QUADRIPLEGIC SEX:
DEMYSTIFYING MISCONCEPTIONS & BREAKING BARRIERS

by

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DEDICATION

This dissertation is dedicated to anyone living with a disability that has ever felt unattractive, sexually invisible, or sexually oppressed by society, due to their disability.

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ABSTRACT

The purpose of this dissertation is to explore and better understand sex for people living with a cervical spinal cord injury for two years or more. Article one utilized in-depth qualitative semi-structured interviews consisting of 10 participants. Four major themes emerged: people with quadriplegia love to give pleasure, are sexual beings, yet are not often viewed as sexual beings by people without disabilities. The second article consisted of a 49 question survey to better understand PWQ's sexual activities and identify biopsychosocial barriers. Findings revealed 53% identified genital function as a barrier to sex and some psychological barriers to sex. However, social barriers overwhelmingly stood out as the most common barrier among the sample, with 78% of participants experience the stereotype that they "cannot have sex."

This research aims to educate society to reduce the stigma surrounding sex, all for people with quadriplegia. Decreasing stigma through education should help to enhance the quality of life for people with quadriplegia. Both studies found that people with quadriplegia have sex but are doing so despite negative attitudes around sex and disability.

TABLE OF CONTENTS

LIST OF TABLES

Article 1

Article 2

LIST OF FIGURES

CHAPTER I: INTRODUCTION

According to The National Spinal Cord Injury Database, in 2020, an estimated 296,000 people were living in the United States with a spinal cord injury (SCI). Around 17,900 people obtain an SCI each year. Men make up 78% of spinal cord injuries, with nearly 60% of spinal cord injuries being at the cervical level; people with tetraplegia are often referred to as quadriplegia. The most common SCIs are incomplete cervical SCI (The National Spinal Cord Injury Database, 2020). Around 187,712 people with quadriplegia (PWQ) are living in the United States in 2021. Generally speaking, PWQs have experienced a traumatic cervical SCI, which results in partially or fully impaired lower and upper limbs. Cervical SCI can impair sexual function, bowel, bladder, leg, abdominal, chest, hand, triceps, wrist extender, wrist flexor deltoids, biceps, diaphragm, and/or neck. SCIs affect damaged areas in two ways: function (movement ability) and sensation (degree of feeling) (The National Spinal Cord Injury Database, 2020).

Specifically, cervical SCI outcomes to the areas mentioned above can vary greatly but result in partial or total physical impairment. Although PWQ may have impairment in more than half of their body, each is still a sexual being, and each still can engage in sexual activity. Sexual function primarily concerns genital arousal for PWQ. According to Krassioukov and Elliott (2017), psychogenic arousal is genital arousal that occurs mentally from arousing sights, sounds, or thoughts. Intact psychogenic arousal is much less common for cervical SCI. Reflexogenic arousal is when genital arousal occurs, from direct physical contact to the penis or vagina. Reflex erections and vaginal lubrication occur when genitals are touched. This reflexogenic arousal is most common for people with cervical SCI (Krassioukov & Elliott, 2017). Sexuality survives cervical SCI, and physically speaking, sexual health and/or genital function for PWQ could surprise many people. Fulfilling and satisfying sexual activity is happening across the globe for many PWQ.

Meanwhile, many PWQ are experiencing non-physiological obstacles that keep them from engaging in sexual activity or experience obstacles that limit sexual activity for PWQ. Stigma is a major sociological obstacle that can interfere with sexual activity (Burr, 2011). For PWQ, health-related stigma is at the root of much oppression. The concept of health-related stigma refers to the social process of excluding, rejecting, and devaluing those with disabilities or health-related conditions. Health-related stigma (disability, i.e., cervical SCI) is essentially what brings about the stigma and social treatment that follows (Weiss, Ramakrishna, & Somma, 2006).

Additionally, stemming from physiological and/or sociological factors post-cervical-SCI, psychological factors interfere with sexual activity for PWQ. Psychological factors and emotional consequences have been found to hinder sexual activity more so than cervical SCI's physical consequences (Dahlberg, Alaranta, Kautiainen, & Kotila, 2007; Julia, & Othman, 2011). In multiple forms, ableism, stigma, and stereotypes in some way work towards sexually oppressing PWQ. These negative attitudes from society and social interactions directed at PWQ are internalized, and depending on their self-concept, they either fester or are overcome (Chance, 2002).

Sexual health and sexual activity influence the quality of life (QOL). Engaging in sexual activity can increase the overall sense of well-being and, thus, their QOL. QOL, simplified, refers to overall happiness and life satisfaction (Brajša-Žganec, Merkaš, & Šverko, 2011; Iwasaki, 2007). Flynn, Lin, Bruner, Cyranowski, Hahn, Jeffery, and Weinfurt (2016) found that "sexual health was a highly important aspect of quality of life for many, including participants in 'poor health'" (p. 1649). Whether healthy or unhealthy, research shows that sex plays a significant role in their QOL. Psychosocial obstacles disrupt sexual activity for PWQ, and limited sexual activity then decreases well-being and QOL. Therefore, until the psychological and sociological factors are explored, some PWQ will experience lower overall happiness and life satisfaction. If increased sexual health can lead to better overall health, disruptive psychosocial obstacles should be removed.

This research issue matters because it affects the health and daily lives of PWQ. A powerful sexual movement for PWD has yet to happen, but the time is approaching. Utilizing semi-structured interviews, the preliminary research by Christian, Gray, Roberts, and Eller (2020) sought to gain insight into the sex lives of people with quadriplegia through lived experiences. According to the authors, benefits from sex for PWQ include exercise, emotional and physical connection, intimacy, mood enhancement, and increased confidence. That preliminary research explored much of why PWQ have sex. The majority of PWQ engaged in sexual activity as a favorite leisure activity and believed sexual activity strongly influenced their QOL. PWQ described themselves as very sexual beings but stressed that many non-disabled people view them as nonsexual (Christian et al., 2020). For a better understanding, this research will explore how PWQ have sex. Through illustration, rich narratives and data can help normalize sex and cervical SCI. By exploring what psychosocial factors enhance sexual activity and hinder sexual activity for PWQ, findings will educate the non-disabled on what needs to be addressed. With the results educating the non-disabled majority population, the stigma will decrease, which will reduce psychosocial obstacles experienced by PWQ pursuing sexual activity. Compared to previous research, which focuses primarily on physiology, this research shifts toward interpersonal, intrapersonal, and community determinants for sex and PWQ.

Overview of Literature

Critical Disability Theory

Critical disability theory (CDT) is the guiding foundation for this research on PWQ, sexual activity, and stigma. PWQ are not the objects of this research. They are the subject of investigation. They act as experts to share information about how PWQ experience sexual activity and stigma (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019). Using a critical disability theory lens, having quadriplegia is merely one component of being human. According to Creswell and Poth (2016), in this sense, quadriplegia is not a human defect; it is a dimension of human difference constructed by society. CDS focuses on how society reacts and communicates with PWQ when it comes to sexual activity. Reality is based on the non-disabled population holding power over PWQ, creating oppression and struggle (Creswell & Poth, 2016). CDS and this research does not exist merely for academia. A major reason for choosing CDS is that the research aims to share the findings with the general population to change actions and societal norms. According to Minich (2016), PWQ share common experiences with sexual oppression. This research seeks to explore the themes and patterns of sexual activity as experienced by PWQ. CDS is an effective approach to explore how normative ideologies and social norms stigmatize PWQ, affecting the pursuit of sexual activity (Annamma, 2017). Additionally, it will look at how social norms and stigma influence psychological factors for PWQ.

Sex

This paper explores the topic of sexual activity and persons with quadriplegia (PWQ). Traditional definitions of sex require three things: penis, vagina, and penetration. The *Medical Dictionary for the Health Professions and Nursing* (2012) defines sexual activity (sex) as “physical contact between two individuals involving stimulation of the genital organ” (para. 1). Therefore, regarding this paper, sex and PWQ involve physical contact and stimulation of the genitals between two or more individuals. At least one of the individuals involved has a cervical spinal cord injury (PWQ). Additionally, the sex being discussed refers to sexual activity that is chosen freely by consenting individuals for various motives such as leisure, pleasure, intimacy, and/or reproduction. Research conducted by Herbenick, Reece, Schick, Sanders, Dodge, and Fortenberry (2010) assessed the sexual behaviors of both men and women in the United States. Herbenick et al. (2010) sought to capture an image of what American sexual behavior looks like over their life span. Sexual behavior was measured based on if it had occurred in the last month, last year, and/or lifetime. This study shows that America is having sex and how they are having sex. According to Herbenick et al. (2010), the “trajectory of sexual expression is apparent” across their lifetime (p. 261). Herbenick et al. (2010) examined the types of sex people engage in throughout their lifetime, such as vaginal, oral, anal, and mutual masturbation. Older epidemiological research by Leigh, Temple, Trocki (1993) used similar methods with a national survey to examine sexual behavior in the United States and how often the general population has sex. According to Leigh et al. (1993), “the great majority of American adults are sexually experienced, and most, except for the elderly and widowed, are currently sexually active” (p. 1405). Data showed that of the sexually active individuals, 70% had “intercourse” weekly. Gender, race, and education did not affect this frequency.

Sex, Disability, and PWQ

As fruitful as the sexual activity research mentioned by Flynn et al. (2016) on sexual health and QOL, by Herbenick et al. (2010) on sexual behavior across their life span, and Leigh et al. (1993) research on sexual activity frequency is, none included disability as a demographic. These data offer medical and public health professionals much insight into PWD sexual activity yet tell us nothing about sex among people with a disability (PWD). Thus, including disability as a demographic might change the purpose and findings of the data. A dated but relevant study by Corbett, Klein, and Bregante (1987) on sex and women with disabilities makes a powerful claim. In essence, sexual activities and sexual behaviors for the non-disabled and PWD are shared. Following the generalized statement from Corbett et al. (1987), we should assume that PWD have the same types of and the same amount of sex as the non-disabled. Preliminary research by Christian et al. (2020) supports this message, finding that PWD engage in various types of sex such as vaginal, anal, and oral, but overwhelming data were demonstrating that oral sex was the most popular. PWQ reported various frequencies of engaging in sex, such as a couple of times a month, weekly, and a few times a week. Whether non-disabled or disabled, the data regarding the types of sexual behavior and the amount of sexual activity reflect each other.

Reitz, Tobe, Knapp, and Schurch (2004) examined SCI, QOL, and sex. Reitz et al. (2004) stated, "knowledge concerning the impact of spinal cord injury on sexual health and quality of life is limited" (p. 167). This statement is in response to the trend of sex and PWD research, primarily focusing on anatomy alone. A dominant trend in research has revolved around reproduction. With sexual activity boosting QOL, individuals with health conditions and impairments could benefit the most from sexual activity.

The two PWQ studies were heavily inspired by the movie *Murderball*. The film *Murderball* portrayed PWQ as very sexual beings, turning away from the media's stereotypical portrayal of PWQ as nonsexual beings incapable of living a fulfilling life. Characters in *Murderball* shared that when pursuing new sex partners, "Can you have sex?" is one of the first questions nondisabled peers ask. Article one confirmed that non-PWQ believed PWQ are incapable of having sex. Through semi-structured interviews, Article 1 found that 9 out of 10 participants are givers and are passionate about pleasing their partner. Article 2 found that 84.3% of PWQ said they engaged in giving oral sex.

Interestingly this provides findings that support *Murderball's* Mark Zupan stating that people with quadriplegia love to give oral sex. Many PWQ credit *Murderball* as a rarity in that it was a movie showing quadriplegic sex in a positive able way. Other motivating influences for these impairment-based studies include the researcher’s personal experiences with quadriplegia and a gap in the literature on PWQ, sex, and psychosocial factors. There is a lack of research conducted on this topic. Even more influential with the existing research on sexual activity and PWQ are the narrow research methodologies utilized. There is a wide variety of SCI-related impairments. Sexual function and sensation can vary, as well as the overall function and sensation post-cervical-SCI of bowel, bladder, leg, abdominal, chest, hand, triceps, wrist extender, wrist flexor, deltoids, biceps, diaphragm, neck, and head. The varying damaged area of the spinal cord can have an extremely different effect on overall function and sensation. Therefore, solely based on physical components with SCI outcomes, C2-3 PWQ versus C6-7 PWQ live in different galaxies. Post-SCI's physiological outcome, combined with varying psychological and emotional outcomes, influences sexual activity for PWQ (Dahlberg et al., 2007). For example, physiological obstacles for PWQ may result in bladder and bowel changes, muscle spasticity, or pain.

Meanwhile, psychological and/or emotional obstacles such as their self-concept or depression combine with these physiological obstacles, uniquely affecting sexual activity for PWQ. Of course, interpersonal and sociological barriers such as stigma and stereotypes combined with the physiological and psychological circumstances post-SCI. Thus, with PWQ, sex, and stigma intersecting with so many physical and psychosocial differences, SCI and sex cannot be scrutinized under a narrow lens. Historically, research has utilized quantitative methods, such as surveys. Surveys are excellent for collecting data but come up short when measuring something that has a scope of unpredictable answers. When quantitative measures are used alone, the findings and, thus, conclusions are not entirely explaining everything. The quantitative measures aggregate across datum, meaning that unique experiences are lost.

Anderson, Borisoff, Johnson, Stiens, and Elliott (2007a) looked at QOL and encouraged research that focuses on sexual activity for pleasure. Yet quantitative measures alone cannot fully measure SCI and sex. For example, common survey questions used are: “1. Can you get an erection?” “2. Can you maintain an erection?” Common among MWSCI are reflex erections, in which psychogenic arousal is not functioning (arousal of the mind does not arouse the genitals), but physical stimulation of the genitals causes erections (arousal). If this were their circumstances, they would say “yes” to question number 1. Often common with reflex erections is for the penis to become flaccid once physical stimulation stops; thus, they would likely answer “no” to question number 2. However, during intercourse or continuous physical stimulation, a PWQ with reflex erections can maintain an erection. The narrow wording of survey questions and close-ended questions does not allow for accurate information regarding PWQ and sex. This is just one example of how the intersection of SCI and sex is too convoluted to be merely analyzed by quantitative methods.

Moreover, from a CDS perspective, we live in an ableist society. Thus, as an institution that people create in this social context, science is constructed based on able-bodied norms and perspectives. Quantitative methods, particularly survey questions, are likely to reflect these able-bodied norms. PWQ should be able to share information about sexual activity with the researchers with an open and flexible method.

Sex is complicated for PWQ due to the intersecting physiological, psychological, and emotional consequences of suffering a cervical SCI. (Dahlberg et al., 2007). Moreover, anyone who has worked with PWQ can attest that any SCI can differ from another (i.e., two persons with a C5-6 injury but with different outcomes). The level of injury, whether the SCI is complete or incomplete, whether the spinal cord was bruised, crushed, or severed calculate to random sets of outcomes regarding unique degrees of overall function and sensation. Also, in this calculus is their mental outlook, emotional state, and interpersonal experiences. Quantitative approaches that have been employed, such as surveys, simply have not captured the wide variety of realities that exist with sex and PWQ. Qualitative methods are essential for researchers to understand sexual activity and PWQ. Research designs utilizing mixed methods can offer the most accurate yet rich results.

Stigma

Stigma is a complex issue, reaching many people and harmful to those stigmatized. According to Goffman's work from the 1960s, stigma occurs when people with certain characteristics are socially rejected or shunned by society. The term "stigma" was derived from ancient Greece. It was defined by the action of free citizens physically marking (branding or tattooing) their slaves. Stigma marked insiders from outsiders. According to Link and Phelan (2001), stigma refers to a cycle of labeling out individuals, use of stereotypes, singling individuals out, and discriminating against individuals. For PWD from ancient times through the twentieth century, heavy stigma and hatred led to horrendous actions (Rodney, & Kathleen, 2010). Ableism is another term associated with stigma. Words such as stigma or discrimination are more widely understood. Some forms of oppression and discrimination are more visible in society. One way to look at society's understanding of ableism is to compare it to other forms of oppression by the majority culture. For example, The Civil Rights Act occurred in 1964, and racism is still a major issue in 2021. To put things into perspective, The Americans with Disabilities Act passed in 1990, so our understanding and awareness of ableism and its impacts are still in the early stages. Another example is that Joe Biden’s 2020 presidential acceptance speech marks the first time that “disability” has been mentioned throughout the history of presidential acceptance speeches in the United States. With ableism, as with any-ism, such as racism, fear is what guides individuals to oppress PWQ (Kress-White, 2009).

Many of the consequences of stigma on PWD that we know about are psychological or sociological, creating feelings of anguish, distress, and misery (Nyblade, 2003). Stigma impacts PWD's health by negatively affecting their overall sense of well-being and quality of life (QOL) (Van Brakel, 2006). Stigma can be internalized, where an individual adopts ableist thinking and applies stereotypes to self or disability. Internalized stigma can also refer to shame or fear of discrimination. Perceived or internalized stigma can be just as harmful as experiencing enacted stigma. Thus, stigma is far-reaching, affecting more than just the psychological. As with psychological consequences, both internalized stigma and enacted stigma can restrict PWD from social participation (Scambler, 2009).

How PWQ Have Sex

Experiencing an SCI is traumatic, physically, mentally, and emotionally. As stated in *Murderball,* after sustaining a cervical SCI (PWQ), they can be “reduced to an infant’s level.” The rehabilitation process is long and strenuous; adjusting and adapting to life post-SCI takes time. Sexuality post-SCI is impacted by a complex mixture of physiological, mental, and emotional outcomes (Dahlberg et al., 2007). It takes time to adjust to bowel and bladder regimens, thus time to adapt to their new sexual world post-SCI. With sexuality being so complex, essentially, it can take a couple of years for PWQ to understand their bodily function and sensation.

There is a majority belief that PWQ cannot engage in sexual activity (Chance, 2002). Regarding sexual activity for PWQ, exists a notion that PWD are too fragile (Corbett et al., 1987) as if the physical act or physical components of sex itself will break PWQ. PWQ are not made of glass and remain very capable of engaging in sexual activity. PWQ can use creativity and collaborate with partners to find preferred and satisfying sexual positions (Dahlberg et al., 2007). The market for sex toys and equipment is vast, and adaptive sexual devices are available. However, adaptive equipment or devices are not a requirement or used by all PWQ. In the physical world of sexual activity for PWQ, adaptive positions and creative uses of pillows are the go-to (O’Toole, 2000).

PWQ pursuing sexual partners in the already complicated social world of dating and sexual activity have a much more difficult time than they did pre-SCI. According to Burr (2011), stigma clings to sex and disability, making finding sex partners more difficult. Due to the many stereotypes stemming from ingrained ableism, PWQ find that to live the fulfilling sex lives they desire, they have to adapt to the climate they are pursuing sexual activity. The ability to flirt well and peruse possible sexual partners is crucial. After all, in most cases, PWQ are pursuing sex partners in competition with their non-disabled peers. Therefore, PWQ must stand out, adapting by becoming excellent at flirting. One way PWQ do this is by using the social circumstances they have at their disposal.

The stereotypes and faulty assumptions associated with sex and disability, combined with the proclamation by PWQ that they are sexual creatures, create an atmosphere of misinformation and curiosity. People without a disability may have an innocent curiosity about sex and PWQ, to the point where the non-disabled bluntly express their curiosity. A scene from *Murderball* highlights this curiosity and how it typically plays out in social scenarios for PWQ. In *Murderball*, the cameras follow PWQ and capture this natural type of curiosity. As Scott later recollects, "usually after a few minutes of working on a girl (flirting), they come right out and ask. Can you do it?" Curiosity comes across most often in the form of, "Can you have sex?", "Can you get it up?", with the follow-up question of, "How do you have sex?"

PWQ from the film claimed that this curiosity is very common, and each proudly admits that they use this curiosity from faulty assumptions to their advantage. Although stigma and stereotypes work to oppress PWQ sexually, many have found it beneficial to use this curiosity in their favor. Essentially, the curiosity such as, "Can you do it? or "Does it (genitals) work?" can act as an icebreaker to a sensitive topic, leading to humor and/or fruitful flirting (i.e., after some friendly talking and flirting with a potential sex partner). The PWQ is asked, “Can you have sex?” with the PWQ replying, “I don’t know….Want to go back to my place and find out?” In the same scenario, the PWQ is asked, “How can you have sex?” with the PWQ replying, “I just have to be on the bottom…How do you feel about being on top?” PWQ are at a disadvantage when pursuing sexual activity; there are physical impairments and socially constructed obstacles. One way of successfully adapting is to use this existing curiosity as a way to break the ice and flirt.

Once PWQ overcome the physical challenges suffered by a cervical SCI and physically adapt to their newly altered body, PWQ must overcome and adapt mentally and emotionally. SCIs are life-altering. PWQ in *Murderball* discuss how adapting mentally post-cervical-SCI is paramount. Mental and emotional consequences that occur after a life-altering cervical SCIs can be the biggest challenge. To quote PWQ from *Murderball*, “it’s a total mind fuck in the beginning, and you either make it, or you don’t.” “Making it” in this strong statement refers to accepting and/or adapting to life as a PWQ, with “not making it” referring to despair. Consider that, as mentioned, sexual activity is physiologically available to PWQ, and sociological aspects of sexual activity such as stigma can be navigated, but only when PWQ mentally adjust. Thus, for PWQ, outlook and healthy self-concept are vital to sexual activity. PWQ must have self-worth and confidence to seek sexual partners. Being confident, believing that they are capable, and feeling worthy are important aspects of pursuing and engaging in sexual activity for PWQ (Chance, 2002).

Impact of Ableism/Stigma on PWQ Pursuing Sex

Stigma surrounds sex, and that stigma is magnified for sex and disability. Flynn et al. (2016) claimed that knowledge about sexual health is limited because discussions revolving around sex are uncommon in our culture. It is noteworthy to point out that Flynn et al. (2016) discuss this regarding the general population. The stigma around discussing sex among PWD runs even deeper but stems from the culture of "let's not talk about sex." Santos and Santos (2018) found that when the topic of sex and PWD is avoided, it results in "absolute ignorance." Research by Christian et al. (2020) concurred, discovering an "innocent ignorance" exists among the non-disabled about sex and PWQ. This ignorant climate is where PWQ are pursuing sex and attempting to live a full and meaningful life. Therefore, it is important to discover the root of such "ignorance"; only then can we find ways towards a solution. Ableism encompasses all aspects of living with a disability, including sex. The intrapersonal and interpersonal determinants of sexual activity for PWD stem from the bigger picture. Ableist norms and attitudes persist throughout cultural systems across the globe. Ableist thinking is still prevalent in society. Thus PWD "are thought to lack a full sexual life" (Santos & Santos, 2018, p. 314). Unfortunately, this cultural determinate of stigma (ignorance) does not come from a few uneducated non-disabled members of society. The stigma around sex and PWD runs deep, often stemming from major cultural systems, education, healthcare, mass media, and even pornography.

Interpersonal Determinants and Sociological Obstacles

Interpersonal communication and relationships play a large role in pursuing and engaging in sexual activity for everyone. The Christopher and Dana Reeves Foundation (2010) once surveyed disabled individuals to find out the *Top 10 Things That Annoy People Who Use Wheelchairs.* The survey found things wheelchair users go through daily such as: “patting me on my head,” “talking over my head as if I'm not here,” and “speaking slowly to me because I'm in a wheelchair.” These are all issues PWD face in a world dominated by ableist views, and this must be kept in mind when considering sexual activity. Kress-White (2009) explained, “For many disabled persons, the greatest handicap many disabled individuals experience is not the limitations imposed by their disability, but the attitude of others toward their disability” (p. 23). These negative attitudes transmitted through interpersonal communication can sexually oppress PWD. Sometimes PWD are attracted to someone and are pursuing sexual activity, and the non-disabled person discounts them as a possible sex partner. Although they may view themselves as sexual, these interpersonal experiences let PWD understand how others view their sexuality (Christian et al., 2020; Lindemann, 2010; Torriani et al., 2014). Social experiences such as these can decrease sexual behavior and frequency for PWD.

Relationships and social experiences are places where PWQ experience stigma and other obstacles that interfere with pursuing sexual activity. The weight of interpersonal determinants on sexual activity and PWQ can also be understood by pointing out that many of the issues surrounding sex and PWQ can be overcome via interpersonal factors. Interpersonal factors that can increase sexual activity for PWQ include self-advocacy and educating others through healthy open communication. The quality of interpersonal communication between PWQ and sexual partners is more influential than physiological outcomes post-SCI, such as genital function and sensation (Reitz et al., 2004). Becoming an advocate by having the confidence to speak up and educating sex partners/potential sex partners also increases sexual satisfaction (Dahlberg et al., 2007). Dahlberg et al. (2007) found that when PWQ educate their partners and collaborate with partners, satisfying sexual activity increases. This is very interesting and can be used to argue that research should include more than just reproduction. Fiduccia stated (2000) how most PWD research predominantly is concerned with "the bio-medical viewpoint of regulating the fertility of the dangerous female, as well as assisting the damaged male to regain his potency" (p. 168). Psychosocial issues should be a primary focus for research on sex and PWD.

Intrapersonal Determinants and Psychological Obstacles

Physical disabilities are most often evaluated by the physical impairments the disability places on a person. Internal subjective states are just as important as physical and social experiences, and they play a large role in sexual activity for PWQ (Julia & Othman, 2011). These cognitive and intrinsic variables include confidence, self-concept, self-esteem, body image, learned helplessness, and anxiety or depression. A low self-concept can occur while PWD are just living life and receiving the message from the non-disabled that they are asexual (Chance, 2002). These asexual experiences increase insecurities for PWD and may have long-lasting harmful effects. Chance (2002) explained, "people with disabilities often internalize prevalent societal stereotypes about the sexuality of disabled people" (p. 197). This research discusses some intrapersonal examples of what can go on in PWD's mind. For example, "Will somebody be attracted to me?" and "Would someone ever choose me over a non-disabled sex partner?" According to Chance (2002), "all these factors affect the changes in the disabled person's body image and self-concept" (p. 198). An unhealthy body image can decrease PWD's sexual activity frequency (Anderson et al., 2007b). Because they face such negative attitudinal barriers, it is imperative that PWD are resilient and build a positive and stable self-concept.

Purpose

This research aims to explore the sexual experiences of PWQ and the biopsychosocial barriers to sexual activity. Utilizing a mix-method approach, this dissertation conducted two studies and will present the findings via two articles.

Article 1

The first article seeks to better understand PWQ perceptions of sexual experiences post-injury and addresses the following research questions: 1) What are PWQ perceptions of their sexuality? 2) How do PWQ feel others perceive their sexuality? 3) Does having sex enhance the overall quality of life for PWQ? and 4) What are PWQ perceptions of sex as leisure? This research explores PWQ, stigma, and sexual activity as PWQ interprets it via lived experiences. The data source will be participant narratives from PWQ regarding their sexual experiences post-injury. Article one uses a Phenomenological Social Constructivism approach, also known as Interpretive Phenomenological Analysis (IPA). This approach allows researchers to recognize the shared lived experiences for PWQ on sexual activity post-SCI (Creswell & Poth, 2017). IPA focuses on understanding the outside world from co-constructed realities (Creswell & Poth, 2017). This approach is useful to provide a detailed look into a small population, searching for common group themes. According to Pietkiewicz and Smith (2014), the goal with IPA is to gather rich and detailed narratives on a specific phenomenon. The interview questions about participant's sexuality focused on pre and post-SCI sexual experiences and included personal circumstances regarding unique characteristics of each participant's SCI and sexuality. Seeking to gain a narrative in participants' own words that give insight to participants' emotions and personal sexual experiences, scripted open-ended interview questions were utilized as a qualitative method.

Article 2

The second article consists of a 47-item questionnaire to explore biopsychosocial factors that impact PWQ intimate sexual activities. This article seeks to better understand how stigma and ableism might interfere with the pursuit of sex partners and activity for PWQ. As such, the study explores the perceptions of sexual experiences and biopsychosocial barriers to intimate sexual activity. The article aims to demystify misconceptions of PWQ sex and educate and enlighten society that PWQs want to have sex, are having sex, and how they have sex, and perhaps most importantly, are indeed sexual beings! The purpose of this survey is to identify critical biopsychosocial barriers PWQ may face regarding sexual activity.

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CHAPTER II: QUADRIPLEGIC SEX – DEMYSTIFYING MISCONCEPTIONS

Introduction

Academia no longer ignores sex and disability, but research focusing on the perceptions of people with quadriplegia (PWQ) regarding their sexuality extending beyond reproduction is needed. Burr (2011) maintains, “sexuality of people with disabilities continues to be overlooked, avoided or even dismissed as a component of holistic care because of a longstanding stigma that shrouds disability and sex” (p. 259). Despite expanding acceptance, recent research reveals that disability and sexuality remain understudied and uncomfortable to discuss. Santos and Santos’s (2018) study consisted of interviews with 30 women with a disability to explore ways to combat ableism and sexism through narratives concerning disability and the sexual experiences of women. Women with a disability shared how they avoided discussing their sexuality. They even avoided the topic with a close family member or medical professional. Santos and Santos revealed that one doctor refused to answer questions about sex, suggesting they ask another woman with a disability. There is still much to be done for this stigma around disability and sexuality to be resolved. Descriptions of sex as leisure for people with disabilities (PWD) may enlighten people, combating stigma.

The purpose of this study is to explore PWQ perceptions of their sexual experiences post-injury. We aim to provide an in-depth view of the sexual perceptions of PWQ by exploring the following research questions: (1) What are PWQ perceptions of their sexuality? (2) How do PWQ feel others perceive their sexuality? (3) Does having sex enhance the overall quality of life for PWQ? and (4) What are PWQ perceptions of sex as leisure?

Literature Review

Disability and sexuality research reside primarily in the medical field, but sexuality is too complex to simplify with only an understanding regarding sexual organs (Torriani, Britto, da Silva, de Oliveira, & de Figueiredo Carvalho, 2014). Despite this, most research focuses on reproduction, while others focus on rehabilitation after obtaining a disability such as a spinal cord injury (SCI). Anderson, Borisoff, Johnson, Stiens, and Elliott (2007) presented their research on SCI in three articles. Though medically driven, the articles address psychosocial topics such as sexual sense of self and the relationship between sex and quality of life (QOL), breaking from the norm of predominantly focusing on anatomy. When Anderson et al. (2007a) surveyed 286 SCI participants regarding the primary reason for pursuing sexual activity, they discovered fertility was the least common reason. Only 1% of participants engaged in sex for reproduction. However, the majority of PWD sex research revolves around reproduction. As Anderson et al. (2007a), emphasize "past attitudes that people with SCI should be 'happy to be alive' and should 'learn to live without sexual pleasure' are outdated" (p. 329).

Disability is a broad term, but it is essential to focus on specific impairments, as suggested by Shuttleworth, Wedgewood, and Wilson (2012), instead of grouping all people who are disabled together. Grouping all PWD can be useful for parking, but issues as complex as sexuality require more attention and detail. Comparing persons with SCI to persons with other disabilities is of limited value as they are often significantly different in terms of feeling and functions. A person with quadriplegia is an individual affected by paralysis in all four limbs compared to people with paraplegia who are affected in the lower extremities only. Even the differences between quadriplegic (cervical SCI) and paraplegic (thoracic, lumbar, or sacral region SCI) and their daily living skills are vast. Differences in the damaged area of the spinal cord can have an extremely different effect on function. Both PWP and PWQ predominantly use wheelchairs for mobility purposes. Many PWP live independently or are primarily independent in their daily living needs. Although some PWQ reach total independence, others depend on assistance for some of or all their daily living needs. These physical differences affect psychosocial factors, as well. People with quadriplegia are experiencing the physical world, and arguably the more challenging social world from a different angle than people with paraplegia in general (Torriani et al., 2014) and specifically when pursuing sexual activity as compared to PWP. Given these discrepancies, our study focuses on PWQ perceptions of sex.

Men with SCIs face emasculation regarding their sexuality and are deemed sexually passive by people without disabilities (Lindeman, 2010). Dahlberg, Alaranta, Kautiainen, and Kotila (2007) examined men with SCI regarding sexual activity and satisfaction using a cross-sectional design with a structured questionnaire and optional follow-up appointments. During the follow-up appointment, a physician examined participants to determine their feeling and function level, and a therapist interviewed men regarding their sexual satisfaction. The authors found that once a person sustains an SCI, their "sexuality is complicated by marked physiological, psychological and emotional consequences" (p. 152). They conclude that men with a more severe locomotory quadriplegia may have more difficult sex lives than men with paraplegia. The ‘severe locomotory’ referring to the impairment of lower and upper extremities does not prevent sex; instead, it is an obstacle for PWQ to manage. More impairment does not necessarily mean less sex or satisfaction, though more adaptive measures are necessary. Dahlberg et al. (2007) suggest sexual satisfaction can increase for PWQ by educating and collaborating with sexual partners.

One part of successfully readjusting post-injury is a person's sexuality. The relative worth sexuality plays in QOL is determined by individual factors such as how vital sexuality was to the person pre-injury. Torriani et al. (2014) examined 14 participants’ sexual activity before SCI, sexual activity after SCI, difficulties with sexual activity after SCI, and adjustments made in sexual activity after SCI. Sexually invisible social experiences can lead some PWQ to feel they are viewed as being asexual. Whether PWQ are seen as asexual due to reproductive irrelevance or societal gender expectations, the result can limit sex as leisure for PWQ. In their study on sexuality and PWD, Rohleder, Braathen, Hunt, Carew, and Swartz (2018) found zero participants identified as asexual. However, a possible reason PWD are perceived as asexual or undesirable is the accepted mainstream standards of what constitutes beauty (Torriani et al., 2014), potentially impacting individual body self-awareness.

Women with a disability also experience sexism in daily life and are underrepresented in disability and sexuality research than men. Despite this, about 22% of people living in the United States with SCI are women (National Spinal Cord Injury

Statistical Center, 2018). Post-SCI women may have a more difficult time becoming involved in sexual relationships, mainly due to psychological and social factors (Anderson et al., 2007c). This absence warrants further investigation as physical factors often do not make it more difficult for females with quadriplegia to have sex. Rather, social and psychological differences stemming from societal and gender expectations make it harder for females with quadriplegia to have sex. The world must do a better job of recognizing sexuality, particularly concerning sex as leisure is within everyone, regardless of ability or disability (Torriani et al., 2014).

Women face stereotypes and discrimination in multiple aspects of their lives, as do PWD. When disability and gender intersect, stereotypes multiply. The literature has highlighted stereotypes encountered by women with disabilities. These stereotypes take control and choice away from women with disabilities. Hyler (1985) wrongly implied that PWD need helpers, not lovers. He further maintained that if a person is not entirely self-sufficient, then they cannot handle a sexual relationship. Hyler's findings have been widely refuted. Even now, female PWDs face stereotypes, including avoiding romantic relationships if they do not have full bodily sensation, highlighting shortcomings of sex education, and the lingering notion that sex equates to penetration. Santos and Santos (2018) concluded that the shortage of disability-specific information on sex could result in absolute ignorance, particularly regarding women and sexual orientation. Women who identify as LGBTQ face additional discrimination of homophobia by people without disabilities. According to O'Toole (2000), those who are open about being lesbians not only face accessibility barriers but also experience homophobia, even from within the

PWD community. When gender, ability, and sexual orientation intersect, discrimination magnifies (O’Toole, 2000).

Historically, quadriplegia and sex research focused on reproduction ability, ignoring sex as leisure. Corbett, Klein, and Bregante (1987) focused on the marginalized sexuality of women with disabilities and the need for better sex education, something which has traditionally been geared more towards men. Despite this call in 1987, little has been done to address these issues for women with a disability. To overcome PWD's sexual invisibility, Corbett et al. (1987) stressed that no matter the disability, someone with the same disability is living their life to the fullest, including sexual activities. Some PWDs are thinking about sex, some are enjoying sex, and some are even confident in their sexual abilities. Essentially, sexual thoughts and activities are much the same for PWD as they are for people without disabilities. Corbett et al. posit that everyone is a human being first, without regard to disability status, and every human experiences leisure. The pleasurable qualities of sex are inherently related to leisure. Thus, sex as leisure for PWD needs further exploration to improve our understanding and appreciation of PWD as sexual beings.

Leisure, Disability, and Sex

Despite the call by Aitchison (2009) for more research exploring leisure and disability, not unlike sex and leisure, the topic remains understudied. Leisure is often defined by what it is not as opposed to what it is. Aitchison’s study found conventional definitions typically do not adequately explain leisure for persons with a disability, clarifying that their leisure was less defined by time, activity, or space and more defined "by who they encountered and interacted with as part of their leisure" (p. 383). Due to mobility limitations, leisure is often about interactions and experiences with other people for PWQ, but physical activity can also be enjoyable. In seeking an inclusive definition of leisure, scholars today conceptualize leisure "as time, activity and state of mind that is differentiated from 'work' in that it entails an activity that is relatively freely undertaken primarily for purposes of pleasure that is internally rewarding to the individual" (Carr & Poria, 2010, p. 4). Like most people without disabilities (PWOD), people with quadriplegia experience and enjoy leisure, including mental and physical leisure experiences. Notably, sex often incorporates both physical and psychological pleasure. Berdychevsky and Nimrod (2017) describe sex as "a self-contained activity with intrinsic sensual, diverting, and/or relational meanings" (p. 224).

Sex as leisure

When leisure and sex are defined, it becomes evident that sex, when consensually pursued for pleasure, embraces definitions of leisure (Godbey, 2008; Meaney & Rye, 2007). Sex can be considered serious leisure, comprised of substantial interest and fulfillment. Alternatively, it may be deemed as casual leisure, a hedonistic experience engaged in for pure joy or pleasure (Stebbins, 2007). According to Csikszentmihalyi (1980), through sex, we can enter *flow*, "a state of concentration so focused that it amounts to absolute absorption in an activity…an exhilarating feeling of transcendence" (p. 1). Given the vast attributes of leisure, scholars present solid reasoning to view sex as leisure.

There has been a peak in interest regarding the various intersections of sex and leisure (Berdychevsky, 2018; Berdychevsky & Nimrod, 2017; Berdychevsky, Nimrod, Kleiber, & Gibson, 2013; Parry & Penny Light, 2014), yet research surrounding the nexus of sex, leisure, and disability, is still lacking. A possible reason may be related to society's heteronormative hegemonic ideas of sex (Rembis, 2009), leading to perceptions of PWD as asexual (Esmail, Darry, Walter, & Knupp, 2010), or as persons unable to have sex for enjoyment and pleasure (Tepper, 2000) (i.e., sex as leisure). Despite this fact, the literature surrounding sexuality and disability has continued to focus primarily on the medical and physical components (Sakellariou, 2006), lacking a thorough examination through a social and cultural lens (Tepper, 2000). Exploring sex as leisure for PWQ will add a much-needed socio-cultural perspective to sex research, furthering our understanding of the perceptions and sexualities of PWQ.

Sex, leisure, and quality of life

Quality of Life (QOL) is a common yet complex concept composed of personal, social, and cultural dimensions. Defining QOL and determining which factors comprise it is challenging due to different individual, social, and cultural values (Iwasaki, 2007). According to Brajša-Žganec, Merkaš, and Šverko (2011), QOL measures a person's objective circumstances and subjective well-being, such as one's general life satisfaction. Despite the personal and socio-cultural complexities when measuring QOL, the primary factors involved are happiness and life satisfaction (Iwasaki, 2007). Sinha and Van Den Heuvel (2011) concur QOL is multidimensional, primarily concerned with happiness, and best determined by the individual.

Iwasaki (2007) conducted an extensive literature review on leisure and QOL, identifying how “existing QOL literature highlights the role of leisure as a contributor to QOL in many countries” (p. 235). A cross-sectional and longitudinal analysis by Wendel-Vos, Schuit, Tijhuis, and Kromhout (2004) found a link between physical leisure activity and health-related QOL. The link between leisure and QOL is not present in physical activity leisure alone. Brajša-Žganec et al. (2011) found that intimate leisure activities contribute to subjective well-being, a significant component in QOL. The study of leisure and QOL for PWD has yielded findings noting the significance of leisure on QOL. A QOL model for psychosocially adapting to chronic illness and disability acknowledges that leisure is one of the 10 domains of QOL (Bishop, 2005). Nosek, Hughes, Howland, Mullen, and Shelton (2004) examined the meaning of health for women with physical disabilities. The study revealed how participating in leisure activities increased life satisfaction, self-esteem, and self-fulfillment for women with physical disabilities. An exploration of serious leisure and QOL for PWD conducted by Patterson (2001) found that serious leisure activity increases self-esteem and self-respect for PWD. Patterson’s work discusses how this boost to self-esteem and self-respect makes one more likely to be accepted by the community, further increasing QOL for PWD participating in serious leisure. The significant impact that various forms of leisure have on QOL is evident in the current literature. However, literature examining sex, leisure, QOL, and PWD, specifically on PWQ, is limited.

Sinha and Van Den Heuvel (2011) examined QOL and amputees. They discovered that QOL for amputees is affected by body function and structure, which affects activity participation. Reitz, Tobe, Knapp, and Schurch (2004) explored participants' sexual activities, abilities, desires, satisfaction, and overall sexual adjustment post-SCI. The study found that participants' relationship with their partner and the ability to move had the most impact regarding satisfying sex life, but no significant correlation between sex and QOL. The authors admit this finding is confusing and suggest bias in the studied population may be the cause. They also speculated that variance in SCI levels might be a possible factor behind the findings. Pre-SCI sexual abilities remaining post-SCI "are not necessarily correlated with better satisfaction in sexual life" (Reitz et al., p. 173). This finding suggests there is more to sexual satisfaction post-SCI than mere genital function. Reitz et al. conclude that subjective influences play a more significant role in sexuality post-SCI and emphasize sexual health and QOL for those with SCI warrants further study. Hence, the present investigation utilizes a qualitative methodology to unravel the unique sexual experiences and perceptions of PWQ.

Methodology

Using a Phenomenological Social Constructivism approach, researchers sought to understand quadriplegics' sexuality and sexual experiences through semi-structured interviews with people with quadriplegia. Semi-structured interview questions were open-ended and required more than a yes or no answer. They were designed to keep the interview on track to gather rich narratives. This approach provides the opportunity to understand participants' worldviews from the co-constructed realities, allowing researchers to recognize the shared experiences of quadriplegia and sexuality (Creswell

& Poth, 2017). Notably, the primary investigator also has quadriplegia. Genoe and Liechty (2016) maintain this can assist with insight into the phenomenon and improve access and rapport with participants. Ensuring the diverse experiences of all participants were represented, the study utilized reflexive journaling to record personal perceptions and experiences (Dupuis, 1999; Genoe & Liechty, 2016). Much of the vernacular and examples presented in this manuscript are representative of the quadriplegic everyday reality. Semi-structured interviews were guided by the following research questions, seeking participant perceptions of (1) their own sexuality, (2) how people define sexuality without disabilities, (3) how sexual experiences impact participant QOL, and (4) quadriplegic sex as leisure. See table one for the semi-structured interview guide.

Table 1

Semi-Structured Interview Guide

Questions
1. Please share with me your (age, sex, gender, sexual orientation, relationship status)
2. Tell me about your disability (level, complete/incomplete, function/sensation, yrs)
3. Tell me about your dating/relationship/married history as a person with a disability?
4. How important is it for you to be sexually active? (If not active, do you want to be?)
5. As a person with quadriplegia, how do you think non-disabled people perceive your sexuality?
6. How do you view your own sexuality?
7. How often do you have sex?
8. When you have sex, what type of sex do you engage in?
9. Tell me about your favorite sex position?
10. What modifications, if any have you used during sex?
11. How do you relate sex to your sense of well-being and quality of life?
12. How would you define leisure? Do you consider sex leisure?
13. Is there anything else you would like to say share about disability and sexuality?

Data Collection

Upon securing informed consent, most interviews took place in person, with the participant choosing a safe and private location, and lasted between 36 and 65 minutes. Due to scheduling and transportation issues, two participants were interviewed via Skype or FaceTime. Due to the sensitive nature of discussing one's sexuality, a relaxed conversation-style atmosphere was used during interviews. Seeking to gain a narrative in participants' own words and give insight into participants' personal sexual experiences, scripted open-ended interview questions were utilized. The interview questions about participants' sexuality focused on pre and post-SCI sexual experiences as a PWD and included personal circumstances regarding the unique characteristics of each participant's SCI.

In an effort not to influence subjects' perceptions of sex as leisure, we purposefully did not define sex before the start of the interviews. Participants were able to speak about their past and current sexual experiences, preferences, and activities without restriction. Multiple coders, member checking, journalistic field notes, and reflexive memoing were used to ensure methodological rigor. Participant narratives were the sole focus, allowing the data to flow from the participants' opinions and experiences in the direction of their choice. Interviews were audio-recorded to enhance transcript accuracy during data analysis.

Data Analysis

The narratives were coded and analyzed via categorical content analysis as suggested by Creswell et al. (2017). Analysis began by reading transcripts and referring to journalistic field notes to uncover the topics consistently shared by participants. After reading the narratives repeatedly to attain immersion to inherit a sense of the whole story, we identified patterns that appeared within-participant narratives and carefully coded the data by highlighting key words or concepts in the text. Examining our initial impressions and analysis, we created labels for codes. Codes were then sorted into categories and organized into themes with the most insightful themes discussed in this manuscript. Analysis of participant narratives provided an understanding of people with quadriplegia's lived sexual experiences and perceptions, which expanded our understanding of quadriplegic sex beyond physicality. The most prevalent themes were: (1) quadriplegics are givers, (2) quadriplegics are sexual beings, (3) non-disabled perceptions are not reality and (4) quadriplegic sex as leisure.

Participants

Recruitment of participants took place in fall 2018 among a large and diverse disability community in the middle Tennessee area utilizing an open invitation by word of mouth and snowball sampling, encouraging people with quadriplegia between the ages of 21-60 to participate. Ten participants who had quadriplegia (7 men, 3 women) represented a fair proportion of various levels of quadriplegia, with nine having an incomplete SCI. Participants were assigned pseudonyms to ensure confidentiality. See table one for participant demographics.

Table 2

Participant Demographics

Pseudonym	Injury	Age	Gender	Sexual Orientation	Relationship Status	Yrs. Quad	Quad Sex Active	Orgasm Ability/Type	Erection During Sex
Aero	C5	54	male	heterosexual	single	25	yes	Ejaculation	w/ED inject
Aldous	C5-6	32	male	heterosexual	relationship	15	yes	Ejaculation	w/o meds
Carlos	C-4	32	male	heterosexual	engaged	14	yes	Ejaculation	w/o meds
Chad	C5-6	36	male	heterosexual	single	19	yes	Ejaculation	w/o meds
Willy	C5-6	41	male	heterosexual	married	23	yes	Ejaculation	w/oral ED
Richard	C6-7	39	male	heterosexual	single	15	yes	Ejaculation	w/ED inject
Stormy	C5-6	47	male	heterosexual	married	30	yes	Mental	w/oral ED
Jess	C4-5	26	female	gay	single	7	yes	Clitoral	n/a
Claudette	C7	26	female	gay	single	6	yes	Mental	n/a
Sherry	C5-6	32	female	heterosexual	single	12	no	Not attempted	n/a

Findings

People with Quadriplegia are Givers

Nine out of ten participants described oral sex as their preferred method for delivering pleasure. Jess said, “Oral for me is the go-to because my face still works perfectly fine.” Jess went on to share what she enjoys about giving oral sex, “If I give oral, I’m automatically in the mood; that’s what does it for me.” Claudette said her favorite sexual position is to be “just giving” sexual pleasure and explains the various ways she is a giver. “I like to be the giver, not the receiver. So, I use my mouth, my hands, and any kind of toy.” The words “give” or “giver” are prevalent throughout participants’ narratives.

The two quadriplegics, both married and givers, described the rationale behind their pleasure-giving preferences. While discussing oral sex and giving pleasure, Willy passionately stated, “The actual act itself, just making sure that she is satisfied, is how I get my satisfaction, watching her pleasure. I take pleasure in that.” Stormy explains, “In my mind, I’m glad that my partner is happy. I’m like, ok, this is really for you for the most part. I’m getting psychological satisfaction, she’s getting the sexual satisfaction, so you tell me what you want.” When asked how important being sexually active is post-injury, Stormy discloses, “Sex, right now, is about a seven or eight out of ten. It’s more because of what I want to do for the significant other than it is for me.” Aero reveals, “I like kissing around on a girl, everywhere…the whole body. Oral as well, this whole fifteen minutes and moving on to something else, I don't like that. I like hanging out for a little while."

> Aldous: I really get off on giving pleasure and making the sex as awesome as possible. So, for me, sex, oral or vaginal, I'm mentally aroused and just like in the moment. I have sensation in my penis, so I can feel it as well, to a point...so it's just wonderful, and it's not about if I finish.

Aero, Aldous, and Chad discussed marathon sex, sex lasting for hours, focusing on pleasure for their partner. During the interview, Chad referred to his sexual activities as "sessions." Aldous and Chad explain they want to make sex the "best" sexual experience for their partner. Chad demonstrates a strong sense of community for his quadriplegic "brothers and sisters." Chad exclaimed, "I feel like I'm having sex with her for all the quads out there. I have to represent for us, and I go way out of my way to try to overcompensate or blow their mind. I'm just trying to give us a good name!"

People with Quadriplegia are Sexual Beings

Eight participants shared how they are very sexual people, and sex is very important in their overall QOL. Chad explains, "Sexuality isn't depending on abilities or capabilities. I think everyone should be entitled to sex, consensually obviously, and everyone should experience it. It's a beautiful thing; it's healthy." Jess explains she is a very sexual person who enjoys sex, just as she did pre-injury. Jess stated she "likes boobs, touching butts, and porn. I just am a sexual person. I've always been that way. I remember masturbating when I was a kid. It's just always been there. There's no denying it and no suppressing it." Willy expressed, "I still have the same testosterone and hormones running through my body. Sex itself is an important part of my life." He describes discovering how sex as a person with quadriplegia and his body is different from his pre-injury body:

> I was going to have to start changing it to get the mental satisfaction. I've heard it called a mental orgasm in the disability community. That's really what I discovered I had. Once I discovered that and accepted it, my sex life became satisfying and fulfilling.

Chad compares sex with his quadriplegic body to pre-injury. Chad explains, "I don't orgasm every time or even the majority of the time, but I still love it...that feeling right before you orgasm, that's basically the feeling that I feel the entire time."

During the early stages of being a quadriplegic, Stormy said sex was important because "[Sex] made you feel like you were more than a person in a wheelchair. You could be as close as you could be to someone that was an able-body." Participants stressed sex was important and a top priority shortly after sustaining an SCI. Stormy explained, "The very first question I asked the doctor when I injured myself had nothing to do with, will I walk? It was, will I ever be able to have sex? That was my very first concern." Immediately following his injury, Richard wondered, "would I ever be able to have sex again. That was one of my big things. I was 22,…sex was always on your mind.

It’s still on my mind today.” Eager to persevere with their sexual identity, several participants engaged in sexual activity soon after their SCI. Willy engaged in his first sexual experience about six weeks after his accident, and Jess was also eager to “try out” sex post-injury. “As soon as I got home, was calling up somebody, ‘hey, come try this out.’ Because I can’t do it myself!” Jess exclaims. Aldous proudly shared that he had sex while still in the hospital post-SCI. Both Aero and Aldous revealed what it meant to know a cervical SCI would not stop them from remaining sexually active.

> Aero: I’m lying there; doctors told my wife, ‘you’re going to have to feed him, clothe him, basically take care of his every need the rest of his life.’ That was freaking painful. I was freaking out. Then a couple of nurses were in, and they were changing me or giving me a bath. I got wood, and I could tell, like hey, what’s going on down there? … it was definitely a good day. I thought life wouldn’t be over then.
>
> Aldous: In the hospital, my girlfriend noticed when I first got a boner and pointed it out…very happy moment; she smiled then I was smiling; it was awesome to know. I just couldn’t control it; I get what they call reflex erections, which means instead of like mentally being turned on and then getting a boner, I get a boner anytime somebody touches my penis. I had to figure stuff out, though. The first time I had sex was actually in the rehab hospital with my girlfriend weeks after my accident.

Simply discovering a traumatic SCI is not the end of one’s sexuality contributes to the will to adapt and live a fulfilling life. Participants shared how being sexual affects their QOL, particularly describing attributes relating to leisure. Richard said when he has sex, he “feels better all around.” Carlos is happier with his sexual activity and well-being intertwined. Others explained how feeling an emotional connection with their partner is what makes sex an important part of their leisure experience and their QOL. For Claudette, it is the emotional connection she values most. Emotionally connecting with his wife is the pinnacle for Willy, “the intimacy we get from being sexually active with each other is important.” Jess, who values the companionship from being sexually active, discussed her love for the physical and psychological benefits and the self-esteem boost sex gives her:

> I feel like I’m more upset or get more in a funk when I’m not having sex. One, I think, the companionship is part of it, I feel like, accomplished with sex because I can get somebody off. I can still do something. I do like that part. It makes me feel good, and it releases energy. I’m definitely a lot happier when I’m having sex and feeling wanted.

Chad admits the physical connection of sex is most important and alludes to the concept of flow:

> I think as long as you're doing it safely, I think sex is fun and healthy. And it just kind of takes you away. There is a lot of aspects of our lives that are just completely shitty, and I don't think about any of those while I'm having sex.

When Chad was asked how sex relates to his sense of QOL, he said:

> I have it going hand in hand because that's just how important sex is to me. If I'm not having sex, something is not going right. I'm just not happy. Sex is a big part of my happiness. I think when you are having sex, you feel more confident, you feel better about yourself, and it's good exercise.
>
> Other participants shared how sexuality is tied to their leisure and QOL.
>
> Aero: I'm extremely sexual; it keeps me sane and makes me feel good about life. As far as quality of life, I think it's important. I'm in a better mood. I think I would kind of relate it to the people that need to see sunlight. When they don't see sunlight in winter, I think it would be like that; I would be in a downer mood.
>
> Aldous: Sex is extremely important, and it definitely has an effect on how I feel. So much happier when having sex, I have less anxiety and stress. So, it really sucks if something interferes with sex night. So, it's really important in my life, and my life is going better, and I'm feeling better, and I'm just overall happier and more confident if I'm having sex. When I don't have it, I am sexually frustrated and just not complete. Ya know, the endorphins you get, it's great exercise too!

From the sample, eight sexually active participants revealed sex is an integral part of their lives. Given participant descriptions of sex, it is an important leisure activity connected to their QOL.

Perception is Not Reality

Nine participants conveyed perceptions regarding non-disabled assumptions about their sexuality. Participants' felt they were perceived as being incapable of having sex and talked about how some experiences left them feeling misjudged and hurt. Aero: "I wish people would be able to look at people and not pre-judge." Stormy explains, "I'm happy to teach and talk to people about sexuality. There may be somebody that says 'F off!' but it makes you a better person for asking."

Participants sharing experiences of being perceived as nonsexual was common. Sherry explains, "I don't think able-bodied people look at us and think, 'Oh, they're definitely having sex.'" Claudette agrees, "They definitely think that I can't have sex. I think that they think that we all can't." Others talked about how engaging in sexual activity post-injury is much more difficult due to the challenges of pursuing a partner while labeled as nonsexual. Chad explains, "Initially, I don't think they are able to see us sexually."

> Richard: It's a lot harder to go out and pick women up being a quadriplegic. I feel like women would look at me different, or they wouldn't see me for who I am. I think they see us as 'They don't have sex.'

This nonsexual perception is explained and understood as the disability overshadowing the person. Carlos feels like women do not look at him and think sexual thoughts:

> They don't think of you as that person. They aren't thinking that maybe they are going to have a relationship with you. They just think of you as not intimidating, like a puppy dog. Like, 'Aww! You are so sweet, but ok, see you later.' I think they just assume that we can't have sex.

Carlos feels he is viewed differently, indicating he once went four years without sex. He frustratedly reported he would not have gone that long without sex as a non-disabled person.

Sherry discussed how she has been in public places and "petted" like a child. Aldous shared a similar perception of feeling like a "pet," seen as cute rather than sexual. He speculated:

> They just think that wheelchair equals being paralyzed, and being paralyzed from the chest down means you can't feel anything, so they assume we don't want sex. You can't move anything, so obviously, you can't get an erection. They are like I was before my accident; I had no idea how spinal cords work. As a quadriplegic, I'm not even an option.

Another example of this perception came from Chad, who spoke about a girl he flirted with one night. He explained how she wrote down her number and snapped, "give me a call if you ever get out of this thing...the chair.” For Aldous, “there was a girl I really wanted to hook up with. I found out through friends that she said, ‘Aldous is so hot, too bad he is in a wheelchair...’” He explained how outraged he was because she was not willing to “look past the wheelchair.” Participants shared experiences where men also considered male quadriplegics as nonsexual.

> Aero: This girl and I were talking, and this guy kind of crowds in. I put my arm like, ‘Her, and I need a little space here.’…He’s like, ‘What are you talking to him for? He’s in a chair.’

Based on their accumulated experiences with the non-disabled population, the participants perceived that they are labeled as asexual by their non-disabled peers, making finding a sexual partner more challenging. Those who identify as lesbian/gay face additional stereotypes, creating more obstacles. Jess shared her views reflecting others’ sex normative and heteronormative attitudes:

> People assume that I’m asexual or straight. I am neither. I think most of them either think ‘she doesn’t have sex’ or ‘she doesn’t want to have sex,’ but I probably do. [laughs] In my mind, I think, ‘ah, just give me twenty seconds to talk to you, and I can change your mind!

Quadriplegics and Sex as Leisure

Six participants viewed sex as leisure, and the remaining four described sex using leisure qualities. When asked, “Do you consider sex leisure?” participants shared their beliefs. Claudette answered, “Yes, I would consider it leisure.” Aldous said, “Sex is leisure; it’s my favorite thing to do. I love doing it, and it makes me feel so much better physically and psychologically. I would always choose sex over any other leisure activity.” Both Aldous and Richard believed the physical aspect of having sex fits into leisure. According to Richard, “it’s a good workout.” Jess recognized how sex involves “getting off and relaxing,” making it leisure.

> Willy: It’s a stress reliever. It’s the thing you look to do to unwind everything. You want to feel that touch, you want to see...you want to have that physical sensation with someone. Just to reset your mind. It’s definitely a leisure activity. It sets your mind at ease.

While sex as leisure did not fit into four participants’ personal definitions of leisure, three participants appeared to value sex as a pleasurable activity and ascribed leisure qualities to sex. This notion is best captured by Stormy, who shared how playing video games is his preferred leisure activity, but he will “drop a video game in a heartbeat” to have sex. Three participants described sex as of higher importance than leisure, or resembling “work” more than “downtime,” yet indicated they valued the enjoyment and pleasure of sex. Aero explained, “I’ve always thought of it as a way higher priority than leisure. I think of it as more of a challenge, and like, here I go. I guess it’s more of a competition and more getting it done.” Three participants’ definitions of leisure referred to passive activities. Sherry stated, “I always thought of sex as a job. Leisure is...naps, movies, reading, and media.” Chad concurred, “Leisure is me taking it easy. When I’m having sex, I’m not taking it easy. I’m on a mission. My mission is to make this girl feel like she’s the only girl on the planet.” Stormy defined leisure as downtime, saying, “I wouldn’t consider [sex] a job, but I wouldn’t consider it downtime either.” While these three participants did not specifically define sex as leisure, they certainly ascribed leisure qualities to sex.

Discussion

Based on our sample, people with quadriplegia are sexual beings. All sexually active quadriplegics in the sample, nine out of ten, conveyed how they were more sexually gratified by the psychological enjoyment of providing pleasure for their partner. “Giving” became more important and pleasurable post-SCI. For example, the importance of sex for Stormy is based on his wife’s pleasure. Reaffirming quadriplegic sex more often consists of the leisure aspects of sex rather than one’s reproductive abilities. Participant narratives highlight the importance of psychological arousal and the influence of psychological factors in sexual satisfaction. Whether pleasing a loving partner of many years or engaging in casual sex, providing pleasure for partners was a major theme of participants’ sexuality. More than simply aiding their partner in achieving an orgasm, participants expressed profound mental enjoyment in the process. Supporting the work of Chance (2002), participants' narratives suggest they feel confident and take pride in giving pleasure to their partner. Chance discusses how men with disabilities often become more "tender" in their sexual roles post-injury, increasing sexual satisfaction for both partners. Some men with a disability assert that they are better lovers as a result of focusing more on pleasing their partner. Chad's efforts to give "quadriplegics a good name" through giving pleasure provide some evidence for this claim.

Short-duration sexual encounters were not popular, suggesting that being a giver may be a part of adapting to a quadriplegic's sexuality. Mental orgasms and a focus on psychological satisfaction rather than relying on physical satisfaction seemed to be a fulfilling adaptation. Decreased sensation can result in immersion in one's other senses. Our findings indicate that being in the moment with any sensation experienced, visually taking in the bodies as they engage in sexual activity, and psychological arousal to the point of experiencing a "mental orgasm" can be sexually satisfying. Although most particpants in this sample engage in penetration, they receive the most pleasure while sexually pleasing others. Regardless of the underlying motives, it is clear that the act of giving is gratifying and increases sexual pleasure for people with quadriplegia in this study.

Sex is an integral part of life for most of this sample. As was the case with multiple participants during interviews, pre-injury sexuality seemed to predict post-injury sexual desires supporting the findings of Torriani et al. (2014). Even though pre-injury sexuality is vital in understanding post-injury sexuality, our results suggest sexual experiences for people with quadriplegia provide an opportunity to experience their disability as a non-issue. For example, Jess loves the ‘accomplished feeling’ of engaging in sexual activity as a person with quadriplegia and providing pleasure for her partner just the same as non-disabled peers. Being sexually active enhanced positive moods, boosting self-esteem and confidence for many participants. People with quadriplegia in this sample suggested that sexual confidence may be crucial in adapting to sexual life post-injury. This supports the claims of Reitz et al. (2004) that one’s state of mental well-being can directly relate to sexual satisfaction.

Most participants shared how they do not physically orgasm every time they have sex but find sexual fulfillment in sexual activities. This supports the findings of Reitz et al. (2004), who noted the physical orgasm or intercourse has no important association with sexual satisfaction. Participants' narratives overwhelmingly indicated that emotionally connecting with another person and giving pleasure increased their QOL. This also supports Reitz et al.(2004) findings that achieving self-orgasm is not as favored as hugging, kissing, touching, and giving oral sex. Regardless of physical ability, sexual desire exists in almost everyone and is assigned personalized levels of importance. SCI can disrupt daily living, but if one adapts to ability level, SCI need not negate sexuality. Our findings suggest being sexual or not depends on the person, not on their physical capacities. While almost all participants described sex as leisure or assigned leisure qualities to sex, for those who are sexually active, sex contributes to their overall QOL.

Overall, participants of both genders agreed that non-disabled persons who do not know them often view them as asexual, supporting the findings of Esmail et al. (2010). Admittedly, several participants held this same view pre-SCI. Most participants felt they were very sexual beings, supporting the findings of Rohleder et al. (2018). Our findings support the idea that the misconceptions surrounding quadriplegic sex are largely derived from lack of education and seeing the wheelchair/disability instead of the person. A problem for many people with quadriplegia, sexual invisibility comes from societal standards linked to the idea that ability denotes sexual capability and attractiveness. Chance's (2002) work affirms that many non-disabled people stereotype PWD as asexual and, as such, are unwilling to be romantically involved with PWDs. All participants agreed that most non-disabled persons perceive them as asexual and/or incapable of having sex. Some participant narratives suggest sex provides a sense of wholeness. Whether stating proudly, "My face still works," striving for the best sexual experience possible, or making the sexual encounter all about the partner, these participants not only engage in sex—rather, it is also an important part of their QOL.

Chance (2002) explains, "societal stereotypes about the supposed asexuality of disabled people deny the full humanity of people who in reality have the same need and capacity" as people without a disability (p. 207). Asexual assumptions lead quadriplegics to perceive that their sexual interests, availabilities, and abilities are not to be taken seriously. Consistently receiving messages from non-disabled peers that disability translates into asexuality can cause harmful and long-lasting consequences for people with quadriplegia, specifically concerning a quadriplegic’s sexual self-concept and self-esteem (Chance, 2002). Although much of the non-disabled world has tried to deny people with quadriplegia are sexual beings, participants resiliently refuted these stereotypes and have established a satisfying sex life post-cervical-SCI.

Six participants viewed sex as leisure, assigning the same leisure qualities to sex as leisure scholars. Of the four who indicated sex was something nobler or more work than leisure, they also admitted or assigned leisure qualities to their sexual activities, supporting the results of Berdychevsky et al. (2013). Thus, given we did not define leisure for participants, our findings reveal people with quadriplegia can be sexual beings, and most identify sex as leisure. Some people with quadriplegia view sex as a high form of leisure, sharing various reasons for valuing sex as leisure. Richard and Aldous believed sex was great exercise, and Willy and Jess loved how sex releases endorphins and helps one unwind.

After a cervical SCI, one’s life may undergo a series of drastic changes on a day-to-day basis (Reitz et al., 2004). Sex, as a pleasurable leisure activity has the power to make one oblivious to daily hassles and may be a coping strategy (Berdychevsky et al., 2013). In addition to pleasurable distraction, some participants, like Aero and Chad, discussed sexual activity as achieving a state of flow. While Aero did not define sex as leisure, his description of sex resembles flow: “sex is a higher priority than leisure.” In this context, he also viewed having sex as a "challenge." Some participants described how having sex makes them feel "more alive" afterward. This rejuvenating effect has been discussed in sex and leisure research by Berdychevsky et al. (2013). All sexually active participants agreed that physical and emotional connection is what is most pleasurable, with personal orgasm being much less important. The contact between partners, with bodies interacting together, is abundantly satisfying (Chance, 2002). In this sense, narratives from Claudette and Jess support Aitchison's (2000) findings that sex as leisure is about the connection or intimate relationship with a person rather than the activity itself. Our conclusions indicate quadriplegics are sexual beings who find that sex as leisure contributes to their QOL. Most importantly, these findings assist in providing an understanding of why and how people with quadriplegia engage in sex as leisure as part of our shared humanity, demystifying misconceptions of quadriplegics and sex.

Limitations

Recruitment yielded participants who all identified as white, resulting in a lack of racial diversity. Furthermore, it is crucial to recognize that only three participants were women. The current findings represent a small sample and are not necessarily representative of all people with quadriplegia. People have wide-ranging experiences, which the current participant views might not embody. These issues suggest important avenues for further research but do not dilute the importance of the findings presented in this paper.

Conclusion

The qualities of leisure bind us together regardless of ability, with many respondents identifying sex as leisure. By studying the perceptions of people with quadriplegia regarding sexuality and sex as leisure, we can help negate the misperceptions held by non-disabled people concerning quadriplegics and sex. Our findings reveal people with quadriplegia can be sexual beings. Most of the respondents identify sex as leisure or associate leisure qualities with sex. After cervical SCI, the body is altered, sensation is reduced, yet we do not always detach from sensation. Despite SCI injuries, we found a satisfying sex life is more than physical satisfaction. Reitz et al. (2004) suggest that sexual ability (genital function) is not completely linked to sexual satisfaction post-SCI. Our findings discovered how engaging in sex is more for pleasure than reproduction, noting that quadriplegic sexual satisfaction is often more about providing pleasure for their partner than traditional orgasms. As Reitz et al. (2004) predicted, subjective influences have a greater impact post-SCI. Sexual activity was strongly related to QOL in our participants. Perhaps with Wendel-Vos et al. (2004) finding a link between physical leisure and QOL, and Brajša-Žganec et al. (2011) linking intimate leisure and QOL, sex as leisure increasing QOL for the people with quadriplegia in this study is due to sexual activity sharing both physical and intimate pleasure components of leisure.

Several participants in this study admit that pre-SCI, they were uninformed regarding SCIs and sexuality. Until the masses are more educated about sex and people with quadriplegia, incorrect assumptions by non-disabled people will continue to persist. We must continue to utilize academic investigations to dispel false assumptions, reducing all areas of stigma surrounding disability and sex. Specifically, examining the sexual activities opeople with quadriplegiacs could reduce misconceptions of non-disabled and assist individuals with SCI in adapting to their sexuality.

Future studies on sex as leisure should focus on impairment due to the variances among types of disabilities. Behind every physical difference between disabilities lies even more psychosocial and sexual differences. Our work suggests additional exploration is needed regarding the role of hegemonic masculinity in quadriplegic male "givers." Finally, it is noteworthy that two of the three women noted body image issues as a serious factor regarding their sexual activity. Notably, none of the men mentioned body image, highlighting a difference female quadriplegics may face. Although body image did not rise to the level of a predominant theme, it warrants further investigation.

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CHAPTER III: EXAMINING BIOPSYCHOSOCIAL BARRIERS TO HAVING SEX AMONG PEOPLE WITH QUADRIPLEGIA

Introduction

Utilizing semi-structured interviews, the preliminary research by Christian, Gray, Roberts, and Eller (2020) sought to gain insight into the intimate sexual relationships of people with quadriplegia (PWQ) through lived experiences. According to the authors, benefits from sex for PWQ include exercise, emotional and physical connection, intimacy, mood enhancement, and increased confidence. The majority of PWQ engaged in sexual activity as a favorite leisure activity and believed sexual activity strongly influenced their quality of life. PWQ described themselves as very sexual beings but stressed that many non-disabled people view them as nonsexual (Christian et al., 2020). Moreover, the authors found that PWQ do seek to and are participating in sex post-injury but face sexual barriers that most non-disabled people do not. Thus, the purpose of this study is to build on the work of Christian et al. (2020) and examine the biopsychosocial barriers PWQ face in perusing intimate sexual relationships. Specifically, this research aims to identify these biopsychosocial barriers and better understand how they may affect PWQ sexual activities.

Cervical spinal cord injuries are traumatic, often resulting in significant impairment to one’s function and sensation of lower and/or upper extremities. Spinal cord injuries can occur in the blink of an eye and lead to an instant and often lifelong alteration of mobility, function, and sensation. These types of injuries can impact some to all daily living skills and every aspect of one’s life. This includes sexual function and sensation. Paralysis and decreased mobility and function impair the human body, altering one’s movement and sensation, yet paralysis does not break the human body. Sexual activity, mental and genital arousal, orgasms, and reproduction are still possible post-SCI. With cervical spinal cord injury, physical obstacles are present, especially for those still in the rehabilitation stages. For some, there are physical obstacles with genital arousal, which can be overcome by taking medications. Bladder and or bowel management may create physical obstacles to sex, as well as movement and body positioning during sex for some. Fiduccia (2000) shared that much of research, and predominantly the medical world, is concerned with bio-medical factors. This focus would suggest physical obstacles are the biggest challenge to sex for PWQ.

Psychological factors interfere with sexual activity for PWQ as well. Cervical SCI is life-altering, not only because the majority are permanent but also because of its impact on one’s daily living. Post-SCI, some PWQ have their independence partially or fully taken away. The inability to suddenly be able to dress oneself, bathe oneself, feed oneself, use the bathroom on ones own can take a psychological toll. After this life-altering event, PWQ essentially mourn their nondisabled selves. Identities, anger, depression, anxiety, frustration could affect one’s sex life. PWQ may experience decreased self-esteem, self-confidence, and self-concept until one accepts and adapts to life post-cervical-SCI. Impairment in lower and upper extremities post-SCI results in less gross motor skill activity, which may lead to reduced muscle mass and/or increased fat tissue. Negative or unhealthy body image issues can present challenges and obstacles to sex for some PWQ. Psychological factors and emotional consequences have been found to hinder sexual activity more so than the cervical SCI's physical consequences (Dahlberg, Alaranta, Kautiainen, & Kotila, 2007; Julia, & Othman, 2011). Some researchers believe psychological obstacles to be of the greatest concern regarding sex for PWQ.

Sociological factors are crucial to consider when seeking to explore and examine sex and PWQ. Immediately following a cervical SCI, PWQ join a minority group—one that has a long history of oppression, discrimination, and sometimes abuse. Long-standing stereotypes and negative attitudes exist that present themselves to PWQ via interpersonal communication. Whether from peers, community, or society, stigma and stereotypes in some way work towards sexually oppressing PWQ. These negative attitudes from society and social interactions directed at PWQ may serve as obstacles to sex partners. Stigma and stereotypes act as and produce harmful obstacles to sex for PWQ (Burr, 2011; Chance, 2002; Christian et al., 2020; Santos & Santos, 2018). Such research suggests sociological obstacles may hinder PWQ the most when pursuing sex. For PWQ, whose injury was two or more years ago, who have had time to adapt/or adjust, how do these different obstacles weigh in? By measuring physical, psychological, and sociological obstacles to sexual activity for PWQ, findings from this study will shed light on which barriers pose the greatest challenges and contribute to the topic of sex and disability by highlighting which areas researchers should investigate further.

Additionally, the findings and discussion may open the door for researchers to explore which obstacles are causing others. For example, is the physical impairment inducing stigma that increases psychological barriers or vice versa? The physical impairment leads to psychological issues that get magnified when encountering social barriers. The results can give a direction for future researchers, educate the non-disabled majority population, and combat stigma.

Methodology

Upon approval from the Institutional Review Board, PWQs ages 18-64 of any sex, gender, sexual orientation, race, or ethnicity were invited to participate in the study. Participants were recruited via word of mouth, social media, and medical discussion boards to participate in the study and provided a link to the survey on the Qualtrics survey platform (www.qualtrics.com). This research utilizes a 46-question survey to explore the intimate sexual activities and barriers to sex for PWQ. Using a 6-point Likert scale, 27 questions pertain to addressing potential biopsychosocial obstacles to sex (7 physical, 11 psychological, and 9 sociological). The remaining 19 items consist of demographic questions regarding age, gender, race, education, and level of SCI.

Measures

This research utilizes a 46-question survey to explore the intimate sexual activities and barriers to sex for PWQ. Using a 6-point Likert scale rated from strongly disagree to strongly agree, 27 questions pertain to addressing potential biopsychosocial obstacles to sex (7 physical, 11 psychological, and 9 sociological). The remaining 19 items consist of demographic questions regarding age, gender, race, education, and level of SCI. Participants were also provided the option to indicate if an item did not apply to their current situation. See appendix A for full survey details.

Data Cleaning and Analysis

Of the 90 original participants, 39 were excluded from analyses because they did not meet the age or SCI specifications and/or did not complete all survey questions were removed from analyses. The remaining 51 participants met all study requirements (n = 51). Data were analyzed using IBM SPSS v26, and Qualtrics reports to generate descriptive statistics and crosstabulations. PWQ's obstacles to sex were categorized into three different types: physical, sociological, and psychological. Descriptive statistics were used to analyze how various obstacles impacted sexual activity for people with cervical spinal cord injuries. Participants were asked to indicate if each potential obstacle was not a barrier for them, if they indicated that they somewhat through strongly disagreed, then the item was coded as a barrier, whereas if they reported that they somewhat to strongly agreed that it was not an obstacle then it was coded as not being a barrier to having sex.

Participants

Participants consisted of 51 PWQ with a complete (33.3%) or incomplete cervical (66.7%) SCI, for at least two years, with an average of 17 years since their SCI (*SD* = 11.8). Participants in this research represented a wide range of cervical spinal cord injury levels, from C2 – C8. The majority of participants, 63.3%, had cervical SCI at the C5 – C7 level, and out of all PWQ, 66.7% had incomplete cervical spinal cord injuries. Not surprisingly, many of the participants appear to be very active and mobile, with 47.1% being able to transfer from a chair to another location such as a bed or toilet, 50% being able to dress themselves, and 37.3% being completely independent with daily living skills.

Thirty-seven males and 13 females participated in the study with an average age of 45.2 years (*SD* = 12.3). Regarding sexual orientation, 48 of the participants identified as heterosexual or straight (88.2%), three as gay or lesbian, and two identifying as bisexual. A little more than half of the participants (56%) indicated they were either married or in a serious relationship, and 44% indicated they were single/dating. Most participants (92.3%) identified as White and 1.9% as Asian, with the remaining 5.8% preferring not to answer. All participants had at least a high school diploma or equivalent, with 62.8% having earned a bachelor's degree or higher.

Results

Out of 51 participants, 46 (88.2%) indicated they had sexual partners before their SCI. When asked about their total number of sexual partners post-SCI, 45 (88%) participants indicated they had had one or more sexual partners since their injury (Table 1).

Table 1

Number of Sexual Partners

	Before SCI		*Post-SCI*	
#	%	Count	%	Count

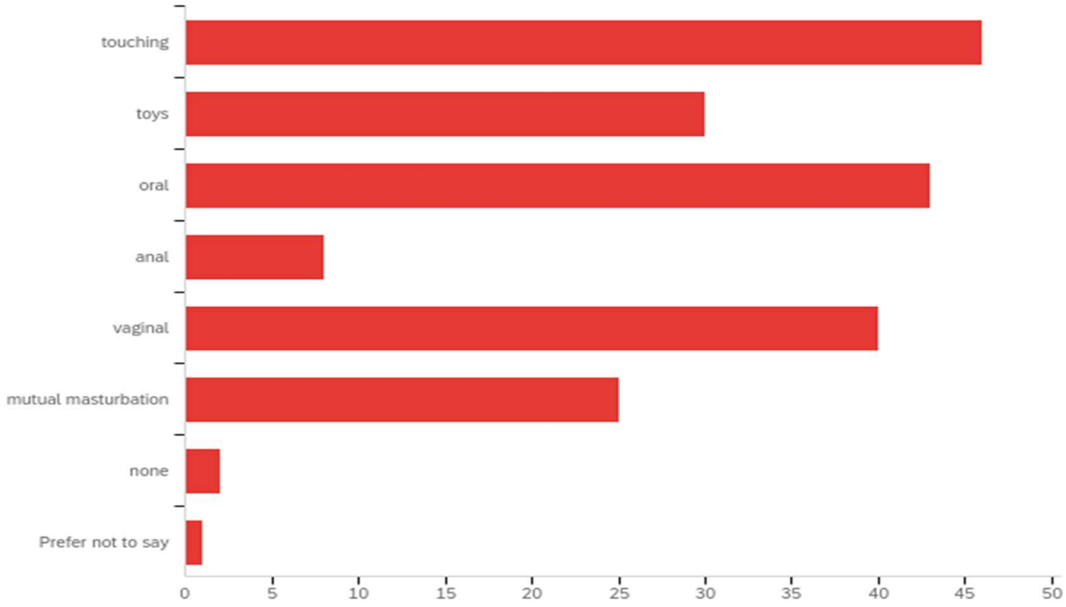
0	9.8	5	11.8	6
1 to 2	27.5	14	35.3	18
3 to 5	23.5	12	17.7	9
6 to 10	17.7	9	13.7	7
11 to 20	9.8	5	13.7	7
21 or more	9.8	5	7.8	4
Prefer not to answer	2.0	1	0	0

Note. Post-SCI includes only the number of sex partners since their spinal cord injury.

Of the 45 who engaged in post-SCI sex, they indicated their activities consisted of touching (90.2%), oral (84.3%), vaginal (78.4%), sex toys (58.8%), and mutual masturbation (49%). Notably, participants could and did often indicate more than one sexual activity (Figure 1).

Figure 1

Types of Sexual Activity Post-SCI



Sexual arousal, for most, is an essential part of engaging in intimate sexual activity. Participants were asked how they experience genital arousal and the ways genital arousal is maintained during sex. Psychogenic arousal (i.e., when mentally and visually arousing thoughts and images lead to arousal of the genitals) still functioned for 27.5% of participants. The majority, 60.8%, of participants experienced reflexogenic arousal, wherein their genitals would become aroused as a response to physical contact with the penis or vagina. A little over half of the participants (54.9%) of the sample were able to maintain an erection or vaginal lubrication during sex through continuous physical contact of the genitals (i.e., reflexogenic measures). However, physical stimulation had to be present because there is no genital function. Only 41.2% of the participants needed medication to achieve genital arousal, and 45.1% used medication to maintain genital arousal during sex. Although they can maintain arousal for sex, medication is necessary based on their cervical SCI.

When participants were asked what facilitated their genital arousal post-SCI, various responses were given: physical contact to their genitals (32.6%) and medication (22.1%) were among the most frequently reported methods. Interestingly, 17.9% indicated they "get mentally aroused, but it does not lead to genital arousal," whereas, 14.7% said, "my mental arousal leads to genital arousal" (Table 2).

Table 2

Post-SCI Experience Sexual Arousal

	%	Count
My mental arousal leads to genital arousal	27.5%	14
Physical contact of my genitals leads to genital arousal	60.8%	31
I get mentally aroused, but it does not lead to genital arousal	33.3%	17
Using a device such as a pump, implant, ring, or vibrator	5.9%	3
Medication	2.0%	1
Unsure	0.0%	0
None	15.7%	8
Does not apply	41.2%	21

Note. Genital arousal for men is how you experience an erection. Genital arousal for women is how you experience vaginal lubrication.

Further, given the physical limitations of PWQ, it is important to understand how sexual arousal is *maintained*. A variety of methods are used to maintain sexual arousal with primary modes, including continuous physical contact of the genitals (28.3%), erectile dysfunction medications (23.2%), and touching or stimulating other areas of their body (14.4%) (Table 3).

Table 3

Post-SCI Maintain Sexual Arousal

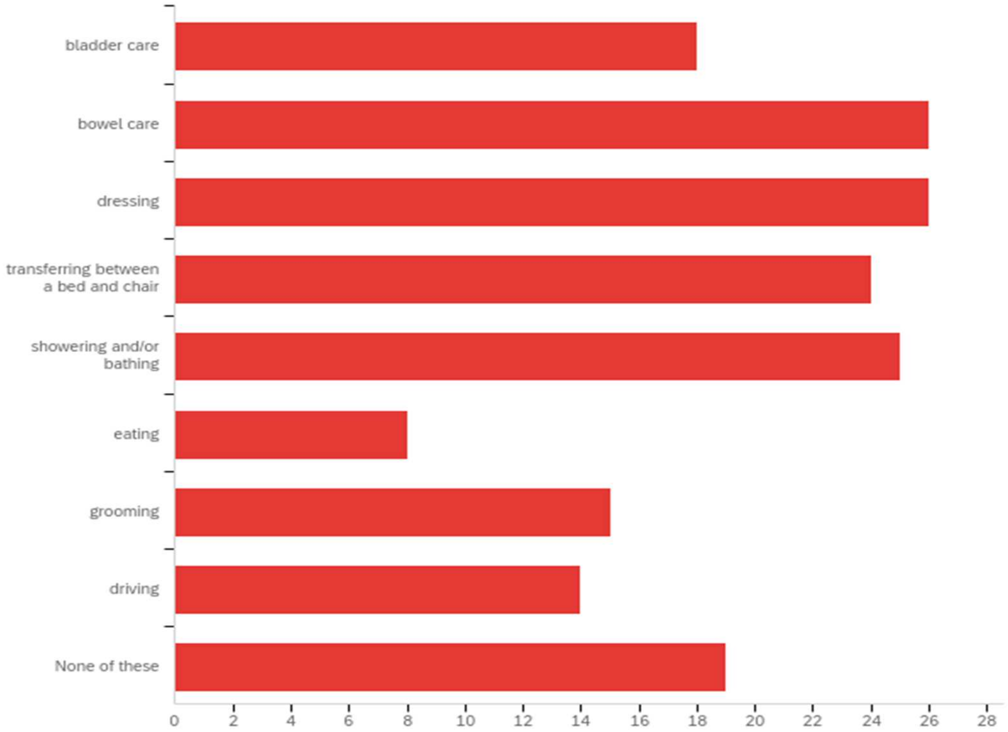
	%	Count
Touching or stimulating other areas of my body	27.5%	14
Mentally	19.6%	10
Through continuous physical contact of the genitals	54.9%	28
By applying lubricant	11.8%	6
Using a device such as a pump, implant, ring, or vibrator	21.6%	11
Erectile dysfunction medications	45.1%	23
Does not apply	13.7%	7

Note. Genital arousal for men is how you experience an erection. Genital arousal for women is how you experience vaginal lubrication.

Genital function/and sensation, body positioning, bowel and bladder maintenance, spasticity, and regulating body temperature were explored as potential biological and physiological obstacles. When considering the accommodations many people with an SCI need to make to engage in sexual activities, we must consider the daily living assistance participants need. These accommodations can also sometimes be perceived as barriers to sexual activity. Daily living assistance, such as bladder management, can have a significant impact on PWQ intimate sexual activities. The data revealed 32 out of 51 (62.7%) participants needed partial or full assistance with daily living skills such as bladder and/or bowel care, dressing, or eating (Figure 2).

Figure 2

SCI Daily Living Skills Partial or Full Assistance Needed

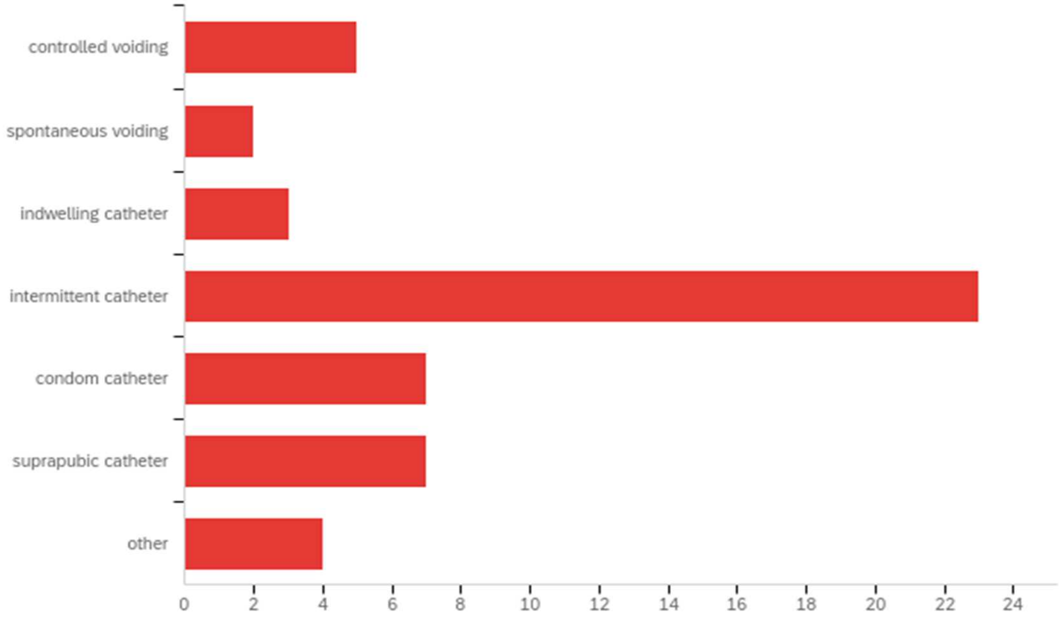


All participants (100%) indicated they used some type of bladder management assistance, with the majority (45.1%) using an intermittent catheter. This in-and-out catheter routine frees up genitals and decreases obstacles to sex for those PWQ.

Controlled bladder voiding was employed by 9.8% of PWQ, which resulted in fewer obstacles to sex. Approximately 19.6% of PWQ used medical supplies constantly (24 hours a day) for bladder management, such as condom catheters and indwelling catheters. Although indwelling catheters and condom catheters can be removed briefly for sex, these participants face additional biological obstacles to engage in sex. The longer the indwelling and/or condom catheter is out, the more the possibility of uncontrollable bladder accidents during sex. This could be viewed as a genital function barrier for some PWQ, compared to bladder maintenance in general (Figure 3).

Figure 3

Bladder Management



With these needs in mind, participants were then asked to consider the physical, psychological, and social obstacles they had encountered during their sexual activity post-SCI. Of potential physical barriers, genital function (54.9%) was the only one to be identified as a barrier by a majority of participants. Lack of genital sensation (46%) and difficulty moving and getting their body into position (45.1%) were considered a barrier among a large minority of participants. Contrary to popular belief, paralysis does not equal no sensation. For some PWQ, most or all sensation may be lost, whereas others may only lose some sensation. Those who lose the majority or all of sensation in their genitals may be able to "feel" genital sensation through other parts of their body, most often the head and neck. Those who have only lost some sensation, can mean that they still feel textures but cannot feel the difference between hot and cold (or vice versa). A smaller minority of PWQ considered bowel programs or accidents, not being able to regulate body temperature or sweat, and muscle spasms to be physical barriers to sexual activity (Table 4).

Table 4

Physical Barriers

	Yes Barrier	Not a Barrier
Genital function is not an obstacle to having sex.	52.9%	43.1%
Genital sensation is not an obstacle to having sex.	46.0%	48.0%
Movement and getting my body into position is not an obstacle to having sex.	45.1%	51.0%

My bladder maintenance and/or bladder accidents is not an obstacle to having sex.	24.0%	70.0%
My bowel program and or bowel accidents is not an obstacle to having sex.	31.4%	60.8%
Not being able to sweat and regulate my body temperature is not an obstacle to having sex.	24.0%	66.0%
Muscle spasms are not an obstacle to having sex.	29.4%	64.7%

Note. The remaining participants indicated that the question did not apply to them and was not included in the calculations.

Fear of embarrassment, stigma, and stereotypes can yield significant psychological barriers to sexual activity for PWQ. Concerns over their ability to perform sexually (44%) and low self-esteem (41.2%), level of dependence on others (39.2%), and body image (39.2%) are major psychological barriers participants experience when pursuing or during sexual activities (Table 5).

Table 5

Psychological Barriers

	Yes Barrier	Not a Barrier
A fear of bladder accidents is not an obstacle to having sex.	19.6%	74.5%
A fear of bowel accidents is not an obstacle to having sex.	29.4%	64.7%
Concerns over my ability to perform sexually is not an obstacle to having sex.	44.0%	54.0%
My level of self-confidence is not an obstacle to having sex.	37.3%	60.8%
Low self-esteem is not an obstacle to having sex.	41.2%	54.9%

My body image, the way I feel about my appearance is not an obstacle to having sex.	39.2%	58.8%
My level of dependence on others with daily living skills is not an obstacle to having sex.	39.2%	54.9%
Anxiety is not an obstacle to having sex.	29.4%	66.7%
Depression is not an obstacle to having sex.	30.0%	56.0%
Anger is not an obstacle to having sex.	17.6%	70.6%
Frustration is not an obstacle to having sex.	37.3%	52.9%

In addition to the physical and psychological barriers, PWQ also encounter social stigma and misconceptions that impact their sexual activity. Social barriers were perceived to have a significant impact on sexual activity for PWQ. The majority of participants indicated social barriers such as finding a willing partner (67.34%), under-representation in pornography (66.7%), ignorance of non-disabled people (62%), society's attitudes on sex and people with a disability (54.9%), and portrayals of people with disabilities on movies and TV shows (54%) were obstacles for PWQ and sex (Table 6).

Table 6

Social Barriers

	Yes Barrier	Not a Barrier
Society's attitudes on sex and people with a disability has not been an obstacle to having sex.	54.9%	41.2%
Others (my peers, friends, family) attitudes on sex and disability have not been obstacles to having sex.	35.3%	60.8%

When I pursue a new potential sex partner, their attitude is not an obstacle to having sex.	51.0%	33.3%
Finding a willing partner is not an obstacle to having sex.	66.7%	23.5%
My attitude on sex and disability is not an obstacle to having sex.	27.4%	72.6%
The ignorance of people without disabilities is not an obstacle to having sex.	62.0%	36.0%
Portrayals of people with disabilities on movies and TV shows are not an obstacle to having sex.	54.0%	44.0%
People with disabilities are not underrepresented in pornography.	67.3%	20.4%

Supporting the findings of Christian et al. (2020), when asked to identify stereotypes and/or misconceptions that have at some point created obstacles to having sex, a majority of participants indicated that the two most common stereotypes or misconceptions that impacted their sexual activity was, “I cannot have sex” (78.4%) and, “I’m incapable” (58.8%). Almost half of the participants indicated that the misperception that they were not interested in sex (47.1%), would not make a suitable sex partner (45.1%), were incomplete or broken (45.1%), and/or too fragile for sex (41.2%) had been an obstacle to sex that they had experienced post-SCI. This finding emphasizes the ignorance that still exists in our culture and the paramount need to continue to educate society about the sexual lives and abilities of PWQ. See Table 7.

Table 7

Perceptions of Stereotypes/Misconceptions

Question	%	Count

I cannot have sex	78.4%	40
I'm not interested in sex	47.1%	24
I'm too fragile for sex	41.2%	21
I'm affectionate but would not make a suitable sex partner	45.1%	23
I'm incomplete or broken	45.1%	23
I'm incapable	58.8%	30
I should be pitied	27.5%	14
Other, please specify:	5.9%	3
None of these	1.7%	3
I prefer not to say	0.0%	0

Discussion

This research aims to better understand the sexual activities of PWQ and the biopsychosocial barriers they may experience. The findings of this study not only support the work of Christian et al. (2020) it also provides much-needed insight regarding the sexual activities of PWQ, which is missing from the current literature. Perhaps more importantly, it serves as a tool to educate non-PWQs that the majority of PWQ are indeed desire and do have sex. Despite the common belief that PWQ cannot have sex and are not sexual beings (Chance, 2002; Christian et al., 2020; Santos & Santos, 2018), the majority of participants had been sexually active to some degree—only 6 out of 51 (11.8%) of participants indicating they have not had sex post-SCI. This is an interesting finding considering the perception among many non-disabled people that PWQ do not have sex, are not interested in sex, or are a-sexual (Christian et al., 2020). On the contrary, this study found that PWQ sexual activity varies much like that of non-PWQ.

Supporting the work of Corbett (1987), what non-PWQ are doing sexually is similar to what PWQ do. Specifically, subjects indicated their activities consisted of touching (90.2%), oral sex (84.3%), vaginal sex (78.4%), sex toys (58.8%), and mutual masturbation (49%) in varying degrees; there was not a glaringly dominate sexual activity among PWQ. Touching is particularly interesting as PWQ's hands and fine motor skills are, in most cases, impaired in some way. Over 89% of the participants are not only having sex, but they are engaging in the same sexual activities as non-PWQ despite biopsychosocial barriers they face due to their SCI. This should in no way imply that biopsychosocial barriers do not have a profound impact on many PWQ's sexual activities. While the study results describe the various types of physical and social barriers PWQ face with sexual activities, we would be remiss not to understand that these barriers can and often do, act as a psychological barrier for PWQ sex as well.

Nearly 100% of dependent PWQ said the need for assistance from a partner or caregiver is a barrier to sex. This is a much-needed area of research. Dependency on family, caregivers, and nurses interfere with the privacy needed for intimate relationships. Does dependence reduce confidence and significantly interfere with sex? Is the issue around this barrier concerning trust with potential partners? Researchers should explore the amount of hesitancy to have sex with new partners since dependent PWQ rely on their potential sex partners to help them dress afterward or transfer them back into their chair. The dependency of dressing, undressing, and transferring necessitates a relationship that consists of some amount of trust. This also could dampen spontaneous sex as some level of preparation for sex is important, and as such one-night stands are often not an option for most PWQ.

PWQ can rarely rip off their clothes and spontaneously engage in sexual activity because of the need for preparation, for example, due to bladder and bowel concerns. Anderson et al. (2007a) found that bowel and bladder concerns were important for sex post-SCI, particularly for women. For this study, 35.3% PWQ relied on others partially or fully for bladder maintenance, and 51% required assistance partially or fully for bowel care. But when asked about the fear of bowel accidents as a psychological barrier to sex, only 29% said yes, and only 20% said bladder accidents were a psychological barrier to sex. These interesting results may be because most PWQ have some type of trusting relationship with their sexual partner. One possible reason that fear of bowel and bladder did not rank higher is that, on average, there were 17 years since cervical SCI for this sample. Additionally, for some PWQ, even though they need assistance going to the bathroom, they have a comfortable bowel and bladder routine, and it is not keeping them from being sexually active. This study is predominantly male (74%), so further work should examine the link between gender and bowel and bladder concerns or whether the time since SCI helps reduce psychological concerns.

Genital function may be more of an issue in the minds of non-PWQ than PWQs. Forty-four percent of PWQs said concerns over their ability to perform during sex were a barrier, but 54% claimed the ability to perform sexually was not a barrier. However, seventy-eight percent of PWQ said that non-PWQ assumed that PWQ cannot have sex or that their genitals do not work. Yet, the majority of participants (60.8%) experienced reflexogenic arousal (54.9%) and could maintain vaginal lubrication or an erection during sex through reflexogenic measures. Medication is at times necessary for 41.2% based on their cervical SCI. However, the most important of these findings is that PWQ can and do have physical and/or psychogenic arousal. The obstacle to sex likely is more a misconception social barrier than a physical one.

A physical impairment as severe and life-altering as cervical SCI can have a profound psychological impact, especially if one has not accepted their disability and adapted to their new circumstances (Dahlberg et al., 2007). Of this sample, 41% believed their low self-esteem acted as a barrier to sex, supporting the findings of Chance (2002), who found that self-esteem and self-concept can be major obstacles to sex for people with disabilities. But an important question is to what extent are the barriers to sex more about physical obstacles versus social misconceptions and ignorance of non-PWQ? Social barriers such as stereotypes and stigma can also infiltrate one's self-concept and even further lower self-esteem (Chance, 2002). The influence of stigma and discrimination can at times lead to internalized stigma, where an individual adopts ableist thinking and applies stereotypes to self for disability. Internalized stigma can also refer to shame or fear of discrimination (Van Brakel, 2006). Although self-confidence was not ranked high as a sexual barrier (37%), it could be due to the high number of years since SCI. The prevalence of internalized stigma among PWQ should be further explored, specifically regarding the damage it can cause to one's self-esteem, confidence, and self-concept.

Individual and societal attitudes were viewed as barriers to sex by PWQ. Fifty-five percent agreed that society’s attitudes about sex and people with a disability had been an obstacle to having sex, and 51% agreed that new potential sex partner’s attitudes were an obstacle to having sex. This suggests more than ignorance or lack of knowledge but refers to deeply-rooted feelings and views of people without disabilities. The nondisabled majority population has pitied PWD throughout history, feared PWD, and viewed them as incapable of living fulfilling lives (Kress-White, 2009; Rodney & Kathleen, 2010). Of this sample, 58.8% said they had encountered the stereotype of “I’m incapable” when pursuing sex. Christian et al. (2020) found that PWQ are extremely enthusiastic about giving pleasure during sex. PWQ gained great pleasure from pleasing their partner. Yet, the degree to which they please can also be influenced by a desire to disprove stereotypes about PWQ as incapable sex partners. Survey results support findings that negative attitudes and a lack of information are ever-present. Other survey items on social barriers explored obstacles for PWQ from major cultural systems such as media. Media serves as one of society's most essential tools for shaping and reinforcing people’s attitudes (Gard & Fitzgerald, 2008). Portrayals of people with disabilities in movies and TV were barriers to sex for 54%, and 67% believed disabilities are underrepresented in pornography. This suggests PWQ feel they are negatively or inaccurately portrayed in movies and TV or otherwise missing altogether.

Summary

The findings of this study clearly show that PWQ sexual experiences are in some ways much like that of non-PWQ. Clearly, most PWQ are interested in, physically capable of, and engaging in sexual activities. They engage in the same type of sexual activities of non-PWQ, such as sexual touching, oral sex, vaginal sex, sex toys, and mutual masturbation. However, PWQ face many biopsychosocial barriers most non-PWQ do not. Of course, some PWQ may have to take medication or use other methods to maintain an erection or vaginal lubrication, but many non-PWQ do so as well. According to Selvin, Burnett, and Platz (2007), 18.4% of all men twenty years and older have erectile dysfunction. Participants in this study revealed 41.2% of the participants needed medication to achieve genital arousal, and 45.1% used medication to maintain an erection. However, perhaps the most critical finding of this study is that the biopsychosocial barriers straight forward; they are cofounded in and by the lack of education and understanding of non-PWQ. Obstacles and barriers with genital functioning were not as prominent as many might have assumed. A large majority of PWQ relied on reflexogenic arousal, with a small portion of PWQ experiencing psychogenic arousal, but notably, all that engage in sex experienced sexual arousal. The findings suggest social obstacles are more of an issue than physical barriers.

The majority of PWQ said there is an ignorance about sex and PWQ. Whether it be that PWQ are not interested in sex or that PWQ cannot have sex, those misconceptions do not match the reality for PWQ and create barriers to pursuing partners. As Anderson et al. (2007a) explained, the biological components of SCI have been extensively researched. PWQ are sexual, and their bodies are functioning sexually at a much higher level than society perceives, but social barriers are staggering. Today, it appears that the most significant issue regarding sex and cervical SCI lies mainly within the mind and attitudes of people without disabilities.

Conclusions

While the findings of this study add to the work of Christen et al. (2020) and general knowledge of PWQ and sex, we still have a great deal to learn and share with scholars and society as a whole. Future research should examine whether specific demographics or disability-specific traits are experiencing obstacles to sexual activity differently. For example, do participants who identify as women experience more sociological barriers to sex than those who identify as men? Do participants with more years since their spinal cord injury report fewer psychological obstacles than participants with a more recent spinal cord injury? Perhaps, as years since SCI increase, confidence and body image increase as well. If so, it would be interesting to explore how years since spinal cord injury and psychological adjustment influence the severity of psychological and social barriers.

Disability-specific information such as participant bladder management (e.g., different catheterizations) may have correlations with physical obstacles. Due to every SCI's complex and random outcomes being unique, a question on independence with daily living skills should be included in future surveys. Incomplete cervical SCIs are too complex to only gather data on SCI level and type. Without the daily living question—an inside look of their unique function and sensation—accurate results for future research directions will be lacking.

Survey findings suggest that social obstacles and barriers to sex for PWQ are critical areas for future research. This sample of PWQ ranging from C2-C8 injuries, 21-64 years of age from all over the United States, identified social barriers to be more common than biopsychological barriers to sex. More PWQ reported social barriers to sex than the barriers imposed by genital function and bladder and bowel obstacles, focusing on traditional SCI research. It is apparent that PWQ face stigma and experience stereotypes that interfere with sexual pursuits (Christian et al., 2020). However, it would be optimistic to believe that one-size-fits-all is one-size-fits-all when it comes to stigma and disability. Based on the survey findings, further research should investigate whether increasing physical impairments correlate with social obstacles and barriers.

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CHAPTER IV: DISCUSSION

The findings of this dissertation confirm many PWQ want to and are having sex, but there is still a vast sea of questions remaining about the sex lives of PWQ. How frequently are they having sex ,and how does that compare to the frequency of non-PWQs? How do PWQ sex lives and activities compare to non-PWQ? How might we educate society that some PWQ have very happy and healthy sex lives despite the barriers they face? What is certain is that many PWQ can and do have sex and that a better understanding and education of the sexual activity of PWQ is deeply needed to demystify misconceptions and combat barriers PWQ often face.

Utilizing qualitative methods, Article 1 yielded PWQ's words and experiences that they are very sexual beings who believe sex is important to their quality of life. Article 2 used survey data to connect and support Article 1 findings b, exploring how PWQ are sexually active. The survey also showed that sexual function is not absent for PWQ and even identified how PWQ achieved and maintained genital arousal during sex. The qualitative methods in Article 1 shared rich experiences that PWQ have had with nondisabled peers assuming that PWQ are nonsexual. Article 2 findings identified this social barrier that assumes PWQ are incapable of having sex.

The findings and results of both Article 1 and Article 2 effectively highlight that psychosocial issues and barriers outweigh anatomical problems. The research focused on SCI has well established the ability to achieve and maintain erections and should no longer be the central area of focus. Future research can focus more on the biological components of sex for PWQ to educate others on the surprising sexual capabilities of PWQ. This will help further society's understanding of disability and sex. However, a more important goal for future research should primarily focus on understanding psychosocial components and barriers to sex for PWQ. With a better understanding of psychosocial factors and unique cervical SCI outcomes, we can address the psychosocial causes of obstacles and work to combat these barriers. The connection of findings between Article 1 in Article 2 should demonstrate that impairment-based research is the most effective way of understanding sex for different disabilities. Therefore, future research should be conducted using the same or similar methods for various impairments. To gain fruitful and accurate findings for other disabilities, impairment-based studies are the most effective route.

Future impairment-based studies are needed to better understand sex, disability, and psychosocial factors. Meanwhile, to truly understand this opic, and hopefully bring about change for all PWD, other crucial factors cannot be ignored or left out. There are three critical components to this topic: PWQ, individuals who are non-disabled, and society. Researchers should investigate stereotypes from the non-disabled perspective, exploring negative attitudes and faulty assumptions directly from people without disabilities. This will shed light on bias and the root of these faulty assumptions and harmful attitudes. Future researchers should explore the significant cultural systems such as healthcare, education, and media. According to critical disability theory, each of these systems operates on ableist norms, thus oppressing PWD. To make deep and lasting change in the daily life of PWD, ableist aspects of these cultural and institutional systems will need to be understood and challenged.

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APPENDIXES

Appendix A: Article 2 – Survey Questions

1. Have you had a spinal cord injury for at least 2 years or more?
   - ○ Yes
   - ○ No

2. Please select your spinal cord injury level Select all that apply
   - C2
   - C2 – 3
   - C3
   - C3 – 4
   - C4
   - C4 – 5
   - C5
   - C5 – 6
   - C6
   - C6 – 7
   - C7
   - C7 – 8
   - C8
   - T1
   - T2
   - T3
   - T4
   - T5
   - T6
   - T7
   - T8
   - T9
   - T10
   - T11
   - T12
   - L1
   - L2
   - L3
   - L4
   - L5
   - S1
   - S2
   - S3
   - S4
   - S5
   - Other or none of the above

3. What is your biological sex?
   - ○ Male
   - ○ Female
   - ○ Other, not listed
   - ○ I prefer not to say

4. How do you currently describe your gender identity?
   - ○ Man
   - ○ Woman
   - ○ Non-binary
   - ○ My gender isn't listed
   - ○ I prefer not to say

5. What is your Age in years?
   18 - 64

6. Which ethnic group best describes you?
   - ○ Hispanic or Latino
   - ○ Not Hispanic or Latino
   - ○ I prefer not to say

   Which Race best describes you? Select all that apply
   - ○ American Indian or Alaska Native
   - ○ Asian
   - ○ Black or African-American
   - ○ White
   - ○ Unknown or prefer not to say

7. Select your highest level of education
    - ○ Less than high school degree
    - ○ High school diploma or equivalent
    - ○ Associate's degree
    - ○ Bachelor's degree
    - ○ Graduate or professional degree
    - ○ Other please specify:

8. Do you consider yourself to be:
    - ○ heterosexual or straight
    - ○ gay or lesbian
    - ○ bisexual
    - ○ fluid
    - ○ pansexual
    - ○ queer
    - ○ demisexual
    - ○ questioning
    - ○ asexual
    - ○ Other, please Specify:
    - ○ I prefer not to say

9. Please share your relationship status. Select all that apply
    - ○ single
    - ○ married
    - ○ in a relationship
    - ○ just having fun
    - ○ dating
    - ○ other Specify:

10. How long has it been since your spinal cord injury in years? 1- 40 yrs

11. Please select your type of spinal cord injury
    - ○ complete
    - ○ incomplete

12. What do you primarily use for bladder management?
    - ○ controlled voiding
    - ○ spontaneous voiding
    - ○ indwelling catheter
    - ○ intermittent catheter
    - ○ condom catheter
    - ○ suprapubic catheter
    - ○ other

13. What daily living skills do you need partial or full assistance with? Select all that apply to you:
    - ○ bladder care
    - ○ bowel care
    - ○ dressing
    - ○ transferring between a bed and chair
    - ○ showering and/or bathing
    - ○ eating
    - ○ grooming
    - ○ driving

This portion of the survey asks questions about your sex life, and your sexual behaviors. This can be a sensitive subject for some people. Please remember that you can skip questions or dropout at any time. Sex refers to any activity between two or more consenting individuals, that involves stimulation through physical contact of a genital organ.

14. Prior to your spinal cord injury, how many sexual partners did you have?
    - ○ 0
    - ○ 1-2
    - ○ 3-5
    - ○ 6-10
    - ○ 11-20
    - ○ 21 or more
    - ○ I prefer not to answer

15. After your spinal cord injury, how many sexual partners have you had? Counting only the number of sex partners since your spinal cord injury.
    - ○ 0
    - ○ 1-2
    - ○ 3-5
    - ○ 6-10
    - ○ 11-20
    - ○ 21 or more
    - ○ I prefer not to answer

16. How do you experience genital arousal since your spinal cord injury? Note: Venital arousal for men is how you experience an erection. Genital arousal for women is how you experience vaginal lubrication. Select all that apply to you:
    - ○ My mental arousal leads to genital arousal
    - ○ Physical contact of my genitals leads to genital arousal
    - ○ I get mentally aroused but it does not lead to genital arousal
    - ○ Using a device such as a pump, implant, ring, or vibrator
    - ○ Medication
    - ○ None
    - ○ Unsure
    - ○ Does not apply

17. When you have sex post spinal cord injury how do you maintain genital arousal? For example, men maintaining an erection during sex, or for women maintaining vaginal lubrication during sex. Select all that apply to you:
    - ○ Touching or stimulating other areas of my body
    - ○ mentally
    - ○ through continuous physical contact of the genitals
    - ○ by applying lubricant
    - ○ using a device such as a pump, implant, ring, or vibrator
    - ○ erectile dysfunction medications
    - ○ Does not apply

18. When you have sex post spinal cord injury what types of sex do you engage in? Select all that apply to you:
    - ○ touching
    - ○ toys
    - ○ oral
    - ○ anal
    - ○ vaginal
    - ○ mutual masturbation
    - ○ none
    - ○ Prefer not to say

This portion of the survey asks questions about obstacles. The definition of an obstacle is something that gets in the way of progress or that slows or stops progress. An obstacle can refer to challenges, but obstacles do not totally block progress like barriers do. For example, John overcame the obstacles of poverty and neglect. Pam must overcome a number of obstacles before she can open her restaurant.

19. Please rate the following statements while considering your sexual experiences within the past 1 to 2 years.

1	2	3	4	5	6	Does not apply
Strongly disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly agree	

- Genital function is not an obstacle to having sex.
- Genital sensation is not an obstacle to having sex.
- Movement and getting my body into position is not an obstacle to having sex.
- My Bladder maintenance, and/or bladder accidents is not an obstacle to having sex.
- My bowel program and or bowel accidents is not an obstacle to having sex.
- Not being able to sweat and regulate my body temperature is not an obstacle to having sex.
- Muscle spasms are not an obstacle to having sex.

20. Please rate the following statements while considering your sexual experiences within the past 1 to 2 years.

1 Strongly disagree	2 Disagree	3 Somewhat disagree	4 Somewhat agree	5 Agree	6 Strongly agree	Does not apply

- A fear of bladder accidents is not an obstacle to having sex.
- A fear of bowel accidents is not an obstacle to having sex.
- Concerns over my ability to perform sexually is not an obstacle to having sex.
- My level of self-confidence is not an obstacle to having sex.
- Low Self-esteem is not an obstacle to having sex.
- My body image, the way I feel about my appearance is not an obstacle to having sex.
- My level of dependence on others with daily living skills is not an obstacle to having sex.
- Anxiety is not an obstacle to having sex.
- Depression is not an obstacle to having sex.
- Anger is not an obstacle to having sex.
- Frustration is not an obstacle to having sex.

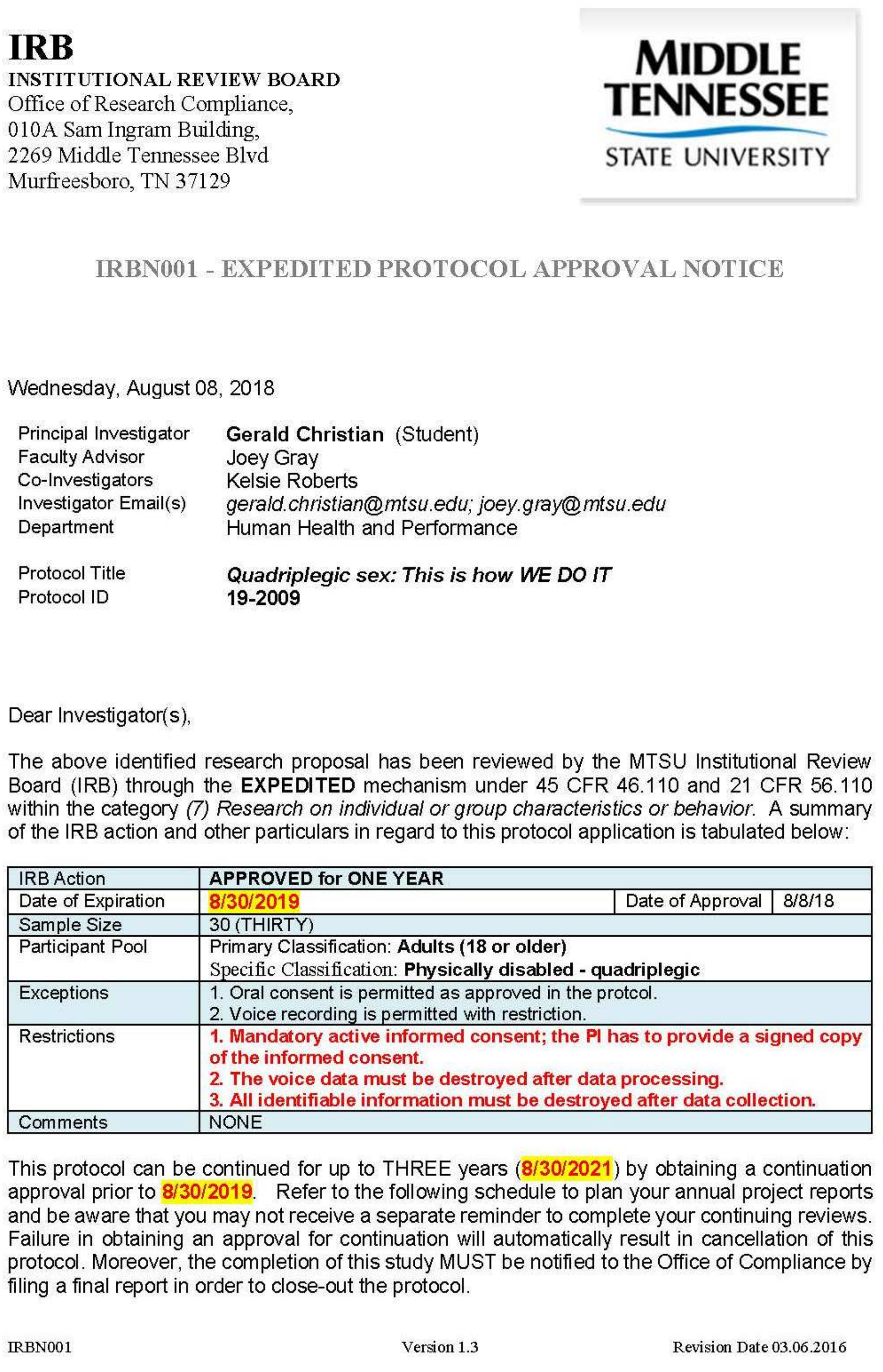
21. Instructions*: please* answer the following questions about sex in general since your spinal cord injury. For example, if you are currently in a relationship, consider times before your relationship while you were pursuing a new sex partner post spinal cord injury.

1 Strongly disagree	2 Disagree	3 Somewhat disagree	4 Somewhat agree	5 Agree	6 Strongly agree	Does not apply

- Society's attitudes on sex and people with a disability has not been an obstacle to having sex.
- Others (my peers, friends, family) attitudes on sex and disability has not been an obstacle to having sex.
- When I pursue a new potential sex partner their attitude is not an obstacle to having sex.
- Finding a willing partner is not an obstacle to having sex.
- My attitudes on sex and disability is not an obstacle to having sex.
- The ignorance of people without disabilities is not an obstacle to having sex.
- Portrayals of people with disabilities on movies and TV shows is not an obstacle to having sex.

22. Some people may have certain thoughts or beliefs about people with a spinal cord injury. Please select stereotypes below, if any that have at some time created obstacles to having sex for you in general since your spinal cord injury. Because I have a spinal cord injury people have thought.
    - ○ I Can't have sex
    - ○ I'm not interested in sex
    - ○ I'm too fragile for sex
    - ○ I'm affectionate but would not make a suitable sex partner
    - ○ I'm incomplete or broken
    - ○ I'm incapable
    - ○ I should be pitied
    - ○ Other, please specify:
    - ○ None of these
    - ○ I prefer not to say

Appendix B: Article 1 – Institutional Review Board Approval Letter



IRB
INSTITUTIONAL REVIEW BOARD
Office of Research Compliance,
010A Sam Ingram Building,
2269 Middle Tennessee Blvd
Murfreesboro, TN 37129

MIDDLE TENNESSEE STATE UNIVERSITY

IRBN001 - EXPEDITED PROTOCOL APPROVAL NOTICE

Wednesday, August 08, 2018

Principal Investigator	**Gerald Christian** (Student)
Faculty Advisor	Joey Gray
Co-Investigators	Kelsie Roberts
Investigator Email(s)	*gerald.christian@mtsu.edu; joey.gray@mtsu.edu*
Department	Human Health and Performance
Protocol Title	***Quadriplegic sex: This is how WE DO IT***
Protocol ID	**19-2009**

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU Institutional Review Board (IRB) through the **EXPEDITED** mechanism under 45 CFR 46.110 and 21 CFR 56.110 within the category *(7) Research on individual or group characteristics or behavior.* A summary of the IRB action and other particulars in regard to this protocol application is tabulated below:

IRB Action	**APPROVED for ONE YEAR**		
Date of Expiration	**8/30/2019**	Date of Approval	8/8/18
Sample Size	30 (THIRTY)		
Participant Pool	Primary Classification: **Adults (18 or older)** Specific Classification: **Physically disabled - quadriplegic**		
Exceptions	1. Oral consent is permitted as approved in the protcol. 2. Voice recording is permitted with restriction.		
Restrictions	**1. Mandatory active informed consent; the PI has to provide a signed copy of the informed consent.** **2. The voice data must be destroyed after data processing.** **3. All identifiable information must be destroyed after data collection.**		
Comments	NONE		

This protocol can be continued for up to THREE years (**8/30/2021**) by obtaining a continuation approval prior to **8/30/2019**. Refer to the following schedule to plan your annual project reports and be aware that you may not receive a separate reminder to complete your continuing reviews. Failure in obtaining an approval for continuation will automatically result in cancellation of this protocol. Moreover, the completion of this study MUST be notified to the Office of Compliance by filing a final report in order to close-out the protocol.

Post-approval Actions

The investigator(s) indicated in this notification should read and abide by all of the post-approval conditions imposed with this approval. Refer to the post-approval guidelines posted in the MTSU IRB's website. Any unanticipated harms to participants or adverse events must be reported to the Office of Compliance at (615) 494-8918 within 48 hours of the incident. Amendments to this protocol must be approved by the IRB. Inclusion of new researchers must also be approved by the Office of Compliance before they begin to work on the project.

Continuing Review (**Follow the Schedule Below:)**

Submit an annual report to request continuing review by the deadline indicated below and please be aware that **REMINDERS WILL NOT BE SENT.**

Reporting Period	Requisition Deadline	IRB Comments
First year report	7/31/2019	This protocol will be closed on 08/30/2019 as requested by the PI unless a continuing review request is obtained before the mentioned deadline
Second year report	7/31/2020	NOT COMPLETED
Final report	7/31/2021	NOT COMPLETED

Post-approval Protocol Amendments:

Only two procedural amendment requests will be entertained per year. *In addition, the researchers can request amendments during continuing review. This amendment restriction does not apply to minor changes such as language usage and addition/removal of research personnel. .*

Date	Amendment(s)	IRB Comments
NONE	NONE.	NONE

Other Post-approval Actions:

Date	IRB Action(s)	IRB Comments
NONE	NONE.	NONE

Mandatory Data Storage Requirement: All of the research-related records, which include signed consent forms, investigator information and other documents related to the study, must be retained by the PI or the faculty advisor (if the PI is a student) at the secure location mentioned in the protocol application. The data storage must be maintained for at least three (3) years after study has been closed. Subsequent to closing the protocol, the researcher may destroy the data in a manner that maintains confidentiality and anonymity.

IRB reserves the right to modify, change or cancel the terms of this letter without prior notice. Be advised that IRB also reserves the right to inspect or audit your records if needed.

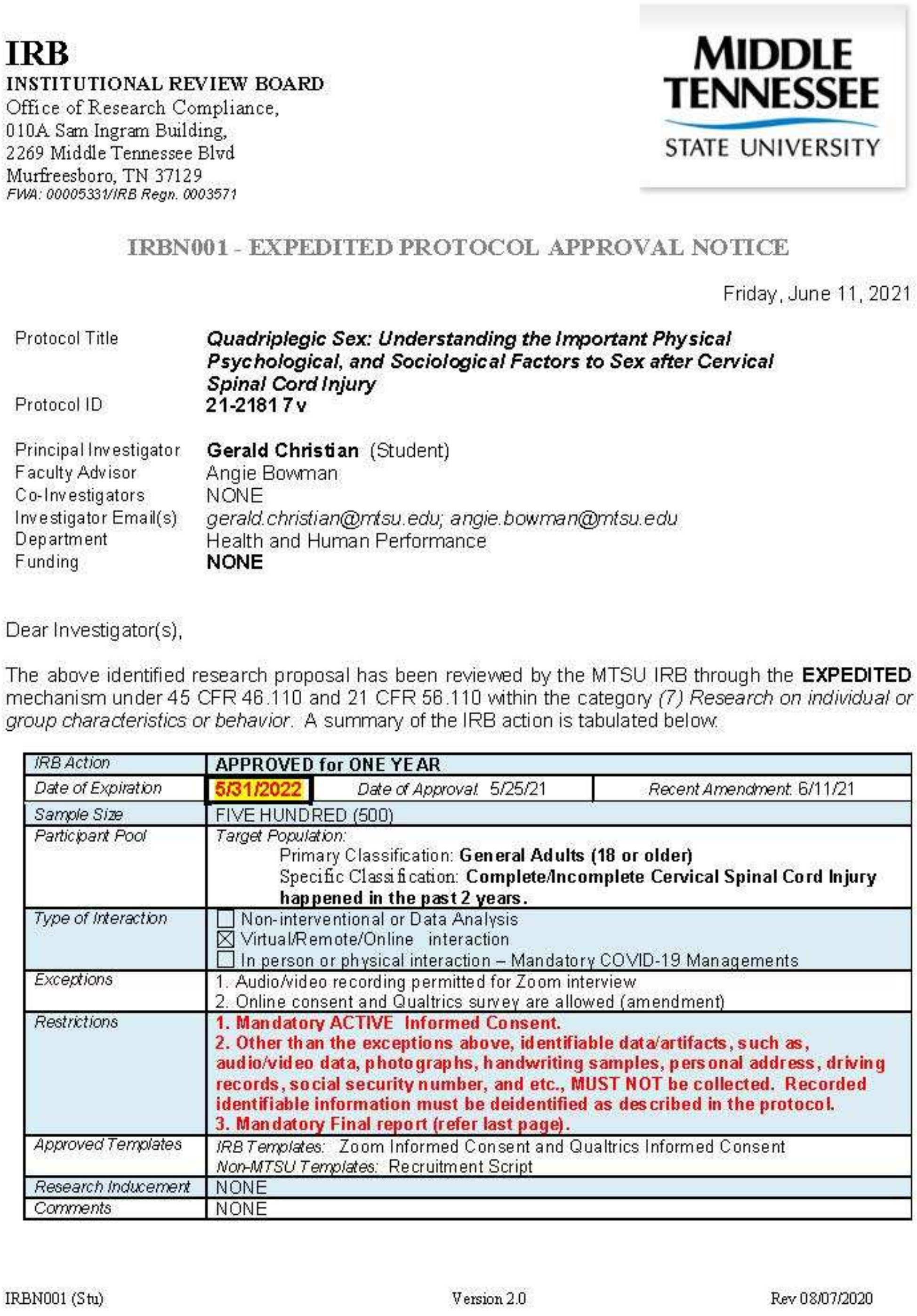
Sincerely,

Institutional Review Board
Middle Tennessee State University

Quick Links:

Click here for a detailed list of the post-approval responsibilities.
More information on expedited procedures can be found here.

Appendix C: Article 2 – Institutional Review Board Approval Letter



IRB
INSTITUTIONAL REVIEW BOARD
Office of Research Compliance,
010A Sam Ingram Building,
2269 Middle Tennessee Blvd
Murfreesboro, TN 37129
FWA: 00005331/IRB Regn. 0003571

MIDDLE TENNESSEE
STATE UNIVERSITY

IRBN001 - EXPEDITED PROTOCOL APPROVAL NOTICE

Friday, June 11, 2021

Protocol Title — ***Quadriplegic Sex: Understanding the Important Physical Psychological, and Sociological Factors to Sex after Cervical Spinal Cord Injury***
Protocol ID — **21-2181 7v**

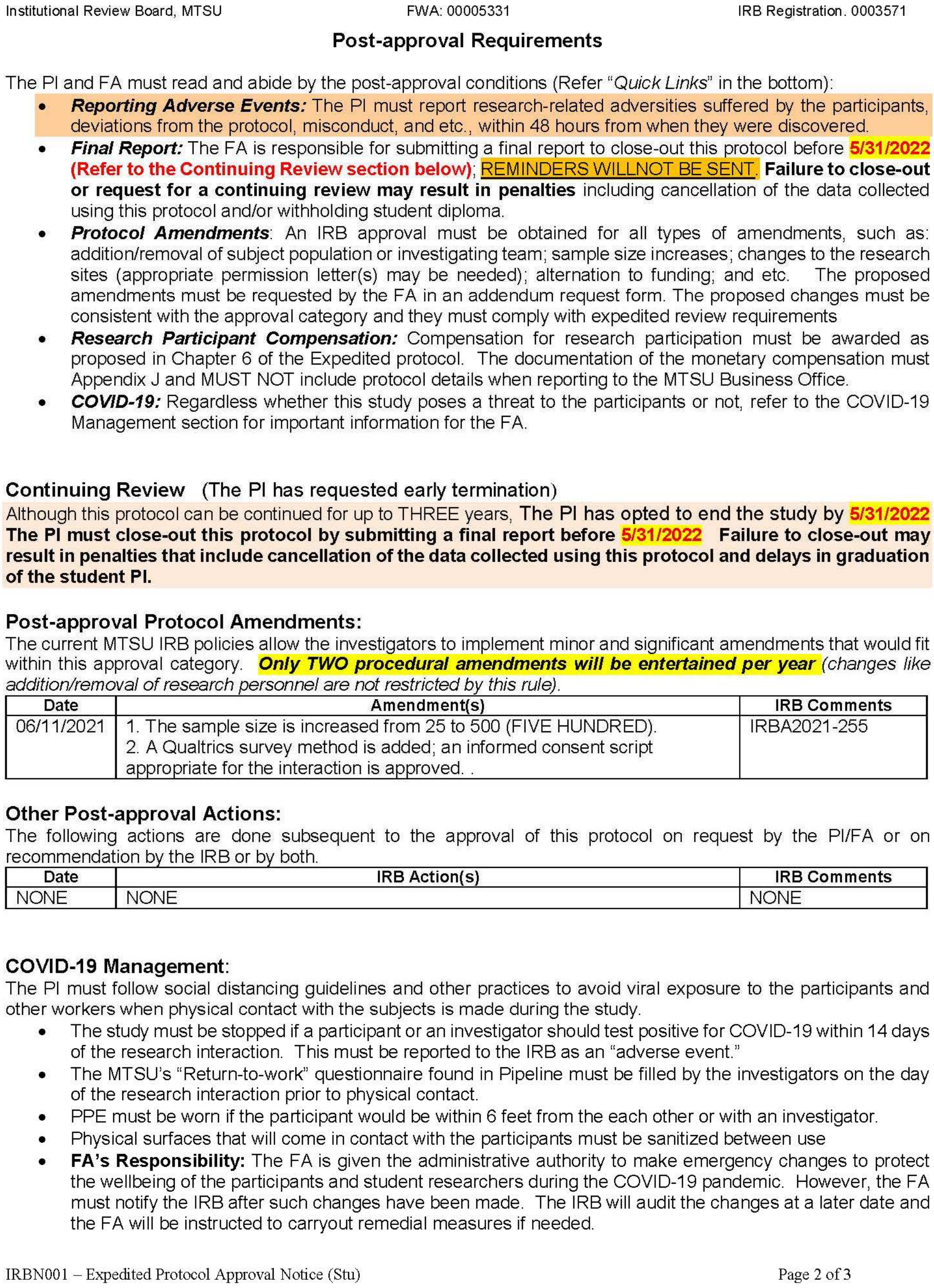
Principal Investigator — **Gerald Christian** (Student)
Faculty Advisor — Angie Bowman
Co-Investigators — NONE
Investigator Email(s) — *gerald.christian@mtsu.edu; angie.bowman@mtsu.edu*
Department — Health and Human Performance
Funding — **NONE**

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU IRB through the **EXPEDITED** mechanism under 45 CFR 46.110 and 21 CFR 56.110 within the category *(7) Research on individual or group characteristics or behavior.* A summary of the IRB action is tabulated below.

IRB Action	**APPROVED for ONE YEAR**
Date of Expiration	**5/31/2022** *Date of Approval:* 5/25/21 *Recent Amendment:* 6/11/21
Sample Size	FIVE HUNDRED (500)
Participant Pool	*Target Population:* Primary Classification: **General Adults (18 or older)** Specific Classification: **Complete/Incomplete Cervical Spinal Cord Injury happened in the past 2 years.**
Type of Interaction	☐ Non-interventional or Data Analysis ☒ Virtual/Remote/Online interaction ☐ In person or physical interaction – Mandatory COVID-19 Managements
Exceptions	1. Audio/video recording permitted for Zoom interview 2. Online consent and Qualtrics survey are allowed (amendment)
Restrictions	**1. Mandatory ACTIVE Informed Consent.** **2. Other than the exceptions above, identifiable data/artifacts, such as, audio/video data, photographs, handwriting samples, personal address, driving records, social security number, and etc., MUST NOT be collected. Recorded identifiable information must be deidentified as described in the protocol.** **3. Mandatory Final report (refer last page).**
Approved Templates	*IRB Templates:* Zoom Informed Consent and Qualtrics Informed Consent *Non-MTSU Templates:* Recruitment Script
Research Inducement	NONE
Comments	NONE

IRBN001 (Stu) Version 2.0 Rev 08/07/2020



Post-approval Requirements

The PI and FA must read and abide by the post-approval conditions (Refer "*Quick Links*" in the bottom):

- ***Reporting Adverse Events:*** The PI must report research-related adversities suffered by the participants, deviations from the protocol, misconduct, and etc., within 48 hours from when they were discovered.
- ***Final Report:*** The FA is responsible for submitting a final report to close-out this protocol before **5/31/2022** **(Refer to the Continuing Review section below)**; REMINDERS WILLNOT BE SENT. **Failure to close-out or request for a continuing review may result in penalties** including cancellation of the data collected using this protocol and/or withholding student diploma.
- ***Protocol Amendments***: An IRB approval must be obtained for all types of amendments, such as: addition/removal of subject population or investigating team; sample size increases; changes to the research sites (appropriate permission letter(s) may be needed); alternation to funding; and etc. The proposed amendments must be requested by the FA in an addendum request form. The proposed changes must be consistent with the approval category and they must comply with expedited review requirements
- ***Research Participant Compensation:*** Compensation for research participation must be awarded as proposed in Chapter 6 of the Expedited protocol. The documentation of the monetary compensation must Appendix J and MUST NOT include protocol details when reporting to the MTSU Business Office.
- ***COVID-19:*** Regardless whether this study poses a threat to the participants or not, refer to the COVID-19 Management section for important information for the FA.

Continuing Review (The PI has requested early termination)

Although this protocol can be continued for up to THREE years, The PI has opted to end the study by **5/31/2022** **The PI must close-out this protocol by submitting a final report before 5/31/2022 Failure to close-out may result in penalties that include cancellation of the data collected using this protocol and delays in graduation of the student PI.**

Post-approval Protocol Amendments:

The current MTSU IRB policies allow the investigators to implement minor and significant amendments that would fit within this approval category. ***Only TWO procedural amendments will be entertained per year*** *(changes like addition/removal of research personnel are not restricted by this rule).*

Date	Amendment(s)	IRB Comments
06/11/2021	1. The sample size is increased from 25 to 500 (FIVE HUNDRED). 2. A Qualtrics survey method is added; an informed consent script appropriate for the interaction is approved. .	IRBA2021-255

Other Post-approval Actions:

The following actions are done subsequent to the approval of this protocol on request by the PI/FA or on recommendation by the IRB or by both.

Date	IRB Action(s)	IRB Comments
NONE	NONE	NONE

COVID-19 Management:

The PI must follow social distancing guidelines and other practices to avoid viral exposure to the participants and other workers when physical contact with the subjects is made during the study.

- The study must be stopped if a participant or an investigator should test positive for COVID-19 within 14 days of the research interaction. This must be reported to the IRB as an "adverse event."
- The MTSU's "Return-to-work" questionnaire found in Pipeline must be filled by the investigators on the day of the research interaction prior to physical contact.
- PPE must be worn if the participant would be within 6 feet from the each other or with an investigator.
- Physical surfaces that will come in contact with the participants must be sanitized between use
- **FA's Responsibility:** The FA is given the administrative authority to make emergency changes to protect the wellbeing of the participants and student researchers during the COVID-19 pandemic. However, the FA must notify the IRB after such changes have been made. The IRB will audit the changes at a later date and the FA will be instructed to carryout remedial measures if needed.

Data Management & Storage:
All research-related records (signed consent forms, investigator training and etc.) must be retained by the PI or the faculty advisor (if the PI is a student) at the secure location mentioned in the protocol application. The data must be stored for at least three (3) years after the study is closed. Additional Tennessee State data retention requirement may apply (*refer "Quick Links" for MTSU policy 129 below*). The data may be destroyed in a manner that maintains confidentiality and anonymity of the research subjects.

The MTSU IRB reserves the right to modify/update the approval criteria or change/cancel the terms listed in this letter without prior notice. Be advised that IRB also reserves the right to inspect or audit your records if needed.

Sincerely,

Institutional Review Board
Middle Tennessee State University

Quick Links:

- Post-approval Responsibilities: http://www.mtsu.edu/irb/FAQ/PostApprovalResponsibilities.php
- Expedited Procedures: https://mtsu.edu/irb/ExpeditedProcedures.php
- MTSU Policy 129: Records retention & Disposal: https://www.mtsu.edu/policies/general/129.php