

**PRIORITIZING PLEASURE: A QUALITATIVE EXPLORATORY STUDY OF
DISABLED SEXUALITY AND REHABILITATION**

by

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ABSTRACT

Sexual activity has positive emotional, mental, physical, and cognitive health outcomes coinciding with the benefits of leisure engagement. While there has been some research on the topic of disabled sexuality, this topic has not been studied from a leisure perspective. Similarly, the leisure research related to sex has not included a disability lens. The purpose of this study was to explore the experiences of people with acquired physical disabilities, how the onset of disability impacted their sexuality, and the role of rehabilitation in addressing sexuality. This qualitative included five individual interviews and one focus group with four people. Participants discussed dating and potential partners, gaps in knowledge of healthcare practitioners, pain and pleasure, expectations of able-bodied people, and the future of sexuality support and education. Connections are made between sexuality, power, identity, health care and education. Recommendations are made for community programming, education, and future research on disabled sexuality.

Keywords: Disabled Sexuality, Leisure, Physical Rehabilitation, Sexuality Education, Sex

LIST OF ABBREVIATIONS USED

LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer, and beyond
TR	Therapeutic Recreation

GLOSSARY

The following key terms have varying definitions and context. This section clarifies how these terms will be defined and used in the context of this thesis.

Acquired physical disability encompasses a broad array of physical conditions that limit a person's movements, senses, or activities of daily living (ADLs), resulting from trauma or disease (Dunn & Brody, 2008; Kattari, 2014). Examples include, but are not limited to, arthritis, spinal cord injury, Ehlers-Danlos syndromes, loss of limb(s), vision or hearing impairment, and some neurological conditions. The World Health Organization (2016) defines disability as “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)”. Bullock and Mahon (2017) take a biopsychosocial approach to further develop this definition, by emphasizing the importance of personal, contextual and environmental factors, and how each has the potential to affect how disability is defined for an individual. They also stress the importance of emphasizing ability rather than *disability* in practice, regardless of classification. This approach to disability follows a social constructivism paradigm, by acknowledging the way individual, subjective experiences of persons with disabilities shape definitions of disability. Therefore, in this study, *disability* is defined broadly, and open to interpretation by research participants.

Disability Language: In healthcare settings, it is common practice to use person-first language when discussing conditions or patients, meaning it would be appropriate to say “a person with a disability” rather than “a disabled person” (Bullock & Mahon, 2017). However, in disability communities, using identity-first language is often considered important, to acknowledge the connection between a person and their disability (Dunn & Andrews, 2015). In this study, both terms will be used, depending on context. When discussing ideas held by

or identity associated with people with disabilities, the term “disabled” will be used. When discussing healthcare related issues, diagnoses or other broad topics, the term “with a disability” will be used.

Queer and Trans will be used to refer to participants of the research who identify within LGBTQ+ communities. LGBTQ+ stands for; Lesbian, Gay, Bisexual, Transgender, Queer and Questioning, and beyond. I have chosen to use the term “queer and trans” instead of the acronym based on my own queer identity, and the preferences of the research participants. I chose not to add ‘2S’ (referring to Two-Spirit, a term specific to Indigenous individuals and communities) to the acronym I use throughout this thesis, because none of the participants in this study identified as Two-Spirit or Indigenous, and I felt it was not appropriate to speak for these communities without their input.

Sex describes a wide range of pleasurable behaviours, and is subjectively defined by each individual. Sex may or may not include masturbation, oral sex, anal sex, vaginal penetration, tribadism (non-penetrative genital contact), and other forms of stimulation to erogenous zones. Sexual assault falls outside the definition of sex because it is not engaged in by choice and is not experienced as pleasurable.

Sexuality is the ways in which a person or people experience or express themselves sexually. This can encompass gender and sexual expression (outward expression of self), gender and sexual identity (inward understanding), kink practices (the use of ‘unconventional’ practices and fantasies), etc.

Sex positivity refers to a positive relationship with sex, rather than the idea that sex is inherently positive (Glickman, 2009). This definition acknowledges that sex is neither good nor bad, but is a subjective experience that changes over time. Sex positivity implies respect for different between subjective experiences of sex.

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CHAPTER 1 INTRODUCTION

Sex and sexuality are crucial elements of the human experience, but barriers exist to marginalized communities accessing support and education about sexuality. Myths and misunderstandings about disabled sexuality stop people with disabilities from learning about their bodies in relation to pleasure and sexuality. These myths and misunderstandings contribute to the lack of information and misinformation that circulates among healthcare, government and community. Further, sexuality as part of pleasure and identity is rarely the focus in healthcare, government and community spaces for people with disabilities. Disability and sex are explored within alternative media and select literature, but the intersections of disability and sex as a form of leisure have received little attention. Academic health care literature has focused on two themes related to sex and disability: theories that describe the impact of physical disability on sexuality, and theories about disability and sexuality in members of the “sexual minority” (LGBTQ+ community) (Schulz, 2009).

Considering sex as a form of leisure draws attention to its nature as a pleasurable activity engaged in by choice. Research has shown that positive evaluation of one’s sexual lifestyle is closely associated with feelings of happiness (Hooghe, 2012). For those who engage in a safe and consensual way, sexual activity has positive emotional, mental, physical, and cognitive health outcomes (Elders, 2010). Similarly, individuals’ participation in chosen leisure activities is associated with several positive outcomes relating to identity, freedom of choice, and pleasure (Heintzman, 2007), suggesting alignment between sex and leisure.

Rationale

Sex and Disability in the Leisure Literature

Sex has rarely been studied within leisure contexts. Sex has been characterized as a form of casual leisure, focused on sensory stimulation and sharing characteristics of other forms of

casual leisure such as eating, drinking, and sight-seeing (Attwood & Smith, 2013). Casual leisure is viewed as non-productive activity centered on immediate, intrinsically rewarding and relatively short-lived experiences (Attwood & Smith, 2013). Williams (2009) has taken a different perspective, by acknowledging that sex has qualities of serious leisure while also being ‘deviant’, especially from kink perspectives. While some studies have defined sex as a form of positive leisure within aging populations (see Berdychevsky & Nimrod, 2016; Elders, 2010), and individuals with depression (Berdychevsky et al., 2013), there has been little effort within the leisure literature to explore sex and leisure for individuals with disabilities.

Sex in the Disability Literature

Historical perspectives of sex and disability. Throughout much of history, societal perspectives of disability have been appalling. People with disabilities have been regarded as burdens on society, punishments or gifts from religious higher powers, and/or sick and in need of treatment or caretaking (Henderson & Bryan, 2011). Up until the 20th century, few supports existed in North American societies to institutionalize and rehabilitate people with disabilities (Henderson & Bryan, 2011). Accessing these supports typically required relinquishing personal human rights from the individual with a disability to be able to access care (Henderson & Bryan, 2011). As well, social cleansing was practiced in an effort to remove people with disabilities from society altogether, often in the form of compulsory sterilization of people with disabilities (Henderson & Bryan, 2011). The sexuality of people with disabilities as long been ignored, controlled, or pathologized, including both reproductive practices and pleasure and attraction (McRuer & Mollow, 2012). While many of the inhumane practices have been outlawed, the attitudes toward disability that shaped these perspectives of disabilities remain (McRuer, 2006). People with disabilities are commonly characterized as

menaces to society, objects of pity or ridicule, eternal children and holy innocents, or as burdens of charity and sickness (Bullock & Mahone, 2017).

Current literature related to sex and disability. Current disability research related to sex focuses on the history of sex and disability, feelings and attitudes about the “sexiness” of people with disabilities, and case studies of people’s experiences with disability and sex (Hooghe, 2012; McRuer, 2006; Payne, 2016; Wilkerson, 2002). Further, much of the existing academic literature on disability assumes that individuals with disabilities are “asexual” (Schulz, 2009, p. 58). This problematic assumption about the sexuality of individuals with disabilities takes the term “asexual” out of context, by referring to asexuality as a behaviour rather than an identity, highlighting misunderstanding about sexuality and sexual behaviour within some research related to sex and disability (Lund & Johnson, 2015).

The emergence of newer theories, such as Crip Theory (McRuer, 2006), have suggested new ways to understand disability and sexuality. These emerging conceptualizations of disability and sexuality challenge what is considered “normal,” such as being able-bodied or heterosexual (McRuer, 2006). In particular, Crip Theory, as a contemporary perspective on disability, differs from pathological perspectives of disability; rather than trying to change a person with a disability to perform as more able-bodied, this perspective focuses on the abilities of a person and how they fit within an able-bodied society (McRuer, 2008). However, Crip Theory fails to bridge the gap between able-bodied academia and actual disabled people (Bone, 2017), by prioritizing visible disabilities over others, furthering the disconnect among disability communities. Bone (2017) also notes that Crip Theory is more heavily used by able-bodied academics, as opposed to people with disabilities.

McRuer and Mollow (2012) explain that the experiences of people with disabilities are riddled with sexual repression, lack of sexual autonomy, and legal restrictions.

They argue that people with disabilities should be considered a sexual minority distinct from LGBTQ+ communities (McRuer & Mollow, 2012). Further, Rembis (2010, p. 52) noted that “disabled sexuality” cannot conform to heterosexual, able-bodied versions of sex, although many individuals with disabilities do not consider themselves to be within a sexual minority. This statement suggests a discrepancy between the perspectives of some researchers and people with lived experiences of disability, and a need for a broader understanding of sexuality, outside of heteronormative and able-bodied sex. Sex-focused research conducted within leisure studies and sex-focused research in disability studies remain separate (Aitchison, 2003). The bodies of research within these two fields are lacking the interdisciplinary connections that would combine perspectives in necessary ways.

Overview of Therapeutic Recreation

Therapeutic Recreation (TR) is the purposeful utilization or enhancement of leisure to maximize overall health, well-being and quality of life (Robertson & Long, 2008). The outcomes of TR interventions can include a range of emotional, mental, physical, and cognitive benefits, such as improved fine motor skills or higher levels of self-efficacy (Robertson & Long, 2008). As sex can be considered a form of leisure, the purposeful utilization and enhancement of sex could fit within the recreation therapist’s domain. In addition to being an enjoyable leisure activity, sex is also a central component in coping with life transitions (Berdychevsky & Nimrod, 2016). Similarly, from the perspective of TR, leisure is not only valued because its potential for enjoyment, but also has other desired outcomes, such as providing opportunities to learn and practice coping skills (Iwasaki et al., 2006). By working with individuals to improve or reinstate sexual functioning, other aspects of well-being may also be affected, including ability to cope with life transitions. The growing allied health profession of Therapeutic Recreation (TR) may offer a relevant perspective from which to consider how people can be aided through the

rehabilitation process to redefine and embrace sexuality following acquisition of a physical disability.

Gaps within the Research

Currently, there is no research indicating the usefulness of a focus on sex in TR practice. Sex is a valued human experience for many people, and losing the ability to engage in sexual activities may be traumatizing and in some cases dehumanizing (Rubin & Shapiro, 2005); however, this experience is not explored in leisure research, although interest is apparent among individuals with acquired physical disabilities (Eglseder & Webb, 2017). This study focused on the role of sexuality in the lives of individuals with physical disabilities, and the potential for focusing on sex in rehabilitation settings.

Purpose, Methodology and Research Question

The purpose of the research was to explore the experiences of individuals with acquired physical disabilities, how their sexuality was impacted, and how disabled sexuality can be supported within the rehabilitation process. Data was collected through five individual interviews and a focus group with four individuals with acquired physical disabilities. Constructivist grounded theory was used to inform recruitment, data collection, and analysis. This study explored the following research questions:

1. How does acquiring a physical disability affect how people experience their sexuality?
 - i. How do people view themselves as sexual beings after acquiring a physical disability?
 - ii. How has their identity changed following the acquisition of their disabilities?
2. What is the role of rehabilitation in supporting people to explore and practice their sexuality after acquiring a physical disability?

- i. Is there a potential role for TR in supporting people with acquired physical disabilities to explore and practice their sexuality?

CHAPTER 2 LITERATURE REVIEW

Sex and sexuality have been explored through multiple research perspectives in a variety of ways. This research is focused on experiences of onset of physical disability, the impact this onset has on sexuality, and the role of rehabilitation in addressing sexuality. Thus, to provide a context for this research, the academic literature on sex as a form of leisure, physical disability and its onset, and physical rehabilitation practices will be reviewed, as well as literature where these topics overlap.

Sex as Leisure

Sex is pleasurable, enjoyable, and sometimes even therapeutic for many people (Elders, 2010). Consensual, safe sex should be considered a form of leisure as it promotes free choice, generally takes place during “free time” and is associated with positive health benefits such as increased mood and physical stamina (Hyde, Byers & DeLamater, 2006). Leisure has been defined in multiple ways, but the definition of leisure for this study is a freely chosen, enjoyable activity, which is meaningful to the participant (Heintzman, 2013).

As described by Attwood (2011), sex has the potential to align with leisure, because of emerging conceptualizations of sexuality as a means of expressing personal tastes and lifestyle choices. Attwood uses the term “recreational sexuality” to refer to specific kinds of sexual encounters such as one-night stands, masturbation, use of pornography and sex toys.

Recreational sexuality creates space for self-pleasure, as well as opportunities for adventure, experimentation, exercising choice, experiencing variety and sensation (Attwood, 2011; Illouz, 1991). Much of the leisure research is focused on sex as deviant (Williams, 2009) or risky (Berdychevsky & Gibson, 2015; Miller et al., 2014), sex at specific life stages (i.e., sex later in life for older adults, Berdychevsky & Nimrod, 2015, 2016), or sex and its health impacts (Nimrod et al., 2013). Attwood and Smith (2013) advocate that sex should be understood as

more than just frivolous and hedonistic, while also recognizing that, for some people, it might be just that.

Current Discourse on Sex in the Leisure Literature

Although leisure research has begun to discuss sex as it relates to its benefits and connection to well-being, the leisure literature generally frames sex as either frivolous or deviant, and has not included a disability lens thus far. The term ‘deviant leisure’ typically refers to behaviour that violates criminal or noncriminal moral norms (Williams, 2009), and while there has been work done by leisure scholars to depict deviant leisure as just as important to people as other forms of leisure (Franklin-Reible, 2006), the term deviant still has the potential to elicit negative stereotypes related to activities that are labeled as such.

When sexual acts are labelled as deviant, the motivation behind performing these acts is ignored and the acts themselves becomes stigmatized (e.g., using certain toys or devices to improve or access sex). This means that a person with a physical disability utilizing an assistive device could be perceived as violating moral norms, which is stigmatizing to people with physical disabilities. As well, simple and common sex acts such as sexual chat online have been understood as deviant or risky activity (Ko, 2014). This activity does not inherently violate any criminal or noncriminal moral norms when performed by adults, but it is crucial to acknowledge the risk involved in sharing sexual pictures or having sexual conversations online, such as a lack of control over the sharing of those pictures and conversations. Literature with adolescents has explored deviant leisure, describing it as negative, but often failing to acknowledge the positive effects that deviant leisure activities can have for youth, such as the emotional excitement and stress release associated with sexual chat online (Ko, 2014). Berdychevsky and Gibson (2015) found that sexual activity can be related to sensation seeking in tourism for young women, and

other research has attributed sex to risk seeking behaviours to combat boredom (Miller et al., 2014).

When sex is aligned with casual leisure, often considered a more frivolous and superficial form of leisure, it is conceptualized as less important than other aspects of health and well-being than serious leisure. Attwood and Smith (2013) have defined sex as casual leisure while also asserting the importance of casual leisure in the lives of human beings. Other leisure researchers have attempted to address the importance of casual leisure (Attwood, 2011; Hutchinson & Kleiber, 2005), however serious leisure, which is associated with goal achievement and personal benefits (Stebbins, 2007), is generally considered more legitimate from a health care perspective. Overall, activities demanding skills and longevity, characteristics associated with serious leisure as well as other activity domains such as paid work, are typically seen as more beneficial than casual forms of leisure (Higgins, 2010). Sex is often ignored by health care practitioners as it is not considered an 'important' issue, as opposed to employment or other aspects of health (McGrath & Sakellariou, 2016).

Current leisure research on sex as a beneficial form of leisure has centred on older adults, with sex characterized as an enjoyable, gratifying, stress-relieving leisure activity (Berdychevsky & Nimrod, 2016). Sex for older adults has been discussed as a strong, instant form of gratification and a way to spend free time (Berdychevsky & Nimrod, 2015). Berdychevsky et al. (2013) studied sex as leisure within the context of individuals living with depression and found a paradoxical condition. While sex may alleviate depression because of its benefits, it can be constrained by depression because of effects of medication, lower self-esteem and strain on partner relationships (Berdychevsky et al., 2013).

Currently in the leisure literature, sex has been defined as leisure, but is often considered deviant, frivolous or risky, although not necessarily negative. As well, sex has been explored in

relation to older adults and individuals with depression, but has not been explored through a disability lens.

Sex and Disability

Within this study the focus will be the beneficial nature of sex and pleasure for well-being. Based on what is known about sex and its relationship to personal well-being, the ability of people with recently acquired physical disabilities to partake in sexual activity would be a major step in recovery and reintegration. Sex for individuals with disabilities has been described as radicalism and an act of presenting political agency (Wilkerson, 2002), but has also been associated with higher quality of life and overall well-being (Hooghe, 2012). Sex has also been linked to individuals' perceptions of themselves, contributing to identity formation and self-confidence (Payne et al., 2016). Current research has focused on the "superimposing" of disability on otherwise healthy sexuality, essentially concluding that sexuality changes in negative ways when a disability is acquired, and sexual activity is seen through a lens of dysfunction (Schulz, 2009, p. 62).

Changes and Impacts on Sexuality Following Acquisition of a Physical Disability

Changes in sexual functioning often occur during the onset of physical disability, but these changes may not be directly related to the disability itself. Rather, these changes are often related to trauma or comorbid conditions. Manucharian (2013) found that individuals with lower limb amputations did not reveal any decreased sexual function solely due to their amputation, but certain comorbidities, such as diabetes, were a predictor of reduced sexual functioning. Wiwanitkit (2008) summarizes the sexualities of women with lower paraplegia, including how spinal cord injury can impact self-esteem and partner relationships, and how psychological factors were important in satisfying sexual life and relationships. Individuals who acquire disabilities must negotiate changes to many aspects related to sexuality, including

relationships with sexual partners (Kattari, 2014), sense of self and body image (Solvang, 2007), and relationships with personal care assistants (Earle, 1991). Monga et al. (1998) explored the relationship between sexual functioning and chronic pain, finding that sexual dysfunction is common in patients with chronic pain, often because of distraction by pain symptoms, causes of chronic pain affecting sexual function, issues with self esteem and medication side effects.

Navigating Identity

The exploration of a new identity has been a common theme with the research on acquired disabilities, as well as navigating a new identity in relation to existing ones (Higgins, 2010). Drummon and Brotman (2014) tell the story of a young gender non-conforming, queer woman living with a disability, and examine how intersecting identities affected the rehabilitation process. Findings revealed the importance of addressing heterosexism, homophobia and ableism at individual and institutional levels (Drummon & Brotman, 2014). From a similar lens, intersecting identities are usually made the focus when discussing equity and access to employment and services, and the physical health of individuals (Higgins, 2010).

Intersectionality

This study examines intersecting identities through Kimberle Crenshaw's Theory of Intersectionality (1989). Originally used to explain the intersections of gender and race, specifically Black Women's experiences of erasure, Intersectionality Theory explores how the focus on the most privileged in a marginalized group further marginalizes those who hold less power and erases their experiences within broader societal conversation. Since then, the term 'intersectionality' has also been used to identify and explore overlapping marginalized identities experienced by a single person, in an attempt to avoid further marginalization in identity-focused spaces devoted to social change (Carbado et. al., 2013). For example, feminist spaces and movements have been known to ignore or further marginalize queer and trans identities (i.e.

Women's Marches, TERFs – Trans-exclusionary radical feminists). Carbado et al. (2013) discuss the trajectory of the Theory of Intersectionality explaining that, like all theories, it is ever-growing and changing to accommodate new information. As well, Carbado et al. (2013) explain that all social movements must acknowledge and explore intersections of marginalized identities to move beyond what is considered normative and create actual social change.

Sex and the Rehabilitation Process

Eglseder and Webb (2017) conducted a literature review to investigate the need for sexuality education for individuals with adult onset of physical disabilities, with a focus on quality of life and the healthcare field. They found that health care practitioners across disciplines (i.e., physicians, nurses, social workers and psychologists) agreed the topic of sexuality is important for discussion in a clinical setting, although regarded as difficult. Research related to the need to address sexuality in rehabilitation and care settings has generally resulted in recommendations to incorporate sexual counselling and intervention programs into the rehabilitation process (Dune, 2012). Suggested intervention programs typically consist of written information to be given to individuals with physical disabilities or their partners (Song et al., 2011). However, there is a need to incorporate sexual activity and physical exercises into rehabilitation to better learn and understand one's body as well as reading or discussing the possibilities of adaptations.

The Potential of Sex as an Aspect of Physical Rehabilitation

The rehabilitation process generally focuses on the management of a new, often ongoing health condition into areas of daily functioning (Eglseder & Webb, 2017). As a person with a physical disability progresses through the rehabilitation process, each health care provider should ideally perform a role related to sexuality education and adaptation (Eglseder & Webb, 2017). For example, nurses and physicians' practices are often aligned with the medical model of

disability. Related to sexual rehabilitation, they could provide insight on issues related to medications, anatomical changes and illness-related sexual function (Eglseder & Webb, 2017). Other practitioners, such as social workers and psychologists, ordinarily approach disability from a humanistic or social model, and thus are well-suited to address issues related to attitudes, stigma, and coping in the context of sexuality (Eglseder & Webb, 2017). As a person with a physical disability progresses through the rehabilitation process, each health care practitioner should perform a different, but necessary role related to sexuality education and adaptation (Eglseder & Webb, 2017). Despite the apparent alignment of elements of sex and sexuality with the scope of practice of various allied health professionals, patients and clients with acquired physical disabilities report a lack of knowledge or sensitivity regarding sexuality from health care practitioners (Sloane, 2014), discomfort starting the conversation about sexuality with their health care practitioners (Eglseder & Webb, 2017), and outright dismissal of these conversations by the health care practitioners (Eglseder & Webb, 2017).

Barriers to Integrating Sexuality in Rehabilitation

Comfort of healthcare professionals. Although there is some understanding of why sexuality should be included in the rehabilitation process, there are barriers that exist to its inclusion. The main barrier is the comfort levels of health care practitioners in discussing sex with patients. In a study by Verschuren et al. (2013), health care practitioners (including nurses, emergency first aid workers, physiotherapists, and dietetics and prosthetist professionals) indicated they do not feel comfortable enough to address sex with patients. Some clients have described health care practitioners as being insensitive when they have pursued assistance with sexual concerns, while health care practitioners attribute poor interactions with clients as resulting from an inadequate amount of training and education (Sloane, 2014).

Inadequate education on sexuality in rehabilitation. The lack of education about sex and rehabilitation for health care professionals is a common theme within research on this topic (Sloane, 2014; Song et al., 2011; Verschuren et al., 2013). Some researchers have created, implemented and/or evaluated training courses and modules to try to address this lack of knowledge. Higgins et al. (2012) evaluated a one-day interdisciplinary sexuality education program for staff working with people with acquired physical disabilities. The study yielded positive results including positive changes in knowledge, skills and comfort towards sexuality (Higgins et al., 2012). A limitation of this study was that it only included practitioner-reported outcomes, so the impact of this program from the perspectives of patients is unknown.

Current Innovations in Rehabilitation

Some sexual health models have been created and utilized to analyze and summarize the value of sex in relation to contemporary health needs and provide patients with suggestions for specific sexual concerns (Eglseder & Webb, 2017). One of these, called PLISSIT (Permission, Limited Information, Specific Suggestions, and Intensive Therapy), is named for the suggested sequence of activities undertaken by a health care practitioner to assess and treat specific sexual concerns within a rehabilitation context. It has been noted that the term “permission” might reinforce the hierarchical framework of healthcare, where the client may perceive they can only talk about sexuality when their healthcare practitioner initiates it. Dune (2012) notes that PLISSIT problematizes and pathologizes variations in human sexual experiences and expectations, and requires a referral to another, more qualified practitioner to address the sexual concern.

Another model is the Kaplan model (1979), which consists of discussion around a complaint, current sexual and psychiatric status, history, relationships, and a summary of recommendations. This model emphasizes that the healthcare provider take the initiative to

discuss sexuality with their patients, while remaining open and judgement free (Dune, 2012).

Dune notes that this model moves closer to a holistic model of human sexuality, although the practitioner is still expected to start this conversation. This model also relies heavily on referrals to other practitioners.

Another alternative is the ALLOW model (Dune, 2012), which emphasizes collaboration between client and practitioner, and includes the original practitioner in creating treatment plans when a referral has been made. The ALLOW model, the PLISSIT model and the Kaplan model use the term “treatment plan”, which implies a process of correcting some abnormality or pathology (Dune, 2012).

Current literature regarding sex and disability focuses on either dysfunction or the benefits of healthy sexuality and sexual activity on mental health and well-being. To focus on sex as pleasurable and enjoyable for individuals with acquired physical disabilities, it is helpful consider the potential relevance of therapeutic recreation to sex.

Therapeutic Recreation

Therapeutic Recreation (TR) is the purposeful utilization or enhancement of leisure to maximize overall health, well-being and quality of life (Robertson & Long, 2008). The National Council for Therapeutic Recreation Certification (NCTRC) requires knowledge of normalization, inclusion, barriers, diversity, holistic approaches, and the International Classification of Functioning in the knowledge required for certification (Sylvester, 2014). Thus, one might assume that disability and adaptation are well-known to many TR practitioners. Strangely, TR and disability disciplines are somewhat detached from each other, using different approaches, even though both disciplines are committed to studying the effects of disability in the lives of people (Sylvester, 2014).

In TR practice it is essential for practitioners to create strong relationships and therapeutic alliances with their clients (Shank & Coyle, 2002). It may be natural for clients to bring up their concerns about sex with their TR practitioners, because of these strong relationships. However, it is unclear whether clients are already bringing up sex with their TR practitioners, and if so, how TR practitioners are responding.

Like other healthcare professionals, TR practitioners use a systematic and purposeful process that consists of assessment, planning, implementation and evaluation (APIE) to create programs that benefit participants' health, functional status, personal development and quality of life. Client assessment serves as a means to determine the needs and strengths of an individual, and to create and suggest meaningful and appropriate programming that will benefit the client (Stumbo & Peterson, 1998). The information gathered during assessment facilitates goal setting with the client, culminating in the development of a program plan. Implementation and evaluation follow the planning process. In these phases, the TR practitioner creates a safe environment and facilitates or supervises programs and services for the clients and engages in ongoing evaluation. Finally, evaluation determines the effectiveness of implementation, the appropriateness of assessment, and the differences between planned and implemented outcomes (Stumbo & Peterson, 1998). The APIE process guides the work of TR practitioners worldwide, and each step could be used to address sex as a desired leisure activity. For example, in the assessment process, sex could be identified as a chosen leisure activity, and the facilitators and barriers to engaging in sexual activities could be discussed. This step is where the TR practitioner would seek out possible therapeutic modalities and services to address these barriers, while keeping in mind the strengths of the client. The planning process might include other health care practitioners with necessary knowledge and skills, as well as sexual partners of the client, and possibly other supports.

Usually TR practice involves presenting clients with new leisure activities, educating clients on how to identify and participate in leisure activities in their community, helping clients overcome barriers to recreation participation, and/or educating them about the benefits of participation (Mundy, 1998). Often, for individuals with acquired physical disabilities, the role of the TR professional includes adapting previously enjoyed leisure activities or providing substitutions for valued leisure activities that can no longer be completed (Shank & Coyle, 2002). While there is potential for TR practitioners to incorporate support for sex as a form of leisure into their work, exploration related to the current practices of allied health professionals related to sex within rehabilitation for people with acquired disabilities, and the perspectives of individuals with acquired physical disabilities, is needed.

Conclusion

While there is limited leisure research exploring sex, the field of leisure studies has acknowledged the important aspects of sexuality to well-being and overall quality of life (Elders, 2010; Hyde, Byers & DeLamater, 2006). Disability studies scholars have gone further to explore how changes to sexuality impacts identity, and how historical ideas of disabled sexuality inform current misconceptions (Hooghe, 2012; Payne et al., 2016; Schulz, 2009; Wilkerson, 2002). Research related to sex in the context of rehabilitation indicates obvious gaps within the knowledge and skills of health care professionals. This research has described limited education about sexuality, discomfort in discussing sex with patients, and possible discomfort from clients and patients in initiating a discussion around sex with their health care practitioners. Although potentially well-equipped to do so, the field of Therapeutic Recreation has not addressed sexuality thus far, contributing to a gap in sexuality-related health care research. This research will aim to address this gap, by exploring the experiences and perspectives of people with acquired disabilities, their experiences with sex, sexuality, and physical rehabilitation.

CHAPTER 3 METHODS

Methodology, Methods, and Design

Introduction and Overview

This study explored the following research questions:

1. How does acquiring a physical disability affect how people experience their sexuality?
 1. How do people view themselves as sexual beings after acquiring a physical disability?
 2. How has their identity changed following the acquisition of their disabilities?
2. What is the role of rehabilitation in supporting people to explore and practice their sexuality after acquiring a physical disability?
 1. Is there a potential role for TR in supporting people with acquired physical disabilities to explore and practice their sexuality?

This research included the use of individual interviews and a focus group, using constructivist grounded theory (Charmaz, 2014) for analysis. The purpose of the individual interviews was focused on each participant's personal experience with acquired physical disability, sexuality and identity, whereas the purpose of the focus group was to more broadly explore current and future sexuality support and education initiatives in and outside of formal rehabilitation settings.

Epistemology

This research project was framed within a social constructivist epistemology, which emphasizes the subjective interrelationships between researchers and participants (Mills et al., 2006). The goal of research from a social constructivist perspective is to explore participants' perceptions of situations and experiences, and the complexity of such experiences (Creswell & Poth, 2018). Social constructivism is focused on the processes through which individuals

seek to understand the world and develop subjective meaning in their experiences (Creswell & Poth, 2018). This paradigm is seen to lie between objectivism (belief in an objective reality) and subjectivism (the belief that knowledge is subjective and there is no objective truth), as it allows for the presence of an external reality, that is perceived subjectively by the observer (Daly, 2007). Social constructivist epistemology acknowledges the subjective nature of research, in that the researcher is not an objective observer, but rather must acknowledge themselves as part of the research process, and an influence on its outcomes (Mills et al., 2006).

Researchers who use the social constructivist epistemology position themselves within the research and acknowledge how their experiences shape the interpretation of findings (Creswell & Poth, 2018). In carrying out this research I acknowledge that my own interest in sex and awareness of my own sexuality has inspired me to initiate this research. I am a queer person with a long-standing history of mental illness and chronic pain, which has given me a deep understanding of my own sexuality and changes that come from mood-stabilizing medications, pain, wellness and self-perceptions. These insights drew me to this research, as I can empathize with people experiencing changes in the way they view themselves as sexual beings. Through my own experience, I have come to recognize my sexuality as an integral part of who I am, and also how changes to my sexuality substantially impact my quality of life.

Methodology

This research used constructivist grounded theory. Historically, grounded theory has incorporated an objectivist lens, presenting findings as objective truth, rather than constructions occurring during the research process (Charmaz, 2008). Constructivist grounded theory acknowledges the researcher, participants, multiple standpoints, roles and realities (Charmaz, 2017). Further, it assumes a reflexive stance toward the researcher's background, values, actions, situations, relationships with research participants, and representations of them

(Charmaz, 2017). Constructivist grounded theory also situates the research in the historical, social, and situational conditions of its production (Charmaz, 2017). The constructivist epistemology fits well with grounded theory for this project, because this methodology encourages transparent processes of data analysis, thus creating space for transparency of the researcher standpoint. This study used constructivist grounded theory methodology throughout, including the shaping of interview and focus group questions, sampling strategies, coding processes and analysis. Within interviews, Charmaz and Belgrave (2012) recommend beginning with the participant's story more generally and asking open ended questions to delve into topics raised by interviewees. As such, I started each interview asking participants to tell a general story, with questions like "What made you want to participate in this interview?" and "Can you briefly tell me about your experiences living with a disability?" As well, Charmaz and Belgrave (2012) encourage constructivist grounded theory researchers to be reflexive, so I attempted to reflect on the interviews as they were occurring. I was responsive to the unique experiences of the participant, sometimes swaying from the script and delving deeper into information presented to me. For example, when a participant told a story about their experiences with pain and sex, I asked them to continue talking about that if they were comfortable.

I chose grounded theory for this study because it entails attention to meanings and actions from as close to the inside of the experience as possible (Charmaz & Belgrave, 2012). As well, grounded theory focuses on inductively constructing analytic codes and categories from data, rather than from predetermined theories or hypotheses (Charmaz, 2014). In this research, I have attempted to understand the process of experiences with sexuality and acquired physical disability without making assumptions or hypotheses. Grounded theory is also an ongoing process throughout data collection, where early findings can inform future data collection (Charmaz, 2014). This was operationalized in my research in that I began analysis as I completed

my interviews, and used information gathered in the analysis as prompts during subsequent interviews. As well, my focus group guide was not finalized until the interviews were complete, to allow the information gathered from the interviews to inform the focus group.

Combinations of individual interviews and focus groups have been shown to be effective data collection strategies for developing grounded theories (Charmaz & Belgrave, 2012). Following individual interviews, this study used a focus group strategically to understand shared experiences and generate ideas about how to move forward. The focus group primarily focused on how sex and sexuality should be addressed within the rehabilitation process following physical disability. Although sex is considered a personal topic for some, there are benefits to discussing sex and sexuality in a group for this research project. Focus groups within sex research are beneficial as the collective discussion and interaction between research participants enables participants to explore under-researched topics (Frith, 2000). As compared with one-on-one forms of data collection, a focus group may also provide enhanced insight into language commonly used by participants to describe sexual activities, and create conditions under which people feel comfortable discussing sexual experiences (Frith, 2000). Charmaz and Belgrave (2012) advocate for focus group questions that address social worlds, discourses, communications and individual experiences, and for the sharing of space and relinquishing of control of the interviewer. During the focus group, I aimed to follow this advice. For example, during the focus group I asked participants to decide on community guidelines for the durations of the group, and simply wrote them down without adding anything myself. I also started with writing some general themes of interest on a board for all participants to see and asked them to guide the conversation based on what felt exciting or important.

Participants

Interviews

The population for the interview portion of this study were adults with acquired physical disabilities, living in Nova Scotia at the time of the research. Eligible participants for this study were those who:

- Were at least 18 years of age;
- Experienced onset of physical disability within the last five years, after the age of 16.
- Had participated (or were currently participating) in a formal rehabilitation process.

The proposed number of interview participants was six to ten, a number determined by considering both the exploratory nature of this study and the scope of a Masters thesis.

Focus group

Eligibility criteria for the focus group was the same as that for the interviews, except that individuals who had experienced the onset of disability outside of the last five years were eligible to participate in the focus group. Throughout the interviews, it became clear to me that participants who had experienced an onset of disability more recently were either not in a place to think of possible future directions or had just begun their own journey into exploring their sexuality. Because of this, I chose to open the focus group to individuals who had more time to live with their disability, and therefore more time to explore their own sexualities, with the assumption they would be better able to contribute to possible future directions of support and education. Three to six participants were sought for the focus group, as this size is considered appropriate as it ensure all participants have ample opportunity to participate, while also ensuring enough diversity to generate conversation and differing opinions (Frith, 2000).

Recruitment

Interviews

Interview participants were recruited through posters, social media and snowballing. Posters were displayed at Venus Envy, a sex shop and book store in Halifax, and the Halifax Sexual Health Centre. Venus Envy was an appropriate venue for recruitment because the store offers workshops related to sex and disability, sells assistive devices for sexual activity, and does outreach within rehabilitation hospitals in Halifax. This makes Venus Envy a place that is welcoming for individuals with disabilities who may have taken some steps towards discussing and engaging in sexual activity. As well, posters were sent to community organizations for individuals with disabilities, such as Parasport Nova Scotia, Canadian Paraplegic Association (NS), and MS Society of Nova Scotia who were asked to communicate information about the study with their members via social media and email. In addition to these broad recruitment strategies, posters were sent to individual health care practitioners at physical rehabilitation facilities in Halifax, who were asked to share with individuals they thought might be a good fit for the research. Participants from earlier interviews were encouraged to reach out to others they know who might be a good fit for this study. Despite the diversity of recruitment methods, most interview participants were found through word of mouth and snowball sampling.

An effort was made to reach out to diverse populations to help ensure diversity of the participant sample, by recruiting through varied organizations and platforms. For example, I shared recruitment posters for both the interviews and the focus group(s) through LGBTQ+ groups on my personal social media. However, there was no purposive screening process in place for diversity, due to the anticipated challenges associated with screening for diversity among an already-marginalized population (i.e., people with disabilities).

Focus Group

Following the interviews, participants were asked if they would like to participate in the next phase of data collection, a focus group where common experiences of the process of

defining oneself sexually following acquisition of a physical disability, and possible future directions of education and support, would be discussed. As well, interview participants were asked if they knew any other people who might be interested in participating in a focus group on this topic and were asked to give them my contact information. One new participant was recruited through this method. Interview participants had no obligation to participate in the focus group. In addition to inviting interview participants to be part of the focus group, it was also open to individuals living in the community who had an acquired physical disability. While there was no compensation for participating, snacks and non-alcoholic beverages were offered to participants during the focus group.

Setting

Interviews

The study took place in Halifax, Nova Scotia. Two interviews took place in private rooms on Dalhousie campus, another two took place in participants' homes, and one interview took place in a private room at a rehabilitation hospital. Accessibility needs were accommodated as much as possible. For example, I ensured the spaces where interviews took place were physically and emotionally accessible (if they occurred outside the participants' homes), including gender-neutral washrooms that were wheelchair accessible.

Focus Group

The focus group took place at South House Gender and Resource Centre on campus at Dalhousie University, to ensure the accessibility and emotional safety of the participants. Sex is a topic that makes some uncomfortable, so having these conversations in a safe space for the participants is crucial to ensure as much comfort as possible.

Data Collection Procedures

Interviews

Just the participant and I were involved in one on one interviews. I began the process by engaging in some rapport building, such as small talk with the participant, before initiating the consent process and interview. Once some rapport had been created, I reviewed the informed consent document and process with the participant and answered their questions. Once the participant had all their questions and concerns addressed, they were invited to sign the consent form, after which the interview (and audio recording) began. Participants were reminded that they could choose not to respond to any of the interview questions and continue the interview or could end the interview at any time. At the end of the interview, participants were thanked for their time. The time commitment for the interviews was between one hour to three hours, including the consent and rapport building process, and the interview itself. When the interviews went over the 90 minutes noted in the information letter, I made sure to check with participants to be sure they were willing to continue with the interview. All participants who engaged in an interview for more than the previously discussed timeframe expressed gratitude for being able to discuss their experiences fully. At the conclusion of the individual interviews, participants were invited to participate in the focus group.

Focus Group

A focus group was held in July 2019 to further explore common ideas from the individual interviews, and discuss future directions of sexual support and education in both community and health care contexts. The focus group consisted of four participants, myself, and my supervisor, who assisted with logistics, such as preparing coffee and facilitating the consent process. Participants arrived at the focus group location and were greeted by both myself and my supervisor. Once the focus group began, my supervisor remained outside the conversation and the main meeting area, as a resource in case assistance was needed. I encouraged participants to help themselves to snacks and coffee, and then get comfortable in the space. As participants

arrived and settled in, I asked each participant how they would like to go over the consent process, to which they all responded with the option of reading over the form themselves and asking questions if needed. Once the consent process was completed, we introduced ourselves to each other using first names and pronouns (a process that I facilitated), and did another quick overview of the main points of the consent process, allowing time for questions.

Participants were reminded to keep conversations from the focus group confidential, as per the confidentiality agreement, and were reminded of how the data would be disseminated. Once questions and concerns were addressed, we discussed some community guidelines for the conversation. Participants suggested relevant community guidelines, which I wrote down on a whiteboard that was visible to the group. When this process was completed, I asked permission from the group to turn on the recorder, to which they all responded affirmatively, and the focus group began.

When the planned length of the focus group as indicated on the consent form had passed, I checked in with participants about the time. I asked if we needed to take a break, end the focus group, or continue the discussion. Participants requested a ten minute break, so I stopped the recording and resumed recording when the break was over. We then continued the conversation until participants felt that we had covered everything, at which point the focus group ended.

At the end of the focus group, I facilitated a debriefing conversation to discuss feelings that emerged during focus group, to recognize any conflicts individuals had during the focus group, and to provide options for support to participants who found the focus group difficult. This part of the focus group was not recorded. The debrief was framed as a private reflection, where I asked the participants questions (see Appendix A) and asked them to think about their answers silently, and then share if they were comfortable. This process was intended to provide the opportunity for peer support, while recognizing different levels of comfort discussing

personal thoughts and feelings. Participants were thanked for their time and reminded that they could contact me with any follow up questions using the contact information on the information letter. The time commitment of the focus group was five hours, including arrival, the consent process, breaks, and debrief.

My background in TR impacted the way I completed my data collection process. The way I build rapport and created space, the debriefs I held at the end of the interviews and focus group, and the way I asked questions and responded to participants' answers were all based in my TR training and knowledge. This research is based in TR, because my knowledge is based in the TR profession, and steered me in the decisions I made.

Data Collection Instruments

Both the interviews and focus group followed a semi-structured interview guide. The interview guide can be found in Appendix B and the focus group guide can be found in Appendix C. The focus group was created based on the data gathered during the interviews. During the focus groups and interviews, I listened actively and asked for clarification or confirmation of responses as needed. Both the focus group and interviews were audio-recorded so that participants' word-for-word responses and discussion could be analyzed.

Data Analysis

The data from the interviews and focus groups were analyzed as one data set because there was clear overlap between the topics addressed in both forms of data. This overlap resulted from the semi-structured, constructivist nature of the data collection procedures, where early methods of data collection informed future methods. For example, the focus group guide was finalized after the interviews had been completed, in an effort to reexamine some of the themes from the interviews in a group setting. When discussing certain themes in the focus group, it was important for participants to discuss where those themes came from. As well, the data collection

extended over ten months and thus posed potential issues with continuity, so I chose to include possible focus group questions in interviews.

The data was transcribed, analyzed, and coded using constructivist grounded theory using initial, focused, and axial coding (Charmaz, 2014). During the initial coding phase, I went through each line or segment of data closely and identified discrete ideas that were followed with further data collection and analysis. In the focused coding phase, I used the most consistent codes from the first phase to organize that data and develop the most prominent categories. A third phase of coding in grounded theory is axial coding, which specifies the properties and dimensions of a category (Charmaz, 2014). Axial coding was used as a final step used to identify relationships among the categories and define the boundaries that distinguish them.

Memo writing is a common practice within the grounded theory process. Memo writing facilitates analysis of ideas about the codes at each step of the coding process, and prompts the researcher to stay engaged with the analysis and focus on abstract ideas (Charmaz, 2014). There are two methods of memo writing: early memos and advanced memos (Charmaz, 2014). Early memos are used to see what is happening in the data, and direct focus and further data collection. For example, Charmaz (2014, p. 80) suggests asking questions such as “what are people saying or doing?”, “what connections can be made?”, “under which condition does this process develop?”, and “when, how and why does this process change?” Advanced memos are used to categorize data, describe how categories emerge and change, identify researcher beliefs and assumptions that support the category, understand the topic from various perspectives, place it within an argument and make comparisons between data (Charmaz, 2014). Memo writing compels the researcher to deeply engage in the data and hone in on ideas. I used both methods of memo writing in my research, but also used reflexive memos to consider how I was

related to the data on a more personal level. This reflexive process was important for me, as throughout interviews I often felt emotional and incredibly connected to my research participants, because of my own experience with chronic pain and navigating the health care system. I used these reflexive notes to position myself in the research in a constructive way.

Ethical Considerations

The Social Sciences and Humanities Research Ethics Board at Dalhousie reviewed this research in advance of recruitment. The potential risks for this study included stress from reliving grief and trauma from when participants' disabilities were acquired, as well as potential discomfort in speaking about sex, which for many is a personal topic. This research was carried out with the underlying principle of normalizing sex and discussion around sex, which is why a focus group was chosen to build on the individual interviews. A debrief session (see Appendix A) helped to provide closure to participants following the focus group and provided suggestions to any participants who need to seek further support. Prior to the interviews and focus group, I created a list of community and online supports that were provided to participants (Appendix D).

During the interviews, I ensured that each participant was appropriate for the focus group before inviting them to participate. For example, if a participant made homophobic remarks in the interview, I would have opted not to invite them to the focus group to ensure the safety of the other participants. While I was prepared to address inappropriate or hurtful comments in the focus group, the need to do so did not arise.

Researcher Details and Positionality/Reflexivity

I was responsible for the entirety of the tasks included in the study. My supervisor and committee members guided and assisted me when necessary. I graduated from Dalhousie University with a degree in Therapeutic Recreation, subsequently became certified as a Certified

Therapeutic Recreation Specialist (CTRS). During my undergraduate and now graduate education, I have learned a variety of counselling and interviewing skills, and acquired skills and knowledge related to research methods. Further, I have completed an online continuing education course on advanced issues in sexuality through the University of Guelph, where I have learned applied, trauma-informed approaches to discussing sexuality. As well, I worked in the Human Rights and Equity office at Dalhousie University, where I created and implemented workshops on considerably sensitive topics, such as sexualized violence, consent culture, and sexuality and gender identity.

Given that I am a queer person, and have worked with LGBTQ+ communities in Halifax, I have had opportunity to consider aspects of sexuality and to discuss these aspects with others. While working with individuals with physical disabilities, I might be considered an outsider because I appear to be able-bodied.

Summary

The purpose of the research was to understand the process that adults go through, regarding their sexuality, when they have acquired a physical disability, and how this can be supported within the rehabilitation process. To do this, data was collected through five individual interviews and a focus group with four individuals with acquired physical disabilities. I used constructivist grounded theory to inform my recruitment, data collection, and analysis.

CHAPTER 4 FINDINGS

Participants

This study included six participants in total, including three who participated in both an individual interview and the focus group, two who participated only in an interview, and one who participated only in the focus group. Participants were between the ages of 22-40, and identified as queer and/or trans, except for one interview participant who was 76 years of age at the time of the interview and identified as straight and cisgender. All interview participants experienced an initial onset of disability within the last five years and had taken part in some formal rehabilitation services. The majority of participants had experienced gradual onset of disability, rather than a disability caused by an accident or specific trauma. Three participants used wheelchairs, one participant occasionally used another kind of mobility aid (i.e. cane), and two participants did not discuss mobility aids. Participants were not asked to disclose their specific diagnoses, and instead named limitations they experienced in their day-to-day lives, including various forms of chronic pain, mild to moderate cognitive impairments, fatigue, decreased mobility and hypersensitivity. The data are described by five themes: performance of a role, embodied experiences, playing with potential partners, intersecting identities and education and support needs. These themes and their subthemes are explained in further detail in the following sections.

Performance of a Role

Participants explained how throughout the rehabilitation process, they were expected to perform in specific ways to signify their attention and dedication to recovery. Performance expectations were not those of the participants themselves, but rather were imposed by health care professionals and society. When participants made efforts to attend to their personal expectations of recovery, they were often met with disapproval or completely ignored by health

care practitioners. Subthemes within this category include: *the role of a patient, the role of a spouse, and sexuality beyond performance.*

The Role of a Patient

Participants described different variations of doing what was expected of them throughout the rehabilitation process. Most often, participants were expected to work toward returning to some condition of being able-bodied. In contrast, their own expectations for their lives included their own sexuality and sexual health. One participant explained it as “you’re expected to perform as a patient, to improve physical functioning, but that’s about it” (interview participant). Participants also explained that when they did not perform their expected roles, there was a lack of willingness to support their rehabilitation: “The system is really hilarious around chronic disability, where it’s like now, but you should be improving, but you’re not, therefore we’ll discharge you! Because why?! Because you don’t think I’m working hard enough” (interview participant).

One participant explained that it was not just within the health care system that they were expected to perform as a patient, but that the expectations of what was important to recovery trickled into other parts of daily life. Such expectations resulted in limiting access to places deemed unnecessary, such as access to places to socialize and meet potential sexual partners. They explained:

Anything that’s accessible tends to be like, the public building, malls, banks, institutions that are part of the government. Accessible places are not community [spaces], they are not bars, they are not any of the places that you would go to meet people, and not any of the places you would go to explore different sides of sexuality. (interview participant)

Participants shared common experiences around their health care practitioners and care making assumptions about the supports they might already have.

On top of the roles the patients were supposed to perform, participants explained the roles that their support systems were expected to perform. One participant explained:

The health care practitioners I've worked with, most of them have seemed to just be assuming that those around me in my community are able-bodied, have money to spare and have ample time in their schedule to come help me, and why would that be true? It's absurd. (FG participant)

Another noted: "Like the health care system seems to be responding to their cutbacks by putting more on us. And stuff like this [sexuality and pleasure] gets missed. There's just not enough space" (FG participant). Another participant recalled a specific time where the assumptions of their care practitioners stopped them from being able to go on a date: "I was supposed to have a date with someone and then my home care cancelled less than two hours beforehand and I like okay well I'm not taking a bath so I'll just cancel that" (interview participant). When this participant shared their needs, they were not met with understanding:

When I tried to address some of those kinds of issues, they were like you can't expect to get hotel service. As though you're expecting something that is so far beyond realistic that it's absurd and you're like, 'I just would like my clothes to be dry before they're put away'. (interview participant)

Practitioners had trouble valuing aspects of the participants outside their "patient" role, even when asked to do so by participants.

The Role of a Spouse

Some participants explained that on top of performing as a patient, they were expected to perform as a spouse or partner, specifically as the version of themselves they were before the onset of their disability.

One participant explained that going home after their stay at the hospital was met with some anxiety around their expectations as a spouse. This participant explained that sex was always something that just happened, without much discussion, because there wasn't a need for discussion prior to their accident. When asked about priorities in recovery, they indicated sex was higher on the list, mainly because it has been a part of their lives before. They said, "Well, we go home on weekend passes and we share a bed together so it's something that's on my mind" (interview participant). This participant also shared their experience with communicating with their partner about sexuality on their own terms, explaining, "Well, I certainly have to put a stop to it. It's me who says, 'I'm too uncomfortable'" (interview participant).

Another participant recalled their experience with a previous partner who had assigned them the role of the "initiator" in sexual situations, but after the onset of their disability, that was not necessarily the right role for them. They explained:

[There] was like a major conflict that got turned into one of my partners saying we're not going to do this anymore unless you initiate... I'm having a hard time living up to that not only because maybe that's a problematic request but even if it's not, I don't know why I'm not that person anymore. (interview participant)

Sexuality Beyond Performance

While participants had multiple roles assigned to them, they knew which parts of their identities were most important to them and what made them feel like they were not just performing a role. Interest in navigating sexuality was emphasized as something beyond performance from each participant.

Participants were clear that, regardless of the roles that were assigned to them, they had made the decision to try to live their life beyond performance. This meant moving beyond what they were expected to do by doctors and loved ones and taking time to reflect on what they

wanted from recovery and what community reintegration might look like. One participant explained,

I have enough energy that I can do my basic daily tasks of living, and still do fun things... like socializing or fooling around with my boyfriend... but it took cutting out things like work.... I've had to value sex and intimacy over contributing to the economy for my own wellness. (interview participant)

Another participant explained that sexuality was not just important to them, but an integral part of who they are: "The most important thing to me is having a rich, fulfilling romantic and sexual life" (interview participant).

Embodied Experiences

A common thread among participants' stories were those of their relationships to their bodies. This theme is rooted in participants' connections with and changes to their own bodies and making new connections with other bodies following the onset of their disabilities. Subthemes describing this theme are *new and changing bodies*, and *pain and pleasure*.

New and Changing Bodies

Participants explained ways that the changes to their bodies were not just physical, but intersected across spiritual, emotional, social and environmental factors. One participant put it plainly: "There are huge changes, I mean, I'm not the same person" (interview participant). Another participant explained that their body didn't feel like just theirs anymore; as a person with a physical disability they were now representing a whole community of people: "Once I realized 'oh my body is different' that politicized my life and my body in ways I had never expected" (interview participant).

Something many of the participants noted were difficulties with the onset of pain and decreased mobility. Sometimes pain would be intense and surprising, and it was very difficult to ease or control. One participant explained they were scared by their changing body: “It felt like I was haunted by a vengeful spirit, and the doctors didn’t have answers, my body was a terrifying place to be” (interview participant). The same participant explained how during the initial onset of their condition, they felt disconnected from their body, which was especially difficult for them as a person who had once been extremely connected to themselves physically: “I’m not myself if I’m not in my body” (interview participant).

Participants also acknowledged that the changes they were experiencing were not just about themselves, but were layered by interpersonal experiences of socially constructed assumptions about bodies, especially related to sexuality. One participant explained the difficulty and fear stemming from other people’s assumptions about disabled bodies and sexuality: “[there’s this idea] that there’s something gross or uncomfortable about [disabled sexuality], which is just able people projecting all of their issues onto me. It has nothing to do with me, and they’re making it about me” (interview participant). Another participant acknowledged the difficulty and fear within themselves related to being sexual with new partners: “If I’m in pain, can I be present in my body with a partner? And can I be safe, physically and emotionally, with my partner without feeling like I’m too much?” (interview participant). One participant summed up their experience more simply: “My sexuality in some ways has changed, not because I’ve changed, but because other people haven’t” (interview participant).

Pain and Pleasure

Participants talked a lot about ideas surrounding pain and pleasure. They explained that the assumption many able-bodied people make about sexuality is that pain and pleasure are mutually exclusive. All the participants had some sort of chronic pain, and several of them

explained that if they were to believe that pleasure and pain cannot coexist, they would never be able to experience pleasure again. However, they were very adamant that was not the case, and in fact were learning to work with their pain, rather than against it.

Because of this realization, many of the participants made connections to BDSM (Bondage-Discipline, Dominance-Submission, Sadism-Masochism) and kink communities, explaining that these communities already had some understanding of the relationship between pain and pleasure being valuable, rather than always harmful.

One participant explained,

I've been in pain 99% of the time. So why don't we just accept that I'm in pain all the time and with that in mind, think about and talk about sex.... given that pain, and the kink community knowing more than the average person, why wouldn't I as a responsible person trying to take care of my needs and my limitations, why wouldn't I talk to someone who knows about pain and pleasure in a sex kind of context, given that any time I have sex I'm starting in pain? No one needs to cause me pain, I'm not necessarily seeking it out, it's there so let's acknowledge that it's there instead of pretending that I'm somehow magically going to not be in pain cause that's not going to happen. (FG participant)

Another participant noted the danger of trying to ignore their pain in order to receive pleasure,

I mean pain is only part of our experience, how do we engage with that and intentionally be embodied instead of like you know I guess the mainstream medical view would be to disengage from your pain, to disengage from your embodied experience which that's not moving towards health or being whole as a person. (FG participant)

Another participant responded: “Then I dissociate, then I can’t speak up for myself” (interview participant). Alternatively, participants also noticed a direct relationship between pleasure and pain relief and tolerance. One participant explained:

If my pleasure is high enough, a smaller and not abrupt increase in pain is not going to startle me or like derail and it’s like recoverable, it’s okay. If I have more pleasure, more pain is acceptable and I feel like is there space to talk about that. (FG participant)

Another participant explained,

I’ve had like really good sex with someone and the next day my pain level, the next day or two my pain level is just sort of like, how is my pain level a 1 out of 10 and I’m like what witchcraft is this? Then my endorphins go down and my pain comes back and I’m like oh there’s all kinds of neurological stuff going on, so like you know, like, sex is therapeutic. (FG participant)

Participants explained that their immediate care circles needed to be well-versed in the pain and pleasure phenomenon, because they still needed knowledgeable support. One participant explained,

If [a partner doesn’t] know how to touch me without them causing me pain and I don’t know how to, like, train them in how to touch me without causing me pain, when we sit there awkwardly and not do anything, that’s not satisfying, that’s not healthy. (FG participant)

Playing with Potential Partners

A common thread among participants were related to their experiences being with partners who were able-bodied. Some participants were already in relationships prior to the onset of their disabilities, and others met able-bodied people through the communities they were already part of prior to their disabilities. Although participants all had different experiences

being with able-bodied partners, they all described some challenges. One challenge in particular was partners' assumptions of what disabled bodies can and cannot do and taking for granted seemingly simple tasks related to dating, hookups and relationships that able-bodied people may do without thinking. Subthemes within this category include: *a lover, not a caretaker*, and *the work of being sexual*.

A Lover, Not a Caretaker

Participants expressed that when seeking sexual partners, their focus was on those with whom they could have satisfying sexual relationships or interactions, rather than looking for someone to meet all their care needs. One participant explained that able-bodied sexual partners worried they would become a primary caregiver if they started dating. While that was not necessarily true, the participant did explain that there was going to be some work to be done around boundary-setting and access needs, before they could be sexual together. They said:

I'm not looking for a caretaker, I'm looking for a lover, a friend, a romantic partner... when I have a partner they're also going to need to be willing... eager! They're going to need to be eager to do that work with me. (interview participant)

One participant explained the extra caution and preparation involved in being sexual:

It's definitely a lot more work, 'cause I can't just be sexual and then get up and walk away. I have to know that the sex I'm having, whether masturbating or having sex with a partner, I have to know that the things I'm doing are not going to hurt me. (interview participant)

Another participant mentioned how aftercare processes were overlooked by sexual partners, leading them to be stuck in an uncomfortable, and sometimes unsafe situation after a casual hookup. They said:

Afterwards like I might need the person to just like grab a facecloth, and come back,

and help me with whatever for a little bit. And just make sure that I'm okay before you leave me. Like make sure that you haven't set me up in a situation where I physically can't get to what I need. Just some of those basic things, but they're not basic, because they're things we expect people to do independently. (interview participant)

Participants explained that casually dating able-bodied people was difficult because of assumptions potential partners made about their own roles, the role of the disabled partner, and environmental barriers.

The Work of Being Sexual

Participants also explained the lack of knowledge and education able-bodied people had about disabled sexuality, and disability more generally, leading participants to have to do the work to educate possible sexual and romantic partners if they wanted to be safe. One participant explained: "I have to have those conversations, otherwise I'm going to get hurt" (interview participant). Another participant explained that they had little to no support from the system that was supposed to be helping them recover, but the expectation was still there that they would be the ones with the knowledge:

You need to figure it out on your own, independently, without any support from the system, and without any community resources. So that you can come to this relationship and like know how to navigate what you need. (interview participant)

Another participant explained that dating people who were able-bodied often meant their homes were set up for able-bodied people, meaning that they were inaccessible to people with physical limitations. The result was that participants often had to risk bringing a person they did not know very well into their own home and hope they were able to manage their own safety: "If I want to take someone home, I have to take them to my place, because [there's a] 98% chance they don't live in an accessible place" (interview participant). Another participant noted: "The

stakes here are pretty high when the best option for a lot of reasons is to have someone into our space” (interview participant). Another participant explained that regardless of the difficulty, they would be the one to do the work if they wanted to be sexual:

A lot of people haven't learned those skills, or they haven't developed a habit or value of having those conversations as a matter-of-fact. I know I'm going to be doing all the work. I'm going to be doing all the heavy lifting. (interview participant)

Participants acknowledged that although the work was difficult, they were willing to do it so they could be sexual and be the versions of themselves they wanted. One participant described the reward of doing that work,

I'm going to be able to be more happy, healthy and well in this cis, disabled, queer, female body and life experience, because I've found someone who fits my support network so well that I'm not so worried about how I will be perceived. (interview participant)

Intersecting Identities

All but one participant identified as queer and/or trans, so disability created new intersecting identities for those participants who were clearly different from the one participant who was not queer or trans. In particular, the queer and trans participants described the difficulty of returning to (queer and trans) communities where they once felt a deep connection, because of a lack of knowledge relating to the new piece of their identities. One participant explained that being part of their queer community became more difficult when they were diagnosed with a chronic condition, because it was difficult for able-bodied queers to understand the experiences of disability. They explained that they felt better having someone with them who understood disability even if that person was cisgender and heterosexual: “[When] I have a chronic illness ally, it's safer for me to engage with my community, who otherwise is honestly

kind of ableist” (interview participant). Another participant described this experience in great detail:

The complexities of being disabled, having severe mental health issues, being trans and queer, like all those things combined together give me a unique experience and it’s so hard to find people and spaces that can hold me as a whole person. Hold my queerness, my transness, my disability, and chronic illness all at once, right? It’s so rare... and it’s going to cost me so much to face the transphobia from disabled people who aren’t trans, or the general public, or to face ableism from people in my own community who should be holding me as a whole person. ‘Cause most of the world doesn’t hold me, so I really need my community to do that right? Cause where else do I have if they won’t hold me? ...navigating body issues, as a trans person, dysphoria, and how that stuff works, and trauma, as well as physical health issues, that’s a lot of work for a partner to sign up for in all honesty, and a lot of people aren’t looking for that much work. (interview participant)

Participants also discussed the lack of knowledge among health care practitioners in holding these identities in relationship to each other. They explained that health care practitioners were quick to blame mental health concerns on participants’ sexuality and dating preferences.

One participant explained,

When I come in as a queer woman with a disability, as a polyamorous woman with a disability, [the care provider said] ‘well that’s why you’re having all these problems, just stop doing that’. And it’s like ‘no that’s part of my identity, it’s not causing the issues.’ I’ve gotten very used to just asking the questions but it’s automatically [looked at as] ‘well no this is why it’s a problem and yah just go back to being monogamous and

only dating men and then all your problems will go away'. No that's not what I want, that will cause more problems. (FG participant)

Education and Support Needs

Participants had varying ideas about what types of support and education they wanted to see to help them live well as sexual people following the onset of their disabilities, but all of them pointed out that an important place to start is in the health care system. Participants noted that health care practitioners were some of the first care workers they saw and where they got the most information, so they needed to be trained and comfortable with discussing sex. Participants were clear that the current state of the health care system made these conversations difficult to have, if they were had at all. Subthemes within this category include: *the role of the health care practitioner, different forms of knowledge, peer support and community learning, and specialized knowledge.*

In the rare circumstances that sexuality was brought up in rehabilitation settings, it was not in a supportive way. One participant described a time when they attempted to discuss an interest in kink with a health care practitioner and were relegated to suicide watch.

The only ones that addressed sexuality whatsoever were the ones who were addressing it in a pathological, mental illness kind of way... the only people I was being relegated to go talk with were counsellors and the system, so I would kind of approach it in a very weary way of those conversations, like, I just want to talk with someone about these types of things, and I immediately got relegated to suicide watch type stuff, and now there's a whole bunch of shit in my file that is really kind of fucked up. (interview participant).

Another participant commented on the lack of sexuality support and education, explaining, "It's really noticeable by its absence" (interview participant). Another participant

noted the clear discomfort in talking about sexuality, even by health care practitioners who one would think would be comfortable discussing such topics, “Even clinicians are afraid to talk about it and bring it up” (interview participant).

The Role of the Health Care Practitioner

While participants did not want to discuss every part of their sex life with care practitioners, they all recognized that the care setting was an important place to start these conversations, even if it was just so they could be directed to appropriate resources. One participant explained, “I need my clinicians to be able to support me in their capacity, with the appropriate knowledge and skills.... It should be offered to me. They should be like, ‘do you need help with this thing?’” (interview participant). Another participant described a positive experience of a health care practitioner working with them instead of just on them, which was crucial to their care, “One of the first things [my health care provider] said was that her approach is ‘she’s an expert in psychology, I’m an expert in me, let’s work together’.... that health care shift of course impacted my sexuality!” (interview participant).

Participants explained that if health care practitioners were going to bring up sexuality, they needed to be trauma-informed. They explained that many of them had experienced some form of trauma, whether that be sexual or something else, and for them to trust a care provider enough to discuss sexuality, there needed to be a higher level of attention to trauma-informed care. The participants also explained that although trauma-informed care has become a hot topic, many practitioners were not fully skilled in that type of care. One participant explained, “The system thinks that it’s trauma informed but that’s not how it’s playing out so like what would I tell them to do, cause I would say trauma informed, and [they would say] yes” (FG participant). When asked what trauma-informed care would actually look like, one participant explained:

[We] shouldn’t even have to interrupt the flow and appointment and like assert what

[our] needs are. The clinician should be asking what [our] needs are and trying to figure out is there a way we can modify or change how we're doing this to suit [our] needs? The clinician should be making that space, we shouldn't have to say 'I need you to make space for me', they should know to already looking to do that and that might look different for any client so they need to make space for the client to exercise their autonomy in a space where they're supporting us in exercising our autonomy with asserting our needs around our trauma and stuff. (FG participant)

Different Forms of Knowledge

Additionally, many of the participants were clear about needing to be directed to resources by and for disabled people, but that it was difficult for them to bring up themselves. One participant explained:

I got some wellness navigation through a community health team to get some support for some stuff but it was kind of this chicken and egg thing. I didn't bring up sex and neither did the person I was working with and it's not that that's not important to me is that I don't know how to talk about it with the pretty much stranger. (FG participant)

Another participant explained:

It adds a barrier to sex that I then don't have a good health care support like a sex therapist through the health authority or even a rec therapist. I don't know how to access one even though that makes a lot of sense for where I'm at. (FG participant)

When asked about the difference between the role of a health care practitioner versus a disabled person in the community as it related to sexuality support and education, one participant explained that both bring valued knowledge in different ways:

I trust that lived experience. That's where the real knowledge is. But having a professional, like evidence-based knowledge, to back that up—those are two different

things, you can't substitute one for the other. (interview participant)

When asked what types of knowledge participants would be willing to learn about from care practitioners, in addition to community members, interview participants said "practical information" and "nitty gritty stuff" could be covered by care practitioners. In addition, one interview participant asked "What kind of contraptions are available to keep me safe from injury so I can have sex?" and another asked "What kinds of techniques and strategies can disabled people use during sex to make things work?"

Similarly, participants mentioned the kind of supports they might like from health care practitioners that community members may not be able to provide.

If my current vibrator is not suiting my needs and I can't use it without causing flare-ups [and] injuring myself, shouldn't I be able to say 'hey occupational therapist, nurse practitioner, whoever, can you do me up a letter so that I can get something better through income assistance?' But they would probably laugh that off. (FG participant)

Another participant suggested something similar, a box of supplies to take home to explore aspects of one's sexuality, or funding to obtain similar supplies oneself.

Similar to a program of sending the parent or parents of a newborn home with a box of supplies, why isn't there a kit with bondage tape, an assortment of different types of condoms, just this like kit that would be helpful to folks like us to at least get to try these products given that I can't go purchase like different brands of a bunch of different things to figure out which textures won't freak out my body when I can't open them first to see if one of the twelve or ten or 24 pack, whatever, I don't have money to waste on trying stuff. If the system wants to meet me where I'm at, either figure out a way to make

some money available to just be given to us to figure out what will work for us or we need to have people be equipped to write letters on our behalf, to get access to funding, or we need something like a here's a free kit to get you started. (FG participant)

Peer Support and Community Learning

Alternatively, when discussing information that they would want specifically from community members, it was a mix of specific information as well as feeling a sense of community and support. One participant noted, "It's a lot to deal with alone" (interview participant). Another participant explained:

I would like trust another wheelchair user to tell me like you know like okay how have you worked out topping as like a wheelchair user with your limitations. How you have, what's worked for you and I can tell you what's worked for me and like we can combine our knowledge and create like a knowledge base that we all benefit from. (interview participant)

Other participants commented specifically on the validation they receive from talking about sexuality with another disabled person.

This is so good to talk about this and the ways like we've been desexualized and like validate each other and affirm that our sexuality is wholesome and normal and good and valuable, and we deserve like access and opportunities for sexual pleasure. (FG participant).

Community and peer support to also re-humanize us and remind us of who we are when we're seeking care from people who yes are qualified but who really haven't even had exposure to the nuance of our experiences. (FG participant)

Another participant noted that there was a safety and comfort in discussing sex with people who shared similar experiences, and that prepared them for having those conversations in

higher stakes situations: “The easiest place to get started with that is people who share your experience and be validated, and then you can go into scarier or riskier places once you have that foundation” (FG participant).

Specialized Knowledge

Outside of health care practitioners and community members, participants noted one last group of people who had the potential to be crucial to their sexuality with a disability. This group included community sexuality educators, and BDSM and kink communities. Participants explained that individuals in these groups often had specialized knowledge that could contribute to their well-being but were difficult to access because they are not part of the health care system. For example, one participant commented on the knowledge gaps most sexuality educators had around disability but believed there was potential there for learning. They noted, “Allodynia, hyperalgesia, those are words every sex educator should know” (FG participant). Participants also noted that people just outside of the health care sphere, especially sexuality educators, may already have ideas about adaptations to make to toys and practices to create more accessible sexual experiences.

Summary of the Findings

The findings from this research project consisted of themes related to difficulty with dating, performing assigned roles, pleasure and pain, education and support, and expectations for disabled bodies, health care practitioners, and potential partners. Participants expressed a need for more support of sexuality from health care practitioners, and increased access to spaces that support sexuality in community settings. Participants also noted the challenges that come with dating and being sexual with able-bodied people, and discussed the connection they felt between pleasure and pain. Finally, participants expressed hope for people with specialized knowledge in sexuality to have more knowledge on disability and pain.

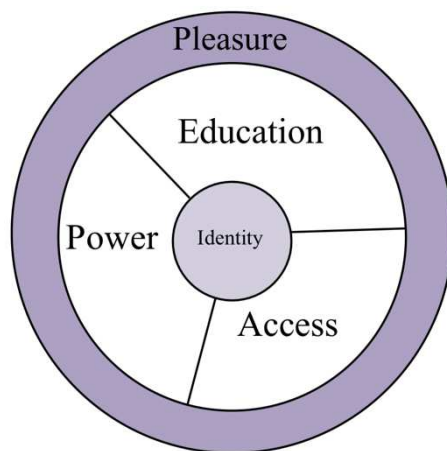
CHAPTER 5 DISCUSSION AND CONCLUSION

Meaning and Importance of Findings

This research explored how acquiring physical disabilities affects how people experience their sexuality, and the role of health care practitioners in rehabilitation settings in supporting these experiences. Participants discussed their experiences with new bodies, performing other people's expectations, dating, intersecting identities, and their thoughts about current needs and moving forward in terms of supports provided by the health care system. During data collection, participants identified their personal prioritization of pleasure within the rehabilitation process, and thus pleasure is an overarching concept around which we can understand the research findings. The following model represents the ways in which the findings can be conceptualized in terms of the prioritization of pleasure:

Figure 1

Prioritizing pleasure model



The shape of this model is meant to signify the interconnections among the components. Each component influences all the others in some way. The research findings describe participants' experiences that prioritizing pleasure requires the power to do so, access to

knowledge and resources, and education about one's body, all of which are inherently impacted by identity. As well, identity navigation is impacted by access, education and power.

The Outer Sphere

The prioritization of pleasure is an overarching theme of this model, and encompasses all aspects of the model, while simultaneously being influenced by its encompassing components. Pleasure is the overarching concept around which we can understand the research findings.

Participants in this study explained the expectations thrust upon them by health care practitioners regularly revolved around goals that would help them contribute to society, such as returning to work, as opposed to goals related to experiencing pleasure for themselves. These expectations are consistent with current social roles of adults that have been informed by religious values, or the "protestant work ethic" (Deterding, 2018, pp. 261), and leave little to no room for an experience of sexual pleasure.

Sexual pleasure has often been understood as a frivolous or hedonistic pursuit in the leisure literature, as opposed to activities requiring more structure or wholesome behaviour (Csikszentmihalyi, 1990; Stebbins, 1999). More recent leisure literature has begun to seek to understand the importance of pleasure in relationship to overall quality of life, (Attwood, 2011; Hutchinson & Kleiber, 2005), and has pushed towards an overhaul of the dichotomy of casual and serious leisure, where experiences of play are recognized in seemingly more structured leisure (Prior & Williams, 2015). Adult play has been defined as "a mode of sensory openness and drive towards improvisation" (Paasonen, 2018, pp. 1), and has been identified as a key motivation for sexual activity (Paasonen, 2018). As well, Paasonen (2018) states that the purpose of play is similar to that of pleasure, in that there may not be any goal beyond the experience of the activity itself. Regardless of goals related to sexual pleasure, there is a clear importance of the opportunity to play and experience pleasure. Hutchinson & Kleiber (2005) have explored the

importance of unstructured, seemingly goal-less forms of leisure, describing benefits related to self-protection and preserving or restoring a sense of self. Since participants in this study noted that their sense of self was affected by the acquisition of a disability, the benefits associated with pleasurable, playful forms of sex seem to be particularly relevant to them.

The Inner Sphere

In this model, identity is the central component in that it is core to each person's experience. Identity is often shaped by context, experience, and conflict in a lifelong, moving process (McLean et al., 2017). As noted in the findings, identity can be influenced by physical or embodied experiences, experiencing marginalization, sexuality, and expectations of practitioners, family members and oneself. The identity sphere is meant to hold the person as a whole. In this research, participants' identities influenced, and were influenced by, opportunities for and experiences of pleasure. All but one of the participants in this study identified as queer and/or trans, in addition to identifying as disabled. They each described the difficulties associated with holding multiple identities in spaces where only one of their identities was considered important. Originally used to explain the intersections of gender and race, specifically Black Women's experiences of erasure, Crenshaw's Theory of Intersectionality (1989) explores how the focus on the most privileged in a marginalized group further marginalizes those who hold less power and erases their experiences in the broader conversation.

Embodiment. Participants discussed the ways in which their bodies changed throughout the onset of their disabilities, and how these changes influenced their identities. These changes, and associated changes to their identities, arose from chronic pain and pain management experiences, the politicization of bodies, and the unwanted disconnection from one's body in some circumstances. Participants described the importance of identifying with and connecting to their bodies in order to feel whole, even though this felt challenging at times. The identity sphere

is meant to hold the whole person, including the physicality of identity. Disabled bodies cannot be removed from the disabled experience: they are one and the same.

Performance. Participants described expectations from practitioners and partners to “perform”, in that they had to behave in ways that implied their commitment to achieving a goal determined by someone else. For example, expectations to return to work or school. These expectations are derived from ableist assumptions, where one is expected to be a productive member of society in order to avoid becoming a burden (Bullock & Mahone, 2017).

Alternatively, performance and disability has been explored in the literature in relation to identity markers (Grue, 2016), in that in order to claim a disabled identity one must display recognized signs of disability. For example, one would have to be using a visible mobility aid to sit in accessible seating on the bus. Both of these expectations of performance are problematic in that ableism becomes the deciding factor for living with a disability, and assumes a static state of ability and identity.

The Middle Sphere: Power, Access and Education

Power, education, and access are often influenced by and affect one another. More specifically, access is often influenced by power and education, education is influenced by access and power, and power is influenced by access and education. Each of these three components has the potential to act as a barrier or facilitator to the overarching goal of pleasure. Identity acts as a foundational component of all three, as each component is influenced by identity.

Power. Power has been defined as the capacity for groups and individuals to exercise influence or authority over others in conflict, decision-making, and building and reinforcing of cultural myths and norms (Gaventa, 1980). Gaventa (1980) categorizes power into three dimensions: visible, hidden and invisible. Visible power refers to the power exercised through

traditional decision-making processes, such as authority associated with high levels of education. For example, health care practitioners making decisions about the goals of rehabilitation. Hidden power refers to the “mobilization of bias” (Bachrach & Baratz, 1970, p. 14) or processes that reinforce longstanding biases as the norm, shaped as void of actual decision making. For example, the ability to make decisions about what topics should be covered in a training session or what constitutes “rehabilitation” involves exercising hidden power. Invisible power refers to control of the construction of meaning based on cultural norms and practices (Gaventa, 1980). For example, the perpetuation of stereotypes related to disability constitutes a form of invisible power.

Overarching power structures, such as government funding and support, limit accessible spaces to activities deemed necessary to health, rather than places of importance to people with disabilities. For example, the inaccessibility of places where people tend to meet or socialize with sexual partners, such as bars and clubs, suggests that these opportunities are not valued by those creating and enforcing policies about accessibility. Participants in this study noted that sexual pleasure is often pushed aside by visible power structures in favour of more “wholesome” experiences, leaving little to no room for people with disabilities to exercise their own decision-making about priorities related to sexual pleasure.

Power, disability, and sexuality. Participants discussed the ways in which they were expected to perform in health care, home and community settings. A common theme among participants were expectations from others that they should be “getting back to normal”, or back to behaving as they did when they were able-bodied. The assumption that people with acquired physical disabilities can get back to a place of able-bodied-ness is not just problematic but leaves little room for people to decide what is truly important for them. Many of the participants explained that some of their biggest priorities related to continuing to be a sexual person, but

health care practitioners and visible power structures created barriers to healthy sexuality. For example, one participant talked about being discharged from care because they were not improving at a pace considered productive enough by practitioners. When health care practitioners favour a certain standard of health, that of presenting and behaving as able-bodied, they stop patients from exploring new aspects of their sexuality and identity.

The power of sexuality has been explored in leisure studies in its relation to resistance. Leisure studies has defined resistance as counter-discourses or actions that allow one to claim agency and self determination (Shaw, 2006). Franklin-Reible's (2006) study on sadomasochism considers the importance of so-called "deviant" forms of leisure in subverting mainstream expectations of sexuality. As well, leisure scholars have attributed leisure to resistance in that different forms of resistance are possible through claiming the right to leisure, and participation in empowering leisure pursuits (Shaw, 2006). The power associated with resisting mainstream expectations of sexuality is a form of hidden power, as it brings to the forefront alternative ways of conceptualizing sexuality, including the intersections of pain and pleasure, and the disabled person as a sexual person. This hidden power and resistance are also prevalent in my findings in participants' accounts of peer support and community learning. Participants described the validation they felt from hearing about sex from other disabled people, as compared with the difficulty of dealing with it alone. Participants also explained their relationship to pain and pleasure, explaining that in some cases, an increase in sexual pleasure made pain more manageable. Some of the participants explained that living with chronic pain had made them feel powerless, but pain management can help to create a sense of control. In a society that constantly desexualizes and dehumanizes people with disabilities, holding sexual power can be an incredibly humanizing and empowering form of resistance.

Education. Participants in this study had countless stories of the work they did to educate possible partners about their bodies. They explained that in order to have a sexual experience, they would need to educate even casual sexual partners about disabled sexuality. They described this work as difficult but necessary if they wanted to be sexual. Some of the participants suggested that able-bodied people should have sexuality education that includes disabled experiences. Not only is this education crucial for a more nuanced understanding of disabled sexuality, but also for a better understanding of sexuality through the life course.

Sexuality education. Current ideas around sexuality stem from early understandings of human sexuality based on the findings of Masters and Johnson (1966) and Kaplan (1979). These understandings of sexuality were incredibly significant to the study of sexuality, and still inform the health care system today. However, these early models of sexuality are not necessarily inclusive to queer, trans or disabled bodies, and create a normative idea of what sex is that turns other experiences into something wrong or abnormal. DiGiulio (2003) explores how the traditional model of sexual response does not best represent disabled sexuality. Further, they offer suggestions for opening up conversations beyond sexual functioning in health care settings, such as modifications to sexual positions and the use of toys to experience pleasure. This is consistent with the findings of this research project, in that participants expressed their interest in finding more ways to experience pleasure and toys to aid in that pleasure, and a deep understanding that sex means more than just orgasm. Unfortunately, many health care systems and practitioners still favour early understandings of sex to inform health care practices (Eglseder & Webb, 2017) which trickles into education systems and therefore informs the general public's knowledge. As health care practitioners and educators who ultimately hold power, we must look to broader understandings of sexuality influenced by disabled sexuality to better inform our practice and general understanding of sexuality.

If we look at sexuality as fluid and ever-changing, we are better able to set ourselves up for ongoing pleasure throughout our life course, as well as a more nuanced understanding of disabled sexuality. Ultimately, every person, regardless of ability or identity, should have access to sexuality education and support, so we all have the language and opportunity to understand sexuality more broadly, let alone disabled sexuality.

Access. Participants in this study described their sexuality and gender as being invisible in disability-centred spaces and being excluded from queer and trans spaces altogether because of their disability. During the debrief participants remarked how being part of the interview and focus group itself was validating and cathartic to them, because they were able to discuss their experiences with people, including myself, who understood on a personal level. There was a feeling of comfort in being able to tell their stories without having to explain the subtle nuances that outsiders would not understand, as well as a feeling of hopefulness that came from the specific ideas we had about techniques for exploring and supporting our sexualities. It was clear from these conversations, as well as explicit recommendations made by the participants, that a space for people with disabilities to discuss their sexualities with each other in a closed space is crucial to the exploration process. Unfortunately, this is unlikely to happen if health care practitioners and able-bodied community members are not on board, because of the lack of access and visibility people with disabilities already experience. Access does not solely refer to physical spaces, but to a more nuanced understanding of what physical spaces can do, such as increase community connections and knowledge sharing experiences. Being able to physically get into a gay bar means connecting with community members, increased visibility, and opportunities for peer support and community learning.

Able-bodied communities must take more action in provoking social change in terms of social constructions of disability. The need for power-holding groups to support social justice

movements is evident in varied contexts. Banks (2018) discusses this in a case study about an African-American male with cerebral palsy living in an urban community. In this study, Banks (2018) outlines the invisibility and erasure that disabled people face when they hold other marginalized identities. Such invisibility leads able-bodied people to remain ignorant, which leads to a lack of space in human rights movements. Banks (2018) also implies that change can only happen when a dominant group is able to acknowledge their lack of both action and knowledge, and move towards improving. Based on this idea, I believe that in order for closed spaces for disabled queer and trans people to exist, there needs to be some action taken on the part of able-bodied queer and trans people, and disabled cisgender, heterosexual people, as well as people holding positions of authority, such as health care practitioners. Ultimately, in social justice movements pursuing change, the responsibility for improvement cannot solely rest on those who are marginalized, and those with power have a responsibility to shift where power is held.

Summary

When prioritizing pleasure in rehabilitation settings, it is crucial to understand the influenced and influencing factors related to access, education and power, and how these factors relate to identity. Lack of access, lack of education, and lack of power can stop a person from prioritizing pleasure, even when they have named pleasure as an important contribution to their identity. Ultimately access, education and power act as either a barrier to prioritizing pleasure, or a facilitator.

Practical Implications and Recommendations

Recommendations for Conducting Research

Recruitment. As described in the above section, recruitment was a slow and difficult process, because of what seemed to be a mutual exclusivity between organizations that address

disability and organizations that address sexuality. One recommendation I would make for future research is to find ways to access disability specific organizations to have face-to-face discussions with care practitioners and clients. The anonymity of my research posters seemed to be a barrier to people with disabilities because of the trauma from and subsequent distrust of medical systems and researchers. Most of my participants were recruited through word of mouth because rapport had been built with other participants that established me as a relatively safe person.

Consider researcher self-care. As noted in the above section, being close to my research topic was both inspiring and extremely difficult emotionally. Because of the intensity of the interviews, I was thankful that I had ample time between interviews to decompress and consider my positionality. This research process required a lot of self-care and community care practices. It was important to me to feel held by my communities, but also by myself. I scheduled interviews for the early evening and tried to keep the rest of that night clear for decompression and rest. I began wearing comfortable clothing to interviews, brought my own water and snacks, and stated my own access needs in the interviews when asking for the access needs of my participants. I treated myself with the type of care I would give to my participants and friends. I also used memo-writing heavily as a way to debrief.

Representation of the researcher(s). While difficult, I think my personal connection to the project provided insight that may have been missed if I did not have those shared experiences. Although I tried not to share too much of my own experiences while engaged in data collection activities, it built rapport in a deeper way when I did so. Participants shared things with me that were profoundly personal, and I truly cannot say if that would have been different if I had not been facilitating those conversations. However, I do recommend individuals and teams doing research with marginalized populations consider their own identity and privilege, and

ensure someone involved in the research is a member of the communities represented among the participants.

Training for Health Care Practitioners

An ongoing theme within participants' stories were the gaps in knowledge of health care practitioners. These knowledge gaps were evident in a lack of awareness of resources, discomfort discussing sex, and in some cases plain bigotry and disrespect of identities. While there are many ways to deal with each of these gaps, a good start for all of them is training and education. As health care practitioners, we must recognize what we do not know, and find a way to learn more. This learning process begins in healthcare education programs before even entering the field, such as coursework and practicums. One example is a lunch and learn series I have been doing for the occupational therapy students at Dalhousie, organized by the student association. In these sessions I talk about sex as leisure and possible adaptations, from both a clinical and personal perspective.

Ongoing education initiatives can easily be introduced into health care settings. While working in a clinical setting for my internship, there were weekly education sessions entitled "Grand Rounds", where a researcher or guest speaker would discuss and educate the attendees in their subject matter of interest. The sessions were often livestreamed for clinicians who could not be there in person, but also wanted access to the education components. These education components should include people with lived experience, as indicated by the participants of my focus group.

Community Programming

In terms of community programming, some recommendations that result from this research are: (1) more sexuality programming in healthcare and public settings; (2) ample funding for sexuality programming and aids; (3) mainstream sexuality education programs

should include information about disabled sexuality; (4) sex and pleasure-centred spaces, whether private or public, should be updated to accommodate people with physical disabilities; and (5) sex educators should ensure they are educated about disabled sexuality.

Sexuality programming. Currently, the majority of sexuality programming related to disability takes place in small, often private commercial settings, such as Halifax's sex shop Venus Envy, but there is a clear need and interest for more programming, particularly in healthcare and public settings. Government funding is crucial for accessible community programs, so that facilitators and educators can do this work with the resources they need.

Funding. As discussed in the focus group, community programs should be created by and for people with disabilities. However, disabled people often live in poverty for a variety of reasons (Hughes & Avoke, 2010). For community members to do this work and attend programming, it is crucial that financial support is available as it is for other recreation and leisure activities. For example, grants and subsidies often exist within municipal governments to support sports and arts participation, some gyms and community centres have low-income options, and some government health insurance and private insurance companies provide coverage for mobility aids to help individuals get to and experience leisure activities. The same should be possible for sex-focused programming.

Sexuality education. Participants were adamant that sexuality education in schools and community programming for able-bodied people needs to be inclusive of disabled sexuality. Not only do spaces need to accommodate people with disabilities, but sex education for able-bodied people needs to include information on disabled sexuality.

Accessible spaces. Currently, there are a few sex-related educational and pleasure-centred programs in the community (i.e. Society of Bastet), but those spaces are often physically inaccessible. Similar to the way that older recreation spaces are often redesigned to

accommodate mobility needs, these sex-centred spaces should be adapted as well, with the help of government funding. Without education about disabled sexuality and seeing people with disabilities in pleasure-centred spaces, able-bodied individuals may never understand disabled sexuality, or even recognize that it exists at all.

Sex educators. While health care practitioners and educators should learn more about sex and sexuality, sexuality educators need to learn more about disabilities. Anyone who may be involved with a person with a disability (i.e., everyone) should have some understanding of disabled sexuality.

Reflections on the Research Process

Recruitment

Like many research projects before this, recruitment was challenging in this project. Many of the organizations and professionals I reached out to directly either did not reply to my emails or opted not to share my research poster. Perhaps this had to do with fear of causing harm to their members, or their own discomfort with sexuality, or a lack of attention around sexuality more generally from the organization. As well, the spaces where I was able to put up my posters were not particularly accessible, and this may have hindered my ability to reach intended audiences. Many of my research participants learned of the study from word of mouth and snowball sampling. For example, I met one of my research participants at an event I was presenting at, and we just happened to delve into a conversation afterwards where I was able to mention my research, for which they had seen a poster but had chosen not to respond. This participant helped me find almost half of my other research participants through snowball sampling and made clear to me that it was because of the rapport we had built and the knowledge we had shared that they felt comfortable to make those connections. Of the six participants in my project, only two had heard of this research independently and chose to reach out to me.

One of the participants mentioned to me in passing that it was not surprising that I had so much difficulty recruiting through posters because there is an intense distrust of the health care system and researchers among disabled communities. The fact that I had connections to the community because of my own experiences was the main reason I was able to recruit research participants.

Data Collection and Reflexivity

The process of hearing the stories of my participants was more difficult for me as a researcher than I had expected. Being personally involved in my subject matter made it all the more intense and, during data collection activities, not being able to contribute to the conversation to the extent that the participants did was difficult. While the participants became a community during the focus group, I felt pushed to the outskirts of the conversation in order to fulfill my obligations as a researcher.

Qualitative researchers have long transcended the idea that researchers must keep a neutral or objective lens. For years leisure researchers have acknowledged the idea of what I have dubbed the ‘emotional researcher’ (Dupuis, 1999), looking beyond the perspective of the researcher influencing the research. For example, the types of questions that are asked based on the worldview of the person asking the questions and recognizing that there is also a clear effect of research on the researcher. Yuen (2011) discusses the intense emotional toll her research with indigenous women in prison has taken on her, and grapples with academia’s ideas around professionalism and rationalism. She acknowledges the hopelessness and desperation that comes with research with people living in difficult situations, and how supports for the researcher within academia are few.

However, Yuen (2011) acknowledges that she started as an “outsider” who had been taken in and accepted by the community she worked with but, for me, I had an identity similar to

my research participants, and resonated with their stories in a different way. When participants told me their stories of the onset of their disabilities, I felt those experiences at my core, and constantly compared myself to them. I considered whether I was “disabled enough” to claim that identity, if my role as a health care practitioner and educator should stop me from accessing the services my participants had found were helpful, and ultimately, if I could even hold these identities simultaneously. Sheldon (2017) considers identity management in research contexts. His work focuses on disabled youth in education systems and he identifies as having a disability himself. He discusses when it is appropriate and necessary to disclose, how much to disclose, and to whom. For example, in one of his projects, he disclosed his mental health history to the readers, but not to the professionals he was working with at the time. Sheldon (2017) considers the relationship between reflexivity and disclosure, and the power that comes with selective disclosure. He proposes that disabled researchers should use their subjectivity as a catalyst for transforming the experiences of other disabled people (Sheldon, 2017). While he recognizes the careful attention that must go into research to keep participants safe, he does not mention the toll this could take on the researchers themselves.

After completing my interviews and focus group and reviewing the data, I felt excited, but obligated, to do the research and the participants justice. I felt this at a very intense point in my own journey of disability. The responsibility as a researcher, health care practitioner and educator, on top of my changing body and identity, was incredibly overwhelming, and the supports and resources I have contemplated accessing only address one of my identities at a time. There is such obvious importance in connecting to our subject matter as researchers. It drives us to represent our participants’ stories with a great appreciation and care, but it also takes an intense emotional toll on us, because at our core we are humans first, and researchers second.

Ultimately, research is about relationships. The relationships we create with participants and communities are just as crucial to the process as the results and writing. Reflexivity is not just about how we might shape our research, but also about how the research shapes us.

Implications for Therapeutic Recreation

Participants discussed the topics they would like to be addressed in education, programs and funding, many of which directly related to TR's scope of practice. For example, participants indicated they wanted someone to talk to about integrating sex back into their lives following the onset of disability, including the types of adaptations they would need to be able to take part in desired sexual activities, and finding accessible community spaces to meet people to date. While TR practitioners are not inherently qualified to attend to sex and dating, we are often involved in relationship management, activity adaptations, community reintegration, and resource navigation (Robertson & Long, 2008), all of which were noted as important to research participants. However, in order to do this work specifically around sex and dating, TR practitioners and students must receive education and training, so we are knowledgeable in the nuances of these specific activities. I believe the prioritizing pleasure model would be useful in the training and education of TR practitioners, but sex needs to be recognized in the scope of TR practice more generally for this to become a priority.

My work as a TR practitioner does not necessarily follow the traditional trajectory of a CTRS or graduate of a TR program. I mostly work in education settings, including an education-based sex shop. My education informs the work I do. I use the APIE model to plan education sessions and build rapport with clients of the shop before discussing possible options to address concerns, and use the counseling techniques consistent with a TR practitioner. Throughout the process of this research I have been committed to utilizing this emerging knowledge in my practice, and I chose to complete intensive sex therapy training to better amalgamate my

knowledge of sexuality with my TR practice. I have been working towards a private practice model entitled “Sex-Focused Recreation Therapy”, which I plan to flesh out once my thesis is complete. The findings of this research and experience of working so closely with my research participants has also gifted me with a increased passion for working with other health care practitioners to better their understanding of disabled sexuality, so that there are diverse healthcare options for supporting disabled sexuality.

Strengths and Limitations

This research was unique in that all but one of the participants were queer and/or trans, although this study wasn’t specifically recruiting queer and trans folk. The rich data related to queer and trans experiences of disabled sexuality meant that I was able to delve into intersecting identities and how these identities affect people’s experiences connecting with multiple communities simultaneously. As well, the gender diversity among this group of participants was interesting, as the sample did not include any straight, cisgender men. This is both a strength and limitation, as too often the focus of our culture is straight, cisgender men, and hearing about experiences of people outside of this identity is necessary and important. However, it is difficult to say if the experiences described by the participants are relevant to straight, cisgender men, and therefore difficult to assess whether or not it is possible to connect this research to similar research with straight, cisgender men. Similarly, it is difficult to say whether or not the differences between the one straight, cisgender participant and the other participants were significant because of this factor, or because of another factor, such as age, partner experiences or the type of disability experienced.

Another unique perspective of this research came from the choice to focus only on the experiences of people with disabilities, rather than the health care practitioner perspective. Although important, I felt the health care practitioner perspective had been the focus of more

research, whereas the experiences of individuals with disabilities had not been covered to the same extent, and had produced less actionable results. For example, research has explored attitudes of health care professionals in addressing sexuality in general populations (Areskoug-Josefsson & Fristedt, 2019), disability-specific sexuality training for health care professionals (Pieters, Kedde, & Bender, 2018), general perceptions of disabled sexuality (Esmail et al., 2010) and the views of health care professionals in addressing sexuality with patients with disabilities (Haboubi & Lincoln, 2003).

Most of the participants in this study experienced a gradual onset of disability and pain, rather than an acute illness or trauma that is often the focus of research related to physical disability. During the early stages of my research process, most of the research I accessed was about disabilities acquired from specific trauma such as spinal cord injuries (Aikman et al., 2018), stroke (Pryor & Lever, 2018), amputation (Manucharian, 2013) and paraplegia (Wiwanitkit, 2008). However, most of the participants in this research project had chronic illnesses that gradually intensified and became disabling over time, and struggled with finding resources in the health care system because of the wait for a diagnosis. Participants also explained that they became the ‘keepers of their care’, in that they ended up being the ones to push for resources such as specialist appointments and mobility devices, rather than being automatically referred to specific services immediately following emergency hospitalization and critical care settings. Thus, the participants in this study presented a unique perspective on experiences of physical disability unique to gradual onset.

This research project included multiple data-collection mechanisms, specifically individual interviews as well as a focus group. The focus of each form of data-collection had a different purpose: the interviews aimed to understand of participants’ personal experiences in the health care system and how those experiences impacted their

sexuality, whereas the focus group was a way for participants to come together and discuss shared experiences and possible future directions for sexuality support and education for adults with acquired physical disabilities. It was important for me to have both components of data collection in this project for a few reasons. One was to be able to give participants the opportunity to discuss an intense time in their life, in a safe and private environment, with the knowledge that their experiences would help to shape the research findings and consequent recommendations for the future of the health care system. Giving the participants an opportunity to voice their concerns and tell their stories, especially when their voices are often silenced, was a priority for me. As well, I think that individual interviews helped to shape the focus group in a productive, but also emotional, way. I was able to build rapport with participants before bringing them into a bigger group to determine what types of conversations we could have, but also what might be triggering for participants. I feel as though the focus group was successful because of the opportunity I had to get to know participants individually first, as well as the rapport building that took place at the focus group.

Another strength of including both individual interviews and a focus group was the opportunity to explore a few different facets of the same topic, in order to address sexuality and rehabilitation in a robust way. The individual interviews gave participants the opportunity to talk about past experiences and what supports they would have wished for, while the focus group allowed for participants to explore what future programming could look like, with a group of people with similar experiences. Participants also noted each data-collection mechanism allowed for some catharsis, but in different ways. In the interviews, participants noted the catharsis came from being able to express their concerns with someone to listen, while they noted the catharsis from the focus group came from knowing that other people had similar experiences, which created a feeling of community care.

As noted previously, recruitment for this research project proved to be a slow and difficult process, possibly because of our society's general discomfort with discussing sexuality. Not surprisingly, all the participants had a previous interest or experience talking about sexuality more broadly, whether that was from past work experiences or the inability to avoid discussion because of the nature of their sexuality. For example, some participants noted they had no choice but to discuss sexuality because their sexual identity and gender differed from the cis/heteronormative sexuality generally prescribed to them, and therefore had already had a multitude of conversations regarding sexuality. I feel that although the recruitment process was difficult, the individuals that did participate had such a strong background in sexual themes and contributed to a robust data collection and analysis process.

Future Research

I recommend future research focuses on chronic pain and sexual pleasure. Research has explored the effects of chronic pain on sexuality, and the effects of these effects on quality of life (Haddada et. al., 2017; Monga, 1998; Schlesinger, 1996). However, based on the findings from this research, such as participants' interest in learning from kink communities and the idea of increased pleasure being associated with decreased pain, it is likely there is a deeper, and possibly positive connection between pain and pleasure. I would recommend exploring this from a disability perspective in future research. As well, my other recommendation for future research is to evaluate the programs that are created or already exist related to sex within the rehabilitation process.

Dissemination Plan

The research will be disseminated through a thesis document and defence. As well, I will be submitting an abstract to the Canadian Congress of Leisure Research (CCLR) 2020 conference to present this work. The research will be shared with

participants by email upon their request, and with relevant classes at Dalhousie University, such as courses on disability in TR, to encourage discussion on sex and sexuality. I will also offer reports or presentations at the community organizations I attempted to recruit through, to give back to the communities involved in my research. Throughout the research process I have been creating and implementing workshops and lectures on issues related to my thesis work, based on initial findings, prior knowledge and personal experiences (e.g., Manett, 2018, 2019). I plan to continue this work upon the completion of my thesis.

Conclusion

This research project aimed to explore the experiences of adults with acquired physical disabilities, how the onset of disability impacted their sexuality, what supports and education initiatives exist in rehabilitation now, and what supports and education initiatives would be useful in the future. Participants discussed their experiences with health care practitioners in rehabilitation settings, dating in community settings, navigating both new and old identities, and what they wish they could see for support and education now and in the future.

From the findings, it was clear that disabled sexuality is a complex but important aspect of disabled identities and overall health and quality of life. Access to resources, information, and spaces to be sexual and date are the simplest components of these identities, but also the components that are most difficult for individuals to control. Healthcare practitioners and government structures should provide funding and resources to these components, so that people with disabilities can care for and learn from each other, in order to create change related to knowledge and acceptance of disabled sexuality. Sexuality should be prioritized by healthcare practitioners when working with individuals with acquired physical disabilities, but before this can happen, healthcare practitioners need education about disabled sexuality to ensure they are not causing harm to patients and clients, and providing the best care possible.

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APPENDIX A Debriefing Guide (Interviews and Focus Group)

Now that we have completed the interview/focus group, it might be beneficial for us to discuss anything difficult that came up and answer some self-care questions before we go. Feel free to answer the following questions on paper (provided), in your head, or with me/the group.

1. Are there any negative thoughts I am holding onto?
2. What are some positive thoughts I can focus on?
3. Who do I have in my life that I can ask for support?
4. How do I know that I am important?
5. What can I do when I leave here to feel good?

APPENDIX B Interview Guide

00. Introductions (name, gender pronouns, sexual orientation)
01. Tell me a bit about yourself
02. What made you want to participate in this interview?
03. To help me understand where you're coming from as it relates to your experiences of sexuality in rehab, can you tell me a bit about the experience of living with your disability?
 - a. How old were you when you acquired your disability?
 - b. How long ago was it?
 - c. What are some feelings that came up?
 - d. What are some changes that you have experienced?
 - e. What kind of supports did you have? What supports do you currently have?
 - f. What has it been like for you to live with your disability?
04. Can you tell me about your experience of disability as it relates to your sexuality?
 - a. What were your ideas around sexuality before?
 - b. What was new? How have you been able to express this in your everyday life.
 - c. Who did you ask? Who gave you answers?
 - d. Where did you get support/information?
 - e. What was difficult? What was easy?
05. What was the rehab process like – how did it contribute to, or not, your experiences of adapting to your disability and relating to your sexuality
06. How would you describe your sexuality/sex life now?
 - a. What/who got you to this point?
 - b. How did you get to that point?
 - c. Where are you in your journey? Adaptation? Maintenance?
07. The following question will be re-examined in the focus group, but I'm wondering if you have any thoughts now about recommendations relating to sexuality and rehabilitation, thinking about if someone else was to go through the same situation?
 - a. Supports? Education?
 - b. What is being done well?
 - c. What could be improved?
 - d. Where would you want to access these supports? Community? Hospital?
 - e. Who would you want to support you? Health care professionals? Peers?
Community Organization?
08. After being part of this experience, who do you have any recommendations of other people to talk to?
 - a. Practitioners?
 - b. Peers?
09. Do you have any final thoughts or anything else to add before I turn the recorder off?

APPENDIX C Focus Group Guide

Introductory spiel for focus group:

Welcome and thank you for coming to this focus group! My name is Rachele and I use she and they pronouns. As you know in some capacity, I am a Masters student at Dalhousie and my research focuses on sex and disability. Specifically, it explores the experiences of people with acquired physical disabilities in rehabilitation settings with regards to sexuality, sex and pleasure. In this focus group, I am hoping to focus on future directions and initiatives for sexuality support and education, in and out of health care services. To start us off, I would like to share some of the themes relating to this that have come out of individual interviews.

I'll be asking some questions to guide the conversations and may use flipchart paper to record some ideas so we can see them laid out. As a reminder, this conversation will be audiotaped, and transcribed and analyzed for my final thesis. The transcripts will be deidentified to ensure confidentiality, and I ask that you don't share personal information of the folks here today with other people.

Please take care of yourself in whatever way you need to. Grab something to eat, move around, fidget, colour, go to the bathroom, go outside, whatever feels right. We'll create some community standards to make sure we feel as good as we can in this space.

Before we get started, I would love if folks could introduce themselves with names, pronouns, and a little bit about yourself! I can start.

I am a queer person with chronic pain from scoliosis. I'm a sex-focused recreation therapist, I work at Venus Envy, I am a roller derby official, I love to cook and eat....

00. [Go around]

01. Creation of community guidelines

- a. What do we need to keep this space safe and comfortable?

- b. How can we create safer spaces for the people around us?
 - We have differing experiences of disability, gender, sexuality, culture, pain, etc. Keep that in mind during our discussions.
 - Sharing space in a way that feels affirming for us, and other people. I won't be doing much talking myself, other than to help guide conversations and maybe add a piece in here and there. Really, this focus group is about you.
02. Discuss some of the main themes that came up in the interviews around the possibility of a sexuality education program in rehabilitation (i.e. provide a short presentation summarizing data from interviews)

The future of education/moving forward

- education should be by and for people with disabilities
- general sex education (i.e. for able bodied people) should include things about sexuality and disability
- care practitioners shouldn't be the ones leading education for people with disabilities, but should have their own education to understand the issues and resources people may face and need to access
- different levels of education (pamphlets to start, community groups, clinical levels, support groups, etc.)
- need to address the knowledge gap of health care practitioners (and systems)
- there is one good program that exists – need to build on that (Dickson Pain Self-Management program)
- Programs need to be/include:
 - o Practical AND affirming
 - o Skills

- Support
- P4: “It’s a lot to deal with alone”
- P4: “practical information”; “nitty gritty stuff”; “what kind of contraptions are available to keep me safe from injury so I can have sex?” “What kind of techniques and strategies can disabled people use during sex to make things work?”
- Sex toys as assistive devices
- A place to start
 - Inviting conversation vs. not inviting conversation (vs. avoiding conversation vs. hindering conversation)
 - Addressing knowledge gaps (health care providers)
 - a. Ask: Do these themes make sense, given your own experience? Is there anything you would change or add?**
 - b. Decide amongst the group what they would like to focus on in developing recommendations for sexuality education within rehabilitation (i.e. training for professionals, program curriculum, resources)

IDEAS FOR GENERAL THEMES:

1. What health care professionals need to do/know/learn
2. Levels of support/education (i.e. pamphlets, groups, one-one conversations)
3. Settings for sexuality support and education
4. What we want in a pamphlet
5. What we want in a group setting
- 6. What we want in a one-one conversation/questions the health care practitioner should ask**

APPENDIX D Community Support Resources

If you are in distress, or in need of further support, please contact any of the following:

Mental Health Mobile Crisis Team (MHMCT):
902-429-8167

Avalon Sexual Assault Centre/Sexual Assault Nurse Examiner Program (SANE):
1526 Dresden Rowe
1-902-422-4240

Department Against Senior Abuse:
1-877-833-3377

First Nations and Inuit Hope for Wellness Help Line:
1-855-242-3310

Crisis Services Canada (based in Toronto):
437-317-4488

Bryony House (women and families impacted by intimate partner violence):
1-902-429-9002

Alternatively, you may contact your current support organization:
[will be provided based on participants' current support networks]
Example: Multiple Sclerosis Society of Canada – Atlantic Division

APPENDIX E Recruitment Email (Interviews)

Hello! My name is Rachele Manett and I am a graduate student at Dalhousie University. For my Master's thesis, I am looking to explore how acquiring a physical disability impacts how people experience their sexuality, and the role of rehabilitation, including Therapeutic Recreation, in supporting people to explore and practice their sexuality. I am currently recruiting individuals over the age of 18, who have acquired a physical disability in the last five (5) years after the age of 16, and who have gone through some formal rehabilitation, for a 1.5-hour interview.

This interview can take place in person or over the phone, and I would be happy to meet participants at a space of their choice. Participation is completely voluntary, and there is no pressure to take part.

I am hoping that you might be willing to share the attached recruitment poster with your members [or customers], and feel free to contact me at rachele.manett@dal.ca for questions or clarification.

All the best,

Rachele Manett

APPENDIX F Recruitment Poster (Interviews)

**Do you live with a physical disability?
Are you interested in talking about sex and rehabilitation?**

**You are invited to contribute to a research project about sex,
pleasure and disability.**

You could participate:

- If you are 18 or older
- If you have acquired a physical disability in the last five (5) years after age 16 (for example, spinal cord injury, visual impairment, arthritis, etc.)
- If you have taken part in a formal rehabilitation process (for example, through a clinic or hospital)

**Your opinion and experiences are important in
understanding the needs and experiences of individuals
who have acquired physical disabilities, and the impact
this has had on your sexuality.**

**If you would like to take part in an interview at an accessible
location of your choice, or over the phone, please contact:**

Rachele Manett

Email: rachele.manett@dal.ca

APPENDIX G Information Letter and Consent Form (Interviews)



Project title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

Lead researcher: Rachele Manett, Masters Candidate, Dalhousie University; email: rachele.manett@dal.ca

Supervisor:

Dr. Karen Gallant, School of Health and Human Performance, Dalhousie University; phone: 902-494-1196; email: Karen.gallant@dal.ca

Introduction

I invite you to take part in a research study being conducted by myself, Rachele Manett, under the guidance of my supervisor, Dr. Karen Gallant. Choosing whether or not to take part in this research is entirely your choice. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience or discomfort that you might experience. You should discuss any questions you have about this study with the researcher (Rachele Manett). Please ask as many questions as you like. If you have questions later, please contact the researcher by email (rachele.manett@dal.ca).

Purpose and Outline of the Research Study

This study explores the physical rehabilitation process and how sexuality is impacted and addressed. This part of the project explores the experience and process a person goes through when they have acquired a physical disability, and how that experience impacts their sexuality. Information will be gathered through a one-on-one, 1.5 hour interview, at a location of your choice.

Who Can Take Part in the Research Study

You can take part in this study if all of the following applies to you:

- You are over the age of 18
- You are living in the community (rather than in a clinical setting such as a hospital or nursing home)
- You have acquired a physical disability after the age of 16
- You have acquired a physical disability in the last five (5) years
- You have taken part in some formal rehabilitation.

What You Will Be Asked to Do

At this stage in the study, you will be asked to participate in an audiotaped interview. The interview will be about 1 to 1.5 hours long, where I will ask questions to encourage you to tell stories about your experience in physical rehabilitation and how it addressed/impacted your sexuality, from your perspective. You do not have to answer questions if you do not wish to do so, and you would be free to leave the interview at any time. The interview will be audiotaped so that I can listen to the interview and record your responses word-for-word, but if your words are quoted in reports on the study, they will be attributed to a fake name that you can choose.

Possible Benefits, Risks and Discomforts

There are potential risks associated with this study. It is possible that some questions may make you uncomfortable, and that discussing your ideas may remind you of difficult experiences you have had. However, please note that you may choose not to participate, or may choose not to answer any of the questions asked by the researcher.

There are no direct benefits to participation in this project, although I hope it may be empowering to share

your experiences on this topic. This is an action-based project that is intended to improve sexuality education in the rehabilitation process, and you may benefit through future initiatives that result from this project. For example, findings from this project will be shared with health care professionals in relevant areas of practice and community organizations that support individuals with acquired physical disabilities, however developing a program is beyond the scope of this project.

Compensation / Reimbursement

There is no compensation for participating in this interview, and I don't anticipate any cost to you to participating. For example, we will meet at a space where no costs would be incurred by you (i.e. public library or a space you already attend at no cost).

How your information will be protected:

Your identity as a participant in this research will not be anonymous, because I will know that you participated. However, the information collected in the interview will be kept confidential. I will remove identifying information, such as names, from the interview transcript. To keep your contributions confidential, information collected will be stored in a password-protected file on the computer, or in a locked cabinet. I plan to use the information to create reports and presentations. While reports and presentations may include direct quotations from your interview, they will be attributed to a fake name that you can choose. Also, I will use a participant number (not your name) in our written and computer records so that the information I have about you contains no names.

If You Decide to Stop Participating

You are free to leave the interview at any time. If you decide to stop participating, you will also be able to choose whether to allow me to use the information I have already collected, or whether you would prefer that I delete this information. You may contact myself or my supervisor within two weeks following the date of the interview to withdraw your data. The date of this interview is: _____ (participant to initial beside).

How to Obtain Results

I can provide you with a short description of group results when the study is finished. If you would like to receive this study report, please provide your contact information on the consent form. I will also provide a copy of this study report to [focus group host organization] and will request that they post it in a public spot.

Questions

I am happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact Rachele Manett (email: rachele.manett@dal.ca) at any time with questions, comments, or concerns about the research study.

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at (902) 494-1462, or email: ethics@dal.ca (and reference REB file 2018-4516)."

Signature Page: Individual Interview

Project Title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

Lead Researcher: Rachele Manett, Masters Candidate, Dalhousie University; email: rachele.manett@dal.ca

Consent to participate:

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to take part in an interview, and that the interview group will be recorded. I understand direct quotes of things I say may be used, but they will be attributed to the fake name of my choosing. I agree to take part in this study. My participation is voluntary, and I understand that I am free to withdraw from the study at any time during the interview.

Name

Signature

Date

After completing the interview: I confirm I have completed the interview and agree that direct quotes may be used. These should be attributed to the following fake name: _____.

Signature

Date

After completing the interview: The next stage of this study is a focus group to create a sexuality education/support program for rehabilitation contexts. If you are interested in participating in this, please provide your name and email address/phone number:

Option to receive research report:

Would you like to receive a short report about the findings from this research? If so, please provide contact information (name and email address):

APPENDIX H Recruitment Email (Focus Group)

Thank you for participating in an interview about your experiences in physical rehabilitation and the connection to your sexuality. You had indicated that you were interested in participating in a supplementary focus group for this research, and so I am writing to confirm your interest and find a time and date that works for you. This focus group will explore what a sexuality education program could look like in a rehabilitation settings, and will be audiotaped and included as part of the data in this project. This focus group will bring together some of the participants from other interviews and others who have acquired physical disabilities. Currently, there is expected to be between 4-7 people at this focus group, including myself, my supervisor, and the potential participants.

Your participation is completely voluntary. There is no pressure to take part. We will have refreshments at the location for you, in appreciation for your time.

Please feel free to contact me with any questions or if you would like to participate in this focus group, by email (rachele.manett@dal.ca) or by phone (647-223-9460).

APPENDIX I Information Letter and Consent Form (Focus Group)



Project title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

Lead researcher: Rachele Manett, Masters Candidate, Dalhousie University; email: rachele.manett@dal.ca

Supervisor:

Dr. Karen Gallant, School of Health and Human Performance, Dalhousie University; phone: 902-494-1196; email: Karen.gallant@dal.ca

Introduction

I invite you to take part in a research study being conducted by myself, Rachele Manett, under the guidance of my supervisor, Dr. Karen Gallant. Choosing whether or not to take part in this research is entirely your choice. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience or discomfort that you might experience. You should discuss any questions you have about this study with the researcher (Rachele Manett). Please ask as many questions as you like. If you have questions later, please contact the researcher by email (rachele.manett@dal.ca).

Purpose and Outline of the Research Study

This study explores the physical rehabilitation process and how sexuality is impacted and addressed. This part of the project explores the possibility of incorporating sexuality education in the rehabilitation process. Information will be gathered through a group meeting (“focus group”) where approximately six to ten people will gather for 1.5 to 2 hours to talk about your ideas of how to incorporate sexuality education into the rehabilitation process. The discussions from this meeting will be recorded by a graphic recording artist, and the finished product will be emailed to participants with their consent.

Who Can Take Part in the Research Study

You can take part in this study if you have an acquired physical disability, live in the Halifax Regional Municipality, and are over the age of 18.

What You Will Be Asked to Do

At this stage in the study, you will be asked to participate in an audiotaped focus group with about 6-10 other people. The focus group will be about 1.5 to 2 hours long, where the researcher will ask questions to encourage you to discuss your ideas of how to incorporate sexuality education into the rehabilitation process, from your perspective. You do not have to answer questions if you do not wish to do so, and you would be free to leave the meeting at any time. The meeting will be audiotaped so that the researcher can listen to the meeting and record your responses word-for-word, but if your words are quoted in reports on the study, they will be anonymous. My supervisor, Dr. Karen Gallant will be helping with the focus group, and a graphic facilitator will be present for the focus group as well.

Possible Benefits, Risks and Discomforts

There are potential risks associated with this study. It is possible that some questions may make you uncomfortable, and that discussing your ideas may remind you of difficult experiences you have had. However, please note that you may choose not to participate, or may choose not to answer any of the questions asked by the researcher.

There are no direct benefits to participation in this project, although we hope it may be empowering to share your experiences on this topic. This is an action-based project that is intended to improve sexuality education in the rehabilitation process, and you may benefit through future initiatives that result from this

project. For example, findings from this project will be shared with health care professionals in relevant areas of practice and community organizations that support individuals with acquired physical disabilities, however developing a program is beyond the scope of this project.

Compensation / Reimbursement

To thank you for your time, refreshments will be provided to you at the meeting.

How your information will be protected:

Your identity as a participant in this research will not be anonymous, because the researcher and others in the focus group will know that you participated. However, the information collected at the focus group will be kept confidential by the researcher, and we will ask others at the focus group not to share what was discussed at the focus group with others who were not involved. However, we cannot guarantee that they will do so.

We will remove identifying information, such as names, from the focus group transcript. To keep your contributions confidential, information collected today will be stored in a password-protected file on the computer, or in a locked cabinet. The researchers plan to use the information to create reports and presentations, but no names will be used. Your information will be used anonymously along with information from everyone else in the group, so you will not be identified in any way in our reports. The people who work with us have an obligation to keep all research information private. Also, we will use a participant number (not your name) in our written and computer records so that the information we have about you contains no names.

If You Decide to Stop Participating

You are free to leave the focus group at any time. If you decide to leave the focus group, we will not be able to remove the information you have already shared because we may not be able to recognize your voice on the audio recording of the focus group.

How to Obtain Results

We can provide you with a short description of group results, and a copy of the graphic recording when the study is finished. If you would like to receive this study report, please provide your contact information on the consent form. We will also provide a copy of this study report to [focus group host organization] and will request that they post it in a public spot.

Questions

We are happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact Rachele Manett (phone: 647-223-9460; email: rachele.manett@dal.ca) at any time with questions, comments, or concerns about the research study.

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at (902) 494-1462, or email: ethics@dal.ca (and reference REB file 2018-4516).”

Signature Page: Focus Group

Project Title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

Lead Researcher: Rachele Manett, Masters Candidate, Dalhousie University;
phone: 647-223-9460; email: rachele.manett@dal.ca

Consent to participate:

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to take part in a focus group, and that the focus group will be recorded. I understand direct quotes of things I say may be used without identifying me. I agree to take part in this study. My participation is voluntary, and I understand that I am free to withdraw from the study at any time during the focus group, but that the information I have contributed until that point will be unable to be withdrawn because it will be impossible to tell who has said what in the recording.

Name

Signature

Date

Option to receive research report and graphic recording:

Would you like to receive a short report about the findings from this research? If so, please provide contact information (name and email address):

Confidentiality Agreement (for Focus Group)

Project Title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

The nature of sharing information during a focus group means that I will be able to identify other participants of this research project.

By signing this letter of agreement, I am indicating that I agree to maintain confidentiality of all participants in any communication I have with others outside the focus group. I understand the measures being taken in this study to protect my own confidentiality.

Name of Participant (please print): _____

Signature of Participant: _____ **Date:** _____

Signature of Researcher: _____ **Date:** _____

Please sign one copy of this Letter of Agreement. Retain a copy for your records.

Confidentiality Agreement (for Focus Group)

Project Title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

The nature of sharing information during a focus group means that I will be able to identify other participants of this research project.

By signing this letter of agreement, I am indicating that I agree to maintain confidentiality of all participants in any communication I have with others outside the focus group. I understand the measures being taken in this study to protect my own confidentiality.

Please sign one copy of this Letter of Agreement. Retain a copy for your records.

Name of Participant (please print): _____

Signature of Participant: _____ **Date:** _____

Signature of Researcher: _____ **Date:** _____

Please sign one copy of this Letter of Agreement. Retain a copy for your records.

APPENDIX J TCPS2: CORE Certificate of Completion

PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Rachele Manett

*has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)*

Date of Issue: **29 October, 2016**

APPENDIX K Letter of Completion (Applied Approached and Advanced Issues in Sexuality, University of Guelph)



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OPEN LEARNING AND
EDUCATIONAL SUPPORT

Open Learning and Educational Support
University of Guelph, Johnston Hall, Room 160
Guelph, ON, N1G 2W1
Tel: (519) 767-5000
register@opened.uoguelph.ca
<https://courses.opened.uoguelph.ca>

Confirmation of Completion

Student: Ms Rachele Megan Manett

Course: 2009000 - DEOL APPLIED APPROACHES&ADV ISSUES SEXUALITY
Instruction Method: Online
Duration: 11/Sep/2017 to 03/Dec/2017

It is hereby confirmed that the above-named individual has been accepted in studies at this institution as indicated above.



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Open Learning and Educational Support
University of Guelph, Johnston Hall, Room 160
Guelph, ON, N1G 2W1
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<https://courses.opened.uoguelph.ca>

Student Grade Report

15/May/2018
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Rachele Manett
1991 Brunswick Street
Apartment 106
Halifax, NS B3J3J8

Student Number: 179905016
Course Number: 2009000-DEOL
Course Title: APPLIED APPROACHES&ADV ISSUES SEXUALITY
Grade: 96%
Course Duration: 11/Sep/2017 to 03/Dec/2017
Hours: 36.00
Awarded CEUs: 0.0

APPENDIX L Confidentiality Agreement (Transcriber)

Project Title: Exploring Sex as Leisure for Adults with Acquired Physical Disabilities

The nature of transcribing research data means that I will be able to identify participants of this research project.

By signing this letter of agreement, I am indicating that I agree to maintain confidentiality of all participants in any communication I have with others outside the research project. I understand the measures being taken in this study to protect the confidentiality of research participants.

Please sign one copy of this Letter of Agreement. Retain a copy for your records.

Name (please print): _____

Signature: _____ **Date:** _____

Signature of Researcher: _____ **Date:** _____

Please sign one copy of this Letter of Agreement. Retain a copy for your records.