society. According to the originators of this model, an important consideration of this construct is that relative mastery is idiosyncratic to the individual, and therefore the individual must determine whether or not this has been achieved (Schkade & Schultz, 1992).

The last key construct of the occupational adaptation model is that of adaptive response integration. This occurs when an adaptive response is completed. It is this sub process that allows the outcome to be stored within the adaptive response modes to be utilized in the future. The authors of this model propose that this integration will lead to strengthening, or reinforcing of one of three states. These states include occupational adaptation, homeostasis, or occupational

dysadaptation. Occupational adaptation is said to be strengthened when the outcome of the integration is positive. When the outcome requires minor adjustments, homeostasis occurs. If the response produces a negative outcome which is realized by the individual, then occupational dysadaptation is strengthened. The latter of these results in further changes the next time that challenge is presented. These adaptive changes could be positive or negative, resulting in adaptation, homeostasis, or further dysadaptation (Schkade & McClung, 2001).

According to Schultz and Schkade (1992), the occupational adaptation model is supported by several philosophical assumptions. These assumptions indicate that all individuals have an innate desire for mastery within their environments. This desire for mastery drives individuals to face occupational challenges, which requires adaptation energy. Because the amount of energy that a person has is finite, individuals will utilize existing modes to attempt to reach mastery, as these require less energy. If the existing modes do not work adequately, individuals should seek alternative measures to attain mastery. When this does not occur, occupational dysadaptation may ensue.

After an extensive search utilizing all available databases at Towson University and the University of Maryland Medical System, and corresponding with one of the authors of this model, Sally Shultz (personal communication, September 30, 2013), no literature has been found to link this model to sexuality and disability. Despite these findings, it is believed that the process of occupational adaptation provides a framework to inform the development of educational programming to enhance the re-engagement in sexual activity and enhanced sexual well-being (see Figure 6).

Figure 6: Occupational Adaptation for Sexual Relationships

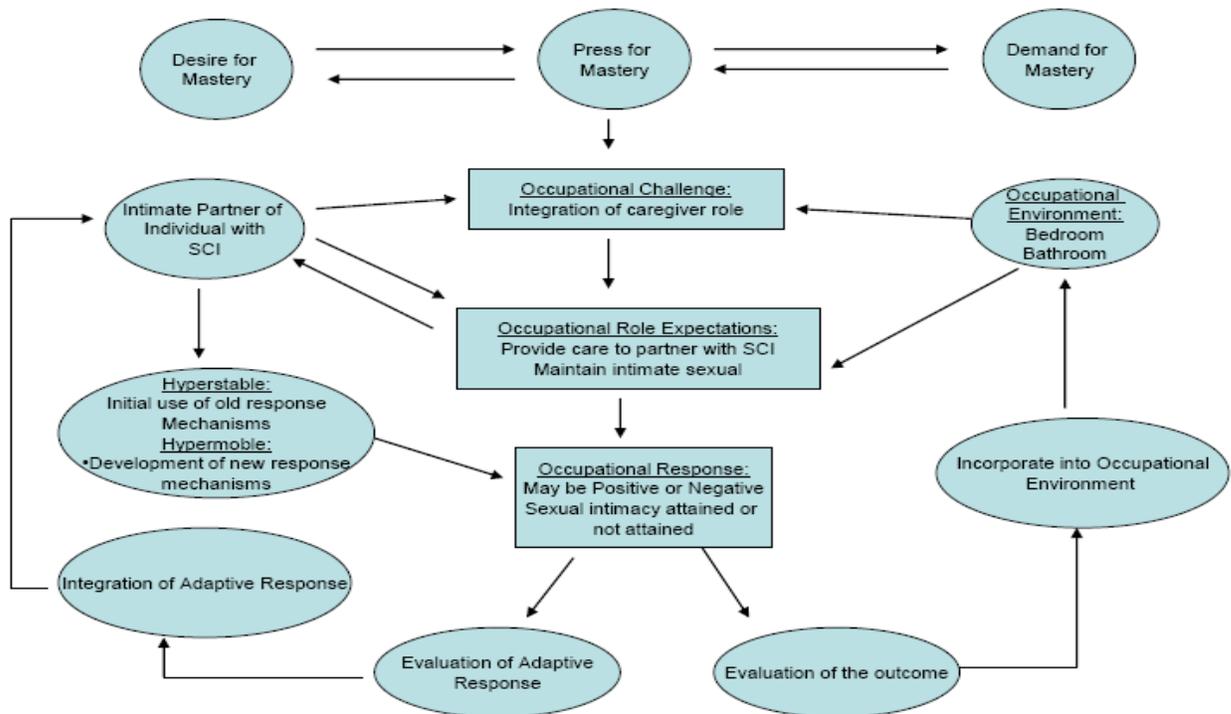


Figure 6. Occupational Adaptation for sexual relationships Adapted from “Occupational adaptation in practice: Concepts and cases,” by J. Schkade & M. McClung, 2001, p. 5. Copyright 2001, SLACK. Adapted under the fair use provision of U. S. Copyright law.

Occupational adaptation related to sexuality. In both the MOHO and Occupational Adaptation the environment plays a very important role in successful completion of occupations. The occupational environment includes the changes in the physical, social, and cultural environments in which the caregiver resides. With the onset of disability, the physical environment often changes to meet the needs of the individual with disabilities (Boschen et al., 2005). This can include the addition of medical supplies, or a complete change in the physical environment such as structural changes to the bedroom and bathroom which can enhance sexual

activities (Boschen et al., 2005). The social environment also changes, as there is a change in role demands from partner to caregiver and changes in how others perceive the client and the caregiver. Additionally, the cultural environment changes in that there is limited acceptance of a disabled person as a sexual being (Tepper, 2005).

The challenge that the individual with SCI and the caregiver faces in these circumstances is the ability to identify and utilize adaptive strategies to create an effective interaction within their new environment. According to the occupational adaptation model, the desire for mastery is constant, and therefore the adaptive response mechanism is initiated at the onset of this change. It is believed that the demand for mastery, created by the extensive environmental changes associated with the onset of disability, is often too great for the caregivers to overcome independently.

From the perspective of the injured individuals and his or her partner, the occupational challenge is the alteration of life roles and the impact that change has on their sexual relationship. These dyads would initially respond to this new challenge utilizing existing adaptive modes. However, given the significance of the challenge, these modes may not be appropriate or effective for the situation. When dyads recognize that their chosen modes are ineffective, they will need to develop new adaptive responses to meet the environmental challenges that they are facing, namely the onset of disability, and their change in life roles (Schkade & Schultz, 1992).

While some individuals with SCI and their partners do achieve occupational adaptation, the literature supports the notion that many of these individuals demonstrate occupational dysadaptation (Belle et al., 2006; Elliott & Berry, 2009; Schultz et al., 2009). Because sexual intimacy is a sensitive topic, initial negative outcomes could result in occupational dysadaptation

being strengthened. As this cycle continues, further strengthening occurs resulting in long term negative effects on the sexual relationship. It is believed that individuals and their partners often maintain hyperstable responses in relation to sexuality and could benefit from interventions during times of hyperstability to aide them in identifying adaptive responses more likely to result in mastery.

It is this author's belief that occupational therapists, utilizing the occupation adaptation model, are well suited to provide the required interventions to aide individuals with SCI and their intimate partners in overcoming the barriers associated with occupational dysfunction. The practitioner can provide education, modifications, and alternative strategies in problem solving the difficulties related to sexuality issues for both the individuals with SCI and their intimate partners. It is believed that by providing these interventions during the acute phase of rehabilitation, both individuals will be better prepared to engage in the occupations related to sexual well-being after discharge.

Summary

Literature on the impact of SCI on sexuality provides insight into the complex physical and emotional changes occurring within the injured individual. This is important because partnered sexual intimacy requires an interaction between both individuals and a comprehensive understanding of the needs of both individuals involved. While not specifically related to the area of sexuality or SCI, the literature on the impact on the partners of individuals with disability informs the study on the complexity of the issue of the caregiver / partner role. Literature on the topic of education for caregivers and injured individuals highlights the positive impact of education and resources on individuals with disabilities and their partners, supporting the importance of the proposed study. Lastly, literature on the topics of occupational adaptation and

the MOHO demonstrate how these models could be used to frame the research and outline potential interventions as occupational adaptation for intimate partners of individuals with SCI is the end goal.

Chapter 3

In this chapter, the researcher will discuss a previously performed pilot study. Next the researcher will describe the methods utilized starting with the research design. Information regarding participant selection, the research setting, the instrumentation, and the procedures will follow. Additionally, data storage, processing and analysis, as well as verification will be addressed. Lastly, the role of the researcher, ethical considerations and limitations and delimitations will be discussed.

Pilot Study

In preparation for this research, a pilot study was performed after receiving Institutional Review Board (IRB) approval from Towson University (TU) and the University of Maryland Medical System (UMMS). The pilot was completed to identify gaps in sexuality education for intimate partners of individuals with SCI and to identify areas of education that the participants would have found helpful. Potential participants for this study were identified utilizing a SCI database from an orthopaedic and rehabilitation institution. This database consists of individuals who sustained an SCI at any level, by any mechanism, and received care at this specific institution. Names and mailing addresses for 204 individuals were available on the database with initial injuries occurring between January 2010 and September 2012. Level of injury and the American Spinal Injury Association (ASIA) classifications were not utilized, as they were not necessary for the purpose of this pilot study.

Inclusion criteria for the pilot study included any partner of an individual with SCI who had a sexual relationship with the injured individual prior to onset of injury, maintenance of that relationship for a minimum of six months post injury, and an age of at least eighteen. Since

information regarding participant eligibility was not available on the database, all potential participants were contacted for participation.

A questionnaire, *Education and Resource Needs of Partners of Individuals with SCI*, was developed with a focus on gaining an understanding the adequacy of the education and resources the individuals received during their partners' rehabilitation stays (see Appendix A).

Questionnaires were mailed to each individual in the spinal cord database with a request to pass them on to their partner. The recruitment letter outlined the purpose and process of the study, as well as the inclusion criteria (see Appendix B). Because the relationship status was not available in the database, it is unclear how many potential participants were among the 204 households who received the questionnaire.

Of the 204 questionnaires, only 8 were completed and returned while 20 were returned as undeliverable due to address changes. According to Fincham (2008), a 60% rate of return should be considered the goal of the researcher. Utilizing the NSCISC's database information, approximately 49% of individuals with SCI are married at the time of injury, suggesting that of the 204 individuals surveyed, 97 would have potentially been in marital relationships (2012). Thus the response rate for this study was estimated at .09%. Although this is an extremely low rate of return, it is unclear how many of the 204 mailings were received by individuals who met the inclusion criteria. Given the consistency in the information that was received from the surveys, it was believed that the results were of value and worth a more in-depth evaluation of the topic.

Despite the small number of returned questionnaires, the results demonstrated a lack of sexuality education for intimate partners of SCI. All participants (8/8), reported that they had received no education or resource information related to sexuality during their partners' inpatient

rehabilitation stay. Likewise, all participants reported experiencing issues related to sexuality once their partners returned home. The participants did not provide any specific concerns, but rather reported that they would have liked to have had some type of sexuality intervention prior to discharge.

The small participation rate in this study could be due to several factors. Due to the length of time since the inception of the database, contact information for potential participants could have been out dated. Other potential factors include a lack of specified participant information, failure of the recipient of the mail to pass it on to their partners, and the sensitivity of the topic. Although there were few participants in this exploratory study, it is clear that the process of addressing sexuality with partners of individuals with SCI could be enhanced at the rehabilitation center, according to the perspectives expressed by the respondents in this pilot study. The purposes of this pilot study were to identify educational needs of partners of individuals with SCI, to identify the best strategies for conducting the research, and to refine the instrument and methods for future studies. The data from the pilot study was used to inform the present study. As a result of the low response rate from the pilot, a different approach for the current research project was developed. Given the sensitive nature of the topic and that, due to the low return rate the survey instrument was not successful in gaining insight into the needs of intimate partners of individuals with SCI, it was believed that it would be more productive to more in depth by utilizing interviews instead of surveys. Although there is controversy over what constitutes sensitive research, there is a general consensus that sexuality is part of this category (McCosker, Barnard, & Gerber, 2001). According to Elam and Fenton (2003), semi-structured or unstructured interviews are the best method of obtaining data on sensitive topics. As a result, instead of utilizing a survey, the current study was performed using face to face

interviews with partners of individuals with SCI. Additionally, in order to elicit a clearer picture of the lived experiences of the participants in relation to sexuality, more specific and open ended questions were developed.

Methods

Research design

For the purpose of this research, a qualitative research design was utilized. Qualitative data was collected utilizing a collective case study design in order to better understand the lived experiences and occupations from the intimate partners' perspectives.

Of the five traditions in qualitative research, the case study design was chosen for this project (Creswell, 2013). The case study focuses on the meaning of real-life experience within the participant's context. The aim of case study research is to explain the connections between factors in real-life situations that are too complex to be identified with other methods, to describe the situations in real-life contexts, and to illustrate the connections in a descriptive fashion (Yin, 2014). For the purpose of this study, a collective case study design was utilized. The collective case study, in which two or more cases are examined, is considered to provide more robust, and therefore compelling results than a single case study (Yin, 2014). The collective case study provides an illustration of the issue from multiple perspectives (Creswell, 2013). Additionally, the multiple case design allows for more powerful analytic conclusions and less skepticism regarding the uniqueness of the case than does a single case design (Yin, 2014).

Participants and setting

A variety of sampling techniques were utilized in identifying potential participants. These included convenience, purposeful, and snowball sampling. Convenience sampling was used, which according to Weiss (1994), is an acceptable method of sampling when evaluating a

group of people who are rare within the greater population and for whom no membership data exists. Participants were recruited via convenience methods, meaning that recruitment took place at only one medical center. This center was chosen as it houses the only SCI specific rehabilitation unit in the state.

Purposeful sampling is defined as selecting participants deliberately because they can provide an understanding of the research phenomenon better than any alternative choices (Creswell, 2013; Maxwell, 2005). Partners of individuals with SCI who had intimate relationships prior to the onset of injury were selected for this study. Actual participation was determined through inclusion criteria and narrowed through stratification. A stratified sample is used to reflect “proportions of certain segments of the population” (Charles & Mertler, 2002, p. 150). The stratification utilized was age and was decided after examining the participant pool. This purposeful method was utilized to provide as diverse a sample as possible and resulted in diversity in age (Creswell, 2013).

Snowball sampling is defined as identifying potential participants through individuals who have insight into interesting cases (Creswell, 2013). Employees of the UMMS’s spinal cord injury unit were recruited to identify potential participants who met the inclusion criteria. Although these recruitment methods yielded only female participants, this was believed to be due to the overwhelmingly large ratio of males with SCI as compared to females with SCI.

After obtaining Institutional Review Board (IRB) approval through TU participants were recruited using three strategies at the University of Maryland Rehabilitation and Orthopaedic Institute -- the caregiver support group, the SCI support group, and the distribution of flyers. The caregiver support group is one evening a month and is designed to provide education, resource and peer support to caregivers. The group is open to those providing care to

a variety of disabilities and is not exclusive for caregivers of individuals with SCI. There are approximately 10 individuals at any given meeting. The SCI support group is mandatory for in-patient SCI patients and is open to community dwelling individuals with SCI. Caregivers and partners are encouraged to attend but this is not required. This group is designed to provide peer support and education and resources to individuals with SCI. There are approximately 20 participants at any given monthly meeting.

Additionally, flyers were provided to the psychiatry staff, attending physicians, allied health professionals, and urologists working on the SCI unit, and were posted in the spinal cord rehabilitation clinic. Past contacts made during the pilot study also were contacted. The population from which the sample was collected includes individuals with SCI and their partners, with ages ranging from 18 to older adulthood who are or have been affiliated with the University of Maryland Rehabilitation and Orthopaedic Institute.

The pilot research project yielded 3 individuals who expressed interest in participating in future research on this topic. Those individuals were contacted for recruitment through the mail (see Appendix C). Short presentations were provided at the support groups which included information regarding the study and presentation of flyers. Additionally, recruitment flyers were posted in the SCI clinic, rehabilitation areas and given to psychology staff for further recruitment (see Appendix D).

Participants were selected based on the following inclusion criteria: (a) partner of an individual with spinal cord injury who had a sexual relationship with the injured individual prior to onset of injury, (b) maintenance of that relationship for a minimum of six months post injury, and (c) an age of at least 18. Four study participants were recruited with stratification of age.

The setting for the interviews was determined by the participants. One interview took

place at University of Maryland Rehabilitation and Orthopaedic Institute, and three interviews took place in the participants' homes.

Instrumentation

A quantitative measure was utilized in an effort to gain insight into the participants' sexual desire which may impact their internal motivation for continued sexual activity after the onset of their partners' injuries. The Hurlbert Index of Sexual Desire was chosen for this purpose (Apt & Hurlbert, 1992). The Hurlbert Index is a 25 question, self-administered questionnaire which evaluates sexual interest and desire. This tool was chosen based on length of time to administer, reliability factors, and validity factors (Apt & Hurlbert, 1992). This tool takes approximately 5 to 10 minutes to administer and although no normative data is available for this test it has been shown to have excellent internal consistency and test re-test reliability. Additionally, this test has been found to have excellent construct, concurrent, and discriminant validity (Rowland & Incrocci, 2008).

Additionally, an Education and Resource Needs Checklist was developed to identify education and resources received and desired during inpatient rehabilitation. This was developed using common education and resource topics in the rehabilitation of SCI patients.

As a qualitative research strategy, interviewing has its roots in social psychology (Denzin & Lincoln, 2005). Over time this method has been utilized in several of the social science disciplines and in education. The utility of information gained from interviews comes from the depth of information provided by the participants (Denzin & Lincoln, 2005). Interviews are believed to provide a deeper understanding of these issues than quantitative measures such as surveys or inventories (Gill, Stewart, Treasure, & Chadwick, 2008). Interviews, therefore, are best utilized when little is known about a topic (Gill et al., 2008). They also are a good method

for research when that research involves a sensitive topic which may be uncomfortable to discuss in a group setting (Gill et al., 2008), such as sexuality.

The purpose of interviews in qualitative research is to explore the views, beliefs, and experiences of the participants (Creswell, 2013). The semi-structured interview technique was chosen for the purpose of this study. A semi-structured interview consists of a set of fundamental questions designed to define the areas to be explored, however also allows for divergence in order to explore answers in greater detail (Gill et al., 2008). Semi-structured interviews provide a guide for questioning, however, allows the participants and the researcher to expand and probe for more depth in some questions in order to obtain more depth from the discussion (Creswell, 2013). This approach is flexible, and therefore allows for elaboration of information which the participants' feel is important, but may not have been previously thought of by the researcher (Gill et al., 2008). According to Bernard (1988), semi-structured interviews are most valuable when the researcher only has one opportunity to engage the participant. This type of interview allows the participant to stray from precise questioning, which may enhance depth and breadth of information obtained (Fontana & Frey, 2005).

For the purpose of this study, an SCI Interview Protocol was developed as a template for the semi-structured interviews (see Appendix E). According to Creswell (2013), an interview protocol should consist of five to seven open ended research questions. Although the recommendation is for five to seven questions, the protocol proposed for this study consists of fourteen in order to fully address the occupation of sex in all of the areas of the MOHO potentially impacted by the onset of SCI. The questions for this protocol were developed utilizing the MOHO with specific questions related to volition, habituation, performance capacity, and environment.

The MOHO's view of individuals as complex dynamic systems was the reason that this theory was chosen to frame the research questions. According to the MOHO, individuals' occupational choices are based upon the interaction of internal motivation, habits and roles and physical and cognitive capabilities within a given context. A disruption to any of these factors can result in occupational dysfunction. According to the MOHO, unsuccessful attempts at occupational performance can then impact an individuals' internal motivation to attempt that occupation again. Because an individuals' sexual expression and performance is complex in nature, encompassing each area outlined by the MOHO, questions related to each area were developed to enhance the understanding of which specific areas were limiting success in sexual activity (Keilhofner, 2008).

The following questions are outlined in the MOHO and were utilized to frame the development of the questions in the SCI interview Protocol.

What is this person's sense of who he/she has been, is, and wishes to become as an occupational being?

To what extent has this person sustained a pattern of occupational participation over time that reflects his / her occupational identity?

Does this person currently engage in work, play, and activities of daily living that are part of his/her sociocultural context and that are desired and/or necessary to his/her well-being?

Can this person do the occupational forms that are part of the work, play, and activities of daily living that make up this person's life?

Does this person exhibit the necessary communication/interaction, motor, and process skills to perform what he/she needs and wants to do?

How does the persons volition, habituation, and performance capacity influence the way he/she feels, thinks and acts?

What impact do the opportunities, resources, constraints, and demands have on how this person thinks, feels, and acts? (Keilhofner, 2002, p. 169)

These questions were narrowed and adapted to specifically address the impact of SCI on sexuality for the intimate partner. The questions on the interview protocol were aimed at identifying the lived experience of intimate partners of individuals with SCI. Questions 1 through 6 were designed to address research question one, “what are the lived experiences of intimate partners of individuals with SCI related to sexual encounters?” Questions 7 through 14 were designed to address the second research question, “what are the education and resource needs of intimate caregivers of individuals with SCI related to sexuality?” The interview questions outlined in the protocol were reviewed by a content expert on SCI for appropriateness and completeness. There were recommendations to include some ice breaker questions at the onset of the interview to increase the comfort of the participants. The form was revised to accommodate this request. As a result, less intrusive questions were purposefully included at the beginning of the protocol to facilitate a comfortable conversation.

The SCI Interview Protocol was developed to guide the interview by providing pre-established questions based on the chosen model for this study. Additionally, demographic information regarding age and gender was recorded on the protocol form at the end of the interview.

Procedures

Four participants were selected to participate in one interview each. The initial contact with the participants began with formal introductions and a description of the research study and purpose. This was followed by presentation and explanation of the informed consent form ensuring all questions were answered. Participants were informed that the interviews would be

audiotaped for transcription to ensure that all pertinent responses would be captured in their entirety. The first interview was scheduled after obtaining informed consent and permission to audiotape the interviews.

At the onset of the interview the purpose and scope of the study were reviewed. At that time, participants were asked to complete the Hurlbert Index (Apt & Hurlbert, 1992).

Additionally, participants were asked to complete an Education and Resource Needs Checklist (Appendix H). This checklist was developed by the author and reviewed by an SCI content expert for completeness. The checklist was aimed at identifying what education and resources they received during their partners' inpatient rehabilitation stay related to sexuality. Data was then collected utilizing one 60-90 minute semi-structured interview per participant. One participant initiated a follow up phone call to provide additional information that she did not recall during the initial interview.

The time frame of 60-90 minutes was established as this allows time for building rapport and in-depth exploration of the interview items, while being mindful about over lengthy interviews. Extended interviews of greater than 120 minutes have the potential of deviating from the interviewer's purpose and produce diminishing benefits (Seidman, 2006). Interviews were recorded for transcription.

The SCI Interview Protocol was utilized to guide the participant through a conversation related to their sexual experiences after the onset of SCI. After completion of the interview questions, participants were given the Education and Resource Needs Checklist again, this time, to identify any areas that they feel would have been helpful in their transition and return to sexual activity. Upon completion of the checklist, the researcher discussed the check list and

probed into identified needs to gain a better understanding of the meaning of the participants' responses.

The researcher concluded the interview with a summary of the key discussion points that occurred during the interview process as a method of member checking to increase validity. The researcher asked the participants if there was anything else that they would like to add and if they have any additional questions regarding the research. Finally, the researcher ensured that the participants had their contact information if any questions or concerns should arise, and thanked the participant for their time.

After data analysis, follow up phone calls were made to the participants in order to validate the researcher's findings (member checking). The findings were described to each participant and feedback regarding the findings was solicited. Participants were asked to judge the findings for accuracy and credibility. All participants reported the findings as accurate.

The researcher maintained a reflective journal for the duration of the study for the purpose of identifying potential biases, assumptions, or expectations (Yin, 2011). After each interview, the researcher reflected on the interview, including personal thoughts relating to participant demeanor, potential themes, and potential biases of the researcher. The researcher reviewed this journal frequently during the analysis phase. This journal outlined ways in which the researcher may have influenced each of the interviews and was utilized to sensitize the researcher to any potential personal biases or prejudices which might influence the outcome of the interviews. According to Yin (2011), reflective journals are beneficial by providing insight into biases to be examined during the data analysis phase.

Data storage and processing

All data was handled in a manner to ensure confidentiality. There is no identifying information on either the hard data or electronic data. Each participant was given a pseudonym for identification during transcription. Hard data is being stored in a locked cabinet in the researcher's office at Towson University. Electronic data is being stored on a password protected computer on the Towson University campus.

Data analysis

Recordings of the interviews were transcribed. ATLAS ti 7 software was utilized to organize the data obtained from the interviews. Although the researcher was responsible for assigning codes, the use of this program aided in organizing and accessing the data by providing frequency of codes and co-occurrence of codes across documents. Qualitative data from one interview per participant was used to identify the lived experiences related to sexuality as perceived by the participants. Within case analysis was used to identify themes for each participant, followed by cross-case analysis to identify common themes among the group of four participants.

For the purpose of this study, a lean coding technique was utilized. The lean coding technique is described as initiating the coding process utilizing five to six categories and further expanding those categories as the researcher continues to review the transcriptions (Creswell, 2013). Creswell (2013) recommends a maximum of 30 categories or codes as larger numbers can make identifying themes more difficult.

A collaborative coding technique was utilized to enhance validation of this study. For this process, an individual with expertise in occupational science and qualitative research was identified. This individual and the researcher reviewed and pre-coded the interviews

individually and then sat and collaboratively discussed the findings until a consensus was reached for each coding cycle.

As outlined by Saldana (2013) two coding cycles were utilized. Descriptive coding methods were utilized as the first cycle coding method for this study. Descriptive coding utilizes a word or short phrase to summarize the topic of the participants' responses. Line by line coding was used to maximize the potential for gathering all pertinent data on individual responses. In line by line coding, all responses are separated into paragraph length units with line breaks added when the topic appears to change. This allows coding for each section of data to be separated (Saldana, 2013). For the purpose of this study, each line was analyzed and given a general thematic title which was input into the ATLAS ti software. These titles were not identified prior to analysis, but emerged from the data. Data that did not appear to fit within the emergent codes was highlighted for further review as the categories expanded. According to Saldana (2013), this method is appropriate for all qualitative studies and is most appropriate for new researchers who are learning how to code data.

The second cycle coding method was pattern coding. Pattern codes are used to identify emergent themes and are utilized to group the summaries from the first cycle coding into a smaller number of sets or constructs (Saldana, 2013). The ATLAS software was used to identify co-occurrence and code frequency which assisted in this second cycle coding. Themes related to the lived experiences and the education and resource needs for partners of individuals with SCI were derived from the pattern codes (Saldana, 2013).

This study was conducted utilizing a social constructivism interpretive approach. The social constructivist holds the ontological belief that individuals have multiple realities which are created through lived experiences and interactions with others (Kincheloe & McLaren, 2005).

The intent of this type of research is to gain an understanding of the meaning that others place on various aspects of their lives (Creswell, 2013). The social constructivist researcher holds the axiological beliefs of honoring the values of individuals. They utilize an inductive method of emergent ideas, and obtain their data through interview, observations, and analysis of texts. Additionally, the epistemological belief of the social constructivist researcher is that reality is jointly created between the researcher and the participant, and is shaped by individual experiences (Vygotsky, 1930). Thus, while the participants involved in this type of research are encouraged to construct meanings in their situations, the researcher's goal is to make sense of those meanings (Creswell, 2013).

In relation to this study, the social constructivism theory was utilized to inform the importance of the topic regardless of the background of the participants (Creswell, 2013). It is believed that the social constructivism approach is most appropriate to frame the analysis of data because the topic of sexuality is complex and shaped by societal expectation, and historical and cultural norms (Crooks & Baur, 2008). This approach leads researchers to investigate the complexity of the participants' views.

This approach was utilized during the interview process in which the researcher, through the use of re-phrasing and reiteration, encouraged the participant to delve into the personal meaning of their responses. During the data analysis phase, this approach was utilized to aid the researcher in understanding the meaning of sexuality to each individual and the importance of that role in their lives. Gaining a thorough understanding of the meaning of sexuality to the spouses of individuals with SCI will demonstrate if there is a need for intervention in this area, and inform future planning for educational practices for partners of individuals with SCI.

Validation

Validation procedures were incorporated into this study to enhance the trustworthiness of the findings (Guba & Lincoln, 2005). One method is the clarification of researcher bias. The researcher disclosed her position at the outset of the study. For this technique, the researcher has reflected on past experiences which may shape the interpretation of the study. These experiences include discussions with intimate partners of individuals with SCI and their expressed frustration regarding the lack of sexual intervention from healthcare providers. Therefore the researcher brings a certain bias that partners of individuals with SCI do not receive adequate education regarding sexuality. Additionally, the outcome of these discussions revealed that the onset of SCI resulted in significant alterations in sexual behavior related to multiple factors including changes in life roles, and physical, emotional, and psychological adjustment. This could influence the study if the researcher guided the discussion to encourage the participants to discuss only the negative issues they experience related to sexuality. This was minimized by following the established research protocol which was reviewed by an expert in spinal cord injury, and by exploring both positive and negative aspects of the topic.

In order to obtain confirmability, the researcher identified one individual who has experience with occupational science and qualitative research to participate in the coding process. It should be noted that this individual did not have extensive knowledge of SCI and therefore was able to view the data more purely. A collaborative coding technique was chosen as this allows for interaction and discussion which can result in new and richer codes (Saldana, 2013). For the purpose of this project, the researcher and one other individual reviewed the transcripts together. This allowed for differing perspectives to be brought to light and discussed prior to establishing a final code.

Role of the researcher

In qualitative research, the researcher is considered a human instrument of data collection. The qualitative researcher understands that research is an interactive process which is shaped by personal histories (Denzin & Lincoln, 2005). Because of the interactive nature of qualitative research, it is imperative that the researcher disclose relevant aspects of themselves including biases, assumptions, and expectations in order to qualify their ability to conduct the research (Greenbank, 2003). For this reason, it is helpful for the qualitative researcher to maintain a reflection journal throughout the interview process (Creswell, 2013). This journal was utilized to write down personal thoughts and feelings which arose during the interview. The journal served as a personal reminder of biases to aide in the prevention of coding based upon the researcher's personal assumptions and expectations.

In this study, the researcher took on the role of an objective viewer with the goal of gaining insight into the views of the participants (Creswell, 2013). The role of the researcher for this study was to build a picture of the lived experiences of the participants. The researcher utilized probing questions, and expanded upon those questions based upon responses to develop a deeper level of conversation with a goal of gathering profound, rich information that gets to the meaning of the experience.

Ethical considerations

There were several ethical principles which needed to be considered when conducting this study. The main ethical principles that needed to be addressed was autonomy, beneficence, and justice (Orb, Eisenhauer, & Wynaden, 2000). Prior to initiating the study, IRB approval was obtained (see Appendix F). The role of the IRB is to ensure that human subject research is done with the previously mentioned principles in mind (Yin, 2011).

The principle of autonomy includes the right of the participants to be informed about the study, the right to freely choose whether or not to participate, and the right to withdrawal at any time. This principle was addressed through an appropriate informed consent (Orb et al., 2000). According to Kvale (1996), informed consent requires striking an appropriate balance between under informing and over informing the participants. In qualitative research, it is imperative to provide adequate information so that the participants can make an informed decision regarding participation, however, it is also imperative that the researcher ensure that the information provided will not sway their feedback during the study. See Appendix G for method to ensure consent to participate.

The second principle for consideration was beneficence, or to do good for others and prevent harm (AOTA, 2010). Beneficence should be considered when developing inclusion criteria. For example, if participants are excluded based upon personal belief systems, and when inclusion of those participants could enhance the study, beneficence could be jeopardized by not allowing those individuals voices to be heard (Orb et al., 2000). Beneficence would have been threatened in this study if alternative sexual orientation was used as exclusion criteria. Individuals with differing orientations may have brought to light alternative issues related to the study.

Another action that is related to beneficence is the oversight of personal identifying information (Creswell, 2013). Because the spinal cord community in the Baltimore area is relatively close knit, and because the information that was collected is sensitive and personal in nature, extra care needed to be taken to ensure the anonymity of the participants. Additionally, the means of reporting was provided to the participants during the informed consent process

(Appendix G). This included the use of this information for the dissertation process and the potential for future publication of this information.

Finally, the principle of justice needed to be considered. This refers to fairness, and the avoidance of exploitation and abuse of participants (Orb et al., 2000), or can relate to reporting of data (Creswell, 2013). The researcher must ensure that the participants are protected, and not further burdened by the study (Orb et al., 2000) and that data is reported honestly, clearly, and openly without bias (Creswell, 2013).

Limitations and delimitations

Lack of prior research on this topic was a limitation. Prior research in this area would have provided a greater foundation for understanding the topic. This would have allowed for a more concise line of questioning and potentially a more thorough understanding of the topic.

A delimitation occurred in this study as a result of the sample selection. The participants in this study were recruited through only one medical system in the state of Maryland. This sample selection was chosen due to proximity and time constraints. This does, however limit the potential pool of individuals who participate and may not provide an understanding of the lived experiences of individuals who participated in rehabilitation in another state.

Summary

The findings of this study are in the form of a descriptive narrative (Sandelowski, 2000). The narrative is an exhaustive interpretation and description of the phenomenon being studied. The lived experience of sexual partners of individuals with SCI and themes related to education and resource needs to enhance their participation in the occupations related to sexual well-being will be detailed in Chapter 4.

Chapter 4

Results

The purpose of this study was to investigate the lived experiences of intimate partners of individuals with SCI related to sexuality. Participants included four individuals, all female, who were married to individuals with SCI and were the primary caregivers of their partners. All but one of the partners was diagnosed with tetraplegia while the last was diagnosed with paraplegia. The participants were stratified by age with ages ranging from the thirty-two to sixty-two. The primary form of data collection was one in-depth interview and a follow-up phone contact designed to ensure that the findings were consistent with the participants' intended meanings. All in-depth interviews took place between October 2014 and January 2015 with follow up interviews taking place in April 2015. Survey data related to sexual desire also was utilized to inform the researcher during the analysis process. Additionally, a second purpose of this study was to identify education and resource needs related to sexuality for the partners of individuals with SCI. This was investigated during the interviews and through the use of an education and resource needs questionnaire developed by the researcher (Appendix H).

In this chapter the researcher will outline the results of this study. First, the researcher will introduce each participant utilizing pseudonyms for anonymity. These introductions will include demographic data and prominent parts of each individual's story both in the researcher's words and in the voices of the participants. Participants are introduced in the order in which the interviews took place. Lastly, thematic description of the emergent themes will be discussed utilizing rich descriptions in the participants' voices to support the identified themes. The results of the sexual desire survey also are included. Conclusions to the research will be discussed in Chapter 5.

Participant Backgrounds

In the initial phase of the interview, the participants were asked to provide some details regarding their life before the onset of SCI including how they met, vocational background information, how their sexual relationship evolved, and information pertaining to the injury including level of injury, how the injury occurred, and length of time since injury. Each participant's background is outlined in the amount of detail that was provided during the interview. An overview of each participant and pertinent information is provided (see Table 4).

Table 4

Overview of Participants

| Participant | Age | Ethnicity | Gender | Time Since Partners' Injury |
|----------------|-----|------------------|--------|-----------------------------|
| Megan | 44 | Caucasian | Female | 13 years |
| Joanne | 62 | Caucasian | Female | 2 years |
| Betty | 52 | African American | Female | 1.5 years |
| Jessica | 32 | African American | Female | 6 years |

Participant 1: Megan and Scott.

Megan and Scott first met when they were both in high school. Megan reports that Scott fell in love at first sight and pursued her vigorously. She dated Scott and one of Scott's friends at the same time until finally deciding that she wanted to be with Scott. She reports that Scott "always wanted me - - he always put me on a pedestal," and that "he was like something I just couldn't be without."

Megan and Scott had been married for seven years and had a five year old daughter at the time of Scott's injury. Prior to the onset of injury, Megan reported that she and Scott had an active sex life with sexual intercourse occurring "very frequently through the week." Megan was working part-time as an administrative assistant and Scott was a large equipment mechanic. Scott was the primary bread winner. Megan and Scott owned their home, a two-story townhouse in which the bedrooms and bathroom were located on the second floor. There were three steps to enter the home.

The injury occurred during an August celebration at a friend's house. At the time of the injury, Scott was 32 and Megan was 31. Scott dove into the pool and sustained a C5-C6 SCI. Despite having a small child to care for, Megan spent much of her time in the hospital with Scott. She was fortunate that Scott's employer continued to pay him despite his inability to work. Later, Scott's employer hired Megan and Scott to be office managers to ensure that they would have financial stability. At the time of the interview, Scott had been injured for 13 years.

Participant 2: Joanne and Joe.

Joanne and Joe first met in college. They were introduced by Joe's brother who is an identical twin. Joanne was dating someone else at the time, but eventually started to date Joe. Joanne reports that their sex life prior to the onset of Joe's injury was "normal." Joanne and Joe had been married for 42 years at the time of Joe's injury. Joanne is retired from her position as a secretary to the principle in an elementary school. Joe is retired from his position as a plumber. They have two grown sons who do not live locally. Joanne and Joe own their home which is a one story detached home with limited accessibility to the main bedroom and the bathroom.

Joe was injured in an automobile accident which resulted in a C5 SCI. Joanne spent most of her time in the hospital with Joe, often assuming his nursing care while there. At the time of

the interview, Joe had been injured for two years, and Joanne had been Joe's primary caregiver for that amount of time.

Participant 3: Betty and Jim.

Betty and Jim met for the first time approximately 30 years ago in a club. Although they would occasionally run into one another at various events they did not re-connect until 20 years later. At that time Betty was 45 years old and Jim was 40. They dated for a few years before getting married. Betty reports that prior to the onset of injury their sex life was good. She states "...it was just like oh Lord, I can't even describe it." She goes on to say, "It was good. It was great, It was good. It - - it just, I don't know, it just, we clicked instantly, you know. It was like, why did we wait this long to get together."

Betty runs a catering business and Jim worked in construction prior to his injury. They live in a two bedroom apartment that is accessible. Jim was injured in a work related accident one and a half years ago and sustained a C5-C6 SCI. Because it was work related, Jim has full time caregivers to take care of his basic needs. Despite this, Betty still feels the impact of caregiving and her change in roles has negatively impacted their sexual relationship.

It should also be noted that Betty says that she believes her husband was being unfaithful at the time of his injury. Although she has no definitive proof, she feels as though "he was still in the party mode." At one point, Betty stated "I started to get settled, but he still wanted to run" followed by "when you be out there like that, you get involved in stuff that you're not supposed to get involved with. Like infidelity." This is extremely apparent throughout the interview and truly seems to impact some of her reactions. Despite her fears regarding infidelity, Betty reports that they still had an active sex life prior to the onset of the SCI.

Participant 4: Jessica and John.

Jessica and John went to high school together. They did not date at that time, but after college Jessica met John again through mutual friends. She remembers “we just kind of cliqued. Our best friends were together, so he just looked interesting, so we started dating then.” Although they are not legally married, they have been together for nine years. Prior to the onset of injury, Jessica describes their sexual relationship as passionate. She states “It was very passionate. We both did touching, and kissing, and very passionate.” John was a truck driver, but does not currently work, and Jessica works for the state as a childcare inspector. John and Jessica live in a two-story townhouse with the bedroom and bathroom on the second floor.

John was injured in an automobile accident six years ago and sustained a T2 SCI, leaving him a paraplegic. For the first two years, Jessica was John’s primary caregiver. Although she still assumes the caregiving role when needed, John’s level of injury allows for much more independence with basic self-care needs as he is able to complete his basic self-care without assistance. Despite this Jessica reports that “I cared so much about him that I didn’t even care about me, because I put so much time to make sure that he was okay.” It should be noted that Jessica and John are interested in having children and are actively pursuing alternative methods of conception.

Thematic Descriptions

Following the data collection and analysis phase, thematic descriptions were established to describe the main elements of the lived experiences of intimate partners of individuals with SCI related to sexuality. The three themes that emerged are outlined in this chapter. These themes are: (a) various aspects of SCI negatively impact experiences of intimacy, (b) perceived deviance in sexual activity with the injured partner, (c) and education and resource needs related

to sexuality not being met. In addition to the main themes, sub themes were identified to further reflect the data (See Figure 7).

Theme 1: Aspects of SCI negatively impact experiences of intimacy.

The impact of the SCI on intimacy was discussed by all participants. For these participants, intimacy was limited by changes in previous role from partner to caregiver, by their partners' physical characteristics, and by fear related to further injury and emotional strain.

Participant's assumption of caregiver role detracts from intimacy.

Each participant recalled that assumption of a caregiving role had a negative impact on their feelings of intimacy. The participants reported that the change in roles from partner to caregiver was not conducive to maintaining a healthy sexual relationship. Two of the participants in this study were assuming all aspects of the caregiving role. This includes basic self-care such as grooming, feeding, bathing, dressing, and toileting. One participant, although initially assisted with basic self-care, is currently assisting only with toileting and mobility such as stair management. The last participant has a paid caregiver to perform basic self-care, and primarily provides the emotional support to her spouse.

Despite the differing levels to which the caregiving role is performed by each participant, all reported that the alteration in the participants' habits and roles greatly impacted their internal interest in sexual activity. For three of the four participants, the largest change in roles is evident in their assisting with basic self-care skills. Although prior to the onset of injury these participants reported caring for their spouses, they report the previous care provided to be more along the lines of traditional female caregiving roles such as cooking and cleaning. The last participant, although she is not the primary care provider for basic self-care, reports similar experiences and role changes as the other three participants. In addition to the role changes, each

participant reported changes in sexual habits which include preparation time, the addition of sexuality devices, and issues related to mobility.

Degradation of boundaries. The caregiving role had an enormous impact on the emotional health of the participants as it relates to the degradation of boundaries between the partners. The participants expressed difficulty in adapting to the role shift from partner to caregiver and discussed the difficulty that they experienced in maintaining both roles simultaneously. One participant stated, “I do everything. Or it’s just that my mind is so set on that nursing feeling I get. And I don’t feel like his partner.”

She went on to say:

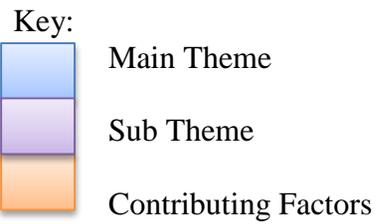
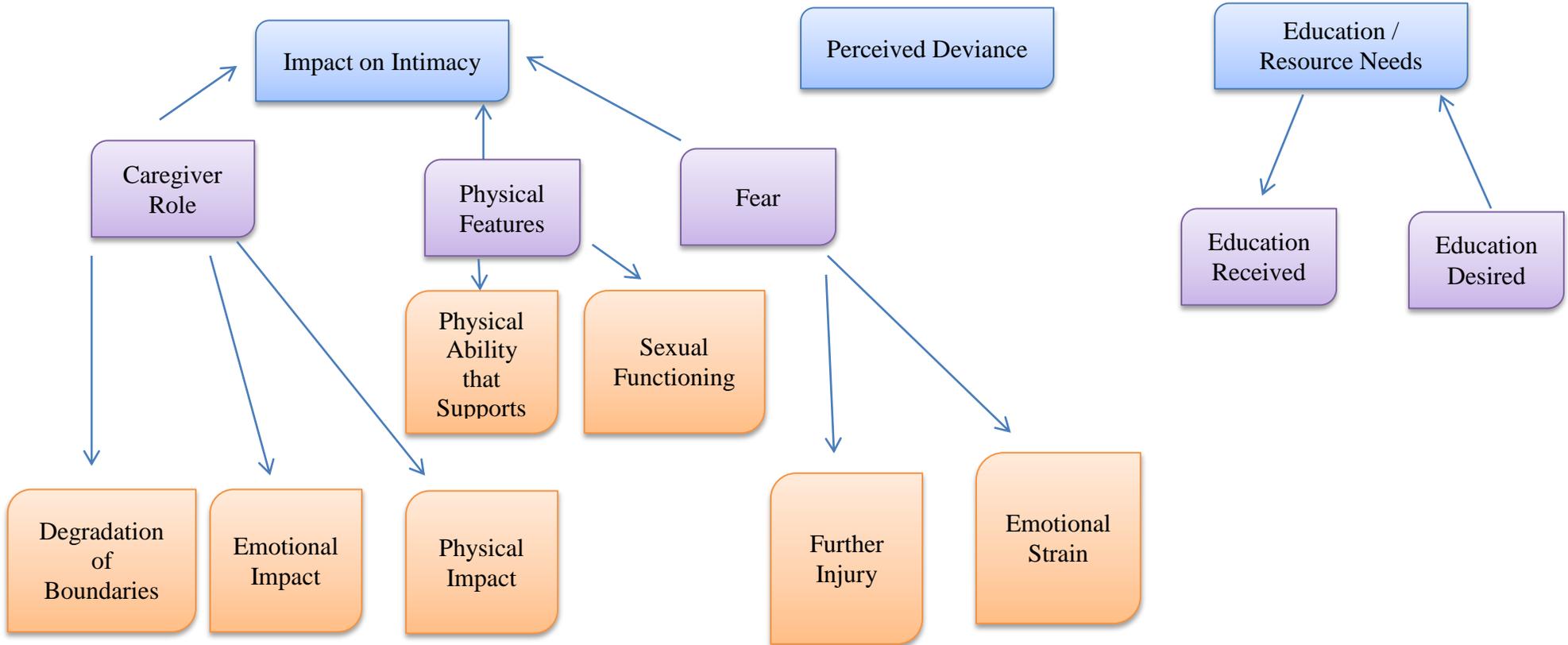
I feel like, you know, to be the caregiver first and then it’s spouse. But I mean the spouse and the friend part are so little. The love I have for him. You can be a caregiver, but anything that happens to him, I feel like it happens to me.

It’s like you’re a Siamese twin or identical twin. You feel what they do. And I do. And I think it’s because we’re together - - I’m with him 24 hours a day.

This participant reports that this perception is due to the amount of time she needs to spend with her partner. When asked if she felt that her sensitivity to her husband’s needs was a result of the SCI she reported:

I think it’s because I am with him more. And he doesn’t want anyone else to take care of him. And I don’t - - I don’t want to say he’s a burden, because he’s not. But sometimes you could go, huh, could somebody else do this?

Figure 7: Themes and Sub Themes



Another reported that it was difficult to separate from her husband even for small amounts of time. This difficulty was due in part to the physical demands and due to emotional strain. She expressed frustration that she needed to be available to care for her husband twenty-four hours a day and that this left her little time to take care of other responsibilities. She stated:

I mean he needs a drink of water. He needs this or he needs that. Again, he can't reach something. You know, I'd rather be close enough. And if I asked to be away from him longer, you know, longer than an hour, I've got to make sure that things are all set up so that he can take care of himself, if he can. But you know he can't take care of himself.

When asked about sexual intimacy since the onset of injury, she went on to say:

I mean I handle his penis more than I did before. Yeah. Because I have to cath him every 4 to 5 hours, every, you know around the clock...I did the bowel training which, you know, I looked at it as, you know, he is so unaware of really what I'm doing. He doesn't feel a thing. I think he removes himself because he doesn't really want to think about what I have to do.

When asked how this impacted sexual intimacy she stated its "not there. I mean, I don't even, it [sex] never occurs to me." It should be noted that this participant has not had any physical or emotional intimacy with her spouse since the onset of his injury.

This participant reported that she always took care of her husband. She reports that she was responsible for the traditional female role within the household. She reports that she did all of the cooking and cleaning, and provided the emotional support for the family. When asked if it has changed since her spouse's injury she stated "only now it's 100%." This participant

described that in addition to her previous roles, she is now responsible for all of her spouse's self-care and all of his medical needs. She explained that the caregiver role was very challenging. She stated "It's hard for me. I can't leave him." She reported the emotional strain associated with this change in stating "When I'm supposed to be out trying to relax. I can't do that. I think about him every minute that I'm away from him."

A third participant reported difficulty in dealing with the degradation of boundaries and the emotional impact of caregiving related to assisting with bowel and bladder training reporting, "having to bring bowel training into the bedroom" had a negative impact on her feelings of intimacy. She stated, "the smell" and having to transport and dispose of the waste was a "real turn off." Although this participant's partner is now independent with his self-care skills, she recalls the impact that the caregiver role played in her intimate relationship. She went on to say:

In the beginning, I felt like I was his nurse. Because he couldn't do anything. He couldn't sit up. He couldn't raise his hands. He couldn't do anything for himself. So in the beginning, I was his nurse. I was his nurse.

One participant reports that since the time of her partner's injury they have resumed sexual activities although the frequency has decreased from several times a week to a few times a month. Although this participant has resumed sexual activities with her partner, when describing the impact of caregiving on resumption of sexual activity after the onset of the SCI she stated:

Thinking back, it probably did [impact resumption of sexual activity]. Because, yes. It did. I didn't want to do anything because I was taking care of him. I couldn't see myself as his girlfriend, as a spouse, because I wasn't in that position at the time. I was helping him out. From the beginning. No sexual activity was happening. Because I couldn't even mentally get there because I was in a different place.

Yet another participant reported that caregiving impacted her feelings of intimacy. This participant reports that her spouse seems to have taken on the role of patient in their relationship. She feels that he views her more as a caregiver than a partner at this point in time stating:

I don't, you know, and I know he loves me, but, I don't feel the love. I really don't. I don't feel that. I just feel like he thinks that I'm just supposed to take care of him...Because I really take care of this man.

Emotional strain. Each participant discussed the emotional impact of providing care and its impact on intimacy. The participants in this study reported that it was difficult to separate the role of caregiver and intimate partner resulting in feeling overwhelmed and feeling increased stress. One participant discussed the emotional strain that the degradation of boundaries has caused for her. This participant feels guilty that she needs to return to work and that she is unable to maintain the role of caregiver and financial provider without causing anxiety for her spouse. She explained that intimacy was impacted as a result of the amount of strain that care providing added to their relationship. She provided insight into what contributed to this emotional strain stating:

Everybody noticed how, like, if I'm not around, he changed. You know, his mood changed. I mean it's like he's just almost lost when I'm not around. So if I leave starting to, you know, get back to, you know, to work, and catering and everything like that, it's - it's kind of making him a little upset because I'm not here - -like that anymore. But, I mean, I know God saved his life, but I think if I wasn't there, he probably wouldn't have made it...I think I became a crutch for him.

When asked if this added to her stress levels she stated:

Yeah, I do. Because I feel bad when I do have to go somewhere or do something, and it's like, he say he understands what I'm doing, you know, but I don't think he appreciates the fact that I am there and it's because I'm doing it for us. And, he can't work anymore, you know, so. You know basically I have to, you know, have something coming in.

The added stress of the role of caregiver is evident with this participant. She goes on to describe how the onset of her husband's SCI has increased her pre-morbid depression. Due to the side effects of the medication and her responsibilities as a caregiver, she has decided not to take her medication resulting in a negative impact on her overall well-being. She reported:

I had deep depression where my - - my doctors, well, they gave me, well I was supposed to take Prozac for my depression before. And it got a little, you know, after the accident, it got worse. So, my doctor told me, I think you need - - in light of the situation that happened, I think we need to increase your Prozac. But when I take it, it has me feeling loopy. So, you know, I told the doctor, I said, I would try, you know, I'm going to try to - - I didn't want to take it, because I couldn't be that way [loopy] with him, you know, being the way he is. So I told the doctor that I was going to try to deal with it.

The emotional impact of caregiving has taken a deeper toll on the participants who have been providing this care for longer periods of time. It was apparent that the participants felt overwhelmed by their responsibilities and that this was taking a toll on their emotional well-being. One participant stated:

I think that I'm doing OK. There are times when I feel like, geez, just give me a corner somewhere and let me cry. But, it's a lot to take on with my family, so we get by, but there are times when I just feel like, Jesus, just don't give me one more thing, okay?

The participant who had been providing care the longest reported that the emotional toll was extremely hard to deal with. She stated:

The caregiver position is always there. It doesn't matter what I'm doing. Whether I am laying by his side as his wife, or getting him dressed in the morning, or you know, making tea or whatever the case may be. I feel like that hat is bigger than any other hat that I wear. And I hate that.

She went on to say:

So after 13 years of doing it day in and day out, you don't really, I guess, you get that numb feeling like I've had and you just go with the flow. It's hard to speak about stuff sometimes, because it's like - - I just want to go to sleep.

An additional emotional and mental strain expressed by one participant was the impact of being the only person who could ensure the family's safety. She stated:

You sleep lighter at night, I guess. You have to make sure that anything that happens, you've got to get up and make sure everything's okay. Especially when you have a kid. I mean, yeah, I do have two dogs that alarm me. As an alarm if something...But you know, ever since the van got stolen right out front of my house, it totally throws you into another degree of life. You can't trust people. So since he can't help me if a burglar comes in, I take many more precautions. So, I'm more cautious. Sometimes it makes me a real bitch. I've been good. And now I am just out there. I will tell it to you straight anymore.

Physical impact. According to the WHO, *Healthy People 2020* (2015), well-being is an important aspect of the human experience. According to their definition, physical well-being contributes to an individual's overall well-being (WHO, 2015). All of the participants in this

study reported some level of physical injury which resulted from providing care to their injured partners. Because pain associated with physical injuries is known to negatively impact sexual functioning and desire, it is believed that this theme is important to address (Laursen et al., 2006; Monga, Tan, Ostermann, Monga, & Grabois, 1998; Schlesinger, 1996).

The caregiving role takes a toll on the participants' physical health and well-being. Many had experienced physical ailments as a result of the extreme physical demands of providing care to an individual with SCI. As stated by one participant:

I have carpal tunnel in my hands, back injuries, sleepless nights and worry, pulled muscles. Like if you were working on a house and you never worked on a house before. Your whole body goes through different pulls and strains and emotions, frustrations. Because you want them to help you and they can't.

Another participant discussed the added burden of having to take on the physical jobs around the house. She stated "I've actually taken on the role of both, you know, what the man does around the house, and I'm the caregiver." A third participant stated:

Before we had a ramp outside, I used to bring him up the stairs. Nobody else could do it. No man has ever been able to bring him up the stairs without falling. I've always brought him up and he's never fell. And I've always done it. I've did it and, even though it was killing my back.

The final participant reported that she had back, neck and hip issues prior to her husband's injury and that they had gotten worse. For these participants the assumption of the caregiver role negatively impacted their experiences of intimacy due to a degradation of boundaries and due to the physical and emotional strains that taking on this role resulted in.

Partner physical characteristics have a negative impact on intimacy.

Another area that impacted intimacy was the partners' physical characteristics. All participants reported difficulties in dealing with their partners' changes in mobility and sexual functioning. Several participants discussed the lack of physical closeness due to altered mobility and ability.

Inability to participate in activities that support intimacy. As noted in chapter one, intimacy is supported by activities which provide feelings of warmth and emotional closeness (Crooks & Baur, 2008). Several participants discussed how the onset of SCI resulted in an inability to participate in activities that support intimacy within their relationships. As stated by one participant when asked if the way in which sexual encounters were initiated has changed since the SCI, she reported "Just certain ways he touched me before. Or the way he looked at me. And now I guess because we can't sit next to each other and hold hands. It's just like a numb feeling inside." Another participant reported that their intimacy was impacted because she could not get her husband into their bedroom. She stated "We have a king-sized bed in the other room, but I can't get him in that room, and you know, he can't—he can't stay on a regular bed any length of time." A third participant stated:

I needed him to - - it wasn't just about sex. It was just touch me, just love me, just kiss me, just hold me, just do something. You know, where a lot of times he'll cry at night, and I'll hold him and rub him, but I just wanted that in return.

Changes in sexual functioning. The inability for their partners to fully participate in sexual activities was also discussed by all participants. This altered sexual ability led to feelings of inadequacies among the participants and impacted on their feelings of intimacy. Erectile

dysfunction was an issue for all four participants but impacted each participant in different ways. For one participant the erectile dysfunction impacted her self-esteem. Although this participant was aware that the erectile dysfunction was a direct result of the injury, she reported feeling disappointed that regardless of her efforts she was unable to physically arouse her husband. She reported:

And knowing no matter, not sounding crude, but no matter how hard I jerk him off,
it - - you know, he doesn't get hard.

This participant went on to describe that the lack of physical response from her husband resulted in a decrease in her own arousal. For this participant, being able to visually see her spouse's arousal was an important factor in their sexual relationship. She stated:

You know, you buy the lingerie and things like that. He picks it out and I have that, and I put that on and then I don't see an erection, it's like, okay. I'm pleasing to the eye, but you know it's not where I get excited. You know, your nipples get hard or something like that.

She went on to say that even when she does get aroused "he can see that I'm aroused, but I can't, I guess see that he is. It's kind of a knock down when you don't see it."

Another participant was very upset over the fact that her husband did not have sensation in his genitals. She believed that she was unable to give him an erection due to this, but was disturbed that he was able to get an erection through bowel training and catheterization. This participant lacked information on erectile dysfunction and did not understand the difference between reflexive and psychogenic erections. The fact that her husband was not able to feel his genitals and get an erection from sexually related activities made her feel as though she was not sexually desirable to her husband. She stated:

And I know it's because of the spinal cord injury and the fact the he, you know, he can't feel. Because he do get an erection....he gets an erection if he's getting catheterized. So it's not like - - he wouldn't get a, you know - - get it right - - he wouldn't get an erection if I started touching him, or maybe like looking at something after dark [pornography]. He wouldn't just get an erection like that. But he gets an erection at different times. You know like sometimes if they give him the bowel treatment.

A third participant stated "I just knew that he couldn't get erect. And with him being paralyzed he wouldn't be able to. The doctor said that Viagra, this, and this, and this, but none of those things worked."

In addition to erectile dysfunction, mobility related to sexual acts was also a deterrent for sexual activity. One participant stated "And this may sound mean, I mean, I'm sure you'll understand this, but in - - if I were to give him that medication and had no erection - - an erection, I would have to do all the work." Another stated "Because their touch is different. Because they can't move like they moved before. Sometimes I don't want him to touch me." It should be noted that this participant's spouse had surgery on his hands resulting in the inability to fully open his hands. This participant reported that the way his hands felt after surgery impacted how she felt about his touch. Each participant reported that the physical changes, including sexual dysfunction and decreased mobility, had a negative impact on intimacy.

Fear has a negative impact on intimacy.

Another aspect that impacts intimacy for these participants is fear. Participants reported fear related to further physical injury which might occur as a result of participating in sexual activities. They also reported fears related to the emotional upset from their perspective as well as the perspective of their partners.

Fear of physical harm. The participants spoke about fears that their partners had regarding the effects of sexual activity on their health. One participant stated:

He thinks, because he can't feel his legs and stuff, that if you sit on his lap you're going to hurt him...He's, I guess, scared that I'm going to hurt him more. You know, I don't lay on top of him, you know, on the bed, because he's afraid that I'm going to injure something, because we can't tell if somethings wrong.

She went on to say:

I mean, I'm like Scott, I can sit on your lap, I sat on your lap before. He's afraid. Whereas before, he would cuddle and you know, and now, it's he's afraid somethings going to happen to him.

Another participant stated:

He's scared. Because he don't know how his body is going to react. And like when we went to the coping group and the- - that subject matter was, you know, sexual contact with the partner, and everything like that, because he has - - he has a Baclofen pump. And before he got that pump, he, you know, would have spasms and all of that. And they were really bad. So, like when - - when things happen, you know, in his body, he's scared.

Additionally, the participants spoke about fears that they had with regard to the resumption of sexual activity. One participant stated:

You know, he did have a stent put in his heart two years before this accident. I'm thinking, you know, they always tell you, make sure that you're - - you're physically - - your heart is ready for sex. I'm thinking, God, we give him this Viagra and he goes into cardiac arrest. No way. Just seems a little risky.

The fear of further physical harm expressed by the participants has resulted in a decrease in physical closeness between the participants and their spouses. This has impacted the participants feeling of intimacy and desire to participate in sexual activities.

Fear of emotional harm for the participants. Another aspect of fear that permeated the interviews was fear of the emotional impact of resumption of sexual activities on the participants. The participants reported negative emotions related to sexual activity due to their spouses' inability to fully physically participate. The methods and habits related to sexual activity were altered by the onset of SCI forcing the participants to find new methods to participate in those tasks related to sexual activity. There was a feeling of guilt related to their ability to please their spouses physically.

One participant discussed a feeling of guilt related to her current participation in sexual activities. She reports:

I feel like I'm getting something that he's not, even though he says he is. I don't know if it's different for females who are paralyzed versus the male. I just feel that he- - because he doesn't work anymore. And I feel guilty. Because it's not him.

She went on to discuss how this impacts her desire to resume sexual activity stating:

He say that he does [like sex] because he's making me happy. But I just lay there. So I would prefer not to even have it. I know that's horrible. It doesn't make me love him any less. I mean, I think I love him more because he still wants to do things for me. But I feel like I don't give back.

Prior to the onset of the SCI, participants reported that they had similar habits and routines around their sexual activities. Given the discussion on the physical impact of the SCI, the

participants were asked if they had formed new habits related to sexual activities. One participant expressed that they had tried to develop new habits and routines but without success.

She stated:

I don't think so. I mean, it's kind of odd right now. I don't do anything to him, he has to do it to me. That's where the weird, you know - - it's just different knowing that he can do things to me and I just lay there or whatever. I mean, we've tried Viagra for him and all of that. But really nothing has changed. I don't know what to change. - -Because he doesn't have the same tools so to speak. I don't feel like it does as much for him as it does for me. You know what I mean? So that's the scary part.

The fear of experiencing the negative emotions associated with sexual activity impacted the participants' desire to participate in the occupation of sex. This has become a cyclical event in that there are negative emotions associated with participation in sexual activities, which results in a decrease in intimacy, which then results in further decreased desire to participate in sexual activity. As stated by one participant:

The way it's going to be the first time, is usually the way it's going to be the rest of the time. And you know what to expect, what not to expect. And you hope you can change it, but it doesn't [crying].

Fear of emotional harm for the partner. There was an over-riding concern that participation in sexual activity would cause emotional strain for the injured partner. The participants seemed very concerned with protecting their partner's feelings relative to sexuality. Each described concerns relative to the emotional impact of erectile dysfunction on their partner and how they tried to prevent further emotional impact from this.

When asked about the first conversation she had with her partner related to sexuality, one participant stated, “I felt sad. It was a conversation that I had to have. But it was also a little scary, because, once again I thought about his feelings and trying to be sensitive to his needs.”

Another participant discussed her first conversation on the topic with her spouse stating:

Well, I did [talk about it]. The day we came home, and I saw how he reacted, I said, look, I want you to understand that I know this is hard for you - - and this is going to make me cry - -but I told him he didn't have to worry about that at all. I didn't want him to worry about it. But on the positive, if at some day it changes and we can do that, it's fine, but for now, he didn't have to worry about it.

She went on to describe her husband's reaction to his erectile dysfunction and explain why she avoids sexual discussions or attempts, stating:

You see, but he's so unwilling to even think about his inadequacies, see, and that - - and that, it seems to me that you know, telling him, well, you have to have Viagra to even have an erection, that , that makes him feel inadequate.

Some participants described their perceptions of their partners' fears related to the emotional impact of resuming sexual activity. These fears were related to the inability to fully satisfy the participants. One participant stated “I think he's scared that he's not going to satisfy me. So he won't try.”

Similarly, another participant stated “He - - I think he just had some hesitancy about not being able to satisfy me like he used to, and not knowing if - - it's hard for a man to not being able to get erect. “

Intimacy for these participants was greatly impacted by the onset of their partners' SCI. The change in roles from partner to caregiver caused emotional and physical strain which greatly

impacted their desire to participate in the occupation of sex. Additionally, the inability for their partners to fully participate in sexual activities led to feelings of inadequacy among participants and added to the emotional strain that these participants were already feeling. Lastly, both the participants and their partners had fears surrounding the potential for further injury and increased emotional strain which impacted their desire for participation in sex.

Theme 2: Self-perceived deviance in sexual activity with the injured partner.

During the interview, all participants in this study discussed their thoughts and feeling related to participation in sexual activity and each of them utilized terminology that was indicative of deviance in sexual participation with their injured partners. Although this topic was not discussed extensively, the findings were unexpected as this is not something that has been found in the literature, making this significant. This phenomenon emerged during different parts of the interview for each participant. The questions that elicited the responses included discussions of role changes, changes in habits, educational needs and assistive devices. While each participant termed their feelings differently they all related their experiences to something deviant. It was clear that they didn't see their sexual experiences as "normal." One participant discussed her feelings that she would be taking advantage of her husband. She stated:

You know that the pill will make - - make it work, so. It would be involuntary on his part. And you know, I don't know that, you know, you think about, well what kind of pleasure would he derive from any of it. I don't know. ...Because I can't - - that would ever feel so selfish anyway. And just like you know almost like you're taking advantage of something.

Her expressions as she discussed this indicated that this would be wrong. During the interview her physical and emotional reaction was that of disgust. She went on to say "It just seems so

unnatural that I can't, I wouldn't even go there." Due to her husband's erectile dysfunction, need for medication to obtain an erection, and his lack of mobility she felt as though it would be inappropriate, as though she would be coercing him to participate in sexual acts.

Another participant reported the role shift made her feel more like a mother than a spouse. She stated:

But I feel like a lot of times, I don't feel like his wife, I feel like his mother. And I can't say it no plainer than that. I feel just like his mother. That's how I feel. And by me feeling that way, that sometimes makes me not want to have sex with him.

A third participant discussed her concerns that her husband was not able to get the same joy out of sexual activity that she did. She reported that his response to sex made her feel deviant. She stated "and he says it's good and thanks me. And, you know, I'm like - - thanks for having sex - - Well, I feel like I'm a hooker or something." Lastly, one participant spoke about the addition of sex toys due to her partners' erectile dysfunction. She recounted how she felt the first time she purchased a strap-on dildo. She stated: "I told you one of the things we used was a strap-on. That's kind of - - the first time getting that was like, oh, you know. A man and a woman don't use this. This is usually a woman and a woman." It is important to note that while discussing assistive devices with another participant she reported the use of sex toys but did not consider this a deviant practice stating, "Oh, yeah. We have, you know, vibrators and pretty much that stuff. The normal. But nothing out of the ordinary that we wouldn't have had before." This suggests that perceived deviance in sexual acts is individual specific and potentially related to each participants' accepted sexual activity prior to the onset of injury. Because self-perceived deviance is specific to each individuals' prior sexual history the themes were generated through analysis of the interviews As the themes developed, the researcher reflected back on interviews

and listened to the tapes to assess the participants' emotional response during that line of questioning. As a result, the researcher was able to ascertain that these statements were representing self-perceived deviance.

The theme of perceived deviance emerged during the coding phase of data analysis. This theme was not more fully explored as it was difficult to delve further into during the follow up phone interview. All participants agreed that this was a feeling that they had, but were not able or willing to discuss any further during the follow up phone conversations. It is believed that this theme emerged during the face to face interview as the emotions elicited during that process allowed for deeper disclosure. Despite the limited information obtained on this theme it was believed to be significant and in need of further exploration. Although all participants termed their feelings differently, all participants reported that some aspects of their intimate activity felt inappropriate. The terms used by the participants included feeling like a "hooker," feeling like a "mother," and feeling like she would be "taking advantage" of her husband. This final participant reported that purchasing sex toys felt inappropriate.

Theme 3: Education and resource needs related to sexuality were not met.

There was consistency among all participants that their educational and resource needs related to sexuality were not met. Prior to and after the interview each participant was asked to complete an educational and resource needs questionnaire. These questionnaires were reviewed for trends in education and resources received and desired. No formal analysis of these questionnaires was completed and therefore results are discussed in descriptive terms. Initially, participants were asked about the types of educational and resource information they received while their partners were in rehabilitation. All but one reported that they received limited information (See Table 5). Although there was one outlier to the consistency in findings, this

participant’s responses during the interview indicate that she was trying to protect the site that provided the rehabilitation. Despite her report of receiving the information, during the interview she reported not receiving those educational and resource services. At the completion of the interview, participants were asked to complete the same questionnaire to determine which educational and resource materials would have been helpful. The results indicated that participants would have liked to receive more information on adaptive devices, medications and peer support (See Table 6).

Table 5

Results of Educational and Resource needs Questionnaire pre-interview

| Question | Participant | Participant | Participant | Participant |
|--|--|---------------------------|-------------|---|
| | 1 | 2 | 3 | 4 |
| <u>What information did you receive on adaptive devices</u> | Erection aides - Vacuum | None | All | None |
| <u>What information did you receive on medical concerns</u> | Medications Impact of current medications Orthostatic Hypotension Autonomic Dysreflexia | Autonomic Dysreflexia | All | “Only that he will be able to have sex” |
| <u>What information did you receive on social supports</u> | Physical Changes due to SCI SCI support groups Online caregiver | Caregiver support-minimal | All | SCI support groups Leisure/ |

| | | | | |
|---|----------------------|---------------------|-----|------------|
| | support | support groups | | Recreation |
| | Leisure / Recreation | Leisure/ Recreation | | |
| <u>What information did you receive on psychological Support</u> | None | None | All | None |

Table 6

Results of Educational and Resource Needs Questionnaire post-interview

| Question | Participant 1 | Participant 2 | Participant 3 | Participant 4 |
|---|--|---|----------------------|---|
| <u>What information would you have liked to receive on adaptive devices</u> | Erection aides | Positioning devices Erection aides | None | Positioning devices Erection aides |
| <u>What information would you have liked to receive on medical concerns</u> | None | Environmental information Medications Impact of current medications | None | Medications |
| <u>What information would you have liked to receive on social supports</u> | Caregiver / partner support | All | None | Mentoring / peer support for partner |
| <u>What information would you have liked to receive on psychological Support</u> | Mentoring / peer support for partner None | None | None | None |

Education received during rehabilitation.

Each participant reported that they received incomplete or inadequate information relating to sex during the rehabilitation process. When asked about the information that was provided during the rehabilitation phase of recovery one participant stated:

We watched a video and you know, my first thought was, okay he's still got his mouth. [the doctor] told us that - - you know the other thing won't work, and you know, to try the Viagra, or the vacuum, but - - and then, we also tried the little suppository insert and that didn't work either

Another participant also recalled watching the videos and reported that her husband had a one on one discussion with one staff member who also had an SCI. She reported that she was not present for that session. She stated "so that, you know, basically - - that was like all of the - - that was the only things that we had when it came to, you know [that type of education]." It should be noted that this is the participant who stated she received all information outlined in the educational and resource needs questionnaire. One participant recalled the impact of the video, stating that healthcare providers should:

Give people an opportunity to ask questions, because, other than putting them up in this little room with this TV and that video, where everybody was so uncomfortable. That was so funny that day. I remember because there was one man, who was, actually [my husband's] roommate, who actually said I'm leaving. He said, I didn't know this was going to be this. Get me out of here. He didn't want to be in a - - in a room with strangers watching porn.

She went on to say that other than the video "no one ever talked about it. I mean nobody ever spoke to us about that at all. Not even [the doctor] until after we left." Another participant

reported that she received the Christopher Reeves book, but could not recall whether it had information on sexuality. She did report that the doctors provided limited information. She stated “The doctors told him, yes, you’ll be able to have sex. But what they never said is that your penis may not get erect.”

It is clear from the results of the interviews that participants received generalized education in an inappropriate context for all, which was not specific to their individualized educational needs. Each participant discussed the use of a sexuality video provided during a group educational session but reported that the video was not adequate in addressing their educational needs.

Education desired during rehabilitation.

When asked what information they would have liked to receive the participants all reported that having someone to talk to was important. Information and education on peer and caregiver supports was one area that the participant’s felt would be helpful. One participant discussed her desire to have someone to talk to. She states:

I - - I tried through - - we’re with Kaiser and our base sent me to a support group that was for caregivers. But it turned out that nobody there was really a true caregiver. They had a mother who lived across the country and they had to deal with the nursing home or things like that. There wasn’t anybody there who had any idea what I was going through. And you know, I would sit there and I’d listen to these people and I think, oh my God, you don’t have a clue. When it comes right down to it, I really couldn’t - - I could relate to their, their anguish, but there was no way they could offer any kind of help for me, because they don’t know what it’s like to take care of someone 24/7.

When asked if having someone to talk to would be helpful, she stated “It would be really helpful. I think it would be good. Because I honestly have never been able to talk to anybody like I’m talking to you.” Another participant also discussed her desire to have someone to talk to. She stated:

If I actually met someone who was going through my situation or if there were someone else that I could talk to. I later met someone in life, another woman like myself, but we never talked about sex all the way. Her spouse was 80. His penis was able to get erect. So she didn’t have that problem....Resources or support groups that I could go to or people that I could talk to, or somebody like myself, and that’s why I’m doing this, for somebody like me. Because I don’t know any - - other than one other person, and was great. But outside of her, I don’t know anyone else going through my situation.

Similar to the others, yet another participant talked about the need for peer support. She discussed how speaking with someone would be beneficial. She stated:

I don’t know if other people would get an erection or not, for real. You know sometimes doctors tell you that this will work. You know, this should work. But they don’t tell you - - or you’re afraid to ask someone else who has done through this if it really happens. Can you get an erection? And you think you’re doing something wrong...Like if there would have been something, I mean, written that you could’ve read, or kind of like what we’re doing. I mean, like someone else could hear what someone else went through. That really went through it, not just by talking to someone...See what it’s actually like. And this - - we didn’t get that. And I think - - that’s a big thing.

Because the expressed desire for support was notable, the participants were asked to describe what information would have been helpful to hear from a peer. One participant stated:

That your life is going to change. Your life is going to change. But if you love the person, you stick it out with them. And you have to create your own new normal. It's not going to be like it used to be, but you have to figure out what it was about your partner that you loved in the beginning. You have to find him or her, you have to figure out what -- sex is not just about the penetration. It's about where you can kiss, where you can touch, what you can use, where you can nibble. It's more about -- stimulating a person's mind, then all of the other things come in place, you know. Because for me, I had to figure out how to get the erection... but I would say don't be embarrassed to try different things... And to go to the doctors even when they won't come to you. And just be patient with yourself and be patient with him, but don't be afraid to have the conversation if the intimacy hasn't happened within your timeframe.

Another participant stated very simply "It takes a lot of love, it takes a lot of love. And if you don't have a lot of love and understanding, it'll never get better." Lastly, the final participant provided the following statement:

That nothing's going to be the same. I mean, it depends on your desires, I guess. How freakish you like things to get, so to speak. But I just think that being able to talk to someone that's going through it. And has been able to work through it. That's the best thing I can say, actually. To hear, you know, or read their story. Because it's -- it's kind of like when you have a child and you didn't read all the books. You know, you learn, oh, the different cries, what they mean, and things like that. That's exactly how it is with a spinal cord injury. You know, you don't know exactly what's going to happen. So you've just got to go with the flow. And try to make things work. You try different things. But, it can get frustrating. So if somebody else, not that they're giving you a handbook, exactly.

You know, just do this, this, this, and this. But, this is what we have found to work. Or, it's a struggle. Don't expect, you know, anything. In the very beginning, don't -- don't look down. Because you will be able to have some type of sex, but it's not going to be the way it was before. And I think in the beginning you're so hopeful that things are going to be back the way they used to be. That it's only temporary. But it's not. You just kind of -- just go.

Another area of desired education was individualized information regarding sexuality.

When asked what advice they would give to healthcare providers related to discussing sexuality in their practice the participants were very clear in their expectations. One participant stated:

I would tell them that nobody's situation is the same. And when both parties are ready, that they should encourage them to come in and encourage them to speak to somebody....if that person has another spouse, to have them come in and ask those questions and we can give their input....nobody is the same and to be as honest as possible with each couple and to actually meet with them, so when you talk to someone else, you can give information based on what the last person said, or based on their injury, or a recommendation. But I would tell them to be as honest as they possibly can and meet with both parties.

Another participant stated:

I wouldn't put it on the back burner or be afraid that someone's going to be worried about you talking to them - - not worried, but kind of stand-offish. Because it is a real thing in life...Because of course, everybody has sex. And it's no different from your teaching them how to use a fork or brush their teeth. You know, you have to totally relive, re-do

your lifestyle the way that you lived it. So that should definitely be one of the points that you really pinpoint on how to do things. And, you know, don't be shy.

A third participant stated:

The advice that I would give is education. Education. And what you're doing now. You know, you - - if they had more programs like what you're doing now, I think that it would really educate other people. You know, and I mean, what you would be looking forward to - - in a case of SCI and the things that you think that may happen, I generally found they won't. So I think if they had more programs to educate, you know, educate the people about things that they would have to go through, I think that would be helpful.

Lastly, another participant stated that she believed that the education provided was pre-determined without regard to the individual or their stage of healing. She reported:

Because you know they have their set, you know, those different classes that we have to take. And they put them in a line and boy they want to make sure you've got all your classes in a line because you can't get out of here until you've done everything that you're supposed to do...I don't think that they consider much about who could be ready or who would be ready.

She went on to say that having someone grant permission to discuss the topic and then waiting for them to be ready would have been a better approach.

The participants in this study voiced a strong desire for education and resources related to peer and caregiver support. Additionally, the participants felt that a more individualized approach to sexuality education would have been helpful.

Sexual Desire

To evaluate the participants' sexual desire, the Hurlbert Index of Sexual Desire was administered. Because this measure utilizes detailed questioning related to sexual activity and feelings toward sexual partners it was administered prior to the interview to reduce the likelihood of the results being impacted by the emotions brought out by the interview questions. The Hurlbert Index is a self-administered subjective assessment of sexual desire (Apt & Hurlbert, 1992). It is rated on a scale from 0 to 100 with 0 meaning hypo-sexual and 100 meaning hyper-sexual (Apt & Hurlbert, 1992). The results for each participant are provided in a table below (See Table 7). Because it is unknown whether the participants had ever been administered this assessment prior to the onset of injury, the researcher is unable to provide any meaningful analysis of sexual desire related to the onset of SCI. The self-reported sexual desire scores are not consistent, with two participants rating on the hyper-sexual end of the spectrum and two rating on the hypo-sexual end of the spectrum. Potential reasoning for this discrepancy will be discussed in Chapter 5.

Table 7

Results of Hurlbert's Index of Sexual Desire

| Participant 1 | Participant 2 | Participant 3 | Participant 4 |
|----------------------|----------------------|----------------------|----------------------|
| 35 | 22 | 84 | 82 |

Conclusion

In this chapter, the participants were described and the themes of the interviews identified. The purpose was to describe the experiences of four partners of individuals with SCI related to sexuality. Three themes were discussed which included (a) loss of intimacy has a

negative impact on resumption of sexual activities, (b) perceived deviance in sexual activity with the injured partner, (c) and education and resource needs related to sexuality not being met.

Collectively these cases demonstrate that the participants experienced a loss of intimacy which has had a negative impact on the resumption of sexual activities. This loss of intimacy is a result of the role shift from partner to caregiver resulting in a blending of boundaries between the two roles, and emotional and physical impacts of the caregiver role. Additionally, the physical characteristics of the partners with SCI resulted in a decrease in feelings of intimacy for the intimate partners. Lastly, fear of further injury and emotional strain resulted in a decrease in intimacy.

The participants in this study all described what this researcher has termed as perceived deviance in sexual activity with their injured partners. Although each termed their feelings in a different manner, the terminology chosen indicated feelings of inappropriateness with engaging in sexual activities. This is an area for future study.

The participants in this study indicated that their education and resource needs were not met during their partners' inpatient rehabilitation admission. Each describes the need for resources related to support and the need for individualized education regarding the resumption of sexual activities with their injured partners.

In Chapter 5, the researcher will outline the findings of the research as it related to the research questions. Additionally recommendations for future research in this topic area will be discussed.

Chapter 5

Discussion

The purpose of this study was to describe the lived experiences and occupations of intimate partners of individuals with SCI related to sexuality. This study also set out to explore the educational and resource needs of intimate partners of individuals with SCI related to sexuality. Participants included four intimate partners of individuals with SCI. Participants described their experiences regarding their sexual relationships after the onset of SCI, reflecting on changes in roles and habits and the impact that those changes had on their sexual experiences.

As explained in chapter 4, three themes were identified which describe this experience from the partners' perspective. These themes were (a) loss of intimacy has a negative impact on resumption of sexual activities, (b) perceived deviance in sexual activity with the injured partner, (c) and education and resource needs related to sexuality not being met. In addition to the main themes, sub themes were identified to further evaluate the data. In addition, participants also completed surveys related to sexual desire and education and resource needs. The findings from these surveys are discussed in relation to the research questions.

Aspects of SCI negatively impact experiences of intimacy.

Participants in this study described in detail the impact that the onset of their partners' SCI had on intimacy. These participants also discussed multiple factors which hindered the intimacy within their relationships. Significant sub-themes were identified to organize the participants' responses with regards to the contributing factors to the loss of intimacy.

Participant's assumption of caregiver role detracts from intimacy.

The participants in this study indicated that the role shift from spouse/partner to caregiver negatively impacted their feelings of intimacy. This finding is consistent with the literature

which suggests that individuals providing care to their partners experience a role shift which alters their view of the injured partner as a sexual being (Gilbert, Ussher, & Hawkins, 2009; Hawkins et al., 2009).

The participants also discussed the emotional impact that providing care had on their feelings of intimacy. All participants reported feeling emotionally strained by this responsibility and felt that this emotional strain contributed to their lack of desire to participate in sexual activities. The emotional burden of caregiving that these participants also described is consistent with the literature. Although not specifically linked to sexual desire, the emotional burden of caregiving has been shown to impact the quality of life of the care providers (Blieszner & Roberto, 2009; Boschen et al., 2005; Dickson et al., 2010; McPherson, Wilson, Chyurlia, & Leclerc, 2011).

The physical burden of caregiving also was identified as an issue for the participants in this study. All participants reported an increase in fatigue and issue with physical impairments as a result of the caregiving duties. Consistent with the literature, the participants reported that the identified physical ailments greatly influenced their levels of sexual desire (Froud et al., 2014; Laursen, Overvad, Olesen, Delmar, & Arendt-Nielsen, 2006). Of the identified physical impairments, back pain was the most prevalent among the participants.

All participants in this study reported that their partners' physical limitations impacted their feelings of intimacy. Although the participants were cognitively aware that their partners were unable to demonstrate their interest from a physical perspective as a result of their SCI, all participants reported that this lack of physical demonstration of interest impacted their feelings of attractiveness. The participants reported feeling less desirable due to their partners' erectile dysfunction which contributed to their emotional well-being. Although not widely found in

current literature, Esmail, Huang, Lee and Mruska (2010) did identify similar findings in partners' of individuals with multiple sclerosis. This study evaluated couple's experiences related to sexuality when men were diagnosed with multiple sclerosis. One of the themes identified was the impact of sexual dysfunction on the female / care partners feelings of attractiveness. This study found that female partners of males with multiple sclerosis felt discouraged because the decrease or absence of sexual activity made it seem as though there partners were no longer interested in them.

The last sub-theme related to intimacy is the impact of fear on the intimate relationship. One aspect of fear that was discussed by the participants was a fear of further injury during sexual activities. Because so little literature is available regarding the intimate partners of individuals with SCI related to sexuality, the researcher was unable to validate this finding through other studies. This, therefore, is seen as a unique finding for this study.

Another aspect that was discussed by the participants was the need to protect their injured partners. This finding was also identified by Esmail et al. (2010) in which the participants felt that their partners were more vulnerable and in need of protection. The participants in both studies reported a need to emotionally protect their partner from feelings of inadequacy (Esmail et al., 2010). No further literature was found to support this theme.

The participants in this study identified the lack of physical closeness as having a negative impact on their intimacy and sexual desire. This lack of closeness was due to many factors including environmental factors, physical limitations on the part of their partners, role strain, and fear related to further injury and emotional distress. The degradation of boundaries related to the participants' previous roles has impacted how they view themselves as occupational beings. Similar to other studies, the participants in this study indicated disruption of

their occupational identity as spouse and sexual partner as a result of the caregiving role (Hawkins et al., 2009; Sipski, & Alexander, 1997). The findings from this study are consistent with current literature which outlines the negative impact that caregiving can have on sexual desire, and intimacy. Although the findings from this study contribute to the current knowledge of the impact of caregiving, this theme is not unique to this study with the exception of the issues relating to fear of further injury.

Self-Perceived Deviance in Sexual Activity

Participants in the present study identified negative feelings toward participating in sexual activities with their injured partners. Given the decreased physical ability of their partners and the role change from spouse to caregiver, each participant described sexual relations using terms that are associated with sexual deviance. The terms identified were “taking advantage,” “mother,” and “hooker,” while the last participant reported feeling deviant about purchasing sex toys that were made for two woman to use. Although each participant described this feeling utilizing different analogies, the theme was consistent across interviews. These comments were not thoroughly explored during the interview process as they were briefly mentioned throughout the interview and were not identified as a theme until the analysis phase of the research. Further, this was not explored in depth during the follow-up interviews as it was difficult to re-establish the context and emotions that occurred during the initial face to face interviews.

After an extensive search of the literature including the use of all databases available at TU and the UMMS, and with the assistance of the resource librarian at TU, no literature was found to describe self-perceived deviance in relation to sexual activity with an individual with disability. Although no research related specifically to partners’ perceptions of sexual activity with their disabled partners was found, some literature suggests that societal perceptions indicate

that individuals with disabilities are asexual. Tepper (2000) describes the view of disabled individuals by society stating “Disabled populations are not viewed as acceptable candidates for reproduction or even capable of sex for pleasure. We are viewed as child-like and in need of protection” (p. 285). This is consistent with additional study outcomes which indicate that the non-disabled general public often views the physically disabled individual as asexual or less desirable (Esmail, Darry, Walter, & Knupp, 2010; Rojahn, Komelasky, & Man, 2008).

This social phenomenon may play a role in the participants’ perceptions of sexual activity with their disabled partners. Because deviance is defined as participating in activities that are outside of the normative standards of an individual’s membership group or broader society, there may be a conscious or unconscious relationship between the literature and the findings of this study (Kaplan, Gostjev, & Johnson, 2013).

Education and Resource Needs

The present study aimed to identify information related to education and resources for partners of individuals with SCI related to sexuality. The trends that emerged demonstrated that education and resources needs were not being met. The sub-themes of education and resources received and desired are discussed below.

The Education and Resource Needs Questionnaire issued prior to the interview was intended to identify the information that the participants received during their partners’ rehabilitation admission. The results demonstrated inconsistencies in the amount and quality of the information received.

All participants reported participating in a standardized education program which included the use of a sexuality video designed for individuals with disabilities. This video was shown during in a group education session for individuals with SCI which proved difficult for

some participants. Although one participant reported finding the video helpful in generating ideas for future sexual activity the information was not adequate to support occupational performance in the future. Because the education provided was general and lacked individualization, participants were not adequately prepared to successfully engage in sexual activities that were conducive to their partners' individual abilities and desires.

Many participants reported receiving information on the medical management of sexual dysfunction from their physician after discharge from the hospital. All discussed frustrations surrounding the ineffectiveness of the recommendations and expressed some degree of distrust in the medical community in providing honest assessments of sexual potential for their partners.

The Education and Resource Needs Questionnaire issued after completion of the interview was intended to identify the information that the participants would have liked to have received during their partners' rehabilitation admission. All participants reported a desire for open and honest information regarding their partners' ability to participate in sexual activity. All reported that they were told that their partners would be able to engage in sexual activity, however they were not told to what extent this could take place. This resulted in frustration as several participants have tried multiple methods with little success. It should also be noted that none of the participants had participated in sexuality counseling.

Although the participants in this study reported a desire to receive further education related to adaptive devices and medical management, the over-riding desire was for peer support. Interestingly, in the Education and Resource Needs Questionnaire post interview no participants reported a desire for psychological support or resources. It is unclear if they believed that peer support was in this category.

Three of the four participants felt that having a peer to communicate with would have been, and would continue to be helpful. Participants reported that having the ability to share information with someone in their situation would be beneficial. This was discussed by the participants with regards to both the caregiving role and sexual experiences. They believed that someone in their situation would not only be able to empathize, but provide insights or ideas that the health care community may not have thought of. The results of the questionnaire and the interview demonstrate that although further individualized education is desired, the overwhelming desire is for support from individuals who are living with the same experience. All participants indicated that they would have liked to have a peer or mentor to discuss concerns and issues.

Sexual Desire

The participants in this study completed Hurlbert's Index of Sexual Desire prior to the interview process (Apt & Hurlbert, 1992). Interestingly, two participants scored well below average in their sexual desire, while two scored well above average. From the measure utilized in this study, it is impossible to discern whether the lack of sexual desire is a contributing factor to occupational dysadaptation related to sexual activity, and/or if it is a result of the above mentioned themes.

Sexual desire is a complex phenomenon involving mental and emotional functions as well as physical properties, namely hormonal. Decreased sexual desire, therefore, can be caused by a disruption in any of these areas. Factors that could contribute to or cause low desire include hormonal changes (typically age related), depression, fatigue, stress, and relational issues (Crooks & Baur, 2008).

Again, the Hurlbert's Index of Sexual Desire is rated on a scale from 0 to 100 with 0 meaning hypo-sexual and 100 meaning hyper-sexual (Apt & Hurlbert, 1992). In reviewing the participants' overall scores and comparing to the participant demographics no potential relationships were found. The individuals with the lowest scores were 43 years old and 62 years old, while the individuals with the highest scores were 31 years old and 52 years old. Although there was not enough data for statistical analysis, a few observations were noted. The participants with the lowest scores had fewer supports and more responsibility in the caregiving role than the other two participants, as both were full time caregivers. Of the two participants who scored the highest, one had a full time paid care provider, and one had a partner who was able to complete his basic self-care independently. Additionally, one of the participants with the highest score was actively seeking alternative methods of conception. It is unclear from the current data whether these factors contributed to the differences in sexual desire among participants. Although the data is not sufficient to draw conclusions regarding the impact of SCI on the intimate partner's sexual desire, noted differences in scores suggest that this is an area for future exploration.

Relation to Theory

As outlined in Chapter 2, the MOHO was utilized in developing the research questions. As a result, analysis will be discussed utilizing this model.

The MOHO describes occupational identity as a culmination of who one is and who one wants to be. An individual's volition, habituation, and performance capacity can change over time based on experiences within the environment and are all integrated into the occupational identity. Therefore, the occupational identity allows for self-definition as well as a plan for future action (Keilhofner, 2002).

The participants in this study were greatly impacted by the onset of their partners' SCI. The most prominent impact identified was on habituation. Each participant described the impact of the injury on their roles and habits. The alteration in roles from spouse to caregiver had a significant impact on their feelings of intimacy. The participants in this study reported that their responsibilities had significantly increased since the onset of their partner's SCI. They discussed that they were now responsible for all household maintenance, financial tasks, and caring for their partners. As stated by one participant:

We have always worked on things around the house together...but, for me, I've actually taken over the role of both, you know, what the man does around the house, and I'm the caregiver. So, I really don't- - you know, my role has changed in that respect.

Another participant stated "the caregiver position is always there. It doesn't matter what I'm doing. I'm always that protective hoverer."

As a result of this role change, habits related to sexuality were impacted. The participants describe that the methods of sexual initiation and sexual activities were no longer the same. Participants described their partners were no longer able to take on an active role in relation to sexual activities and that this has changed how they perceive the sexual experience. One participant discussed that sexual initiation prior to the onset of her partner's SCI would often include the way her spouse would look at her or touch her. These habits have changed due to her spouse's lack of mobility. She stated:

There's no variety. Like before, you know, certain things - - certain ways you touch someone, or whatever you'd be like, oh, that's different. You know or you try a new position or things like that. Well, now it's just straight the same thing all the time. So it's you know, boring I guess. I know it's sad.

Additionally, all participants discussed the impact of erectile dysfunction on their sexual habits requiring planning for positioning and/or the introduction of sexual devices.

The result of these role and habit changes was disruption to the volitional subsystem. All three areas of the volitional subsystem were impacted by the onset of SCI. Although all participants reported valuing sexuality in their relationships, many felt that ensuring the well-being of their partners was more important. As stated by one participant, “You sleep lighter at night, I guess. You have to make sure that anything that happens, you’ve got to get up and make sure everything’s okay.” Another participant discussed that the value of sexual relations has fallen below the rest of her responsibilities stating, “It’s just too much. We’d have so much to deal with every day. That, we just don’t need anything else.”

Although all participants indicated that participation in sexual activity was important to them, each reported a decrease in their personal causation or their feelings of competence and effectiveness. All participants discussed the impact of their partner’s erectile dysfunction on their personal causation. All reported that it made them feel ineffective in their sexual relationships. As stated by one participant, “I feel like I’m not doing my part. I’m not participating enough.....He can see that I’m aroused, but I can’t see that he is.”

These feelings of ineffectiveness, for some, resulted in a decrease in interest in participating in sexual activities. As stated by one participant when asked how the onset of SCI has impacted her interest in sexual activity, “Deeply. Majorly. Major. The drive just isn’t there anymore. For me.”

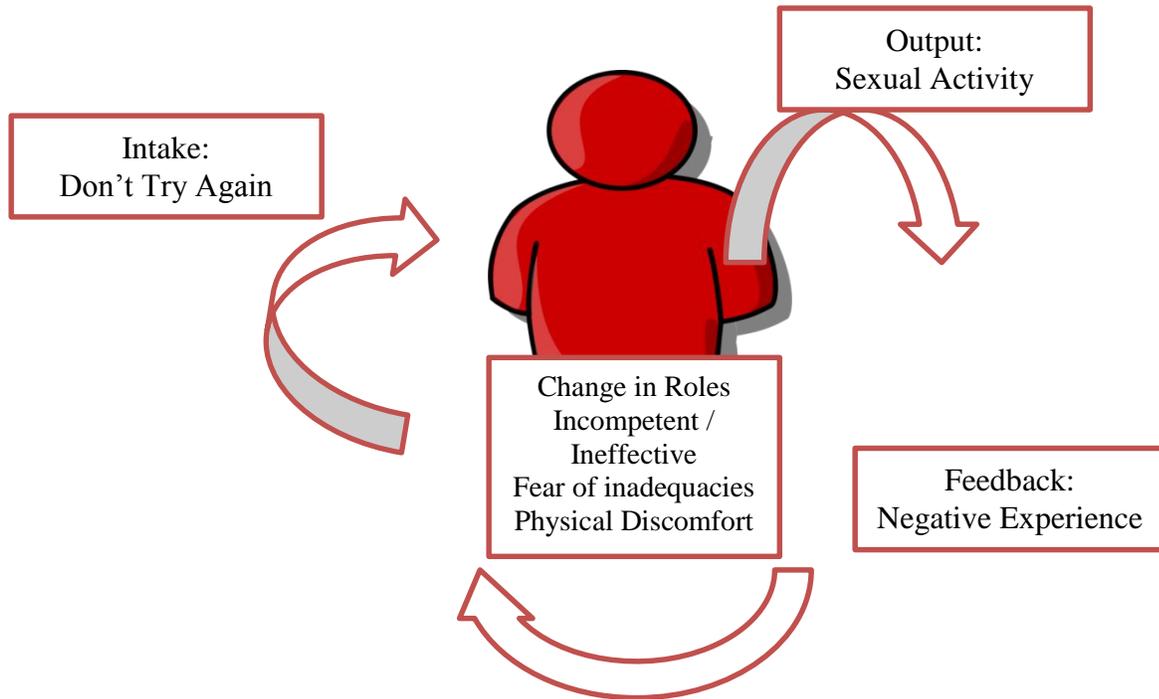
Lastly, performance capacity contributed to the participant’s decreased participation in sexual activities. As previously discussed, the mobility and sexual changes of the participant’s

intimate partners greatly impacted on how they valued sexual activity and effective they felt in this occupation. Additionally, however, the performance capacity of the participants also impacted their desire to participate in sexual activities. As stated by one participant:

If I don't feel good myself, I just don't want to be touched, I just want, you know, to lay there and go to sleep. But you know when you're in pain, it's kind of hard to make somebody else feel good or hope that you're making them feel good.

Many of the participants had tried several methods and techniques to increase their successful participation in sexual activities with little or no results. Thus, the internal feedback that these participants received was negative resulting in further disruption to personal causation and ultimately a lack of desire to continue trying (See Figure 8).

Figure 8: MOHO Feedback Loop



One example of this negative feedback loop was expressed by a participant when she stated:

The way it's going to be the first time, is usually the way it's going to be the rest of the time. And you know what to expect, what not to expect. And you hope you can change it, but it doesn't [crying].

Utilizing the MOHO, this study was able to demonstrate the complexity of sexual relationships relative to each individual. While each participant reported differing experiences related to the resumption of sexual activity, occupational dysadaptation was present in all cases. The use of the MOHO in developing the research questions for this study allowed the researcher to determine some of the common themes among the participants for future use in developing programs for intimate partners of individuals with SCI.

Implications for Practice

As outlined in Chapter 2, Occupational Adaptation was utilized to frame the implications for future practice. Occupational adaptation will be discussed as it relates to the development of programs to address the needs of intimate partners of individuals with SCI.

Occupational Adaptation.

Occupational adaptation was the framework chosen to frame potential practice in addressing the findings of this research. Occupational adaptation focuses on the adaptive response as it interacts within the physical, social and cultural environments (Schkade & Schultz, 1992). In the case of the participants of this study, the adaptive response is the manner and method that is utilized in the resumption of sexual activity.

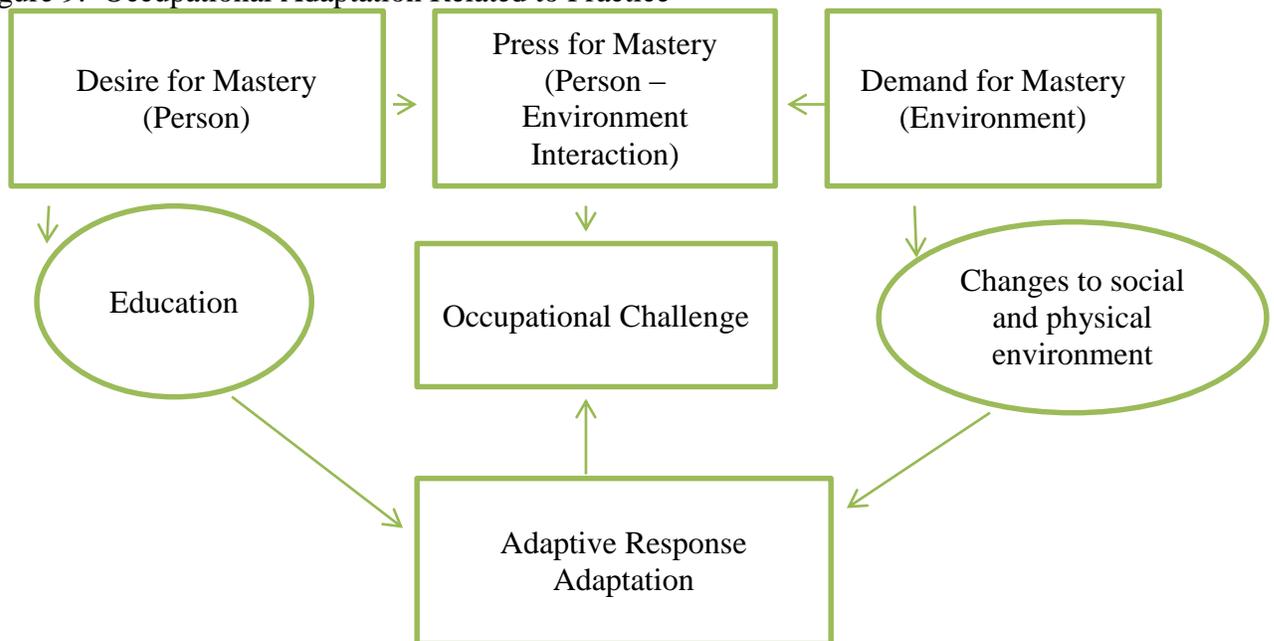
Each participant in this study is facing the occupational challenge of integrating the caregiver role and changes in life circumstances into their intimate sexual relationships. For all but one in this study, the occupational response to this shift has been negative resulting in

occupational dysadaptation or a negative response to the resumption of sexual activities. This negative response, according to Schkade and Schultz (1992), results in a strengthening of the dysadaptation. Each time the participants experience a negative response, despite changes that they make to alter the negative response, this dysadaptation is strengthened, ultimately resulting in a decreased desire for mastery.

According to the occupational adaptation framework, occupational therapists can provide interventions that relate to both the person and the environment in order to enhance occupational adaptation (Schkade & McClung, 2001). For the participants in this study, enhanced and individualized education related to sexual activities could improve the potential for effective adaptation. Additionally, alterations to the environment, including social supports, could enhance the potential for occupational adaptation.

It is believed that occupational therapy could play an integral role in promoting the adaptive response in partners of individuals with SCI related to intimacy. Interventions could be provided at the person level (education) and at the environment level (physical and social) in order to facilitate effective adaptive responses to the occupational challenge (See Figure 9).

Figure 9: Occupational Adaptation Related to Practice



Relation to practice.

The *OTPF* outlines sexual activity as an ADL, indicating that this is within the scope of practice for occupational therapy practitioners (AOTA, 2014). Occupational therapy practitioners are in a unique position to address the issue of occupational role change and its impact on intimacy in the acute phase of the rehabilitation process (MacRae, 2013). During this phase, occupational therapists spend one to two hours a day with the injured individual and their families, thus allowing them to gain a deeper understanding of the dynamics of the issues than other healthcare professionals. Additionally, occupational therapists are uniquely qualified to modify and adapt both tasks and environments to enhance occupational performance (Hattjar, 2012).

Although many of the participants had received some education regarding the impact of SCI on sexuality and sexual functioning, many also reported that the information was incomplete and not specific to their individual needs. By providing the education prior to the participants having the opportunity to engage in sexual behaviors, the initial and subsequent negative experiences could be minimized resulting in more efficient adaptation. Additionally, more complete and concise information regarding the impact of caregiving related to sexuality could be provided.

It is believed that education could be enhanced through training sessions to address specific topics related to caregiving and intimacy for partners of individuals with SCI. The topics addressed should include the impact of SCI on sexual functioning, the impact of the caregiver role on intimate relationships, body mechanics and injury prevention for caregivers, and mindfulness training to enhance the understanding of thoughts and feelings related to the experience of caring for someone with an SCI (Hattjar, 2012). This education could be provided

one on one with the occupational therapy practitioner or through workshops designed to address these topics. Additionally, it is believed that it would be beneficial to provide the participants with interactive resources such as an educational CD or you tube clips that could be referred to as needed within the home environment. Providing information within the home environment could reduce the discomfort reported by participants during the group sexuality training that they received during the rehabilitation process. Regardless of the method of education, follow-up would be instrumental in ensuring the success of any program.

Recent literature supports training and education in mindfulness aides in decreasing stress and increasing sexual desire (Brotto, 2013; Brotto & Basson, 2014). Mindfulness training is based on a Buddhist practice which focuses on a heightened sense of self and self within relationships. Mindfulness encourages individuals to acknowledge and release negative emotions that inhibit forward progress within their lives (Sujato, 2012). This type of intervention has been utilized in psychology and in medicine with promising results (Williams & Kabat-Zinn, 2011). There are several identified approaches to mindfulness training however there is no evidence of a definitive program that would enhance the lived experiences of the individuals in this study. Mindfulness training methods need to be more fully explored in order to identify which methods would be most advantageous for this population. Although this may not impact the necessity of the role change, it could better prepare the partner for this shift. This could be an area for further exploration in occupational therapy practice.

Lastly, occupational therapy practitioners can enhance the occupational environment both physically and socially. The occupational therapist could contribute to enhanced occupational performance by providing recommendations for the physical environment to enhance the ability for physical closeness. Several participants reported a lack of physical closeness due to physical

barriers including ability to share a bed or sit next to one another on the sofa. Providing recommendations on lift systems or home modifications to enhance the ease of mobility could prove beneficial. Additionally, providing social outlets for partners of individuals with SCI through peer support networks or groups could enhance the individual's self-efficacy resulting in increased desire for mastery. Several studies indicate the importance of social support on quality of life for caregivers (Hui, Elliott, Shewchuk, & Rivera, 2007; Post et al., 2005; Rodakowski, Skidmore, Rogers, & Shultz, 2012; Waldron-Perrine et al., 2009). A thorough literature review on the effectiveness of peer support for caregivers revealed limited research in this area.

Although no literature regarding partner support specifically related to SCI was found, several studies have reported the positive impact of peer support related to other diagnostic groups (Boixados et al., 2014; Fowler, Haney, & Rutledge, 2014; Stewart et al., 2006). Fowler, Haney, and Rutledge (2014) found that the use of an online virtual neighborhood in which caregivers of individuals with dementia could share information resulted in decreased social isolation and decreased caregiver burden. Another study demonstrated the impact of peer support for caregivers of seniors with chronic conditions. In this study, the authors established a telephone peer support network for the participants. The results of this study indicated that participants demonstrated increased satisfaction with support, increased coping skills, increased competence and confidence and decreased feelings of isolation (Stewart et al., 2006).

Current literature for the provision of peer support focuses on the potential use of technology including the use of websites and blogs (Boixados et al., 2014; Fowler, Haney, & Rutledge, 2014). Additionally, one article found the use of telephone peer support to be beneficial to the caregivers (Stewart et al., 2014).

Other options for peer to peer support include participation in caregiver support groups. Studies have indicated that participation in face to face support groups are also beneficial in decreasing burden and increasing psychological well-being (Chien et al., 2011; Wei et al., 2012). One additional option would be to establish a registry for peer to peer networking. Given the reports from the participants in the current study however, it is believed that regardless of the chosen method of peer support, participants should be linked based upon level of injury and function of their intimate partners. Because SCI can result in varying degrees of functional independence, this is believed to be an important consideration.

Limitations of the Study

In this study, the lived experiences and occupations of individuals with partners with SCI related to sexuality was explored. In addition, the education and resource needs of these individuals were identified. Although this study resulted in the identification of significant themes, there are inherent flaws in any undertaking of research. Limitations in this study could be related to study design, sampling methods and data collection and analysis.

Although the use of a qualitative phenomenological approach was most appropriate for this topic, it is fundamentally susceptible to bias. Several steps were taken during the course of this study to reduce the risk of bias. Journal reflections were completed after every interview to outline thoughts and feelings of the researcher for review during the coding phase. Great care was taken to reflect on personal biases during the coding phase. Additionally, collaborative coding was utilized in which an individual with no experience in working with individuals with SCI related to sexuality assisted with the coding process. Lastly, themes were brought back and discussed with the participants for validation.

Sampling for this study could also be a limitation. For the purpose of this study, purposeful and snowball sampling was utilized to identify potential participants. Although recruitment took place in only one medical center in the state of Maryland, participants were from varying socioeconomic and racial backgrounds. The main sampling limitation is the sample size. For the purpose of this study, only four participants were recruited. Although this limits the ability for cross case analysis, the purpose of this study was to develop an in-depth understanding of the lived experiences of the participants. Because there was extremely limited data available on this research topic, it was believed that four case studies constitutes an important contribution to the literature and reveals themes to be further explored in subsequent research (Creswell, 2013).

The method of member checking also was a limitation of this study. It is believed that utilizing follow up phone calls may have limited the amount of further information provided by the participants. Given the sensitive nature of the topic, more data may have been yielded through a second face to face interview.

Another limitation of this study is that all participants were females. According to the National Health Statistic Report (2014), approximately 1.8% of the male population in the United States self identifies as gay, while .04% self-identify as bisexual (Ward, Dahlhamer, Galinsky, & Joesti, 2014). Given that 80.7% of all SCIs occur in males, it is not surprising that intimate partners of individuals with SCI are more likely to be female (NSCISC, 2014). Although no literature was found to support the differing experiences of men and woman with relation to sexual activity, it is known that there are differences in the biological make up and social contexts which could result in differing outcomes for this study (Crooks & Baur, 2008).

In addition to gender, another limitation is related to sexual identify and preference. All participants in this study self-identified as heterosexual and were involved in heterosexual relationships. This is an important limitation as there may be unique concerns for same sex couples specifically related to SCI.

The research topic itself could be a limitation to this study. It is possible that participants were impacted by the sensitivity of the topic during the interview process. Because sexuality is often considered a taboo topic, participants could have refrained from fully disclosing their responses to the interview questions. This could result in the inability to gain a full understanding of the lived experiences of these individuals. In an effort to prevent this from happening, the researcher began the interviews with less intrusive questions and informed the participants that they should let the interviewer know if they felt uncomfortable or did not want to answer any of the questions. This did not occur during the interviews.

Additionally, it is possible that only those individuals who were comfortable in discussing sexuality volunteered to participate. This may have resulted in missed themes for individuals who have more significant issues related to sexuality.

Another limitation relates to the impact that the environment plays on sexual intimacy. All participants in this study were living within their home environment with their partners. Issues for individuals whose partners are living in other places may be different and were not considered in this study.

Lastly, the experience level of the researcher could be identified as a limitation. After completion of the research project, through the use of reflective thought and journaling, the researcher has identified a limitation in skill level. Having experienced the interview process it is clear that there were several topic areas that could have been explored more in-depth. Deeper

reflection on participant answers and discussions during the interview process would have enhanced the questioning and ultimately the depth of the responses.

Recommendations for Future Research

While this study has enhanced the understanding of the lived experience of intimate partners of SCI related to sexuality, it has led to further questions and topics for future study to expand insights into this phenomenon. First, this study was performed with a very small sample size. It is recommended therefore, that further investigation with larger numbers of participants be undertaken. It is believed, given the small pool of potential participants in this area, that exploring the potential for a multi-site study would enhance the probability of increasing the sample size significantly.

Another recommendation would be to enhance the participant pool by expanding to other diagnostic groups and including male partners. This would allow for evaluation of themes across disabilities and across genders.

It is also recommended that further evaluation be undertaken with the same group of participants to further evaluate the identified theme of deviance. As this theme was noted during the analysis phase, it was not fully explored during the interview process. Because this theme was unexpected and unique to the literature, further evaluation could provide insights to inform future practice.

The experiences of same sex intimate partners of individuals with disability would be another area for future exploration. Although there is limited research on this topic, one group of authors reports that the difficulties faced by sexual minority couples are different from that of heterosexual couples. Kamen, Mustian, Johnson, and Boehmer (2015), report that fear of

prejudice and exposure can limit the intimate partner's participation in the health care process. This disparity could have a greater impact on the same sex couples adaptation and success related to sexual experiences.

An additional recommendation is to evaluate the intimate partners' prior participation in sex education as well as their beliefs and perceptions of sexuality. It is believed that the prior knowledge and thoughts related to sexuality could greatly impact the willingness to alter the sexual experience as may be required after the onset of disability. Having this knowledge could enhance the understanding of the lived experiences of the intimate partner related to sexuality.

Sexual desire is another area which could be explored further. A longitudinal type study would be most appropriate in evaluating sexual desire over time for intimate partners who are also care providers. This could allow the investigator to evaluate the impact of long term caregiving on sexual desire in order to support the need for interventions related to this topic. Lastly, further research in the area of effectiveness of individualized education programs, mindfulness sexual interventions and environmental supports should be undertaken.

The researcher has identified potential questions for future research. These questions were established as a direct result of the current study. The potential research questions are as follows:

1. What are the contributing factors to perceived deviance in sexual activity with an injured intimate partner?
2. Is the lived experience of intimate partners similar among different diagnostic groups?
3. Does the provision of educational and counseling programs for intimate partners of individuals with SCI and their partners enhance successful occupational adaptation?
4. Is sexual desire impacted by the caregiver role? Does sexual desire decrease over time in relation to this role change?

5. Does instituting a peer mentor program for intimate partners of individuals with SCI increased perceived quality of life for those individuals?
6. Does mindfulness training and meditation increase sexual desire in intimate partners of individuals with SCI?

Conclusion

For the intimate partners of individuals with SCI it is hoped that this research will provide a sense of support for issues related to sexual adjustment by allowing their collective voices to be heard. This research contributes to the existing body of literature by demonstrating that the occupation of coupled sexual activity can be impacted by, not only factors influencing the injured individual, but also by factors that influence their partners. This study also demonstrates the value of further examining the impact that the onset of SCI has on intimate partners which has not been sufficiently evaluated in previous literature. It emphasizes the importance of providing interventions that address the issue as a whole, the couple.

Appendix A: Pilot Study

Education and Resource Needs for Partners of Individuals with SCI

Gender: Male Female

Age _____

Partners level of injury: _____

1. When your partner was in acute rehabilitation, did anyone on the healthcare team address sexuality related issues with you personally? Yes No

If yes, who: Nurse Physician PT OT Other: _____

2. Were you given information on the physical changes in SCI as they impact sexuality?
Yes No

If yes, was the information adequate? Yes No

Comments: _____

3. Were you given information on the emotional changes in SCI as they impact sexuality?
Yes No

If yes, was the information adequate? Yes No

Comments: _____

4. Were you given information on medication / devices to assist in sexual relations?
Yes No

If yes, was the information adequate? Yes No

Comments: _____

5. Were you given information on managing the caregiver / partner role?
Yes No

If yes, was the information adequate? Yes No

Comments: _____

6. Were you given resources for managing the changing life roles as they relate to sexuality? Yes No

If yes, was the information adequate? Yes No

Comments: _____

7. Did you feel prepared to return to the role of sexual partner once discharged from the hospital? Yes No

8. Were there question that were not answered with regards to sexuality?
Yes No

If yes, please explain: _____

9. Once you returned home, were there issues related to sexuality that you wish had been better explained? Yes No

If yes, please explain: _____

10. When you returned home, was there anything that came up or surprised you related to sexuality?

Appendix B: Pilot Study

Dear [Mr. / Ms. LAST NAME],

I am writing to tell you about the “Identification of Sexuality Educational and Resource Needs of Partners of Individuals with Spinal Cord Injuries Study” being conducted by Kate Eglseder, OTR/L at Kernan Orthopaedics and Rehabilitation as part of my doctoral work at Towson University. Dr. Henry York is the physician investigator for this project.

I received your name through the spinal cord injury database maintained at Kernan. The purpose of this research study is to identify educational and resource needs for partners of individuals with spinal cord injury related to sexuality. The intent is to use this information in the future development of educational programs for sexual partners of individuals with SCI.

Your partner may be eligible for this study if they were your partner prior to the onset of injury, if you have maintained a relationship with them for at least six months after the injury, and if they are 18 or older.

If you and your partner are interested in participating in this study, please have your partner complete the enclosed survey and mail it back in the pre-paid envelope. All surveys are anonymous and it is requested that you and your partners do not write your names on the surveys. An additional sheet will be attached to each survey asking you to provide your names and contact information if you would like to participate in a focus group in the future. The names you provide with the surveys will be stored separately from the surveys and no names will be used in reporting of the results or publications from the study.

If you are interested in pursuing further counseling in this area, resources for local sexuality counselors can be found at <http://www.aasect.org/results.asp?state=MD>. It is important to note that the investigators, Towson University and Kernan Orthopaedics do not endorse any specific counselors.

If you are interested in learning more about this study prior to participation, you may contact me at 410-448-6718. For questions or concerns regarding the study design, you may contact my faculty advisor, Dr. Sonia Lawson at 410-704-2313, or the Towson IRB Chair, Dr. Debi Gartland, at 410-704-2236.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with Kernan Orthopaedics and Rehabilitation as a patient.

You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you, but you may receive another letter in the mail which you can simply disregard.

Thank you for your time and consideration. We look forward to hearing from you.
Sincerely,

Kate Eglseder, MEd., OTR/L

Appendix C

Dear [Mr. / Ms. LAST NAME],

I am writing to tell you about the “Lived Experiences of Intimate Partners of Individuals with Spinal Cord Injury (SCI)” study being conducted by Kate Eglseder, OTR/L at the University of Maryland Rehabilitation and Orthopaedic Institute as part of my doctoral work at Towson University. Dr. Henry York is the physician investigator for this project.

I am contacting you as a follow up to the previous study in which you indicated an interest in participating in future research on this topic. The purpose of this research study is to identify educational and resource needs for partners of individuals with spinal cord injury related to sexuality. The intent is to use this information in the future development of educational programs for sexual partners of individuals with SCI.

You may be eligible for this study if you were intimate with your partner prior to the onset of injury, if you have maintained a relationship with them for at least six months after the injury, and if you are 18 or older.

This study will require participating in a 90-120 minute interview in which you will be asked a number of questions regarding your current sexual relationship and any educational information that you received. The interviews will be recorded for transcription however no identifying information will be attached to either the hand written notes or the taped interviews. There is a minimal risk of discomfort in discussing sensitive issues related to this study.

If you are interested in learning more about this study prior to participation, you may contact me at 410-704-2769. For questions or concerns regarding the study design, you may contact my faculty advisor, Dr. Maggie Reitz at 410-704-2131, the Towson University IRB Chair, Dr. Debi Gartland, at 410-704-2236 or Jennifer Richards at the University of Maryland IRB at 410-706-5037.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with the University of Maryland Rehabilitation and Orthopaedic Institute as a patient.

You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you, but you may receive another letter in the mail which you can simply disregard.

Thank you for your time and consideration. We look forward to hearing from you.

Sincerely,
Kate Eglseder, MS, OTR/L

Appendix D

SCI Research

Researchers at Towson University and University of Maryland Rehabilitation and Orthopaedic Institute want to learn about sexuality education and resource needs for partners of individuals with spinal cord injuries. Research is always voluntary!

Would the study be a good fit for me?

This study might be a good fit for you if:

- Had a sexual relationship with your partner prior to the onset of SCI
- Have maintained your relationship for at least 6 months
- Are at least 18 or older

What would happen if I took part in the study?

If you decide to take part in the research study, you would:

- Be asked to participate in an interview describing your sexual experiences with your partner since the onset of SCI and discuss resources and education received during your partner's acute rehabilitation.

To take part in this research study or for more information, please contact Kate Eglseder, MS, OTR/L at 410-704-2769

The principal researcher for this study is Kate Eglseder OTR/L at Towson University The physician researcher for this study is Dr. Henry York at UMD Rehabilitation and Orthopaedic Institute

Kate Eglseder
410-704-2769

Appendix E

Interview Protocol: The Lived Experiences of Intimate Partners of Individuals with Spinal Cord Injury Related to Sexuality

Start Time:

End Time:

Date:

Location:

Interviewer:

Interviewee:

Project Description: The purpose of this study was to identify the lived experiences of partners of individuals with spinal cord injuries related to sexuality. The research questions are as follows:

1. What are the lived experiences of intimate partners of individuals with SCI related to sexual encounters?
2. What are the education and resource needs of intimate partners of individuals with SCI related to sexuality?

These questions are designed to identify the participants' perceptions of sexuality related issues when they returned home from rehabilitation and to identify what, if anything could have made the transition easier.

Volition

1. Could you describe how you and your partner met?
2. Can you tell me about how your relationship developed in regards to intimacy?

3. Could you describe your first sexual encounter with partner after your his / her injury?
 - a. What was this experience like for you?
 - b. How did you feel during this experience?
 - c. As you reflect on this experience, do you think that this experience impacted on your desire to continue to participate in sexual activities? Explain.

Habituation

4. Describe how your habits related to sexuality have changed since your partner's injury. For example: Were you spontaneous prior to injury? Were there certain ways that sex was initiated? How has this changed?
 - a. Do you feel that these changes have had an impact on your sex life? How?
 - b. Have you established new habits related to sexuality? If so, what are they? Are they as effective?
5. Have you had a change in your roles since your partner's injury?
 - a. What is it like experiencing these role changes?
 - b. How do you think that has impacted your sexual relationship?

Performance Capacity

6. Do you feel you have experienced any physical or mental changes since your partner's injury? (e.g., back injury, depression, fatigue) If so describe.
 - a. How have those issues impacted how you view your sexual relationship?

Environment

7. Have there been any changes to your environment which you feel have had a positive or negative impact on your sexual relationship? Describe.
 - a. Have you changed the environment to enable sexual contact?
 - b. Have you added any assistive devices to your sexual activity?

Occupational Identity

8. How do you feel your sexual relationship changed since the injury? How would you like it to be now?

Discussion

9. How is your sex life today?
10. How did you and your partner talk about the new situation in your sex life?
 - a. What was it like discussing or not discussing this issue in your perception?
 - b. What information on communicating about this issue may have been helpful if any?
11. What type of information or counseling did you receive about the sexual changes of your partner during their rehabilitation stay?
 - a. Did you receive information regarding the physical changes that resulted from their injury (educational resources / adaptive technology)?

- b. Did you receive information on the potential emotional changes that can occur with SCI?

12. What information would you have liked to receive?

- a. Would it have been helpful to receive more information on the physical changes associated with SCI? If so, what would you have liked to have known that you didn't?

- b. Would it have been helpful to receive more information on the psychological changes? If so, what would you have liked to have known that you didn't?

- c. Would it have been helpful to receive information on managing the physical or psychological changes related to sexuality? If so, what would you have liked to have known that you didn't?

13. What advice would you give health care practitioners regarding addressing sexuality?

14. What have you learned about this experience, related to sexuality, that others might find helpful?

Age of Interviewee:

Gender of Interviewee:

Age of SCI Partner:

Gender of SCI Partner:

Appendix F

**Faculty Research Sponsor Agreement
Review of Research Validity, Design, and Oversight
(Required for student led Human Subjects Research)**

Name Principal Investigator: Kate Eglseder

Title of Research: The Lived Experiences of Intimate Partners of Individuals with SCI

Purpose of research (i.e., classroom requirement, Master’s thesis):

Dissertation

The IRB will rely on your careful consideration and review of the following 4 questions:

- Is the research likely to achieve its aim? Yes X No ___
- Is the proposed research of sufficient scientific importance to justify the risks entailed? Yes X No ___
- Are there adequate resources to complete the study? Yes X No ___
- Are the research procedures designed to minimize risk to subjects? Yes ___X No ___

As the faculty sponsor of this project, I agree to do the following:

1. Oversee the design and conduct of the study
2. Ensure that the student researchers assuming duties are well-trained and competent
3. Review the protocol application prior to submission to the IRB
4. Provide guidance in the protection of human research subjects
5. Assure proper application and reporting to the IRB
6. Work with the student researcher to identify modifications warranted by unanticipated problems or circumstances involving risks to participants.

Faculty Sponsor Signature

Date

My signature certifies that I have read the application referenced above and found it complete and appropriate for submission to the IRB for consideration.

 S. Maggie Reitz / Department of Occupational Therapy and Occupational Science
Print Name of Faculty Sponsor/Department

APPLICATION FOR APPROVAL OF RESEARCH INVOLVING

THE USE OF HUMAN PARTICIPANTS

Please type, do not print. This form must be completed by the Principal Investigator/Researcher for any research project that involves human participants. Please submit:

- 1) the completed application;
- 2) the informed consent form(s) or cover letter
- 3) all materials, including instruments, to be used;
- 4) copies of any fliers, advertisements, or announcements that will be used to solicit participants.

1. Principal Investigator: Kate Eglseder

Investigator's Affiliation with Towson University (Please check one):

Faculty Staff Student Outside Principle Investigator

Principal Investigator Signature: _____ Date: _____

Title of Research:

The Lived Experiences of Intimate Partners of Individuals with SCI

Period of Research (start and end dates) Start August 1, 2014 End August 1, 2015

Institution & Department: Towson University / Department of Occupational Therapy and Occupational Science

Address to which approval should be sent:

10811 Baronet Rd Owings Mills MD 21117

Applicant's Phone: 410-402-3640 Applicant's E-mail Address: keglseder@towson.edu

Co-Investigator(s): _____

2. If you are a student please provide the following:

Faculty Sponsor Name: S. Maggie Reitz Phone: 410-704-2131

Purpose (*i.e.*, classroom requirement, Master's thesis): Dissertation

Please submit a completed Faculty Sponsor Research Agreement form with your application.

3. Has this research project been previously considered by the IRB?

Yes No Last approval date: _____

Original PI's name: _____

2. What are the education and resource needs of intimate partners of individuals with SCI related to sexuality?

7. What is the research design and what will be required of each participant? (Attach extra page if needed)

A qualitative collective case study design will be utilized. Data will be collected utilizing a research protocol (see Appendix A). One 90-120 minute semi-structured interview per participant will be performed. Follow up phone or in-person interviews will be scheduled if more time is required to complete the protocol.

8. How will the participants be selected? If you intend to recruit volunteers, please attach all advertisements and flyers. (Be specific. If students, will they be solicited from classes?)

Participants will be selected using convenience sampling. Although participants will be recruited via convenience methods, meaning that recruitment will take place at only one medical center, actual participation will be determined through inclusion criteria and narrowed based on age and time since injury. After obtaining IRB approval through Towson University and the University of Maryland Medical System, participants will be recruited through three entities at the University of Maryland Rehabilitation and Orthopaedic Institute --the caregiver support group, the SCI support group, and the spinal cord rehabilitation clinic. Short recruitment presentations will be provided at the support groups and recruitment flyers (see Appendix B) will be posted in the SCI clinic and rehabilitation areas. Additionally, letters will be sent to individuals who reported interest in participating in research on this topic after a previously completed pilot study (see Appendix C).

9. Do you believe that your research should be considered:

Exempt (If yes, indicate category)

Expedited review (If yes, indicate category 9)

**"Anonymous" refers to a study designed so as not to allow the investigator or anyone else to determine the identity of individual participants from the collected data. "Confidential" refers to a study designed so that, even if participants are identifiable to the investigator, their identity will not be revealed to anyone else.

10. What are the risks to the human participant (physiological, psychological)**

Participants may experience negative feelings regarding their current situations related to sexuality. All participants will be offered resources on sexuality counselors in the area.

11. How will confidentiality of the participants be maintained? (Is the study anonymous? Who will know the identity of the participants? If pre- and post-test, how will participants be identified?)

All data will be handled in a manner to ensure confidentiality. Each participant will be issued a participant number. The corresponding names and numbers will be maintained in the

researcher's office in a locked cabinet. All data including the research protocol and notes will be marked with the identifying number only. No other identifying information will be placed on either hard or electronic data.

12. Is there any information with regard to protocol or intention that will not be disclosed to the participant on the informed consent form? If so, what is it, and why will it not be disclosed?

No. See Appendix D for Informed Consent

13. What debriefing information will be given to the participants following their participation? If any information was withheld from the participants, it must be disclosed at the debriefing.

After transcription and initial analysis, participants will be contacted to assure intent and interpretation. Participants will be given the option of receiving a summary of the study findings. For those participants who are interested, a summary of the findings will be mailed following the study.

14. Specify the participant characteristics required (age, gender, etc.) and the number of participants. (Be specific)

Participants must have been in a sexual relationship with a spinal cord injured individual prior to the onset of injury. Participants must have maintained the partner relationship for at least six months post injury. Participants must be over 18 years of age. The plan is to interview a minimum of 6 participants and a maximum of 10.

15. How will the data be recorded and stored? (Be specific). **PLEASE NOTE:** All original data must be kept for a minimum of three years. Data of student researchers must be kept in a secure place in the faculty sponsor's office.

Interviews will be audio recorded for transcription. Additionally, a written research protocol will be used to take notes during the interview process. Hard data will be stored in a locked cabinet in the researcher's office and electronic data will be stored on a password protected computer on the Towson University campus for at least three years.

**"At Risk." A participant is considered to be at risk if the possibility of physical, psychological, sociological, or other types of harm may be the consequence of an activity which goes beyond the application of established and accepted methods necessary to meet the needs of the participant, or which increases the ordinary risks of daily life, including the recognized risks inherent in a chosen occupation or field of service.

Appendix H

In hind sight, what education, resources or supports related to sexuality did you receive prior to your partners discharge from the hospital? Check all that apply:

Adaptive Equipment

- Positioning Devices
- Erection Aides
- Lubricants
- Environmental Changes to Enhance Sexuality
- Other

Medical Information

- Medications for Erectile Dysfunction
- Impact of Current Medications or Erectile Function
- Orthostatic Hypotension
- Autonomic Dysreflexia
- Bowel Management During Sexual Activity
- Bladder Management During Sexual Activity
- Sensory Changes Related to Sexuality
- Physical Changes and Relation to Sexuality
- Other

Social Supports

- Caregiver / Partner Support Groups
- Spinal Cord Injury Support Groups
- Online Caregiver Support
- Community Groups for Leisure and Recreation
- Mentoring / Support from Other Partners of Individuals with Disabilities
- Other

Psychological Support

- Resources / Information on Psychological Services
- Resources / Information on Area Sex Counselors
- Resources / Information on Area Sex Therapists
- Other

Additional Comments: _____

Appendix I



APPROVAL NUMBER: 14-A101

To: Kate Eglseder
8000 York Road
Towson MD 21252

From: Institutional Review Board for the Protection of Human
Subjects Beth Merryman, Member

Date: Monday, July 14, 2014

RE: Application for Approval of Research Involving the Use of
Human Participants



Office of Sponsored Programs
& Research

Towson University
8000 York Road
Towson, MD 21252-0001

t. 410 704-2236
f. 410 704-4494
www.towson.edu/ospr

Thank you for submitting an Application for Approval of Research Involving the Use of Human Participants to the Institutional Review Board for the Protection of Human Participants (IRB) at Towson University. The IRB hereby approves your proposal titled:

The lived experiences of intimate partners of individuals with SCI

If you should encounter any new risks, reactions, or injuries while conducting your research, please notify the IRB. Should your research extend beyond one year in duration, or should there be substantive changes in your research protocol, you will need to submit another application for approval at that time.

We wish you every success in your research project. If you have any questions, please call me at (410) 704-2236.

CC: M. Reitz
File



Date: Monday, July 14, 2014

NOTICE OF APPROVAL

TO: Kate Eglseder **DEPT:** OCH

PROJECT TITLE: *The lived experiences of intimate partners of individuals with SCI*

SPONSORING AGENCY:

APPROVAL NUMBER: 14-A101

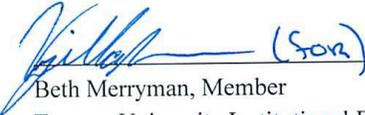
The Institutional Review Board for the Protection of Human Participants has approved the project described above. Approval was based on the descriptive material and procedures you submitted for review. Should any changes be made in your procedures, or if you should encounter any new risks, reactions, injuries, or deaths of persons as participants, you must notify the Board.

A consent form: is is not required of each participant

Assent: is is not required of each participant

This protocol was first approved on: 2014-07-14

This research will be reviewed every year from the date of first approval.


Beth Merryman, Member
Towson University Institutional Review Board

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Kate Eglseder MS, OTR/L, CLT



EDUCATION

| | | | |
|------|------|----------------------|---|
| 2015 | ScD | Occupational Science | Towson University, Towson, MD |
| 2005 | MS | Education | McDaniel College, Westminster, MD |
| 2003 | Cert | Upper Quarter Rehab | Drexel University, Philadelphia, PA |
| 2001 | MS | Occupational Therapy | Dominican College, Blauvelt, NY |
| 1995 | AA | Occupational Therapy | Catonsville Community College, Catonsville, MD |

Specialty Certifications

| | |
|------|------------|
| 2002 | Lymphedema |
|------|------------|

PROFESSIONAL / RESEARCH AREAS OF SPECIALIZATION

Spinal cord injury / Neurologic Rehabilitation

Orthopedic Trauma Rehabilitation

Sexuality in Physical Disabilities

ACADEMIC POSITIONS HELD

| | |
|-----------------------|--|
| 2013 – Present | Towson University, College of Health Professions, Clinical Assistant Professor |
| 2012 – 2013 | Towson University, College of Health Professions, Visiting Faculty |
| 2006 - 2012 | Towson University, College of Health Professions, Adjunct Faculty |
| 1997 – 2008 | Community College of Baltimore County, Adjunct Faculty |
| 2006 – 2007 | Anne Arundel Community College, Adjunct Faculty |

OTHER PROFESSIONAL POSITIONS HELD

| | |
|-----------------------|--|
| 2013 – Present | Per Diem Occupational Therapist, University of Maryland Rehabilitation and Orthopaedic Institute Baltimore, MD |
| 2010 – 2013 | Staff Occupational Therapist, University of Maryland Rehabilitation and Orthopaedic Institute Baltimore, MD |
| 2005 – 2010 | Patient Therapy Manager, Kernan Hospital, Baltimore, MD |
| 2002 – 2005 | Senior Occupational Therapist, Kernan Hospital, Baltimore, MD |
| 2001-2002 | Staff Occupational Therapist, Kernan Hospital, Baltimore, MD |
| 1996-2001 | Staff Certified Occupational Therapy Assistant, Kernan Hospital, Baltimore MD |

SCHOLARSHIP

Publications

Riegal, S., & Eglseder, K. (2009). Occupational justice as a quality indicator for occupational therapy services. *Occupational Therapy in Healthcare (23)*, 288 – 301.

Presentations

National

Eglseder, K. (2015, April). *The use of theoretical models in developing research*. Poster presented at the American Occupational Therapy Association national conference, Nashville, TN.

Eglseder, K., Patria, L., & Marken, T. (2009, April). *Occupational therapy's role in addressing sexuality in adult rehabilitation*. Presented at the American Occupational Therapy Association national conference, St. Louis MO.

Regional / Local

Eglseder, K. (2014, November). *Occupational therapy's role in addressing sexuality*. Presented at the Maryland Occupational Therapy Association conference, Towson, MD.

Eglseder, K. (2014, March). *Recovering intimacy after stroke*. Presented at the meeting of the Annapolis Stroke Support Group, Annapolis MD

Eglseder, K. (2013, October). *Intimacy and stroke*. Presented at the Stroke Conference, Towson, MD.

Eglseder, K. (2009, November). *Splinting for fracture management*. Presented at the University of Maryland Physical Therapy School, Baltimore MD

Eglseder, K. (2008, November). *Serial casting*. Presented at University Specialty Hospital, Baltimore MD.

Eglseder, K. (2008, November). *Fracture bracing*. Presented at the University of Maryland Physical Therapy School, Baltimore MD

Eglseder, K. & Wantz, K. (2009, November). *Complex splint design*. Presented at the Maryland Occupational Therapy Association conference, Baltimore MD.

Eglseder, K. (2004, November). *Splinting: Back to basics*. Presented at the Maryland Occupational Therapy Association conference, Baltimore MD.

Eglseder, K. (2001, September). *Bowel and Bladder Management with SCI*. Presented at University Specialty Hospital, Baltimore MD.

Eglseder, K. (2001, September). *Quadriplegic dressing techniques*. Presented at University Specialty Hospital, Baltimore MD.

SERVICE

University

January Conference Committee - 2014

College of Health Professions

CHP Case Study Committee Member: 2012 - present

CHP Faculty Development Committee, Secretary: 2013 - present

Department of Occupational Therapy and Occupational Science

Departmental Library Liaison

Pi Theta Epsilon Faculty Advisor

PROFESSIONAL AFFILIATIONS

American Occupational Therapy Association, Member: 1996 – Present

Maryland Occupational Therapy Association, President: 2015-Present

Maryland Occupational Therapy Association, Executive Vice President: 2014- 2015

AWARDS AND SCHOLARSHIPS

Recipient Maryland Scholarship for Occupational Therapy
Induction into Omicron Delta Kappa Leadership Honor Society

