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## Wheelchair Bound Not Sex Bound: Reconstruction of Self and Sexual Identity after Spinal Cord Injury

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Wheelchair Bound Not Sex Bound:  
Reconstruction of Self and Sexual Identity after Spinal Cord Injury

By  
Elisabeth Mumford

A Thesis Submitted in Partial Fulfillment of the  
Requirements for the Degree of  
Master of Arts in Sociology: College Teaching Emphasis  
in  
Sociology Department

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Mankato, Minnesota

April 2014

Wheelchair Bound Not Sex Bound: Reconstruction of Self and Sexual Identity after  
Spinal Cord Injury

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This thesis has been examined and approved by the following members of the student's  
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## ABSTRACT

Wheelchair bound not sex bound explores how individuals with spinal cord injuries (SCI) create a new sexual self and identity after their injury. Graduate student Elisabeth Mumford in the Sociology and Corrections Department at Minnesota State University, Mankato examined how individuals reconstruct a new sexual self. Physical disabilities have become more prevalent with the increase of sport injuries. Most of these disabilities are often result in SCI leaving individuals in a wheelchair. In the hospital, individuals receive information on how to live with this new injury, but often rehabilitation programs ignore the aspect of sexuality. Without this aspect being covered individuals with disabilities are required to reconstruct a new sense of sexual selfhood. Most research on this topic lacks a theoretical framework and the purpose of this paper is to use symbolic interactionism and connect this theoretical framework to the literature on the sexuality of spinal cord injuries. This study uses symbolic integrationist's Mead, Cooley, and Goffman in understanding the process and problems of reconstructing one's self and sexual identity after an SCI. In interviewing ten individuals with a SCI in 2013-2014 it was found in order to create a new sexual self and identity individuals with SCI need to rewrite their own sexual scripts, find a partner who is educated and has an open mind to experiment what is possible, and men and women will experience the reconstruction of sexuality differently.

## **Table of Contents**

Chapter One: Introduction .....	1
Chapter Two: Literature Review and Hypothesis .....	5
Chapter Three: Research Design .....	30
Chapter Four: Findings .....	35
Chapter Five: Conclusions .....	53
References .....	59
Appendix .....	64

CHAPTER ONE:  
INTRODUCTION

Finally it is six o'clock on a Friday, the weekend is here, and after a long exhausting work week and there is nothing else you would rather do than drive home and relax on such a beautiful summer day. As you walk toward your vehicle you grab for the keys to unlock the door and start to think about weekend plans. After opening the car door you sit down, start up the vehicle and meander out of the parking lot to head home. This drive is nothing unusual. It is the same road you have traveled many times commuting to work. As a commercial plays over the speakers in the vehicle you decide to change the station to something to set the mood for the beautiful weekend to come. Reaching down to change the knob on the radio you notice in the distance a vehicle passing other vehicles, but think nothing of it since it is far enough away. As you look down to find your favorite radio station and glance back up you notice the car is only a few seconds from hitting you. In order to avoid a head-on collision you instinctively jerk the steering wheel towards the shoulder of the road. You lose control of the car, hit a field approach and tumble end over end out into a field. While the car is tumbling you can hear and feel the roof crumpling around your head and suddenly everything goes black.

As you regain your consciousness you start to believe everything was just a dream until you open your eyes and notice that you are in a hospital room. In looking around you notice a glass of water on the table next to you and begin to find yourself thirsty. You try to reach for the glass and you cannot move your arms and legs. Panic starts to set in as you try to figure out why you are unable to reach for the glass of water. Is this still all a dream? Minutes pass, which feel like hours, until a doctor enters the room. They

introduce themselves and inform you that you have been in an accident and have broken your neck leaving you paralyzed. As the doctor keeps talking everything else seems to fade out and the word paralyzed keeps echoing in your head as you realize this is no longer a dream, but instead reality. Now what would be your first thoughts? What aspects of your life would have suddenly changed the most? In what ways would you imagine that your relationships with others might change? While it is unlikely to be an immediate concern, in due time you will surely discover just how much your life has changed-in even the most personal and private aspects. This thesis explores one of those intimate dilemmas that face people who incur a spinal cord injury.

A disability is defined as “difficulty or dependency in carrying out activities essential to independent living,” (Fried, Ferrucci, Darer, Williamson, and Anderson 2004:255). Physical disability is defined as any impairment which limits the physical function of one or more limbs (Fried et. al. 2004). An example of a physical disability is a spinal cord injury (SCI). It is estimated that approximately 10,000 people in the United States suffer a spinal cord injury and need hospitalization every year (DeVivo 1997). After hospitalization individuals normally enter a rehabilitation process, which often includes physical therapy. In the rehabilitation process the topic of sexuality is sometimes not addressed and at times avoided (Fronek, Booth, Kendall, and Miller 2005) despite the fact that sexuality is an important aspect of an individual’s self-concept, emotional well-being, and quality of life (Milligan and Neufeldt 2001). Often sexual and reproductive health is ignored in individuals with disabilities, “people with disabilities are entitled to the same sexual and reproductive health services as are people without disabilities”

(Omer, Heruti, Navon-Porat, and Hardoff 2012:193). Without attaining sexual therapy people with disabilities often have a difficult time reconstructing a sexual selfhood.

Sexual selfhood cannot be completely understood without understanding self and identity. George Mead (1913) discusses how each human being has a self that provides everyone with a unique sense of character. Self also permits individuals to become an object of their own actions, which allows an individual to designate certain things to themselves (e.g. goals, actions, pains). Mead also distinguishes that self is important because it allows individuals to be able to interact with themselves in order to judge, analyze, and evaluate certain aspects of internally. Without a self an identity could not be created, because identity is the self's specific definition of itself. Stone (1962) illustrates in his book, *Appearance and the Self*, how an identity is established. An identity is established through the interaction with other individuals; it is through this interaction process that individuals assign words that describe a certain individual, but this can only become a part of someone's identity when it is acknowledged. "It is in the coincidence of placements and announcements that identity becomes meaningful to the self" (Stone 1962:93). Self and identity are two important concepts when discussing selfhood since it is all the things (personality, identity, and individuality) that make an individual who they are (Sangrey and Shotwell 2009).

Previous literature has introduced the issue of the lack of sexuality reconstruction education given to people with disabilities, but no study has connected it to a theoretical framework in an effort to better understand. In looking at the sexuality of individuals with spinal cord injuries symbolic interaction is the best theoretical framework to gain a better knowledge of how difficult this identity process is for an individual. The theorists,



## Reconstruction of Sexuality and SCI

Erving Goffman and Charles Cooley's work can be applied when looking at previous literature and applying it to the reconstruction of self and sexual identity after a physical disability.

Another gap within the literature is the way the data is collected. Often quantitative methodology is used to gather information on sexual rehabilitation programs, life satisfaction of individuals with spinal cord injuries, and sexuality among people with disabilities. Qualitative methodology has been used with similar studies but never directly addressing the reconstruction of sexual identity in individuals with debilitating injuries. Being that sexual identity is such an important part of the self, and adult interactions, a study directly on the subject would bring to light important information directly affecting many people with spinal injuries.

My research will use qualitative data to gather information about sexuality among individuals with spinal cord injuries, this type of data collection will provide a better understanding of the reconstruction of the sexual selfhood. By use of a theoretical framework and qualitative methodology outsiders will better understand the issues that are involved in reconstructing a sexual selfhood after suffering a SCI. The data will be collected through semi-structured interviews with individuals who are either quadriplegic or paraplegic and been living with the disability for a year or more. The goal of this research is to examine the journey of individuals with SCI's as they reconstruct their sexuality and what this process entails. Where do individuals with SCIs turn to obtain education when little is given in rehabilitation programs? Where do they find their greatest influences or support systems during the renegotiation of a sexual identity?

## CHAPTER TWO: LITERATURE REVIEW AND HYPOTHESES

Spinal cord injury results in either temporary or permanent loss of motor, sensory, and or autonomic function (The National Spinal Cord Injury Association 2013). There are thirty-one nerves in the spinal cord, and these are divided into four sections (The National Spinal Cord Injury Association 2013). The cervical area is the top of the spinal cord and is identified as C-1 through C-7. The thoracic area is the second section in the spinal cord that is close to the chest; this area is identified as T-1 through T-12. The lumbar area is responsible for the lower back; it is the third section of the spinal cord and is identified as L-1 through L-5. The last section of the spinal cord is called the sacral area and is identified as S-1 through S-5 (The National Spinal Cord Injury Association 2013). Based on the level and the extent of injury, an SCI can be divided into two categories: (1) tetraplegia (formally known as quadriplegia) and (2) paraplegia. Tetraplegia is when there is damage to the cervical region resulting in loss of movement in all four limbs (The National Spinal Cord Injury Association 2013). Paraplegia is injury to the thoracic area, lumbar area, or sacral area; this results in losing feeling in only the lower part of the body (The National Spinal Cord Injury Association 2013).

Issues that individuals face with SCI are inability to move, loss of bodily functions (e.g. bladder and bowel dysfunctions), and pain. The most common help that an individual receives when he/she suffers a SCI is physical therapy (Booth, Kendall, Fronek, Miller, and Geraghty 2003). In physical therapy, individuals learn how to perform daily functions again. Although physical therapy is important for individuals with SCI, physical therapy only briefly touches on the topic of sexual activity (Booth et. al. 2003). Therapists tend to ask their clients if they have any questions about sex; yet,

many individuals do not ask because they do not feel comfortable, or they are not at a point where they understand that their sex life has changed drastically. Many individuals with SCI tend to report sexual dysfunction, and this has a big impact on the individual's relationship with themselves (Knapp, Reitz, and Schurch 2004). Individuals who have suffered a SCI find there are drastic changes to their life and activities that they will need to adjust to. Booth et. al. (2003) argues the most problematic adjustment is sexual because of the lack of education given in rehabilitation programs. Stiles, Clark, and LaBeff (1997) argue the myth concerning the sexuality of people with physical disabilities is asexual.

### *Symbolic Interaction Applied to the Sexuality of People with Disabilities (PWD)*

In examining the literature on individuals with physical disabilities, especially those with spinal cord injuries, there is very little precedence for theoretical framework. This is largely due to the fact that the issues facing people who incur a spinal cord injury are seen as a medical issue and rarely explored from a sociological standpoint. Symbolic interaction has been seen as the most suitable theoretical framework for looking at the reconstruction of self and sexual identity and therefore it is the theory I have chosen to study individuals with spinal cord injuries in this thesis.

George H. Mead (1913) articulates the concept of self and how it is a process an individual experiences. Individuals can gain much knowledge about what they have become as a person by examining the construction of their "self." This aspect of Mead's work is useful in assisting researchers while exploring the identity reconstruction process of an individual that has suffered a spinal cord injury (SCI). In this self-reflection process

SCI individuals reconstruct their very self; this includes a change in their sexual selfhood due to the adaptation required by their consequently altered physical abilities. Leibowitz and Stanton (2007) interviewed a woman who described the difference in her sexuality from pre-to post-injury:

Sexuality definitely means something to me different than it did before my accident...Now I think that it means not only a sexual act, but actually means the feelings you have, the thoughts you have, and how you express yourself...in a nutshell, how you see yourself as a person...how you feel about yourself...It's a whole lot more mental than I ever thought it was...and I think that's just a lesson I had to learn, which was good for me. (Leibowitz and Stanton 2007:47)

Mead (1913) also states how the self is not only created by our own self reflections, but how we interpret our appearance to others. The understanding of individuals with SCI of how others view them in affect, changes the way they see their personal self. This inner dialogue of "other" awareness is known as self-conscious. Being self-conscious entails the individual attempting to comprehend how others perceive them which then influence the self. Individuals with SCI face self-consciousness in regards to individuals perhaps noticing their wheelchair, and maybe compelling them to think they are a nuisance to others or asexual because of their obvious physical impairment. This self-stigmatizing imaginative process is elaborated by a wheelchair user, "My rolling in probably wouldn't affect people in that way, but in the back of my mind I'm afraid it would. I'll have to get over that" (Cahill and Eggleston 1994:302). Reconstructing one's self is a difficult process because it is a dire time in which an individual must wrestle with the conflict between their old and new identity (Mead 1913). The new self can only be obtained once an individual realizes the new consciousness and begins to accept it.

Self was also explored by Charles Cooley with his most famous contribution being the concept of the “looking-glass self” (1902). Among people with disabilities the reconstruction of self is developed because of the imagined perceptions of others. Individuals conform to what others think and start to act the way that others perceive them (Cooley 1902). This theory of looking glass-self can be seen through the way people with spinal cord injuries are perceived to be asexual by society. The myth of asexuality is reinforced by rehabilitation centers where staff tends to ignore the issue of sexuality. By not receiving education on sexuality, individuals with spinal cord injuries tend to fall into the inaccurate belief that they are expected to be asexual. This instills in their self the expectation that they are incapable of sexual activities and desires. In creating a self that begins to accept the idea of being asexual it is adopted as a part of that individual’s identity.

Identity is an important concept in my research since social roles are used in order to form an identity. Gregory Stone (1962) states how individuals rely on others in order to help give them an identity. Once this identity is given there are certain roles that are to be acted out in order to maintain that identity. An individual who suffers a spinal cord injury needs to start understanding the certain roles that are to be followed associated with the identity of being disabled. In addressing the sexuality of men, the norm of what is masculine is that of being sexually active (Burns et. al. 2008). A man with a spinal cord injury faces the obstacle of others perceiving him as asexual and unable to fulfill the role of being masculinity. This societal stigma can and does strongly affect a man’s sexual self (Burns et. al. 2008). This process of norms and identity can create an aspect of stigmatization in people with disabilities which reflects the work of Erving Goffman.

Goffman's (1963) work on stigma is useful when examining the reconstruction process of sexual identity because individuals with SCI are often stigmatized. In his work he discusses two different types of stigma: discredited and discreditable. Discredited stigma is one that is evident or known to other individuals. Discreditable stigma involves something that is not immediately noticeable to others but has the potential to be unveiled and therefore discredit the individual (Ritzer 2011). For this study the stigma that is examined is discredited, since others are clearly able to see from the indicator of a wheelchair that an individual has a physical disability. Goffman examined how individuals that are stigmatized use emotion management in order to protect their identities. In Gardner's (1991) work she finds how individuals with physical disabilities often tend to avoid going out in public because of the stigmatization they experience. As Cahill and Eggleston (1994) found that when wheelchair users do go out in public they often use emotion management in order to protect their identities. This type of emotion work can be connected to that of "face-work", where individuals try to keep a positive image when interacting with individuals.

The reconstruction of self and sexuality by people with disabilities is a topic that needs to be further examined among the theoretical framework of symbolic interactionism. Many researchers (Booth et. al. 2005, Cross, Couldrick, and Sadio 2010, Gordon, Hart, Herson, and Rintala 1999, and McAlonan 1996) have found it is important to help bring to light the lack of knowledge that people with disabilities receive in the rehabilitation program. The deficiency of sexual education given in rehabilitation programs is a problem because it contributes to the idea that people with spinal cord

injuries are asexual. In having this thought process in society and not addressing the issue it creates the problem of this population having a difficult time reconstructing their self.

Cooley's looking glass self (1902) concept discusses the importance of the relationship between oneself and others. Looking glass self has three main processes: (1) individuals imagine how they must appear to others, (2) individuals imagine and react to what they feel others judgment of that appearance must be, and (3) individuals develop a self through the judgment of others (Ritzer 2011). An example that best illustrates this concept of Cooley's is research by Milligan and Neufeldt (2001) of how society perceives people with disabilities as being asexual. Society's acceptance of the myth that people with disabilities are asexual (Milligan and Neufeldt 2001) makes it difficult for these individuals not to conform to how others think of them to be (Cooley 1902). This myth of asexuality being accepted also affects the education that people with disabilities receive in their rehabilitation program; since these individuals are perceived as sexually dysfunctional educating these individuals on the topic of sexuality is not a priority (Booth et. al. 2003). The perception of individuals with a physical disability being asexual can start to make individuals act differently and not seek out sexual education because they may feel they are incapable of sexual activity (Milligan and Neufeldt 2001). If a physically disabled individual develops a sense of self that is asexual, based on the perception of others, that person's identity is altered to that acuity.

Individuals develop a self through the judgment of others (Cooley 1902); this concept can be related to identity as in: "identity is the self's situational definition of itself" (Waskul 1996:26). Interaction with others allows an individual to understand aspects of their identity based on the roles that are given to that particular identity. For

example, in the work of Milligan and Neufeldt (2001) individuals with disabilities view themselves as asexual because that is what others perceive them to be. Their perception in turn leads them to limit their own intimacy with others, this in turn can lead to a 'loss of self' (Charmaz 1983).

An individual that is disabled has to go through the struggle of learning and/or resisting the roles that come along with the new identity of being disabled. This perception of someone being disabled in our society gives the impression that the individual is asexual, since it is difficult to see how someone who is disabled is still able to be sexually active (Gardos and Mona 1994). Fraley et. al.'s research (2007) focuses on the sexual lives of individuals that identify as gay, lesbian, or bisexual who are disabled. In their study they found that these individuals struggle with their mental well-being due to this change in identity. Milligan and Neufeldt's (2001) work illustrates how identity can also be applied to one's sexual orientation, making it difficult not only to be intimate with others, but also to choose sexual orientation. As previously stated, Cooley's looking glass self is how an individual perceives themselves based on the interactions and perceptions of others. This concept can be applied to identity because of how it is created based on the perceptions of others; especially that of sexuality.

Many individuals that have an SCI experience a change to their sexual identity. A study done by Phelps, Brown, Chen, Dunn, Lloyd, Stefanick, Davidson, and Perlash (1983) found that 42 % of men post-injury were sexually dissatisfied, while 20% of men described sexual dissatisfaction pre-injury. The loss of sexual identity can result in matters such as lower self-esteem, body awareness, and denial of the disability. Individuals who are able to find a new sexual identity have a higher sexual satisfaction



(Cameron, Kalichman, Krause, Lesondak, and Mona 2000). Sexual identities take work, and this can vary between women and men. Physical therapy can be effective, but there needs to be more attention placed on sexuality to help individuals with SCIs (Knapp et. al. 2004). Overall, the loss of identity and creating a new self-identity can be hard.

Stigmatization is placed on individuals with disabilities and this can be illustrated by Goffman's work on stigma. "Stigma leaves little to repair and less to add;" (Gardner 1991:251), can help illustrate the work of *Stigma* by Goffman and how stigma happens to everyone throughout their lives. But, those with a physical stigma often are more aware of this because being disabled is easier to see than someone who has a stigma inside of them, like that of being homosexual (Ritzer 2011). Gardner examines stigmatization of individuals in public areas. One of the types of individuals interviewed are those with disabilities. From this ethnography the author was able to conclude that individuals with disabilities receive stigmatization. "A man said to me, "When I was young, we kept people like you [person with disability] in institutions"" (Gardner 1991:255). The stigmatization individuals with spinal cord injuries receive has an effect on their identity. An individual may go so far as to not even go out in public unless they are with someone that society finds as normal (Gardner 2006). The loss of sexual identity can result in the diminishment of self, which can increase the likelihood of suicide (Lombardi, Mondaini, Iazzetta, Macchiarella, and Popolo 2008).

*Suicide Rates in Individuals with SCI*

Suicide is one of the top ten causes of death in the United States and Europe (Centers for Disease Control and Prevention 2012). In individuals that have SCI, the suicide rate is two to six times more likely than the general public (Burns et. a. 2010). Individuals with SCI experience depressive symptoms which is a warning sign for suicide (Centers for Disease Control and Prevention 2012). Men are more likely to commit suicide than women, while women are more likely to *attempt* suicide. The reason men are more likely to commit suicide compared to women is because men are more likely to be under the influence of alcohol prior to committing suicide. Women are less likely to succeed because of taking things into consideration and are able to change the decision of suicide because of not being under the influence of alcohol (Centers of Disease Control and Prevention 2012). The style of suicide differs between men and women; women are more likely to overdose while men are more likely to use firearms (Centers for Disease Control and Prevention 2012). Suicide is a disorder that is multidimensional: biological, psychological, and environmental. SCI individuals tend to commit suicide because they feel isolated from others and have a hard time identifying their sexuality after injury (Chau, Hegedus, Praasma, Smith, Tsukada, Renwick, and Yoshidsa 2008). Isolation is a predominant fact in predicting suicide in people with disabilities and can be evident in the self, peers, and the disabled community. An individual with a spinal cord injury that has used the injury as a personal growth experience, peer support, and is active within the disability community are less likely to commit suicide (Weitzner, Surca, Wiese, Dion, Roussos, Renwick, and Yoshida 2011). Chau, et. al. (2008) did a study looking at perceptions of individuals with SCI and their changed bodies. In this research, they

interviewed individuals with SCI. A female individual living with quadriplegia for seventeen years was quoted:

I still don't enjoy looking at myself in the mirror. Like I can look at, you know, from the chest up sort of thing, but I still don't like looking, you know, I'll be going down a mall or something and I'll see the reflection there, it's not something that I, you know, it's more of a reality thing. (Chau, et. al. 2008: 214).

This quote can be tied to Cooley's looking glass-self (1902) and how the body has an effect on an individual's perception of their self. Individuals that often have a body that deviates from the norm is often stigmatized against, as Goffman's points out in his work on stigma (1963). Having a body that is stigmatized causes individuals to feel shame and they may tend to avoid going out in public so that their faults are not revealed to others (Gardner 1991). As the female's quote indicates, when our body "no longer generates appreciative erotic power, a classic looking-glass (Cooley [1902] 1964) process may compel us to feel undesirable, unattractive, inadequate, and thoroughly unsexy" (Waskul 2002:214). Individuals with SCI experience sexual dysfunction and this can impair the way the individual views him/herself. A sexual dysfunction is referred to by authors Iazzetta, Macchiarella, Mondaini, and Popolo (2008) as any sexual difficulty an individual with a spinal cord injury experiences during any stage of sexual activity. For their study they found erectile dysfunction (ED), lack or loss of sexual desire, and difficulty of having an orgasm to be the most common types of sexual dysfunction in SCI individuals. Iazzetta et. al. (2008) studied SCI individuals that were hospitalized for their injury. They found that individuals with SCI tend to have a difficulty establishing a stable relationship, and this lack of relationship makes them feel isolated and increases their likelihood of committing suicide. Individuals that had romantic relationships before the accident tended to be more successful in their sexual adjustment and created greater

sexual intimacy. The most important way to prevent suicide is to be able to spot the warning signs. Although individuals with SCI suffer depression after the incident, it does not mean that every individual will commit suicide. Sexuality in individuals with SCI is different between the sexes, and this will be explored in the following sections.

### *Spinal Cord Injuries in Women*

Women make up 20% of individuals that have a spinal cord injury (Roop and Sharma 2005). Only a limited amount of information is given on women's sexualities in rehabilitation programs due to the small percentage of women with spinal cord injuries. Most rehabilitation programs tend to focus more on men's sexualities since they make up the majority of the spinal cord injury population. Women overall, especially those with SCI, tend to be more focused on the intimacy of sex while men are more focused on the act of sex. Leibowitz and Stanton (2007) interviewed several women that have lived with SCI for years. One woman was quoted saying:

I think to a woman it [sexuality] is different than [to] man, and it's more of an emotional intimacy and a sharing and a caring. It could *involve* your sex organs and it could not. It could be just a kissing and a ... like I said, a *closeness*... I guess it's more or less a very close intimacy with your partner. (2007: 49).

Sexuality is important to an individual's self-esteem, quality of life, and overall health (Taleporos and McCabe 2001). A study by Tepper, Whipple, Richards, and Komisaruk (2001) examined the psychological, emotional and relationship aspects of women that live with SCI. There were 15 women in this study that had damage between the areas of T6 and L2. These women in study were all volunteers, and the study was focused on their sexuality post and pre injury. When looking at pre-injury, the researchers found no common themes between the 15 women. From this group of women, 14 had

experienced coitus and 13 experienced orgasm. Among these women, they agreed that intercourse was an important part to their sexuality. Although this research found no common theme in the pre-injury, three common themes were seen in the post-injury: (1) cognitive-genital dissociation, (2) sexual disenfranchisement, and (3) sexual rediscovery.

Cognitive-genital dissociation is the process refers to the “experience of purposely “shutting down” or “shutting out” sexuality, based on the assumption that sexual pleasure was no longer possible because of absence of sensation in the genitals” (Tepper 2001:619). The reason for the process of “shutting down” sexual pleasure is because so much energy is used in learning this new life of being disabled sex often becomes a low priority.

Sexual disenfranchisement is when women feel deprived of their sexuality based on receiving “lack of or inadequate sexuality education/counseling” (Tepper et. al. 2001:619). Both cognitive-genital dissociation and sexual disenfranchisement have been seen to constitute a loss of self-esteem after injury.

The other theme seen in post-injury was sexual rediscovery, which is an “increased interest and motivation led to a sexual reawakening and rediscovery that referred to the experience of sexual pleasure” (Tepper et. al. 2001:620). The women in this study discussed how rediscovering their sexuality took several years. Once SCI women are able to reclaim their sexuality, their sex lives improve and they are able to enjoy orgasms again (Tepper et. al. 2001).

Not only is a woman’s sexuality hurt by injury, but there are also other factors. Many individuals with SCI experience significant change because they lose control of

their bodily functions. Other studies found that there are more functions that change for women with SCI. This change of the body can create a change in the sense of self (Waskul 2002). The change between the body pre and post injury changes a sense of self because of the relationship pre-injury; the body gives meaning to the sense of self.

One study done by Sharma and Singh (2005) found that sexual activity, relationships, menstrual, hygiene, pregnancy, and sexual education received in rehabilitation programs have changed the lives for women living with a SCI. In this study, 10 women had quadriplegia, and 30 had paraplegia. Looking at sexual activities in this study, women indicated a decreased desire for sex after post-injury. The main reason for this decreased desire for sex is because of the nature of genital intercourse. Women tend to have difficulty with feeling the penis and issues with bladder and bowel functions. In this study, 19 women rated their sex life worse than pre-injury (Sharma and Singh 2005). This study also found problems with relationships and how they have changed drastically for women. In the interviews Leibowitz and Stanton found that one woman was able to describe her change in relationship with her husband:

I never really had penetration with my ex-husband, because he was always comparing me to how I, we used to be. And, you know, that was an impossibility. It wasn't going to be like that anymore. And he lived a lot in the past. So that probably had a lot to do with...the growing apart. (2007: 50)

Another change Sharma and Singh (2005) found was that there was no change in women's menstruation but hygiene became an issue. Forty-one percent of these women indicated needing to use sanitary pads, while the 59 percent used ordinary clothes. Another hygiene problem women face is bladder and bowel changes. Having menstrual and other hygiene problems lead to infections.

The women in the study also discussed pregnancy and child bearing. Even with losing feeling in their bodies, they discussed no change in child bearing. During the pregnancy, many of the women discussed an “increase in or appearance of bed sores, episodes of UTI, and vaginal infections” (Singh and Sharma 2005:27). These changes in the body can be tied back to cognitive genital dissociation and how these changes result in women making sexuality a low priority.

The last finding in Singh and Sharma’s (2005) study concerned sexual information or education (Teeper et al (2001). The 40 women that were surveyed discussed receiving little to no sexual information when receiving therapy for their SCI; from the 40 women, only 12 said they received information about sexual matters from therapy. The women that did receive sexual information, only a few found it to be useful, while the other remaining women found the information to be fragmented and not at all helpful.

The impact of change to the body that occurs with a spinal cord injury can end up affecting one’s self, in that the body they have no longer is the same as the one pre-injury. With this changed body also comes a changed identity, having to play the accurate role of someone who is disabled. Women with SCI tend to have a difficult time finding their sexuality after injury due to the fact that much attention of SCI is on men (Singh and Sharma 2005).

*Spinal Cord Injuries in Men*

According to the Center of Disease Control and Prevention (2012), men are four times more likely to sustain an SCI. Where women make up 20% of people with SCIs, men make up roughly 80% of those with such injuries (Roop and Sharma 2005). Men constitute most of those with SCIs because men tend to live riskier lifestyles (Center of Disease Control and Prevention 2012). Men also experience change in their sexualities when it comes to SCI. Most men living with SCI report little to no sensation to their genitals, and this is the main reason for loss of sexuality (Phelps, Albo, Dunn, and Joseph 2001). For men, the loss of sexuality seems to be more problematic because it is closely connected to masculine norms. Burns, Mahalik, Hough, and Greenwell's (2008) study focuses on the masculine gender norms and how these tend to be important for constituting what it means to be masculine. These norms can also determine a man's social status or work performance. Within society there is stress of conformity of these norms on men. There tends to be more stress on men who cannot fulfill the gender norms of being masculine, and this is seen in males with SCI. With this higher amount of stress in individuals with SCI, it can put them at risk for experiencing higher feelings of depression. An important factor of what constitutes being masculine is the ability to have sexual intercourse. (Burns et. al. 2008).

As with women, men also report difficulties with sexual satisfaction due to the change of their sexual functionality. Deterioration in a male's sexual function is called erectile dysfunction. Erectile dysfunction does not necessarily mean that individuals are unable to have intercourse; instead, they are unable to acquire or sustain an erection as they used to (Elliot 2010). With many men having SCI, there has been much concern



about the penis. There are two ways that an individual with SCI can sexually function as normally as possible: (1) implantations of three piece inflatable penile prosthesis and (2) intracavernous injection (Wiwanikit 2008). Elliott (2010) explains the various treatments of erectile dysfunction in men with SCI, “first-line treatments in the SCI population are non-invasive oral therapies and mechanical devices, with second choices being the more invasive intracavernosal injections, followed by surgical options” (3809).

The oral medications that Elliott mentions includes medication like Cialis and Viagra, this treatment is the most common due to the cost and that it is not invasive. Intracavernosal injections (ICI) are another option both Elliott (2010) and Wiwanikit (2008) mention in their literature. This is a self-administered penile injection into the base of the penis and is more reliable than the oral medication due to the dose response. Although such methods help a man with SCI to regain sexual functioning, the ability to ejaculate and reproduce can become problematic. These treatments for sexual functioning are rather expensive, but a lower-cost solution may be Viagra. This medication is used to help men with disabilities to gain an erection. These erections are not as functional as they would be in men without spinal cord injuries, but this medication still helps with erectile dysfunction.

Viagra sounds like it could solve the problem of erectile dysfunction in males with spinal cord injuries, but in an article by Emily Wentzell (2006), finds this easy solution is not truly solving the problem. One of the problems of this medication, Wentzell states, is that it brings about stigmatization in those that are disabled. This idea of stigmatization can be applied back to Goffman’s work on *Stigma* (1963) with how being disabled creates this idea of a failure to meet standards of what constitutes normal

intercourse. The author also claims that Viagra should not be used in individuals with disabilities because it cannot enhance their sexual experiences, because the medication does not provide a hard penis; which Viagra claims it can present (Wentzell 2006:377). The author suggests that this idea of what constitutes one's sexuality should not be based on sex alone; rather sexuality should be based on a different type of scope. The use of Viagra is not helping change this scope, rather this medication allows for the sexual identity of individuals with disabilities to be stereotyped based on their bodily and sexual differences. Wentzell concludes that although Viagra creates stigmatization and does not work completely on those with disabilities, some type of medication needs to be created in order to help these individuals. These medications should not be used in order to define one's sexual identity or even one's identity alone.

In bringing Wentzell's work back to that of Goffman's, medication could be used as a way for an individual to help not reveal their fault of an erectile dysfunction. The concept of not wanting to reveal their faults can go into Goffman's work in interaction ritual or also identified as "face-work". "Face-work" focuses on how individuals try to create a positive image of themselves when interacting with others (Ritzer 2008); which can be applied to the bedroom.

Reproduction becomes a problem in men with SCI because they often have deep scrotal temperatures when compared to average men. This impacts the semen quality. This issue of scrotal temperatures could be contributing to the occurrence of lower ejaculation rates. Due to lower ejaculation rates sperm becomes contaminated resulting in lower fertility rates.

A study done by Biering-Sorensen, Hvarness, and Jakobsen (2007) looked at men with SCI and how they tend to have smaller prostate than men without SCI due to fewer ejaculations. In this study the patients were those registered in the Clinic for Spinal Cord Injuries. Thirty-two men were asked to take an ultra sound to look at the size difference of the prostate compared to those individuals that did not have SCI. The results showed that men with SCI tended to have a smaller prostate than those men who did not have SCI. In the test the men also gave blood samples to measure testosterone. The blood tests showed that testosterone levels were different between the two groups of men. The researcher concluded that men with SCI had smaller prostate and lower testosterone due to fewer ejaculations. Researchers found that eight men in the study ejaculated twice per month. Only nine men with SCIs in this study ejaculated but it was while they were using a vibratory stimulation once per month. While fourteen men with SCIs stated they had not ejaculated following the injury and if they had it was seldom (Biering-Sorensen, et. al. 2007: 121, 122). The process of reconstructing their sexuality can be a difficult process for both women and men, but with advanced medical technology and therapy both sexes may be able to reconstruct a sexuality that fits their new lifestyle. Yet, it seems that the struggle of regaining sexuality back in their personal life is not the only struggle, but that relationships tend to be just as troublesome.

### *Spinal Cord Injury and Intimate Relationships*

Chau et. al.(2008) interviewed individuals with SCI and several participants discussed

how seeking intimate relationship after their injury is fairly difficult. One woman in this study

was quoted saying the following:

...the stigma that a physical disability, by virtue of its visual impact, has on people that I think of as potential partners...My options are reduced because of how I'm initially perceived...and understood, just visually. So if you can't get pass the first visual thing, you're eliminated from someone's mind as a potential partner (2008:216).

This quote illustrates Goffman's work stigma, as mentioned earlier. In his work on stigma he focused on how individuals manage impressions of themselves when they deviate from approved appearance. This impression management is used to protect one's identity. An article by Cahill and Eggleston (1994) identifies three ways that wheelchair users manage their emotions: humor, anger, and sympathy. As seen in this woman who was interviewed she clearly understands how stigma impacts her future relationships and how this stigma makes finding relationships more difficult. It is estimated that 80% of individuals with SCI remain single. Many studies have looked at individual's struggles with relationships after injury and how individuals can indeed have pleasurable sex with their partners, but as seen before it is difficult to redefine one's identity and sexuality. A study by Noam Ostrander (2009) looks at the sexual pursuits among men and women. In this article individuals with SCI see themselves as less sexually desirable compared to those without injury. With individuals that have partners they may feel that their partner may view them as incapable of sexual engagements. That thought is deceptive (Ostrander 2009). People with SCI remain sexually active even after their injury; they just have barriers they need to overcome (Booth 2005). As seen in the woman who was interviewed, relationships tend to become more difficult with injury. Many studies have examined individuals with SCIs struggling with starting or obtaining romantic relationships after injury and how they can have pleasure during sex with their partners.

In Ostrander's research he looked at individuals with SCI and their partners and found three barriers that need to be overcome in order to have a successful relationship: (1) society's neutering perspectives, (2) internal oppression, and (3) loss of physical sensation. Society's neutering perspectives is when individuals in the relationship with people with SCIs often tend to see them as being "asexual or incapable of engaging in sexual relations" (Ostrander 2009:11). The idea of being asexual or incapable can be tied back to the research of Milligan and Neufeldt (2001) when they found these are myths held in society about people with disabilities. Internal oppression is the person with SCI viewing themselves as "less sexually desirable and having diminished capacity to express themselves sexually" (Ostrander 2009:11). The third, barrier of loss of physical sensation, is the thought that intercourse will not be pleasurable for either partner. Though these three barriers often affect the individual with the injury, they can also affect the partner. The biggest barrier that affects the partner is that of social criticisms from others. Ostrander (2009) suggests that if these three barriers are overcome the relationship will come to realize that sex does not need to be focused on genital pleasure, but instead sex can be creative and fun.

Phelps et. al. (2001) looked at SCI and married individuals. The main purpose of their study was to look at the sexual satisfaction between married individuals with a partner that has SCI. While looking at the sexual satisfaction they also looked at sexual functioning. Research was gathered through questionnaires and 115 questionnaires were returned out of the 482 that were sent out, giving a 24% return rate. The questions that were developed asked about sexual behavior, functioning, satisfaction, and needs for services, as well as relationship issues. Of individuals that responded at least 96% were

sexually active. These sexual activities were broken down into kissing, intimate touching, oral sex, intercourse, masturbation of partner, and masturbation of self. The highest sexual activity was kissing while masturbation of self was the lowest. The frequency of sexual activity was reported “never was only two percent while every week was the highest with 44 percent” (Phelps et. al. 2001: 595). Few reported genital sensations and of those who reported stated they could only get a partial erectile function. Individuals that were in relationships enjoyed the sexual part of the relationship very much.

Regarding partner satisfaction with individuals with SCI, “74 percent of individuals stated they were satisfied with the sexual activities” (Phelps, et. al. 2001: 596). SCI can change the relationship of individuals in several ways: sexual behavior, enjoyment, and satisfaction. For individuals with SCI who are able to please their partner, they feel better about themselves and tend to find that their relationship is strong. All of these studies illustrate a strong connection to Cooley’s looking glass self with how individuals view their body when a partner finds it appealing and desirable. The general public viewing wheelchair users as an undesirable body plays an important role in how these individuals portray themselves. “When our own nudity no longer generates appreciative erotic power, a classic looking-glass (Cooley [1902] 1964) process may compel us to feel undesirable, unattractive, inadequate, and thoroughly unsexy.” (Waskul 2002:214).

There is a great need for sexual rehabilitation services for individuals with SCI so they can have a successful relationship; if that means continuing a relationship that existed before injury or being able to start a relationship after injury. Education seems to be very important when discussing the sexuality of men and women. It was found in both studies that if individuals received education on sexual functioning then they seemed to

## Reconstruction of Sexuality and SCI

perceive sex not as genital sensation but as a creative and mutually rewarding activity (Ostrander 2009). It is crucial that individuals with SCI receive education and sexuality training programs so they can reclaim their sexuality which they may feel was lost due to the injury (Booth et. al. 2005).

### *Sexuality Training Programs*

Sexual difficulties that a male can encounter with a spinal cord injury (SCI) are the ability to have an erection and ejaculatory failure. For women, the difficulties are the inability to lubricate and experience an orgasm. In a study done by Viroj Wiwankitkit (2008) he that men with SCI have lower sperm count which can limit their ability to reproduce. Education for individuals with SCI has focused on redefining and expanding one's sexual expression, but even this information is limited as Ostrander (2009) finds when examining sexual rehabilitation services that are given to individuals with physical disabilities.

Ostrander (2009) found that the most crucial time for sexual intervention is the within the first six months after discharge. This is seen to be the best time because it is the time where individuals seem to struggle with gaining back their sexuality. Instead of being ignored, their sexuality and sexual relationships should be encouraged. Even though it is stressed that individuals with SCI should receive rehabilitation in sex, many places do not have training in this area. Fronk et. al. (2005) found in their study that the most ineffective rehabilitation programs are those that have staff who are uncomfortable discussing the topic of sexuality, have little knowledge about sexuality, and have a

negative attitude on the matter of sexuality. Within rehabilitation programs there have been several approaches or models dealing with the absences of sexual education.

One of the models was created by a clinical psychologist, Jack Annon (1974) and is called the PLISSIT model, which stands for permission, limited information, specific suggestions, and intensive therapy. This model is to be used by nurses that work in rehabilitation centers with individuals with disabilities, but the nurses are not necessarily limited to the model. The model has four distinct levels. These levels are for the nurses and any other helping professions in the work of the rehabilitation programs to provide some level of sexuality information to an individual with disabilities (Herson, Hart, Gordon, and Rintala 1999). Although this type of model has been the most used in sexual health for individuals with disabilities it has been rather unsuccessful. Researchers Couldrick, Sadlo, and Cross (2010) find that the PLISSIT model is unsuccessful for several reasons. One of the reasons is that the health-care teams in these centers are not working together and believe it is the nurse's responsibility to educate all the patients. The other problem of this model is the lack of exploration of the sexuality of disabled individuals (Couldrick et. al. 2010). With these limitations of the PLISSIT model a new model has been introduced; the recognition model. The proposed new sexual health model for individuals that work with the disabled eliminates the gap of information and takes a team approach (Couldrick et. al. 2010). In this model there are five stages in which each member of the team is responsible for ensuring all stages in sexual rehabilitation program are completed.

The first stage of this model is to recognize that disabled individuals are not asexual and they are sexual beings. The myth of disabled individuals being asexual



comes from the idea that because their body is dysfunctional they no longer have sexual needs (Milligan and Neufeldt 2001). The second stage is being open about discussing sexual concerns with patients. This stage can be difficult with sex being seen as a taboo in society and should be taken with a sensitive strategy. Stage three focuses on exploration. The sexual rehabilitation teams need to encourage patients to explore sexual concerns. The fourth stage is addressing the issues of discussing sexuality within the team's expertise and boundaries. This stage focuses on the workers in the rehabilitation center and how all of them need to gain more understanding and education about sexuality of disabled individuals. The last stage in this model is referral on and advocacy, meaning that when a patient has a question about sex and the team is unable to answer, they should be able to provide the patient with someone who is more knowledgeable in that field, like a sex therapist.

The recognition model that Couldrick et. al. (2010) have proposed should be used to “protect, support or restore the sexual health of disabled people” (297). Because of an increase in physical disabilities, like spinal cord injuries, there has been an increase in rehabilitation programs for these individuals, but the revolution of this program tends to become stalled in the United States due to the fact sex is viewed as taboo. Without educating society that people with disabilities (PWD) are sexual beings society will continue to hold stereotype that these individuals are asexual beings and not suitable for being a romantic partner (Milligan and Neufeldt 2001).

As researchers Booth, Kendall, Fronck, Miller, and Geraghty (2005) find that there is an inclusive focus on sexuality concerns in these rehabilitation programs and tend to focus more on the physical therapy side. As much literature would indicate the reason

for this lack of focus on sexuality in rehabilitation programs comes from that of discomfort on the topic and lack of education (Booth et. al. 2005, Booth et. al. 2003, Gianotten et. al. 2006, and Jones et. al. 2005). The concept of change is seen in rehabilitation program organizations reaching out for education and training in sexology. Training in medical sexology provides workers in rehabilitation programs with the ability to be comfortable with their patients and address the issue of sexuality (Gianotten et. al. 2006).

Often with having sexual education and having models for employees to use in the rehabilitation centers is ignored because of the topic of sexuality being viewed as taboo in society (Siegel 2007). The result of sexual rehabilitation programs not being offered to individuals with physical disabilities affects their life satisfaction. Fuhrer, Rintala, Hart, Clearman, and Young (1992) found that individuals with spinal cord injuries have a lower well-being when compared to people in the general population. One of these reasons of having a lower well-being or life satisfaction was sex life. Individuals felt they have lost control over this aspect of their life and due to having little education felt confused on their sexuality. These findings also correlate with Booth et. al. 2005 study when individuals with spinal cord injuries felt they received little education in their rehabilitation programs about sexuality and felt insecure when it came to their sex life.

### CHAPTER THREE: RESEARCH DESIGN

This research on the sexuality of individuals with physical disabilities used qualitative methodology. Qualitative research is a data collection that is often used in the social sciences to help provide an understanding of human behavior and what influences such behavior. Interviews are commonly used in gathering information on human behavior in using this type of methodology; other forms include group discussions, observation and reflecting on field notes. Qualitative study was the appropriate methodology for this study because it gave insight to the emotions that individuals with SCIs went through in reconstructing a new sexuality, which quantitative research could not illustrate. Also, by using qualitative methodology narratives of individuals can be experienced through quotes, which using graphs or statistical tables would not be able to show. The qualitative research that was used in this study was in-depth interviews. The questions were directed towards looking at the changes individuals experienced with their sexual identity based on their physical disability.

#### *Sampling*

This study focused on individuals that had a physical disability, namely, respondents who have a spinal cord injury (SCI) (quadriplegic and paraplegic). The reason for choosing only spinal cord injuries is because it narrows the focus to one particular group, since the physical disabilities category proves to be quite extensive if it is not broken down into smaller groups. Participants in this study are between the ages of 22-59 and have been living with a spinal cord injury for over one year. The respondents of this study reside in the Midwest region of the United States. In meeting with

participants I did my best to accommodate them for the purposes of the interview and went to great lengths to make sure the interview was a comfortable and convenient experience.

The sampling used for this study was convenience availability which was done in two ways. Sampling was conducted by putting up flyers (see appendix II) around Minnesota State University, Mankato, on social media (ex: Facebook), and in public areas. The flyers provided contact information that they could contact me if they were interested in participating. The second type of sampling that was conducted was after each interview I provided the participant with a poster (see appendix II) that they could pass onto other individuals that would potentially participate in the study. The sample size is ten individuals who are medically defined as being either quadriplegic or paraplegic, nine of them were Caucasian and one was African American, and seven of these participants were men while only three identified as female.

The technique used for collecting participants' stories was by using in-depth interviews. Participants were asked questions regarding the type of rehabilitation they received, education received, dating experiences, experiences with the public, and sex life. The purpose for asking these questions was to identify any difficulties the participants had encountered and what could be done in order to help this population have an easier time transitioning to their new sexual identity. When going into my interviews I had a list of potential questions to ask the participant (see Appendix I) and also used probing questions to receive more information. The group of individuals that were interviewed is considered to be a vulnerable population because of their disability. The

research questions also contribute to their vulnerability because of the sexual and personal nature of the questions being asked.

### *Data Collection*

The data that constitutes this study is the collection of how people with SCI recall the process of how they reconstructed their sexuality. This data was collected through in-depth interviews and the location of the interview was decided by where the participants felt comfortable and provided the easiest access. Many of the interviews took place in the participant's home, an ice cream parlor, and at rehabilitation centers. Before the interviews began the participants were given an informed consent form (see appendix III), to make sure that the participants understood the purpose of the research and their rights. A digital recorder was used during the interviews because it allowed me to focus more on what is being said and less focused on having to write everything down. The interviews took between half an hour to two hours. The interview took form of a structured conversation, where there was exchange between researcher and participant.

Before beginning the interview I talked to the participants about what their day was like just to start small talk which took between 10-15minutes. The purpose of talking to the participants before the study was to get them more comfortable with me. Once the participant and I got comfortable with one another the interview started with asking some of the structured questions. Once the interview was over the digital recorder was turned off and I continued to talk to the participant for another 10-15 minutes before leaving. The purpose for talking after the interview was used to thank the participant for their time.

*Data Analysis*

In analyzing the data I downloaded a program called RCA Digital Voice Manager, which is a program where I could upload the voice recordings to listen to them. All the participants' names and locations in this study were given a pseudonym in order to protect their identity. With all interview files entered into RCA Digital Voice manager software I was able to slow down the audio allowing me transcribe each interview into Microsoft Word. Once I transcribed each interview I began the coding process.

Interviews were coded following each of their transcriptions, during this step I kept an eye out for any themes. This consisted of going through each interview and coding them line by line, conceptualizing and categorizing the data (Charmaz). During this coding is where I examined each line of the transcript for categories of meanings or specific themes. After looking over several transcriptions, several codes started to emerge between them. Once themes continued to occur initial coding was used to get closer to the data, this helped create very specific categories such as being evaluated as a potential dating partner.

After coding I used the method of memo-writing, which was used to explore emerging themes within the codes which allowed me to think about the patterns, concepts, and ideas behind them. If there was a code that appeared in multiple interviews, memo-writing allowed expanding on the code and the context for when it was used. The specific code that prompted the memo was compared across participations for similarities and differences. Direct quotes were taken from the transcription and put into the memo to help back up evidence for that emerging code. These memos were used to develop and

explore themes and categories. The most developed themes that emerged from memo writing were used in the findings chapter for this thesis to show the sociological connection to the reconstruction of sexual identity.

### *Ethical Issues*

There are several ethical issues in this research; the first is that it is a vulnerable population asking questions about one's history of not being disabled could bring up unwanted emotions. In order to deal with this issue I provided the participants with a list of places they could receive counseling if they felt they need it (see appendix IV). The other ethical issue that the research proposes is asking questions that could be seen as sensitive. In order to deal with this potential issue, the research emphasized in the informed consent form and before the interview that they are able to refrain from answering questions they feel are invasive and can stop the interview at any time; which none of the participations in the study did. In order to ensure the protection of these individuals their names were changed and interview recordings were locked away when not in use and destroyed once research was completed.

## CHAPTER FOUR: FINDINGS

The reconstruction of sexuality in individuals with SCI is a change that takes time as it is, in essence, changing the fabric of what it means to be a sexual being. Individuals often create a script that works for their new lifestyle, but some find that creating new definitions of what means to be sexual is difficult due to society's proverbial neutering of wheelchair users. The path in reconstructing a new sexual identity focuses those to view how they are evaluated as a dating partner and also to create a new idea of how sexuality itself is no longer strictly a physical process, but more of a mental process. As these narratives illustrate, creating a sexual self is possible even when one loses the functioning of body parts that are often seen as what defines an individual as capable of being sexual. Gagnon and Simon (1973) focus on sexual scripts which refer to the way individuals learn about their sexuality through social interactions. They find that individuals learn about their scripts at three levels: (1) cultural, (2) interpersonal, and (3) intra-psychic. The participants in this research illustrate different aspects of these scripts, especially when it comes to intimacy. These narratives show how individuals with SCI were able to reconstruct their own sexual scripts through culture, interpersonal, and intra-psychic.

### *Being Evaluated as a Potential Dating Partner*

Individuals with SCI face difficulties when it comes to dating; Sarah confirms this notion, "I think it's [dating] really hard, I think it's [dating] really tough." Several other individuals with SCI had similar responses; having a body that deviates from the norm can make dating difficult due to stigmatization. Goffman (1963) saw that stigma was the gap between what a person ought to be, or the "virtual social identity", and what a person actually is, "actual social identity". He identified two types of stigma: discredited and



discreditable. Discreditable stigma is that the differences are not known to other viewers, since individuals know that person is different based on the usage of the wheelchair discredited stigma is more relevant. Discredited stigma is that the differences are known to other viewers. It is because of discredited stigma that made participants feel undesirable when it came to being evaluated as a potential dating partner.

From the interviews individuals discussed how they felt they were evaluated by others as potential dating partners. Male respondents discussed the difficulties in attracting women due to their wheelchair. Levi reflected on his life before the accident and described how dating was difficult even without a wheelchair, but now with a spinal cord injury it adds more difficulty, “Dating even without a spinal cord injury isn’t easy for some, but when you add a spinal cord injury, it becomes even more difficult.” When asking why individuals believed dating was difficult with a SCI, many of the responses indicated it is because of the discredited stigma. This can be illustrated in how Reginald explained why he felt dating was difficult, “...you know just trying to actually pick up women is hard, because I have this...wheelchair...” Kevin also reflected this stigma explaining the difficulty in attracting a dating partner as he now feels he needs to rely on other aspects of himself, “...it’s just so hard dating with having a disability...I really need to rely on my personality...once they see the wheelchair...they no longer want to date you.” The difficulty in attracting a dating partner as illustrated in these narratives and is because of how their body deviates from the approved appearance. As this 59-year-old man had learned from conversations with able bodied women, being with someone in a wheelchair is frightening, “I have a lot of women who love me...being

friends and that's not a problem with me, but to go beyond that scares them...the idea scares them."

Superfluously the idea of discredited stigma continued to present in explaining the difficulties of finding a partner. Levi confirmed how when it comes to dating it can become difficult because women are not necessarily looking for someone disabled, "...for most woman they are looking for tall, dark, and handsome, not tall, dark, and disabled you know? No woman is looking for that as a dream guy. It can be a bit difficult getting a woman to notice you because of being disabled...just because we are disabled, doesn't mean we are not worthy you know?" The idea of women not wanting to date a disabled man was echoed by Dan when he continues to explain why women are scared of the idea of having a relationship with someone disabled:

I have found that...women are like whoa, it's...like when you buy a car and see a really nice one sitting there and one that needs a lot of work, which one will you generally go for? The new one. It's not being shallow or anything else it's just that's the way it is. If you are going to pick somebody to be your life partner and looking around the room the last one you are going to settle on a lot of times is the injured person.

Although some participants found that their disability made it difficult to find a dating partner, Richard believed that his lack of dating was not due to his wheelchair, rather it was his own personality that was the barrier, "...it's always been my nature to make excuses not to try certain things, like asking out girls I had crushes on before my accident...honestly, if I wasn't in a wheelchair right now, there is a good chance I would find something else...as an excuse not to date."

The conversation of the difficulty of dating continued, but with a focus of participants discussing how they feel they are undesirable. Kevin believes he is unable to

find a partner because of how individuals view those with a disability as undesirable, “...some women don’t want to date me because I am disabled.” For men it seems to be difficult to find a dating partner due the gender norms of what it means to be masculine in a relationship (Burns et. al. 2008). Reginald talked about having to rely on a different aspect of himself because when it comes to finding a partner since he is unable to fit the stereotype of an attractive man, “I have to rely a lot on my...personality, you know? It’s just hard to...be that...you know all around sexy studly guy who can sweep a girl off her feet and take her home, sort of thing, just doesn’t work.” With reconstructing one’s sexual script, it becomes difficult at the cultural level with what constitutes as being masculine. From these narratives it can be seen that individuals feel that they are stigmatized by potential dating partners due to their wheelchair at the cultural level and reconstructing a script of dating is problematic.

#### *Dating Experiences of Wheelchair Users*

Social exchange theory (Sprecher 1998) focuses on the negotiation between two people who have a relationship with each other. This theory also is used to describe why two people choose each other as sexual partner and suggests that individuals choose one another based on rewards and costs, and reciprocity. Respondents narratives illustrate rewards, costs, and reciprocity when discussing how when they received a spinal cord injury, not only did they have to face that change, but also relationship changes. James discusses how his relationship changed after the accident:

...when I was hurt my girlfriend went for a while but she eventually, it was too difficult to figure it out...the relationship changed so dramatically...it was difficult for her to get use to the new reality, as it was for me...we went our separate ways...it’s hard for people to adjust to such a huge difference...for us we don’t have a choice, but for her she can walk away to a different situation...

Experiencing a change in a relationship after the accident was not uncommon for participants. Dave discusses how his previous relationship changed once he ended up in a wheelchair, “I just turned around and well, there ain’t no way you are going to take care of me so you ain’t worth shit to me...” In realizing that this relationship was not going to provide reciprocity it came to a sudden end. A relationship is only considered to be successful if both partners are equal and are receiving an equal amount of rewards. When one individual is no longer benefiting from the relationship it is guaranteed a change will occur (Sprecher 1998) Levi experienced a shift in his relationship after obtaining a SCI which he believed was due to the social pressure of being with someone in a wheelchair, “I remember her mother telling her something about taking care of me, ‘If you stay with him, you will be handicapping your life.’ At the time hearing this was devastating, but reflecting on it...I get it, she was just protecting her daughter...and wanting her to have the best...” These narratives both share this common theme of how partners are selected based on what they are able to do for one another, or the rewards and reciprocity, and once expectations change the search for a new partner might be necessary.

When searching for a potential dating partner all participants indicate a need to find someone who has an open mind. Tasha makes a point that when a person is considering dating a person in a wheelchair they have to think about how it will be more responsibility than dating an able body person. She shared when it comes to dating that it is important to find a partner that is open to the wheelchair lifestyle:

I think that someone dating someone in a wheelchair has more responsibilities...just going to have to accept everything that comes along with that person...if you are not willing to accept that person’s lifestyle of being in a wheelchair, I would say don’t date them.

Having a partner that understands and is open to dating someone in a wheelchair is a challenge. Sarah explains her relationship with a previous dating partner that was not comfortable with her injury and explains how this created tension between them:

...the relationship was really dysfunctional, um...he um...assumed that I should be over it, over my spinal cord injury, yea quit feeling sorry for yourself get over it, and I've, I mean the majority of the time I was very positive and upbeat, but of course everyone has those moments. He was just, he wasn't caring at all. Um...and I was in...uh...a difficult situation, he didn't want to be around when the care attendant was around. We lived together and he didn't want to be around when the care attendant was around so I would have him help me with things, so that would create pent up anger and aggression from him, um...so it was just supper unhealthy all around.

When asking what exactly it means to find a partner that is open minded Tasha explained that it is someone who is comfortable with the wheelchair lifestyle, "...someone that is open minded is a person that can deal with how I go to the bathroom differently, my sleep habits are different, cooking is different. Everything is a little bit different...even sex." Finding an individual with an open mind is perhaps most effective strategy when it comes to having a health relationship because it holds the reward of a pleasurable and gratifying relationship. Without having an open mind, like Sarah explained, creates a cost because it results in a loss (Sprecher 1998).

In dating experiences individuals are illustrating Mead's (1934) process of self-reflection. In this self-reflection process individuals with SCI need to make adaptations when getting back into the dating because of their altered physical abilities. In revisiting Goffman's (1963) work on stigma a body that deviates from the norm can have an effect on dating. Having a stigmatized body can cause individuals to avoid going out in public (Gardner 1991) as James discusses his dating experiences in a wheelchair and the challenges he faced, "...for me it, it seemed like it was hard for me to attach, and I don't

know if that is a part of my psyche or wounded psyche from the injury or what, but it was just difficult for a long time to figure out how do I trust you know, to commit to someone.” It can be difficult to reconstruct one’s sexual script with cultural ideas of wheelchair users being incapable of sexual engagements (Ostrander 2009). When getting back into dating after his accident Levi found that the topic of sex can be intimidating, “You start dating and it comes to the point of intercourse and it’s like oh shit, what do I do.” While Dave on the other hand discussed when it came to dating after his accident he just stopped looking, “I just let it [dating] go as it was, I really wasn’t looking...” The general public viewing wheelchair users as an undesirable body plays an important role in how SCI individuals portray themselves when it comes to dating as Richard illustrates, “I always had a hard time accepting that people are turned off by the fact of someone in a wheelchair, so that plays a big role in my dating life or lack thereof,”

It can be difficult for individuals to find a partner that is comfortable with dating someone with a SCI, as Lauren discussed it limited her options for partners, “...my outlets of dating were pretty limited until I got out of high school...” These ideas of other individuals reacting to their appearance also illustrates what Cooley discusses in his theory about how individuals imagine and react to how others view them and through this begin to develop a sense of self through these judgments of others. As some of these participants illustrate dating can become difficult based on the views of others. It is also just as important how individuals with a SCI also assume how others view them, as undesirable as some participants noted, and the sentiments that result. This is important, for it illustrates Cooley’s looking-glass process.

Finding a partner is possible as two participants exemplified by being in healthy relationships; these individuals explained the importance of having a partner who understands the disability, as Lauren illuminates "...knowing what someone is getting into with dating a person with a disability is refreshing..." With the partner knowing more about the disability it helps provide real expectations about the relationship as Lauren goes on to describe when talking about her healthy relationship, "it's refreshing to be with someone who is understanding of-the reality of being with someone that is disabled..." When asking Reginald about his dating experiences he conveys how dating someone that also has a disability is helpful because of these clear expectations and understandings, "...it's [dating someone in a wheelchair] a little easier because they know what to expect." Dan, who is married, found that having someone who is educated about the disability helps to create a better understanding, "...the more education they have on the subject the easier it is. Otherwise you find a lot of not knowing...doesn't help, you know it makes matters worse." His wife is a PCA, and had a clear understanding of his injury.

As these narratives illustrate, both individuals in the relationship are perform their role. The partner of an individual with a spinal cord especially, as participants stated that having someone that understands their situation it makes everything easier. Getting in a relationship is a reality for individuals with spinal cord injuries, but as Lauren discussed a person who is disabled needs to be cautious on the dating scene because they are more vulnerable, "...with being disabled you got to be extra careful when finding a dating partner because you don't want them to misuse you..." It is also important to think about how dating has changed because of having a disability. When asking Tasha how dating

has changed because of her SCI she found a few things that were different due to the chair, “Things are a little bit different, like...like before we could walk in the mall holding hands, but now I really can’t since I got to wheel myself around...” When asking the participants if they felt there was anything about dating they found would wrap up their whole experience Levi was persistent in wanting to state dating is hard for anyone, not just wheelchair users, “It’s easy to point out all the difficulties, different lifestyles and disadvantages a person in a chair faces when trying to date and the fact is, it’s a bitch in chair or not!”

*Reconstructing Sexuality as a Mental Activity*

Cooley’s (1902) looking-glass self focuses on how people’s consciousness is shaped through social interaction. An aspect of this theory is how individuals shape their self-concepts based on their understanding of how others perceive them. This idea from Cooley’s theory helps frame the stories of individuals with spinal cord injuries in regards to their experience receiving sex education.

When talking to the participants I asked them about the type of education that they received after obtaining their spinal cord injury, especially pertaining to sexual activity. A majority of respondents remembered receiving little to no education. As James states “Mayo Clinic really glossed over the whole sexual part.” Tasha and Dave also illustrated the same feeling when it came to gaining education regarding their sexual activity. When asked about sex education Tasha realized that no one talked to her about it, “My physical therapist was supposed to talk to me about it [sexual intercourse], but she never did.” When Dave was asked about his sexual education, he too remembered not



getting any, “No, I did not receive any sexual education; not at all!” These narratives reflect how the medical community has provided little information to these individuals.

Mead’s work of the generalized other can help explain how individuals develop their self through the interactions of others. With the interaction with the medical community individuals of spinal cord injuries start to develop sexual scripts in the context of a mute medical community and a dearth of information to help them with that process. Participants develop a sexual script of absence due to the medical community providing little to no information pertaining to sex or dating. Due to the medical community rarely educating individuals with SCI of their new sexuality the idea of a silenced sexuality is created. The development of self that evolves after a SCI believes they are no longer a sexual person is because everyone is meeting the requirements of the generalized other. Interpersonal scripts (Gagnon and Simon 1973) can be used to understand how individuals with spinal cord injuries reconstruct their scripts when given just the slightest amount of education regarding sexual activity. It is through interpersonal scripts that an individual is able to reshape their sexuality. This reconstruction of scripts can be easily illustrated in individuals that were in a medical community that fostered a cultural scenario of those with disabilities having a sexual self.

Participants that received sexual education discussed how it was not very helpful, as Reginald remembers, “at the rehab, they do have a very old VHS copy of...it was called discovering new sexuality or something like that, just a stupid video that touches on what you can do now and what you should try now that you are in a wheelchair with your sexual buddy. It was never really that great for anything. Richard also had the option to watch the video, but declined, because “...one I had no desire to see that...and two I

just thought I had it figured out and didn't need help and that it would wear off. So, it was a combination based on the other videos...I don't want to watch another video and then it was just too long." The message that SCI individuals are given is that they are not a sexual, as James stated how he felt about receiving little education from the medical institution and realizes how society views him as a neutered sexuality:

...the cultural barrier is that people in wheelchairs are not sexual beings, we are leaving that behind somehow, which is completely ridiculous because we still are still sexual beings and can express it with our spouse or partner and um...like I said it was pretty much hit or miss and having to guess what was possible and I don't know, it would be nice to have a more quote on quote normalized program that would at least help to help explore what is possible instead of just guessing because it took me a long time, way too long, to figure out what I could do, because I had my first built in limitations you put on yourself and then you also have cultural saying you are really not a sexual being anymore and you are just going to have to deal with it, it's really hard to get over that and somehow realize that you don't have to believe that, I don't have to encourage that cultural standard.

As James illustrates people in this culture have this connotation that those who are in wheelchairs are not sexual; this comes across in the medical institution as well since they provided little to no education. James continues to discuss how the medical community stunted his sexuality "I had no idea whether or not I could ejaculate, the doctors pretty much told me nope that it wasn't going to happen." As James describes in his comment his perception of what he could do was shaped by the medical communities' response. Because of the response given he had to be responsible for his own sexuality.

Reflecting on the information about sexuality that was given, respondents started to develop their own self and sexual self through their interactions with their partners, since the medical community provided little help in viewing themselves sexually. Several respondents displayed this message of their sexual scripts as constructed through

interactions with a partner. Richard explained how his first sexual encounter in a wheelchair:

...one of my concerns was being able to feel something, whether it was tingling or something somehow. During intercourse I realized I could not feel anything and I said out loud 'I can't feel anything!' which the woman I was with took to mean 'you have a sloppy, gapping vagina'-which was not that case! Yea so wow after all this time I realize I cannot physically feel anything...Although it was not very pleasurable it was better than nothing...I still liked it.

When asking Richard to elaborate on why even though this experience was not pleasurable he still felt it was better than nothing he explained, "There was still a naked woman in front of me that I could touch." Although Richard found he had no sensation, he found sex to still be pleasurable with the viewing and touching of the naked body. Being able to touch and view a naked body allows interaction with a partner sexually making the experience feel more natural, "...with being able to touch a naked body makes me feel like an able-bodied person..."

This discussion of sensation was brought up by many participants in explaining how intercourse was different from pre-injury, Richard said, "...there is no feeling of physical pleasure...it is more about a mental thing I guess." Tasha also identifies how sex is more of a mental process, "It's more of a mental turn on than a physical one" and continues later on to say, "It's definitely more of a mental thing than physical one." Dave also reiterates how sex is more mental than physical, "You got to have a mental aspect. Sex is half, if not more mental...than it is physical." While James said, "Part of sexuality in general is mental in terms of...the approach you take and what you feel about your partner and all that, you know mental is a huge piece of that." All respondents discussed

this process of rewriting their own personal script of sex being mental. When asking what rewriting this script meant Levi described what it meant to him:

...I think men can relate their erection to masculinity similar to women do their breasts for femininity, right? Well, okay...if a man is unable to get an erection or a woman loses a breast due to cancer these are example of deep issues a person is going through that not too many individuals can relate, you know, they cannot relate to that individual because it's not happening to them. Imagine going to have intercourse and your unable to get it up, or you only have one breast, I mean, this creates insecurity and it's the same insecurity I feel as a person with a spinal cord injury going to have sex or even dating...performance anxiety is probably another good way to put it. Some choose to avoid sex all together due to this anxiety or insecurity, but instead I find it's best to take things slow you know? Sometimes going slow isn't all that great, because I am sure I have lost plenty of women that way, but it's important not just for me, but for her to understand it's not just a physical thing...it's also mental. I mean sometimes my body cannot hold out for intercourse and instead I got to get creative to get things to work, some nibbling here and there.

Cooley's idea of developing a self through what one feels is also illustrated in this reconstruction of sexual scripts. Realizing that after their injury sensation was not the same, they start to construct their new sexual script of intercourse as more mentally pleasing instead of physically pleasing, Lauren discussed how when having intercourse she experiences a lack of sensation and because of this makes sex more mental, "I will say that I learned that I cannot feel anything...so...I learned it was more of mental thing versus a physical thing." Sarah also reflects this same idea when it comes to sexual intercourse, "it's probably more mental and emotional than physical, but you know the urge is still there," she continues to describe how sex has become different due to her injury:

...it was...it was different, but it was, you know could be satisfying...you are not an active participant really, you know I mean you can do it verbally, you can communicate verbally, but I am not able to use my hands, so touching is, isn't the same it's different,...and you can't move...so you are not, um...like a totally active person in the act.

As Richard illustrated of how touching and viewing a naked body helped him interact sexually with his partner, Sarah is also interacting with her partner through words. Dan finds that having a spinal cord injury entails a shift toward more of the mental aspect versus the physical, “It has to be in that case it [intercourse] is more mental than anything. Um and because...of the fact that you are limited as far as sensations...you can do things physically but you have to think mentally at the same time...” Rewriting one’s sexual scripts is not the only shift, another is rewriting exactly what pleasure means when it comes to the lack of sensation and this differs between men and women.

When asking participants how they are able to make intercourse pleasurable without sensation Dave started to explain how it is all about satisfying his partner, “...ok she is satisfied I am happy...” When asking James the same question he revealed that pleasure came from satisfying his partner, “...I need to help her so she can have a good experience too.” Women also shared the idea of finding it pleasurable to see their partner pleased as Laruen states:

...it’s just this idea of finding it pleasurable to see my boyfriend being pleased and it just being a um...emotional connection between us, I guess. Um...it is really hard to explain, I just don’t really know how to put it exactly, but it’s just different because again I cannot feel anything physically.

Richard also tries to describe this idea of intercourse being mental, but also found there to be a few physiological signs too “...it’s just like a mental excitement, um...and also know that, even if you can’t feel it there is a physiological release your body goes through when you reach orgasm...” When asking Tasha exactly how she gets into the mental process she described it as, “It’s a lot of touch, feeling, kissing. Not a lot of dirty talk...just a lot of touchy feeling kissing stuff.”

In these narratives there are distinct differences in the sexual scripts based on gender. For the women making sex mental is partner-focused. This idea is not all that uncommon when it comes to women in general. The women's narratives all focus on their satisfaction and pleasure as something rooted in their partner's satisfaction and pleasure. Although women with spinal cord injuries face difficulties in their sexuality their scripts tend to still reflect those of normative feminine sexual scripts in our culture.

Men also discussed pleasing their partners as a way to make intercourse pleasurable, but for men rewriting their sexual scripts to become mental is about adapting new ways to act sexual. The reason for adapting rather than partner-focused is because the gender norm of what is masculine is that of being sexually active (Burns et. al. 2008). With masculinity defined by one's sexual activity, men with SCI face the obstacle of a neutered sexuality. Dave describes how he continues to be sexually active with his partner "...put the focus more on oral more than anything...I still got my finger and got my tongue." Even with the lack of sensation Richard concluded how he still views himself as sexual because he enjoys the act, "...I enjoy sex." In understanding how men gain a sense of sexuality after their injury Dan expressed how it is important to find a partner that is willing to try new things, "...because of the fact you don't have control over certain parts of your body you don't know how they are going to react, as far as what your body is going to do. So you got to have someone that is understanding and is willing to experiment to find out." With having to redefine their sexual scripts to still fit the gender norm of masculinity finding a partner that is willing to be creative and fun is important as Levi stated:

The biggest challenge is not whether you can have intercourse or you can't...it's um...more along the line of...finding someone open enough to share both emotional and physical aspects of sex and dating. If you find someone who is able to do this, it is important to try and see what works for the both of you...

All of the respondents were able to create this new construction of identity through the process of making it more mental, but for women it was more important in getting pleasure out of their partner being satisfied; this script that a part of the emotional aspect for women is about feeling sexual. Men also found it pleasurable to see their partner satisfied, but the main focus of rewriting their sexual scripts were to find ways they could still enact sexual activities.

Although they are able to create their own identities they still have the problem of cultural forces enacting upon or intra-psychic scripting. "This intra-psychic scripting creates fantasy in a rich sense of that word: the symbolic reorganization of reality in ways to more fully realize the actor's many layered and sometime multivoiced wishes" (Simon and Gagnon 1973:30). Intra-psychic scripting is the idea that individuals with spinal cord injuries improvise sexual scripts in ways that allow them to participate in sexual acts while still adhering to some parts of conventional sexual scripts. In the case described in this study, individuals focus more on the mental aspects of sexual experience, but they still include some parts of the scripts that society deems as normal; the physical act of intercourse itself. Intra-psychic scripting was illustrated more with the men, in this study who emphasized the mental aspects of the sexual experience, but also explained the need for medication in order to get an erection. They saw the social meaning of intercourse as focused on the genitalia and the physical response performed by the penis during sex acts. Dave discusses his frustrations of trying to get an erection without using any forms of medication, "...hard to get an erection and that and um...the reason it makes it so hard

is because that without the feeling...the stimulation that you would so that is which stimulates the erection you really got to work at it.” He continues to discuss how when using medication it becomes a little more helpful, but how there is still this frustration:

...Viagra works, somewhat but uh...you know just...and you get frustrated too because you're sitting there and that you can kind of think in your head, in my case you know it feels like um I am going to cum, but you get frustrated because it ain't there, (laughs) where the hell are...oh shit! (Laughs) you got to learn to live with it

Richard's experience with using medication was to experiment, to find whether or not his penis still functioned properly, “Since I took the Viagra I tried to see how many I could knock out in a short amount of time and I got to four in about a half an hour and stopped because I got bored. Everything still works! Again, it took fifteen years, but I figured out to make things work, probably as good as there going to be.” Although the participants discussed how intercourse is more of a mental aspect, there is still a focus on genitalia for the men. For men this focus on the genitalia illustrates the cultural script to normative masculinity. Having medication to help the penis function more normatively helps men feel as they are sexual.

The ability to get medication serves to be a difficult task as Reginald illustrates, “...last time I checked I can't get...Viagra on my health plan, which is a definite tamper on anything...it would certainly help.” When discussing medication with others, Dave talked about the price of Viagra and how it is outrageous, “Viagra is expensive...you can figure if you are paying through the pharmacy you are looking at about \$10 a pill...you know spend twenty, thirty dollars for two days that you are going to have sex...” Dan also discusses the price of Viagra and how it has become problematic, “Well they [doctors] said, well you can do, can do things like Viagra and stuff like that



um...extremely expensive I found out.” When asked about the price he said, “...\$155 for six pills, you have lost your mind, it’s not that important; especially when insurance isn’t going to cover it.” While men have resources when it comes to sex Tasha describes how she found little information on sex education for women, “...I looked on the internet. I didn’t find much, well...I found a handful of things, but it was on men, men who were paralyzed, but there are not many things for girls. Well, there are girls in wheelchairs too, but I guess the world thinks just men are in wheelchairs.”

When asking whether men still felt they were sexual even without the use of medication and with having to reconstruct their sexual scripts to those that are not deemed normative masculine sexual scripts in our society, two respondents replied that they indeed still felt they were sexual. James found his spouse allowed him to feel this way, “...we still are sexual beings and can express it with our spouse or partner...” Levi also felt he was a sexual individual even without the use of medication, “Of course, I mean I still fantasize, I crave and physically desire a sexual relationship...so yes I still would consider myself to be a sexual being, but in a different way than of an able bodied man...but, it feels good to think that you’re still viewed as a sexual being and that catching the eyes of a stranger can make your heart race...”

## CHAPTER FIVE: CONCLUSIONS

The process of reconstructing one's sexual identity after obtaining a SCI offers a window into understanding how individual's gain a sense of themselves through social interactions. Obtaining a SCI presents the individual with the challenge of developing a new meaning in the sexual relationships between themselves and potential partners. This process of creating new sexual scripts remains hidden to viewers and possibly unknown to the individual. These sexual scripts become revised through interactions with the medical community, public community, themselves, and their sexual partners. The message that they get from the medical and public community is a neutering sexuality, but the scripts they ultimately fashion is something else; they are still a sexual being. These meanings from the community that are coexisting with feelings of how they view themselves may conflict when dating progresses and intimacy presents itself.

A problem that all participants brought up when talking about their SCI was there appearance of being in a wheelchair. This is an issue because it affects how they are evaluated as a potential dating partner. The majority of men noted that due to their discredited stigma (Goffman 1963) it made finding a partner difficult because they believed that when others saw the wheelchair it was a sign of a neutered sexuality. As these narratives uncover it is the fear of the unknown for an able bodied person that keeps them from starting a relationship with a disabled person. It is not only the fear, but the cultural idea of what to look for in a potential dating partner. For those who are disabled it is believed they are unable to provide an even distribution of rewards in the relationship and thus this belief of dating someone in a wheelchair is not beneficial.

In dating with a disability the key to finding a partner is to look for someone who is educated and has an open mind to experiment with what is possible. Finding someone who is educated is important as many narratives illustrated because it takes the factor of the unknown out of the relationship. When dating someone educated the expectations of the relationship are clear. Finding someone who is open minded is also important because with an SCI one's body is different and it takes time to explore what will work and what will not work sexually; this is very crucial with the reconstruction of one's sexual identity. It is with their partner that an individual with an SCI can renegotiate their sexual self.

This process of rewriting one's sexual script was different between men and women. Although both men and women discussed how they found intercourse to be pleasurable without sensation due to their partner's being pleased, women showed greater focus on their partner's satisfaction and it was the main way for them to adapt sex to being a mental process versus a physical process. Men more often than women adapted to new ways of sexual gratification through using oral or experimenting with what both partners found to be arousing. For men the reconstruction of their sexual scripts is focused on the gender norm of masculinity being focused on the ability to have sexual intercourse (Burns et. al. 2008). If individuals are unable to claim their new sexual scripts their preferred identity as a sexual being causes them to give up. In creating a therapeutic program one would need to be designed for men and one for women. As women indicated they generally feel sexual while men generally desire to act sexual. Although both sexes want to be sexual the pathway to accomplishing that is different and these

differences should be noted in creating a successful treatment for people that suffer from a SCI.

Through social interactions individuals with a SCI grow a new sexual script as they adapt to impairment. They may lose function of their body, but are able to gain a new sense of self. This journey leads them to think more deeply about who they are as a person and especially sexually. In being evaluated as a dating partner they focus on what truly sets them apart from others and use it to their advantage. In dating they use their creativity to create a healthy relationship in which they view themselves as a sexual being. Although they lose function of their body they no longer focus on sex being a physical act, but rather a mental one. These narratives have showed that although they are disabled their sexual self is not absent. In reconstructing their own sexual scripts these individuals rejected the social idea of wheelchair users being a neutered sexuality. They gain pride in knowing that just because they may have obtained a SCI it does not mean they are no longer sexual, but rather, they know that they were merely put to a test to find themselves sexually. Understanding what they can do, what they need, and how to present themselves to the world is their journey in reconstructing their sexual identity after obtaining a SCI is complete.

This study suggests that after obtaining a SCI one is still able to be a sexual being, but in doing so may come across a major hurdle in finding a partner to experiment with as they find their new sexual identity. They all have unique concerns and experiences with their disability and sexuality. In order to help individuals with a SCI renegotiate their sexuality sooner structures within society need revisions. The first revision is to have rehabilitation programs take into consideration the sexual problems and stigma that

are put upon the SCI population. Second, is to educate and include sexuality in the treatment of people with SCIs. Third, is to educate the public on physical disabilities. Educating the public will help eliminate the stigma associated with individuals with disabilities and allow for more dating opportunities for those with SCI.

The main purpose of this study was to use the sociological perspective on a topic that is often discussed in the medical field. This study was able to use the understandings of symbolic interactionist's Mead, Cooley, and Goffman in understanding the process and problems of reconstructing one's self and sexual identity after an SCI. Mead's work provided understanding of how an individual starts to reconstruct their new sexual identity through a self-reflection process. Cooley's looking glass-self also provides an understanding of how after obtaining an SCI people struggle with constructing self-concept due to how they believe others view them now, as a disabled body. Goffman's work was also crucial in understanding the difficulties wheelchair users face in the public sphere with the negative image of disabled individuals. This stigma has been a main theme in this study as being the primary difficulty in finding a potential dating partner. Another sociological perspective that helps create theoretical understanding is social exchange theory. Social exchange theory helps to understand when those with an SCI date they may have difficulty finding a partner because there needs to be an equal distribution of costs and rewards. As these narratives illustrated relationships would end due to the inability to provide this equilibrium.

The findings of this study can be applied to help people with SCI in three ways. First, an individual that just obtained a SCI can realize they are not alone in experiencing the difficulty of reconstructing a new sexual identity and a new sense of self. Second, this

study has highlighted suggestions when finding a partner to look for someone with education or understanding of physical disabilities and an open mind. Having education creates clear expectations for what both partners need within the relationship. An open minded partner is one that understands the limitations of wheelchair users and is able to work with and experiment with what is pleasurable for each person. Finally, that one can be a sexual being even with a SCI. Although one's sexuality will not be exactly the same as an able-bodied person there are still ways to interact sexually with one's partner; these forms can be that of words, touch, or visual. Of course these suggestions, of finding one's sexuality, are not limited to only those with a SCI, but to any physical disability or mental disability.

Although this unique study is an attempt to understand the reconstruction of self and sexual identity after obtaining a SCI, this study relies on information given by men and women themselves. One of the weaknesses of this study is the small number of participants. It might have been possible to gather more in-depth data if given more time to find participants. Another weakness to this study is time between when participants received sex education in their rehabilitation centers and their interview. Those who were older had their rehabilitation several years ago and stated receiving no education, whereas those who just recently had their injury reported having some sex education in their rehabilitation program. During this time lapse in participants' rehabilitation programs there might have been changes to the health care system, sources of funding, and/or accessibility for people with disabilities to receive more education. It is possible these changes could have changed the participant's responses in the interview. Also the majority of participants were Caucasian and largely men, thus these findings cannot be

## Reconstruction of Sexuality and SCI

generalizable to the population of individuals with spinal cord injuries. Nevertheless, this study provides valuable information to the body of literature regarding the change in one's sexual identity following SCI.

Possible directions for future research include collecting data over longer periods and at a national level to catalog more data on the development of the reconstruction of self and sexual identity in those with a SCI. Benefits of this approach would be a better understanding of how individuals' sexuality change over time and looking at differential impacts of socio-cultural norms on sexuality. Further research will also help increase the understanding of problems faced by individuals with a SCI.

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Appendix I: Semi-Structured Questions for Interview

1. Can you tell me about yourself?
2. How has your life changed since you became disabled?
3. Describe how things changed for you sexually.
4. How has it changed the way you think of yourself as a sexual being, if it has at all?
5. How do you think everyday people view individuals who have spinal cord injuries?
6. How have your relationships or interactions with other people shaped how you have come to think of yourself as a sexual person?
7. How have the way that others respond to you influenced your sexual activity?
8. In what ways might you like to change others' perceptions of people with disabilities?
9. How might the lives of disabilities change if people were to change their perceptions in the way you suggest?
10. What was your experience with the rehabilitation program after obtaining your injury?
11. Describe the type of education you received in these rehabilitation programs?
12. In what ways did the rehabilitation program address sexual activity or sexual identity?
13. What parts of this education did you find extremely helpful and what did you think was missing?
14. Explain how you applied the information you received in your rehabilitation program regarding sexuality to your life today?
16. What type of steps or actions did you take to become comfortable with your new lifestyle?
17. Are there any experiences or ideas that I have not asked about that you think are important to understanding the process of managing sexuality after becoming disabled?

## LOOKING FOR INTERVIEW PARTICIPANTS:

- ✓ Are you 18 years of age or older?
- ✓ Are you an individual with spinal cord injury (either paraplegic or quadriplegic)?
- ✓ Have you lived with this physical disability for at least one year?
- ✓ Would you consider being interviewed as a participant in a research study about identity and sexuality?



I am a graduate student in the sociology program at Minnesota State University, Mankato conducting research for my thesis on the reconstruction of self and sexual identity after suffering a spinal cord injury (SCI). I am looking for individuals who are 18 years of age or older and have been living with a spinal cord injury for at least one year. The study will include questions regarding sexuality, identity and the reconstruction process following an SCI. Participation in this study would involve a single one hour long interview at a location that is convenient for you. If you have any questions, wish to participate, or know someone whom may wish to participate please take the attached contact information and call to set up an interview. Your participation would be greatly appreciated. Thanks!

Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu	Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu	Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu	Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu	Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu	Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu	Elisabeth Mumford (320)221-3263 Elisabeth.mumford@msu.edu
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Appendix III: Informed Consent Form

**Research Consent Form**  
**The Reconstruction of Self and Sexual Identity after Spinal Cord Injury**

I am a student at Minnesota State University – Mankato (MSU-M). You are being asked to volunteer in a research study on construction of self and sexual identity after obtaining a spinal cord injury. You are asked to take part in this study because you have already expressed interest in participating by contacting the researcher. Your participation in this study is completely voluntary. No information that will identify you will be shared in my report of this research. Please read this form carefully and ask any questions you may have prior to agreeing to take part in this study.

Purpose: The purpose of this study is better understanding how an individual reconstruct their self and sexual identity after obtaining a spinal cord injury.

Procedures: The study will involve the collection of no less than 12 stories of individuals who have undergone this reconstruction process. If you choose to participate, I will meet with you any place and time of your convenience to document your story. With your permission I will digitally record your story and the interview will take about one hour.

Risks/Benefits: With this research there are two potential risks participants may encounter, the first is that it is a vulnerable population asking questions about one's history of not being disabled could bring up unwanted emotions. In order to deal with this potential risk the researcher will provide the participant with a list of places they can receive counseling if they feel they need it. Minnesota State University, Mankato is not endorsing any service providers and will not pay for any services; this will be at the cost of the participant. The other potential risk in this research is that some of the questions being asked could be sensitive. Since your participant in this research is purely voluntary, and you do not have to answer any questions, there are minimal risks or benefits to you other than those encountered in day-to-day life. To safeguard your identity and privacy:

- ✓ Records of this study will be kept private and locked in a file cabinet; only the researcher will have access to the records
- ✓ Digital recording of your story will be destroyed after it has been transcribed
- ✓ Your name and all other identifiable information will be omitted from all research records
- ✓ All identifiable locations will be omitted from all research records

Participants Rights:

Your participation in this study is voluntary. You do not have to be in this study if you do not want to be.

You have the right to refuse to answer any question(s) by simply telling me that you would prefer to skip that question.

You have the right to terminate the interview at any time by telling the researcher you wish to end the interview.

Any new information that may make you change your mind about being in this study will be given to you.

You will be given a copy of this consent form to keep.

You do not waive any of your legal rights by signing this consent form.

Initial that you have read this page: \_\_\_\_\_



Questions About This Study or Your Rights As a Research Participant: If you have any questions about the study, you may contact Elisabeth Mumford at telephone (320-221-3263) or e-mail at [elisabeth.mumford@mnsu.edu](mailto:elisabeth.mumford@mnsu.edu). This project has been reviewed and approved by chair of this research, Dr. Dennis Waskul. Any questions regarding the study of this research please contact Dr. Dennis Waskul at 507-389-5673 ([dennis.waskul@mnsu.edu](mailto:dennis.waskul@mnsu.edu)). If you have questions about your rights as a participant, you may contact the Dean of Graduate Studies and Research Barry Ries, 507-389-2321 ([barry.ries@mnsu.edu](mailto:barry.ries@mnsu.edu)).

If you sign below, it means that you are at least 18 years of age and have read (or have had read to you) the information given in this consent form, and you would like to be a volunteer in this study.

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Participant Name (printed)

---

Participant Signature

Date

---

Interviewer's Initials

Date

IRB Case number: 510594-2

Appendix IV: Resources Available to Participants

**Resources for Participants**

These are a list of counseling resources that participants of this study can contact if they feel that any questions in the interview created unwanted emotions. Minnesota State University, Mankato is not endorsing any service providers and will not pay for any services; this will be at the cost of the participant. Please let the researchers know if there is anything that they can do to help with contacting these resources.

*Counseling Centers in Mankato*

Riverview Clinic  
600 Reed Street  
Mankato, MN  
(507) 625-4060

Mind Body Spirit Center  
160 Waynesborough Way  
Mankato, MN  
(507) 625-2660

Mankato Mental Health Associates  
403 S Broad Street Suit #20  
Mankato, MN  
(507) 345-4448

ASC Psychological Clinic  
12 Civic Center Plaza #2090  
Mankato, MN  
(507) 388-3181

Blue Earth County Human Services  
410 South 5<sup>th</sup> Street  
Mankato, MN  
(507) 304-4319

*Other Counseling Centers in Minnesota*

Minnesota Mental Health Clinics  
3450 Oleary Lane  
Egan, MN  
(651) 454-0114

St. Cloud Hospital  
1406 6<sup>th</sup> Ave. North  
St. Cloud, MN  
(320) 251-2700