

At the Intersection of Identity and the Body: One Woman's Experience of Disability and Sexuality

by

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Abstract

This study sought to understand the ways in which the intersections of sexuality, disability, and identity are experienced and understood by one woman living with cerebral palsy. The central research question for this thesis will ask: “How do women with cerebral palsy narrate their lived experience of disability and sexuality?” Through interviews conducted using Arvay’s (2002) narrative method of analysis, a narrative was co constructed to explore the experience of negotiating one’s identity as a sexual being while living with cerebral palsy. A thematic analysis revealed three key processes which facilitated an understanding of one’s self as a sexual being: the identity formation process, the relationship formation process, and the development of a disability identity. This research provides a rich and contextualized account of the intersectional nature of identity and the impact of occupying multiple marginalized positions on one woman’s lived experience with disability and sexuality.

Keywords: disability; sexuality; gender; resistance; intersectionality; narrative inquiry

I would like to dedicate this thesis to Jane. Thank you for your bravery, openness, and willingness to share your story with me. It has been an honour to learn from you, and I am hopeful that your story will help other women on their journey as well.

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Chapter 1.

Introduction

Fourteen percent of Canadians experience some form of physical disability (Statistics Canada, 2013). Statistics Canada defines disability as the “relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors” (Statistics Canada, 2001). Women in Canada are overrepresented within this population; 51 % of the Canadian population is female, and almost 15% are women with disabilities (Statistics Canada, 2013).

Research on quality of life (QOL) as measured by the impact of illness on an individual has found that although QOL and life satisfaction are best predicted by physical and functional wellbeing, social functioning has a significant and substantive impact on these constructs (Tate, Riley, Perna, & Roller, 1997). Women with disabilities have higher rates of unemployment, poverty and a lower personal income than their able bodied counterparts (Statistics Canada, 2011). Women with disabilities are also more likely to be single parents, have fewer education credentials, score below normal on measures of wellbeing, and are more likely to live alone (Statistics Canada, 2011). All of these factors combined with the double discrimination women with disabilities have faced as a result of their disability and their gender act as considerable barriers that prevent full participation within society (Shakespeare, 2000; Tate et al., 1997).

Sexuality and sexual expression, two very important aspects of women’s health, are often disregarded in health and social services provided to women with physical disabilities (Anderson & Kitchin, 2000). Disabled women in our society are viewed as undeserving of a sexual identity, and therefore often do not receive the most basic in sex education; the odds of not receiving sexual education or sexual counselling services among women with disabilities are two times greater than among their male counterparts (Tilley, 1996). Women with disabilities often face more difficulty in the development of romantic, sexual and intimate relationships due to the multiple barriers associated with poverty, as well as the impact of common comorbid health concerns such as depression and isolation (Shakespeare, 1996).

Significance and Rationale for the Study

What is not known about this population are the ways in which the intersections of disability, gender, and sexuality play out in the lives of women living with cerebral palsy. The lack of knowledge in this area has led difficulties in the ability of community and health care organizations to provide adequate support for this population (O'Toole, 2000).

Disability is an extremely stigmatizing phenomenon, the effects of which are more profound when combined with women's societal devaluation; as such the complex intersectionality between disability and gender should not be ignored. Many scholars have viewed gender and sexuality as intersectional and have imagined these two constructs as being viewed in a venn diagram, which presumes a combination of two separate and distinct identities that happen to overlap (Hirschmann, 2012; Schulz, 2009). The intersections between gender, disability and sexuality are best viewed not as a venn diagram, but as a double helix, constantly overlapping and separating at different points (Hirschmann, 2012). Many psychological theories of disability and sexuality address identity development in individuals with disabilities who also identify as a sexual minority, however, research examining how these multiple identities are developed and negotiated in relationship to one another is scarce (Schulz, 2009). Furthermore, many of the psychological models of sexuality identity development largely ignore disability status as well as other identity categories such as gender, race, and ethnicity (Schulz, 2009). Disability is often viewed as a fixed aspect of one's identity, primarily marked by a universalized "inability" (Schaller, 2008) as shown in the common belief that a physical disability often represents a form of cognitive impairment as well. The dominant discourses about disability rely upon these restrictive and fixed images of individuals with disabilities; such a unitary and unchangeable view of the self is inadequate to express the complexities of any person.

Purpose of the Study

The purpose of this study is to provide a better understanding of the intersectional nature of identity, and the impact of occupying multiple marginalized positions on women with disabilities experiences in the world. This study explores the ways in which the dynamic interplay of one's internal and external representations of the

self interact to challenge the restrictive cultural and stereotypical assumptions about the unitary disabled self.

Research Question

The central research question for this thesis will ask: “How do women with cerebral palsy narrate their lived experience of disability and sexuality?”

Overview of the Thesis

In Chapter One, I discuss the significance, the research topic and question, as well as the rationale for this study. In Chapter Two, I further situate this research with a review of the literature on sexual expression, sexual citizenship, the social of disability, and feminist disability theory. In Chapter Three, I provide an overview of the current study, including the research question, methodology, interview process, and trustworthiness of the proposed study. In Chapter Four, I present the results of this study using Jane’s story. Lastly, in Chapter Five, I provide a discussion of the results in relation to the relevant literature. Additionally, I identify strengths and limitations of this study and discuss implications for counsellors and for future research.

Chapter 2.

Literature Review

Research on the experiences of sexuality for disabled women is scarce. During the past decade, the main peer reviewed journals in the field of sexuality research have seldom published articles focusing on the experiences of women with disabilities (Vaughn, Silver, Murphy, Ashbaugh & Hoffman, 2014). A search for articles using Google scholar using the keywords “disability”, “sexuality”, and “women” reveals that during a period of ten years, from 2000-2010 the journal *Sexuality & Disability* published 224 articles, 23% of which focused on women with disabilities (Vaughn et al., 2014). Other top sexuality journals, such as *Sexuality & Culture* and *The Journal of Sex Research* published 869 articles about sexuality, 6 % of which were about women with disabilities. *Sexuality and Culture* published 194 articles, 5 % of which contained the key words “sexuality” and “disability”, but not one featured women with disabilities (Vaughn et al., 2014). One of the reasons why women with disability are invisible within sexuality research is due to the societal belief that individuals with disabilities are either asexual beings, uninterested or unable of participating in sexual activities (Anderson & Kitchin, 2000). In reality, asexuality is a sexual identity characterized as an individual who is not attracted to others; this identity category can be seen within the heterosexual, lesbian, gay, bisexual, transgender, queer, questioning, and intersex community (Vaughn et al., 2014). Although there may be individuals who identify as asexual within the disability community, the two identity categories are not synonymous (Vaughn et al., 2014). One of the simplest conditions of sexual inclusion is the right to recognize or acknowledge an individual as a sexual being; viewing individuals with disabilities as asexual is a violation of this condition (De Boer, 2015). Cultural representations of disabled people as “sick and sexless” have been supported and sustained by a set of myths about individuals with disabilities, myths that have been used to reinforce heteronormative and patriarchal ideologies in relation to disability, sexuality, and gender roles and have resulted in the avoidance and mistreatment of individuals with physical disabilities (Anderson & Kitchin, 2000; Kopala & Keitel, 2003 as cited in Brodwin & Frederick, 2010).

Barriers to Healthy Sexual Expression

Negative attitudes about individuals with disabilities have been seen in early Egyptian, Greek, Roman and Chinese civilizations and still persist in modern day (Brodwin & Frederick, 2010). These attitudes are portrayed in all forms of communication and media in most cultures and nations and they have tremendous impact on the way individuals with disabilities are treated within our society. Negative attitudes perpetuate myths and incorrect assumptions concerning individuals with physical disabilities; both of which affect the sexuality, self-concept, and motivation for independent living (Brodwin & Frederick, 2010). These myths include:

- Disabled people are asexual.
- Disabled people are over-sexed and have uncontrollable urges.
- Disabled people are dependent and child-like and, thus, need to be protected.
- Disability breeds disability.
- Disabled people should stay with and marry their own kind.
- If a disabled person has a sexual problem, it is almost always a result of the disability.
- If a nondisabled person has a sexual relationship with a disabled individual, it is because she or he cannot attract anyone else (Cornelius, Chipouras, Makas & Daniels, 1982, p.2-4 as cited in Brodwin & Frederick, 2010).
- Disabled persons lack basic biological sex drives.
- It is unacceptable for people with disabilities to be sexual beings.
- People with disabilities are incapable of functioning sexually.
- Persons with disabilities lack the requisite social skills and sound judgment needed to behave in a sexually responsible manner.
- No able-bodied people will find persons with disabilities desirable as romantic and sexual

- partners, or if they do, it implies something is wrong with them or that they are settling for less.
- Women with disabilities are less affected sexually than are men with disabilities, because of their presumed more passive sexual role (Olkin, 1999, p. 227-228 as cited in Brodwin & Frederick, 2010).

Sexuality is a vital means of pleasure, interpersonal connection, self-efficacy, and acceptance of one's body and of the self more generally (Wilkerson, 2000). Sexuality and its uses in advertising, entertainment, and other capitalist forms of media is a culturally feared aspect of the body, with especially serious implications for those whose bodies are perceived as falling outside of the rigid norm (Wilkerson, 2000). Dominant cultural ideals related to sexuality, such as the belief in orgasm as the height of sexual pleasure and the aesthetic importance of a "sexualized body" posit the able body as the norm, ignoring or devaluing the bodies of many individuals and representing a clear instance of cultural attitudes diminishing sexual agency and the sense of self (Wilkerson, 2000).

Our society values bodily characteristics that people with physical disabilities are less likely to possess, including physical fitness, sporting attainment and the 'body beautiful,' as it is represented in the media (Talepros & McCabe, 2002). The inability to attain these cultural ideals has many repercussions for individuals with physical disabilities. Individuals with disabilities often report struggles with self-image, as a result of their being socialized in a society which views them as asexual or unattractive (Shakespeare, 1996). Shuttleworth (2000) found that amongst men with cerebral palsy, cultural ideals of attractiveness worked as a major impediment in the development of sexual relationships, in particular society's ideals of attractiveness as conveyed by the media.

Several studies have documented disproportionately low sexual and body esteem in women with physical disabilities (Hassouneh-Phillips & McNeff, 2005). Sexual esteem refers to one's sense of self as a sexual being, ranging from sexually attractive to unattractive, and sexually competent to incompetent (Hassouneh-Phillips & McNeff, 2005). Women with physical disabilities have been found to internalize negative societal messages about the desirability of themselves and others with physical disabilities as

sexual partners (Hassouneh-Phillips & McNeff, 2005). As a result of this pervasive societal devaluation, women with physical disabilities have greater difficulty forming and maintaining intimate partner relationships than non-disabled women, and are more likely to have low sexual confidence and greater body dissatisfaction (Taleporos & McCabe, 2002; Hassouneh-Phillips & McNeff, 2005). This had led to a belief, for some women with physical disabilities, that it is better to be with a less desirable mate than to be alone. “Less desirable mates” have, at times, been found to include those who are physically and emotionally abusive (Hassouneh-Phillips & McNeff, 2005). Self-concept and body image have also been found to have both positive and negative effects on sexuality. If one has a negative perspective about their disability, one’s sexuality is negatively affected (Olkin, 1999 as cited in Brodwin & Frederick, 2010). An individual’s comfort with their self as sexual is influenced by feelings of attractiveness, self-esteem and ability to perform sexual activities; sexual self-acceptance (comfort with one’s body as a sexually responsive organism) is key in the development of positive self-esteem (Shakespeare, 1996).

Sexual Citizenship

In the past the concept of sexual citizenship has been explored in relation to lesbians and gay men (Shakespeare, 2000), and in more recent theorizing has also been applied to others considered “sexual minorities” (Siebers, 2008). Individuals with disabilities often share experiences with individuals who identify as sexual minorities (Sherry, 2004). Both Disability studies and Queer theory invite people to question the public and the private, the social and the biological, and to acknowledge difference, stigma and deviance, and the construction of identities (Sherry, 2004). Both challenge socially accepted norms that serve to marginalize those who don’t conform to the rigid, narrow definition of normalcy; and both engage with the lives of people who often experience high levels of discrimination, violence and unacceptance by others (Sherry, 2004).

Sexual citizenship reflects the challenge faced by many individuals to have control over their body, feelings, and relationships as well as access to representations, relationships, and public spaces. It is also reflective of the desire to be able to make choices regarding one’s own identities and gender experiences (Weeks, 1998). The sexual citizen is one who is able to claim their sexual rights through the fight for “sexual

justice” (Weeks, 1998). Sexual rights exist across three domains: practice, identity and relationships (Richardson, 2000). Sexual rights as pertaining to practice can be understood as the right to engage in various forms of sexual practice in personal relationships (Richardson, 2000). Sexual rights pertaining to identity are developed through the seeking of rights which relate to one’s ability to define themselves and the development of individual identities (i.e. the right to identify as gay or bisexual) (Richardson, 2000). Relational sexual rights are sought within social institutions, and the public validation of various forms of sexual relations (i.e. same sex marriage) (Richardson, 2000).

Shakespeare (2000) has identified three domains necessary for the development of sexual citizenship for sexual minorities. First, is a demand for control; individuals demand control over their bodies, feelings, and relationships. Second, is a demand for access; access to representations, relationships, and public spaces. Third, is a demand for choice; individuals must be able to make choices regarding their own identities, lifestyles, and gender experiences. The demand for sexual citizenship has stretched beyond the sexual minority community and can now be seen within the disability community as well.

Disability has been viewed as a denial of citizenship (Oliver, 1992 as cited in Drummond & Brotman, 2014). Too often, individuals with physical disabilities are viewed as incapable of sex and love, independent living, parenting and the enjoyment of family life (Shakespeare, Gillespie-Sells & Davies, 1996). Women with disabilities have long fought for their rights in many areas of life, including the right to sexual citizenship. For many individuals with physical disabilities, sexual rights are beginning to be seen as having equal importance to all other rights (Shakespeare, 2000). Sexuality, for many individuals with disabilities, has been viewed as an area of distress, and exclusion, and self-doubt for so long, that it has sometimes been easier not to consider it, than to engage in an area of life from which so many are excluded (Shakespeare, 2000). Discussions about sex and love are representative of acceptance at a very basic level—both self-acceptance and acceptance of the self by others—and force individuals to confront things which have previously been silenced (Shakespeare, 2000). As Anne Finger suggests “Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier for us to talk about—and formulate strategies

for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction” (as cited in Shakespeare, 2000).

Individuals with physical disabilities face many barriers to sexual citizenship including difficulties finding partners, lack of sexual education, and other societal and environmental factors. People with disabilities may have more difficulty finding partners and forming personal relationships leading to intimacy than do people without disabilities (Rintala, Howland, Nosek, Bennett, Young, Foley, Rossi & Chanpong, 1997). Illness and disability have been found to remove individuals from accustomed personal, social, and sexual interactions, all of which have a tremendous impact on feelings of self-worth and attractiveness (Rintala et al., 1997). Social and environmental factors such as inadequate social skills, social isolation, lack of opportunity to date, difficulty finding partners, lack of sexual knowledge, and other behaviors involved in forming intimate relationships possibly leading to sexual activity are often most prominent in adults whose disability began at birth or during childhood and represent significant barriers to the development of sexual citizenry (Rintala et al., 1997). Traditional societal expectations dictate that women with physical disabilities do not, and should not, seek out intimate partner relationships (Rintala et al., 1997). Women with disabilities are viewed as either asexual beings, uninterested or unable of participating in sexual activities; or underserving of attention from those who desire intimate relationships (Anderson & Kitchin, 2000; Rintala et al., 1997).

Social Model of Disability

Disability is a natural part of human existence; due to medical advances and technology, greater accessibility to health insurance, and generally higher standard of living that allows for more services and support, individuals who in the past may have succumbed to their illness now survive with a disability (Smart & Smart, 2006). Many models of disability have been proposed in order to better understand this aspect of human existence. Models of disability have great influence over the lives of disabled individuals; these models define disability, determine which professions serve people with disabilities, and help shape the self-identities of those with disabilities (Smart, 2009).

One of the earliest models of disability, the Medical Model, was developed based on the belief that disability is a disorder or disease of the body that should be minimized, or corrected, with medical intervention (Schriempf, 2001). The Medical Model defines disability in the language of medicine and views it as a wholly individual experience; the definition, the problem and the treatment of disability lie solely within the individual with the disability (Smart & Smart, 2006). As such, it fails to acknowledge issues of social justice, such as the way in which “disability” is maintained by societal standards of how a body should look, act, and perform (Schriempf, 2001). The Medical Model makes little to no distinction between impairment and disability; the two are used interchangeably to indicate a disorder or dysfunction of the body or brain (Schriempf, 2001). This places individuals with disabilities in stigmatizing categories, allowing non-disabled members of the public to view them as existing solely within their category (“the blind,” “the deaf” or “the mentally ill”) (Nagi, 1969 as cited in Smart & Smart, 2006). This categorization according to disability type has many pervasive, institutional, and systematic consequences, some of which have resulted in inferior services or a lack of services from the helping professions (Smart & Smart, 2006).

In response to the limitations of the Medical Model, disability theorists began to shift towards a new understanding of disability that aimed to take the “problem” of disability out of the body and into society. The Social Model is the most recently developed model and represents a fundamental and radical shift away the Medical Model; proponents of the Social Model view disablement as socially created and see the experience of disability as a form of social oppression (Lloyd, 1992; Smart & Smart, 2006). The Social Model locates the problem of disability squarely within society, and allows for the exploration of some of the day-to-day struggles faced by individuals with disabilities (Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004). In this view, the problem of disability is not the disabled person themselves, but instead, is the lack of appropriate goods and services; disability is not an individual, biological, condition – it is a social condition (Dewsbury et al., 2004; Schriempf, 2001). For most disabled individuals, the prejudice and discrimination placed on them by those within the broader society represent more of an obstacle to full societal participation than do medical impairments or functional limitations (Smart & Smart, 2006).

Unlike the highly individualized Medical Model, the Social Model works on both an individual and a societal level. Many individuals with disabilities credit the Social Model

with providing them the tools to challenge prejudice and discrimination, the opportunity to speak about their disability experiences, and a sense of community based on shared experiences with others (Smart, 2009). The strength of the Social Model is twofold; first, this model most closely reflects the day to day lives of individuals with disabilities. After medical stabilization, most of the difficulties disabled individuals face are related to reduced opportunity, lowered expectations, and being viewed as a member of a stigmatized category (Smart, 2009). The Social Model also has the power to mobilize individuals with all types of disabilities, rather than dividing individuals with differing disabilities by categorizing them based on disability type (Smart, 2009). The Social Model of disability has contributed greatly to the way in which disability is understood within our society, however, it fails to acknowledge the unique experiences of women with disabilities (Lloyd, 1992; Schriempf, 2001).

Disability and Feminism

The Social Model, in focusing on the social construction of disability, failed to acknowledge the body (especially women's), thus ignoring the complex interaction of biological and social needs that shape disabled women's experience (Schriempf, 2001). In response to being left out of both the Medical and Social Models of disability, disabled feminists turned to feminist theory to assist in the development of a theory that accurately represented their lived experience (Schriempf, 2001). Feminist theories have, in the past, focused solely on gender differences within society and subsequently failed to pay attention to disability theory; as a result, they were unable to recognize the lived experience of disabled women who exist in both a sexist and an ableist society (Schriempf, 2001).

Feminist disability studies emerged out of second wave feminism in response to gaps identified within the Social Model of disability and previous feminist theories. Feminist theories of disability have encouraged a more inclusive social model that acknowledges the reality of both bodily and societal limitations (Schriempf, 2001). Instead of seeing medical and social factors as existing separately, feminist disability theorists seek to acknowledge the disabling reality of both able bodied societal structures and bodily symptoms of chronic illness and disability (Drummond & Brotman, 2014). The return to acknowledgement of the body has been criticized by some as a slippery slope backwards towards the Medical Model; in response to this, many have

argued for an interactionist model similar to those adopted by others in attempt to understand disability and its intersections with other identities, such as race and sexual orientation (Schriempf, 2001). An interactional, or intersectional, model would allow for acknowledgement of both the reality of pain and the experiences of impairment within the context of existing as an outsider in an able bodied society (Schriempf, 2001).

In reviewing the literature, the complex relationship between disability, sexuality, and gender is clear. Research on the experiences of sexuality for disabled women is scarce and is necessary in order to combat the negative attitudes towards individuals with disabilities that persist in our society. Negative attitudes perpetuate myths; the endorsement of myths surrounding disability have a number of negative consequences on the lives of disabled individuals including lower rates of sexual and self-esteem, decreased body image, difficulties finding and maintaining romantic relationships, and a number of other pervasive, institutional, and systematic consequences, some of which have resulted in inferior services from the helping professions. In an effort to understand the lived experiences of individuals with disabilities, it is necessary to first understand the history of theories of disabilities, and the shortcomings of research conducted in the past using a medical model approach. The development of a social constructionist model of disability as located in society helped better reflect the day to day lived experience of individuals with disabilities. The social model of disability was initially developed based on an understanding of societal disability and bodily impairment as separate and distinct spheres. Disability was linked to a failure on the part of society, while impairment was connected to the body, to biology and to the traditional medical model. The development of the Social Model has its limitations, but it has also helped propel discussions about disability towards their current conceptualization as interactional. Recognition of the ways in which both bodily impairment and societal disability interact to form disabled women's oppression has led to current theorizing of disability as intersectional.

Chapter 3.

Methodology

In order to develop a deep, rich, and contextualized account of lived experience, I interviewed one woman living with cerebral palsy on several different occasions. Through the use of narrative inquiry, I aimed to create a dialogue that allowed for exploration of critical moments and turning points in the participant's lived experience of disability, sexuality, and gender. This process which will allow for a deeper understanding of her lived experience. Narrative inquiry is an established research methodology which uses storytelling methodology. Focusing on how individuals make sense of their experiences and communicate those experiences to others, the stories told are treated as primary sources of data (McLeod, 2011). Dialogical analysis will allow for a richly contextualized and dynamic understanding of the meaning women living with cerebral palsy make of their gender identity and sexuality (McLeod, 2011). The interplay and contrasted elements of meaning within the participant's story will generate a level of inquiry that is rarely found in non-narrative research.

The study sought to give voice to women's experiences of disability and sexuality, expanding understanding of this topic and providing insight into the experience of one woman living with cerebral palsy. I hoped to explore these aspects of identity and the ways in which they have shifted over time through addressing moments in the narrative where her experiences of disability and sexuality intersect and diverge, highlighting any tensions and critical moments that occur, while also addressing the meaning that the participant has made of her experiences.

Research Question

The central research question for this thesis asks: "How do women with cerebral palsy narrate their lived experience of disability and sexuality?"

The sub questions used to narrow the focus of this study will examine the use of narration as one instance of construction of self. More specifically:

How do women with cerebral palsy construct self identities around the notion of both self with disability and sexual self?

How do women with cerebral palsy make meaning of their experience of being both female in a patriarchal world, while also being disabled in an able bodied world?

How are the meanings of gender and disability related for women with cerebral palsy?

How do women with cerebral palsy perform their sexual selves?

How do voices of resistance to cultural ideals related to the body, gender, and sexuality appear in the narratives of women with cerebral palsy?

An Interpretive Method of Inquiry

Narrative Approach

This research question was addressed through a narrative methodology. Narrative inquiry is a suitable method for analyzing the lived experiences of women with disabilities because it provides the researcher with the opportunity to examine the participant's worldview and offers insight into a personal construction of the participant's world. Narrative inquiry is located in a social constructionist epistemology. From a social constructionist perspective, reality is socially constructed and understood only through the perceptions of individuals. How we see the world and what we know is not understood through objective observation, but instead through the social practices and interactions in which people constantly engage (Burr, 1995).

Narrative Inquiry

Narrative inquiry allows for the exploration of aspects of human life which have traditionally been ignored in the human sciences. It has been proposed that human beings are story tellers who live their lives in a storied manner; making sense of their lives and the lives of others through the stories that they construct (Riessman, 2008). Narratives are not meant to be factual accounts of exactly what occurred, but instead represent a system of meaning making that allows for an understanding of the intricacies

of human experiences and perceptions (Spence, 1982). The telling of stories helps us understand the complexities of our experiences and the ways in which we connect the different events in our lives in meaningful ways. The task of the researcher in narrative inquiry is to construct a narrative that reflects personal experience as told from the perspective of the participant (Riessman, 1993). These notions of narrative as a meaning making process provide individuals with a way to understand their experiences and, in turn, their selves. Narrative inquiry proposes that knowledge is co constructed through dialogue; both the participant and the researcher are tasked with constructing meaning, and both are located in a larger societal and cultural context (Riessman, 2008). Narrative research methodologies allow for the exploration of people's lived experiences and an appreciation of the temporal and fluid nature of that experience. Narrative also promotes the empowerment of research participants, allowing them to contribute to determining the most salient themes in their stories. Common themes found across research that pay attention to narrative have also expressed an interest in the notions and representations of the self.

Researcher Subjectivity

The narrative method of research is inherently reflexive, in that it requires the researcher to “re-story” the participant’s narrative. In order to re-story in a non-exploitative way, researchers need to explore their own personal and political background, which will inevitably shape the way in which they “re-story” the participant’s narrative (Elliot, 2005). In order to engage in reflective practice throughout the course of this research, I kept a reflexive journal to document any thoughts, assumptions, and observations that come up over the course of the research process. Reflexivity in narrative also involves the recognition of power relations within the research relationship (Elliot, 2005). It is also important to recognize that the inclusion of the participant in the analysis by way of member checks does not resolve the problem of power relations (Burr, 1995).

Recruitment and Selection

Narrative research often focuses on one or two individuals, rather than a larger group of people (Creswell, 2007). The individual being studied needs to be accessible,

willing to participate, and have unique experiences that allow them to shed light on a particular phenomenon or issue (Creswell, 2007).

Recruitment

Once receiving university ethics approval (See Appendix A) I recruited participants through the use of a poster (See Appendix B) displayed with the assistance of the Cerebral Palsy Association of British Columbia. The narrative method required that individuals have stories to tell about their lived experience (Creswell, 2007).

Once I established a willing participant I arranged for an in person meeting to assess participant suitability and to begin to develop rapport. First I asked whether they are comfortable discussing topics pertaining to their sexuality. I then ascertained their availability and commitment of time, and their ability to share their narrative. Once their suitability to participate was established, in an effort to maintain full transparency as a researcher, I explained the research question and process in detail, describing the roles and the responsibilities of both researcher and interviewee, expressing my values about the research relationship, and briefly explaining the philosophy behind narrative inquiry.

Participant criteria

Participation in my study required that the interviewee be a biologically born female, aged twenty to thirty, living with cerebral palsy who is open to discussing her sexuality.

Participant Recruitment Strategy

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Data Collection and Analysis

Four Stage Narrative Method

This research utilized the four stage narrative method developed by Arvay (1998, 2002). In the first stage, once a participant had been identified, I primed her to think about sexuality for about a week prior to the interview by asking “Please reflect on how you came to understand yourself as a sexual being” and to journal any questions or thoughts that come up as she engages in the process. I also invited her to bring any personal artifacts that represent sexuality to her and the role it plays in her life (this can be journals, photographs, poetry, art, etc.).

The Interview

I conducted a semi structured interview with my participant at a location of her choice. I utilized a loosely structured interview guide based on the themes presented in my research sub questions (See Appendix D) that allowed for a conversation as well as space to explore unanticipated experiences responses.

During the interview I did not take notes, instead utilizing the active listening skills that I have developed throughout my counselling training. I maintained eye contact and an open and inviting body posture. When the desire to write anything down arose, I wrote it on a large whiteboard that faced by myself and Jane, in an attempt to facilitate a feeling of co construction and reduce any power imbalances that may have existed between “researcher” and “participant.”

The first interview lasted approximately 2.5 hours. I built rapport with my participant by openly sharing information about the research and using basic counselling skills such as supportive listening, empathic reflecting and paraphrasing, and active attending.

I began the interview by delivering the orienting statement provided to my participant the week prior “Tell me the story of how you came to understand yourself as a sexual being.” I acknowledged that many women, particularly women with disabilities, are not often encouraged to speak about their sexual desire or experiences, and attempted to express my genuine wish to understand her lived experience of sexuality as a women with a disability.

Arvay’s method (2002) states that researchers attend participant’s narratives on two levels: the level of individual experience and of cultural discourse. This was done by listening to both the content of the stories *and* the ways in which the stories are told by paying attention to body language, pauses, imagery, metaphors, silences, and contradictions.

Transcription

After the interview was completed, I transcribed the conversation. I attempted to reproduce the speech as closely as possible. I also video recorded all elements of speech including laughter, pauses, silences, gaps, and tone of voice. I watched the video recording of the interview in order to observe body language, movement, facial expressions, and other contextual cues (Arvay, 2002).

Narrative Analysis

Once the interview was transcribed, I conducted four separate readings of the transcript as developed by Arvay (2002).

Reading for Content

Is the content of the interview coherent? Are there any changes or corrections that need to be made?

Reading for the Self of the Narrator

During the second reading, I read for the participant's various "I" positions in order to highlight the ways in which the narrator (participant) constructed herself through the telling of her story (Arvay, 2002). Questions which guide this reading as laid out by Arvay (2002) include: Who is telling this story? How is she situated in the story? What is she feeling as she tells the story? What struggles became apparent during the telling of the story? How has my participant presented herself? What meaning is conveyed through the telling of the story? What parts of herself are shared and what parts are kept hidden? Why? What does she want to convey to the reader?

Reading for the Research Question

The purpose of this reading was to find moments in which the participant spoke about her lived experience of sexuality as a disabled woman. Questions which guide this reading include: What meaning did the narrator make of her experiences? How did she make sense of these experiences? What was not said? What were the contradictions between her words and actions and/or my interpretations as a reader of the narrative? Were any metaphors used? How did the use of metaphor help my participant to make meaning of her experiences? (Arvay, 2002). During this reading I looked for examples of the participant's personal experience with the research question, while also reading for layers of tacit knowledge (Arvay, 2002). This process is known as "reflexivity in action" and involves different instances of meaning making as the researcher moves from the "story as told by participant" to other possible interpretations (Arvay, 2002).

A Critical Reading: Reading for Relations of Power and Culture

The final step of analysis in Arvay's method (2002) involves a critical analysis. As I read the transcript, I looked for instances of power imbalances along the lines of gender, race, sexual orientation, and any other areas in which people experience oppression; for this study, it was imperative that I include disability in this critical reading (Arvay, 2002). Questions which guide this reading included: In what ways does the participant appear to struggle with social justice? In which ways has she been silenced? When did she lose her voice? Is she aware of instances in her life that have been impacted by political and cultural influences? How do I, as researcher, understand her history, her context, and her social world? In what ways have her "personal realities"

been challenged? (Arvay, 2002). The goal of this reading was to uncover any cultural or political discourses within the narrative.

In order to work more closely with the transcripts I printed them out and coded and analyzed them by hand following the four step method. I attempted to achieve clarity on each reading, and then formulated a chronological timeline of the participant's story. A narrative thematic analysis will be presented in the results chapter.

Sharing the Narrative

Once the narrative had been transcribed and reviewed by my supervisors for content and flow, I gave a copy of the narrative to my participant. I asked her to read her story in my presence and express any reactions, thoughts, feelings and opinions regarding my interpretation of her narrative as well as the conclusions that I have made. During the transcription and analysis process, many questions came up for me which were addressed during this follow-up.

Ethical Considerations

All research involving human participants requires attention to ethical considerations that ensure the participant can make an informed decision regarding consent to participate. This includes providing information to the participant about ways in which their identity will be kept confidential and anonymous throughout the research process and the dissemination of the results of the study. In accordance with TCPS 2 (9.9), approval to conduct this study was obtained from Simon Fraser University's Research Ethics Board (REB). Narrative research that involves participant stories about their personal experiences, understanding of identity and the meaning of their lives brings forth additional ethical considerations.

Consent

The data collection process of narrative interviewing involves in depth conversations about intimate subjects similar to those that take place within a therapeutic context (Riessman, 1994). In order to ensure voluntary and informed consent, I provided my participant with a consent form (See Appendix C), which she read and signed prior to participating in any interviews. In order to ensure full informed consent, I read the consent form aloud in order to allow for an open discussion about

any questions or concerns that may arise. The consent form met all requirements for informed consent as outlined by the Simon Fraser University Research Ethics Board.

Confidentiality

The unique nature of case studies combined with the “specific constellation of attributes” (Elliot, 2005, p.142) makes full assurance of confidentiality difficult. Given that this study utilized a case study approach it is possible that my participant will, despite my best efforts, potentially be identifiable by those who know her based on the information she provides. In considering this risk, I made sure to discuss all possible avenues of research dissemination with my participant. The consent form provided outlined that the findings of this study will be used to fulfill the requirements of a master’s thesis and may be disseminated in research journals and conference presentations. The consent form explained that I will make every effort to ensure her privacy and that any identifying information will be disguised and she will only be referred to using the pseudonym of her choice.

Retention and Destruction of Interview Recordings

I video recorded the interviews in order to observe parts of speech that cannot be heard (body language, movement, facial expressions, environmental influences), as such, the consent form also included information explaining that all audio and video recorded data, notes, transcripts, and documents will be password encrypted and stored in a locked cabinet only accessible by myself and my supervisor and will be destroyed a year after the completion of the study.

The video recordings were stored on a password protected USB. File transfers were managed through SFU Vault. As mentioned, recordings of the interviews were destroyed soon after the process of meaning making. All transcribed electronic documents are identified only by a code number and will be kept on a password protected USB. These documents will be kept, along with other digital and hardcopy data relating to this research study, in a locked filing cabinet at SFU in an office in the Faculty of Education (5210). The USB will be kept for five years and then destroyed. During this time, only the principal investigator and senior supervisor, Dr. Sharalyn Jordan will have access to the data.

Criteria for Evaluating the Worth of this Study

In order to evaluate the worth of this study, I used three of the criteria set out by Arvay (1998): resonance, coherence, and pragmatic use. These criteria are fitting for narrative research due to its uniqueness and ungeneralizability and are based on Riessman's (1993) writings about the importance of evaluating worth in narrative research. This study's ability to meet this criteria was assessed by two peer reviewers: one with a background in disability studies, the other with a background in gender and sexuality research, both of which are documented below.

Reviewer 1

I do feel this was a coherent and cohesive narrative - written in a way that allowed me to get a sense of Jane as a person and of her journey. Emotionally, I could identify in many ways with Jane's sexual experiences, despite being able-bodied, which I believe indicates the realism in the narrative for women. It would be a useful case study/representative example in my human sexuality course in drawing attention to various themes (exclusion, sexual dissatisfaction, faking out of fear of loss of intimacy, discrimination and judgement - among many others).

This was a very pragmatic story. I believe it to be an accurate representation of what many women experience - regardless of their disability status. This intersectionality - Jane experiencing a physically disabled, being bisexual, and being a woman - is a very important story to hear and a very useful learning tool. Parents, counsellors, educators, etc. could certainly use this story as a strong illustration of sexual, emotional, and personal growth."

Reviewer 2

"This is a coherent story and it does flow with clear content and clear themes that recur. I believe that I have a good sense of who Jane is as a person, what her experience has been, and some of the issues with which she has to cope. The narrative was very real for me, and it was easy to imagine Jane's situation. Jane's lack of education about sexuality and disability is a real problem for so many people with disabilities. Her concern that perhaps people with disabilities are incapable of having sex is not uncommon. Jane's worry that she would never have sex and would never satisfy a partner because of her disability rang true for me. The description of her feeling

that she must do things that she didn't want in order not to lose her partner was sad and frustratingly common. The fear of forever being alone is such a motivating factor for people to stay in soul-destroying relationships. Her inability to bring herself to speak to her partner about her own dissatisfaction and her feeling and her need to fake noises of sexual pleasure are also typical of so many women with or without disabilities. Having a disability exacerbates the feelings of insecurity and undesirability for women with disabilities. This makes Jane's story all the more poignant.

Jane's desire to have partners who currently have no disability is also real to me. She needed acceptance in a non-disabled world to feel okay about herself, and to feel desirable. Her willingness to go into uncomfortable situations where accessibility was compromised or non-existent also felt real. She was trying to "pass" as non-disabled because there was little discussion of what her needs were as a person with a disability. When she does become sexually involved with a man who also has cerebral palsy, her initial feelings of discomfort with how she would be viewed in the non-disabled world were sadly familiar to me. The worry that Jane has that non-disabled people will see her and her partner as undesirable to "normal" people so that they are "stuck" with each other as two undesirable people together is a true problem.

Jane's involvement in the disabled community and getting to know people who are disability activists is also wonderfully real to me. This connection happens for some people, and when it does, it is often empowering and liberating. It is important for people with disabilities to become visible and to demand their rights. When Jane realized that she was not alone in the problems she was experiencing, she felt relief and that helped her enormously. From my interpretation of the narrative, this was a turning point for her.

I have to say that I feel delighted for Jane now that she is in a satisfying relationship. She is confident both sexually and emotionally, and has great communication with her partner. She is also finding that medical personnel are providing the couple with information (sometimes more than they need!) so that they can accommodate their disabilities when being active sexually. Jane seems prouder to be someone with a disability and has found support both within and without the disability community. A happy ending.

I think this would be useful for others to hear and to present at workshops. Jane's negative experience was often a result of people's ignorance about cerebral palsy and/or their discounting of disability in general. This narrative describes a number of themes that are not just specific to issues people with cerebral palsy face, but are relevant to people with disabilities in general. There are several aspects of the narrative that would be very good for parents and professionals who work with women with disabilities to know."

Chapter 4.

Results

Introduction

Jane is a 27 year old, college educated, bisexual woman living with cerebral palsy¹. She grew up in a small town just outside of a large Canadian city, where discussions about sexuality and disability were not had openly. Jane's disability is a thread throughout her experience of sexuality; with her experiences as a bisexual and disabled woman taking her on a journey through secrecy, silence, and dissatisfaction, towards knowledge, understanding, and pleasure. Her experiences of disability and sexuality have been closely linked, intersecting and diverting at different points in her life. Throughout her journey Jane has found support in the disability and queer community; her growing involvement in the disability rights movement has impacted the way she understands her body and herself as a sexual being.

Early Childhood and Adolescent Sexual Development

The Influence of the Media

Jane experienced herself as a sexual being from a very early age recalling that she used to "try to be sexual" with a male friend by mimicking things they saw on television. One of Jane's earliest memories of this sexual exploration involved kissing underneath a blanket in her family home and being caught by her mother. Jane stated:

Um, when we we're really little, like we used to kind of try and be sexual, I guess cause we see stuff on TV and like my mom caught us and they're like "You can't do that.", and like I remember he used to like kiss me like under blankets and stuff and so they ended up getting mad at us and they're like "You can't do that. You guys are too young.", but I remember he's still wanting to and I was like "No, we can't. My mom says we can't.", [Laughs] and so yeah I guess we just grew up.

¹ The participant did not narrate her ethnic background in the interviews. Readers are encouraged/advised not to invoke whiteness as the default race for Jane.

Later, around age twelve, Jane would find herself influenced by media portrayals of sexuality once again. Jane describes herself as curious about sexuality at this age, recalling that she would often wonder what it would be like to enact the sexual behaviours she saw on television and film. Jane recounted one time in particular, while watching a film with a female friend whom Jane described as being “sexually active from a very young age,” as the first time she experienced same sex attraction. Jane stated:

I guess like we were both kind of at the stage where we were both curious. Like we would watch stuff on TV. Like If we're watching like sexual scenes and then where's-- like well, I wonder what that'd be like. And it was kind of like, "Well, do you wanna try and see what it's like?", and then yeah that's kind of what happened.

Jane described the experience as confusing at first because she felt like she should not be doing this and also conflicting because it was sexually arousing. Jane did not pursue this relationship recounting that she instead kept it hidden. While reflecting on her identity as a bisexual woman, Jane recalled feeling attracted to women from a young age. She described this as her “deep dark secret.” Jane recalled feeling a sense of shame about her attraction to women, an experience she believes was a result of having never been exposed to same sex relationships.

Exclusion from the Sexual World

Despite feeling like a sexual being, as Jane entered middle adolescence and her peers began to date and experience sexual growth, she experienced exclusion from the sexual world.

I was the only disabled person in the community right? And I remember feeling like “Oh, like, am I ever going to have sex?” like, “Is it ever gonna happen for me?” Because it doesn't seem like anybody is interested in me in that way. So [sigh]...

Jane experienced significant disappointment and isolation during this period of her life and although she experienced invisibility in terms of recognition as a sexual being, she also felt that “all eyes were on her.”

The isolation Jane experienced, coupled with a refusal of others to acknowledge her as a sexual being, led to a lowered sense of sexual self esteem. A combination

which would have great impact on Jane's sense of self when it came to her romantic and sexual relationships later in life.

Jane also experienced exclusion from the sexual realm when it came to the sexual health education that she received both in school and at home due to lack of acknowledgement of individuals with disabilities as sexual beings. She stated:

Disability isn't something that was talked about. Like I know that we had like sex ed and stuff, but like it was never focused on disability and I didn't even know if I could have sex, you know? It's weird...because no one actually sat down and had this conversation with me. Which I find to be really strange, like looking back now. I mean, because I was the only disabled person. Like, able bodied people can talk about it and it's no problem, but no one's going to sit down and talk to the only disabled girl.

This erasure was particularly confusing due to the fact that Jane experienced sexual arousal and romantic attraction but lacked knowledge of whether she was even capable of having intercourse. This lack of knowing contributed to Jane's sense of isolation and exclusion and served to further the silence her from sharing the attraction she was experiencing both physically and emotionally. Jane interpreted this silence as a denial of her existence as a sexual being. The realization that no one was going to talk to Jane about sex left her believing that "they don't expect me to do this...so I wonder if it's even a possibility for me." Jane did not see able bodied individuals experiencing the same level of erasure noticing that "they can talk about it [sex] and it's no problem, but no one's going to sit down and talk about sex with the only disabled girl."

Wanting to be Wanted

At the age of eighteen, Jane relocated to a major Canadian city. During a visit to her hometown shortly after moving, Jane had her first sexual experience with a member of the opposite sex. This experience was again confusing for Jane given that she had come to believe that sex was an aspect of human existence that she may never experience. Jane experienced difficulty engaging in intercourse due to her physical limitations, lack of experience, and discouragement from speaking about sex. Jane shared:

We actually didn't know what we're doing. Like we're both virgins at the time and yeah, and we're both really drunk. I couldn't really

believe this was happening because like I started having feelings for him but I was like "Oh, this was never gonna happen." I kind of wanted to keep it that way but then that night he-- we were in his dad's truck, we were sitting in his dad's truck and he started holding my hand and then we went inside and then he kissed me and then brought me to his room and then we started making out and then trying to have sex. Um, but then yeah we couldn't like actually have sex... like he wanted me to be on top, like on top of him and like I had no idea what I was doing and like, um, so like we couldn't get it in because like I was a virgin and yeah. We just really didn't know what we were doing.

Jane described this experience as dissatisfying. Although she experienced arousal during foreplay, her partner's narrow view of how sex should look (woman on top position) for two young people having sex for the first time resulted in frustration and disappointment.

Jane's first relationship occurred in this same year, but was experienced as disappointing quite early on due to a perceived sense of power imbalance within the relationship. Jane felt like she was being kept on the side by someone that she wanted to be in a relationship with, a pattern that would play out with a few different men in Jane's life. In reflecting on this pattern, Jane believed that her disability played a part in this because she was "kind of limited as to what I could do and stuff...I think he became slightly dissatisfied."

Although marred by disappointment, Jane remained in this relationship. When asked about her sex life during this time, Jane recalled that she did not enjoy herself sexually with him and felt like she "was not living up to her full sexual potential." Jane never spoke up about her dissatisfaction, instead internalizing the message that "this is just what sex is like" for women. Jane was once again silenced in this relationship, feeling that it was better to remain dissatisfied sexually than to be without a partner. The lack of sex education Jane received left her with no point of reference for what healthy sexuality looked like and resulted in further silencing around the discourse of pleasure. Jane had seen women enjoying themselves sexually in television and film, and used these media representations as scripts for the way she performed her sexual self, stating that:

I never orgasmed, I never like, I never really enjoyed myself like I always kind of faked it and I guess like that's what I felt like I had to do...you know the way you see things in the media. Like, they're (women) so loud and like out there. I felt like I had to be that way,

because I had nothing else really to compare it to. And also to keep my boyfriend happy at the time.

A desire to be wanted by someone else kept Jane in this relationship and resulted in an external sexual self; her view of herself as a sexual being was entirely dependent on whether someone else wanted to have sex with her. This lack of ownership over her own sexuality manifested as a lack of ownership over her own body. Although not explicitly demanded, Jane felt that she had to dress and groom her body hair in a certain way in order to appease her partner's preferences for revealing clothing and a clean shaven vulva:

I remember one time I was uhm – like I was getting dressed and I think I was gonna wear a t-shirt, it was just a standard t-shirt because they're comfortable and he's like, "oh, you're gonna wear that today?" He always kind of liked me to wear like low cut stuff and like kind of revealing stuff and yeah. It's like kind of I dressed up for him I guess, yeah. Like, he said he preferred when girls shaved so I always shaved.

After years of feeling frustrated and dissatisfied, Jane began to question whether she wanted to remain in this relationship, but felt trapped because of the emotional labour she provided to her partner. This made ending the relationship particularly difficult. To feel important and needed by someone else was what Jane had desired for so many years. She would soon come to realize that being wanted and needed was not enough to feel fulfilled in a relationship. Jane wanted more.

Early Adulthood

A Time of Sexual Exploration

After the resolution of Jane's first relationship, she set out on a quest to discover herself sexually. Jane described her motivation for this quest as a realization that she wasn't "living up to my full sexual potential."

Jane began a casual sex relationship with another man and recalled having a satisfying sexual experience with him almost immediately. This experience made Jane realize that sexual intimacy could, and should, be mutually satisfying. This shifted Jane's view of sex in relationships, from something that "you just do" to something that was a fundamental part of her relationship and a source of enjoyment, connection, and

pleasure. This realization made Jane feel more confident in speaking out about her needs and desires.

I started casually dating someone else and then I had a really good sexual experience with that guy but like I never orgasmed with him but that's simply because he just didn't take the time and I kind of started realizing like if-- I guess if someone really cares about like your sexual pleasures, they're gonna take the time to like make that [orgasm] happen.. But he never did like in the whole entire time when we were together. I realized that like sex is a big part of relationships.

When reflecting on this experience, Jane noted that in the past she had been silenced by her desire to remain in a relationship, even if she was dissatisfied. Jane's silencing was maintained by a fear that speaking out would result in the dissolution of her relationship, a sacrifice that was not worth it to her at the time. When asked what advice she would like to give this past silenced self, Jane shared:

You don't have to be with this person if he doesn't make you sexually happy and that's what you want. You don't have to be with these people. There are people other than him that didn't please me sexually but I didn't wanna be alone. I wanted to be wanted.

After reaching a level of sexual satisfaction that was previously unknown to Jane, she decided she would no longer have her pleasure made invisible and realized that remaining silent wasn't "really worth it" given her new found belief that "there's someone else out there that's gonna want you and want to take the time to get to know your body and respect your body."

After moving to a larger urban center, Jane found it difficult to meet people in bars or other social settings, and preferred online dating. Jane was very upfront about her status as a woman living with cerebral palsy, refusing to remain invisible and making no attempts to hide the fact that she used a chair through her pictures. This visibility was important to Jane, however she later found herself in a pattern of relationships with individuals that Jane believes only wanted to have sex with her because they were curious about having sex with a disabled girl.

People just wanted to have sex with me because they – it's almost like they were curious about wanting to have sex with a disabled girl or like so I kind of think that's what it was for them. Like they would like only contact me for sex and only come over and have sex and watch a movie and that's it... and it's not real relationship building.

Jane described the basis of these relationships as purely sexual, something she tried to convince herself she was okay with, but later acknowledged left her feeling used and “always wanting more.”

Jane coped by attempting to convince herself that she only wanted a casual, sexual relationship with these individuals, but knew that deep down she always wanted more from them. Jane experienced a sense of self blame for allowing herself to be treated this way despite making attempts to express her desire for something more in these relationships. Jane’s resistance to being silenced was met with further erasure, as she felt the responses she received were disingenuous, describing one instance as an attempt for her partner to “find an easy way out” by “just going along with whatever she wants to hear” before “letting it going gently.”

Jane’s resistance to invisibility led to exploration of the same sex attraction she experienced when she was young. Jane considered this her “deep dark secret” for many years, never speaking about it to anyone. When Jane’s Uncle came out as two spirited this challenged Jane’s notion of an exclusively heterosexual world, but it would still be some time before Jane felt comfortable affirming her identity as a pansexual woman. Relocating to a large urban centre where sexuality was discussed openly helped Jane become more accepting of her sexual identity.

It [his coming out] was kind of reassuring. Um, but that wasn't like the point in my life that reaffirmed that it's okay for me to have these feelings and it's okay for me to admit that I have these feelings. I only started doing that because like-- even after that point I kind of felt like, you know, we live in a world where like I guess bisexuality and homosexuality is not accepted. Like it's not the norm. Yeah, but um, I also grew up in a really small town where that wasn't-- like we didn't have like gay pride or anything like that. I guess I just grew more accepting of myself coming out with time.

The first time Jane disclosed her same sex attraction was to her cousin. Jane’s cousin also disclosed that she had experienced same sex attraction and had experimented with women. This disclosure prompted Jane to feel comfortable talking about her own experiences with same sex desire:

It was almost kind of like liberating, like this was the first time I've actually said this all out loud. But like what it was was that, um, we were talking and my cousin is very big in the like fetish community and she’s pretty open about that and she was just talking about that and experimenting with women and, um, I'm like “Well I have too

when I was younger but I've always kind of felt like it was a bad thing" and she kind of like encouraged me that it wasn't, that you know it was normal and she too kind of grew up in the same situation. She grew up in a very Christian family and her Mom didn't want her to hang out with one of her friends because she thought she was a lesbian.

Jane reflected on what it was like for her growing up and experiencing same sex attraction, and reflected on the difficulty and shame she experienced especially difficult to hear her step father use words like "fag" and make derogatory statements about LGBT individuals on television. Jane credits these experiences as one of the reasons she was silenced for so long, stating:

Part of the reason why I hid it for so long, and like to this day I won't-- I can't picture myself telling my parents that I'm bisexual. My mom, maybe, but not necessarily my dad. It's not so bad now because I mean I'm in a committed relationship with a male. Um, but like I kind of feel like I can't-- I still can't embrace that part of me. If we were to ever separate or whatever, something were to happen, it would still kind of be an issue for me to go and be with a female.

Jane expressed further disappointment at never having been able to explore "that side of [her] self" due to getting into a committed monogamous heterosexual relationship quite soon after realizing being with another woman was something that she wanted, but she does not rule it out as an option for the future. When asked how this inability to speak about herself as a bisexual women impacted her view of herself as a sexual being, Jane reported that it is not an issue within her life right now that anyone needs to know about and that despite the continued silencing, she is accepting of her own sexuality.

Finding Voice within a Community

The men that Jane engaged in casual relationships with during her early twenties were all able bodied. Jane acknowledged that this was no coincidence; she wanted to be with someone who was able bodied. Jane described her reasons for seeking out able bodied partners as partly functional, in that they were able to help her navigate an able bodied world by assisting with cooking, cleaning, and other domestic duties; and partly in an attempt to challenge the myth that individuals with physical disabilities can only date other individuals with physical disabilities:

I always kind of wanted to be with somebody who was able bodied and um, figure out just like well, he can help me you know, he can help me with cooking, cleaning and whatever I need help with, but... I guess society was kind of just looking at me like, oh, they're with them because they had to deal with them or like something like that, you know?"

Jane recalled an experience when one of these partners, whom Jane described as accepting, became quite frustrated by having to assist her during sex due to the limitations Jane's cerebral palsy presented. Jane described feeling that she was "a burden sometimes" because he was "able bodied" and "had to help me sometimes."

Another partner informed Jane that people would approach him and say things like "good for you for dating her." While dating these individuals Jane disclosed that her disability identity became erased in an attempt to perform able-bodiedness, which often left her struggling to find accessibility in non-accessible places.

Jane's move from a small town into a large city allowed her to find a place within a larger disability community. Before moving, when Jane felt like "the only disabled girl," she often performed able-bodiedness by navigating inaccessible spaces, and not speaking up about her need for accessibility. Establishing a sense of community helped Jane to find her voice as a woman living with a physical disability and reclaim a sense of dignity:

I have this huge group of friends now who are disabled too. I prefer to hang out with because we have to consider like um, you know, our limitations. We have to take all these factors into consideration whereas when I'm always with able-bodied people, they don't think about these things, they don't have to, and um, one thing I really like, is like, and we all kind of understand that piece around like, dignity. It feels like when I'm always with able-bodied people, they may see it as, 'Oh yeah, you can use the washroom, I'll just help you.' But like, people have to realize like, it's so important for a disabled person to be able to do that themselves, and access those places themselves and like, have access to a building themselves and be able to come and go as they please because it's their dignity, as a person.

Jane described one of her friends in this group as "pro disability" and introduced Jane to the use of the word "Cripple" as a reclaimed word to resist oppression; an experience which Jane recalls as one which was formative on her journey towards self-acceptance. A large shift in Jane's self-concept occurred after finding a place within the disability community:

She is pro-disability and like um, using the word 'cripple' and against ableism and all that stuff and, so she really kinda changed my view on that and helped me be more accepting of myself.

A connection to a larger disability community not only meant that Jane felt understood, but also that she was finally able to see individuals with disabilities existing within society and the realm of sexuality:

I have a lot of disabled friends and like, they're my "go-to" friends now, like I would much rather hang out with them than my able bodied friends cause there's another level of understanding, I'm not the only disabled person that's like gotten into a relationship recently like among my friends and yeah...I think it's made me more comfortable with myself sexually because, yeah, because of my disability I do have limitations, but that's ok, like I've come to realize that's ok because I'm not the only one that has limitations.

It was through this group of friends in the disability community that Jane met her current partner. Their relationship started as friends, they often hung out around the same people in the same places, and attended the same adapted yoga class together at their local cerebral palsy association. When Jane began to suspect that he wanted more than a friendship, she was initially reluctant to date someone else living with a physical disability. Jane described this reluctance as a fear of becoming "doubly disabled" stating:

If I dated another disabled person, it kind of makes me out to be more disabled in a sense. And also, I always worried about us being very limited in terms of like, what we can do, because things are very inaccessible already. Like we can't just go out and do this and this and... things like that. Whereas I'm like fairly mobile, so if I dated someone who is more disabled than me, would that make it harder? You know would that make things more challenging?

Jane also worried about how others would react, both people close to her, and the general population. Jane described experiencing fear that her relationship would be viewed negatively due to myths about sexuality and disability. Over time Jane's feelings for her partner grew, but she still experienced significant fear and doubts over what other people would think:

I asked my sister, what she would think if...or how would she feel if I started dating somebody with a disability or I told her that um, I had like -- I had thoughts and thinking of dating someone with a disability and I'm not sure how people would react to that.

Jane could not recall her sister's response, but remembered that it was a positive one, and left Jane feeling that it was better for her to follow her feelings than to worry about the reactions of others. Over time, Jane's friendship evolved into an intimate relationship after she revealed that she was curious what it would be like to have intercourse with another individual with a disability:

I've always kind of felt like there was something missing with my sexuality I thought maybe it's because, like I haven't been open to having sex with anybody with the disability...anybody that will understand my body and like I was -- I haven't been 100% comfortable, so like I've always kind of wondered what would that would be like. And we ended up getting talking one night and I told him that."

This open and honest communication was new to Jane, as she feared being open with partners in the past would result in being abandoned. Jane's partner responded very positively to this vulnerability, reciprocating with stories of his own struggles with depression and loneliness. This method of open communication has been key to the success of Jane's current relationship, as she feels safe to communicate her needs and desires, and no longer fears being viewed as a burden.

Jane describes her current relationship as the "most sexually satisfying" relationship she has ever been in, and believes that this is due to having a shared experience of living with a disability, and a willingness to communicate with each other. Jane no longer "suffers in silence" in her relationship because she feels comfortable notifying her partner if she is uncomfortable or in pain because she is not made to feel that her physical limitations are a burden. This has allowed Jane to feel like an equal participant in her relationship who is deserving of her own sexual satisfaction, instead of just "faking it" and engaging in dissatisfying sexual interactions.

Jane identified an openness about physical limitations and bodily differences as one of the most important forms of communication in her relationship:

[We talk about] what is pleasurable for me or pleasurable for him, like what we want to experiment with, like positioning, like how I'm feeling today like, if I'm tired I'll be like "no I'm tired" and then we'll talk about it. And um, yeah. We do a lot of that

This open communication allowed Jane and her partner to feel comfortable seeking out support and education from a local rehabilitation centers' sexual health

program. Jane described this experience as transformative in that it helped to normalize her experience of being a woman with a disability who was also a sexual being:

We went to see the sexual health nurse at [local rehabilitation centre]...because we really wanted to experience [me] being on top and how to have control and -- but we can't figure out a way to make it work and then we realized that we're not the only people that have this problem.

Becoming connected with professionals who saw disability also marked the first time that Jane felt visible by medical professionals, being asked to openly discuss her concerns with a nurse that was knowledgeable about the realities of being a sexual being and a woman living with cerebral palsy. The sexual health support available to Jane provided her and her partner with educational resources, sexual advice and “tips”, a sense of normalcy, and some practical tools and strategies that would allow them to experiment with different sexual positions through the use of “pillows and props.” Jane acknowledged that although the information and support provided was valuable, the physical work required in order to facilitate certain sexual positions was “too much trouble” and at times “exhausting” work which “took a lot of patience.”

This experience also facilitated a connection to health professionals specializing in women's health who were willing and capable of addressing Jane's unique needs:

I was trying to get a pap test done, at a walk-in clinic and I remember thinking there has to be something out there [for me], so I, I think I googled a little bit or I called somebody asking for like a referral or something and this lady passed me onto them. When I went to [the woman's hospital], there was this lady who um, I think she had disability too but she was like really like she took her time and like, she like expected me to seize up and she's like, 'Oh it's okay' And like 'I've dealt with this before' And even before she examined me, she sat me down and talked to me about everything and very procedure, she sat me down and talked to me.

The Present

At the time of the interviews, Jane described herself as knowledgeable, open, sexual, bisexual, curious, and in control. Whereas she used to feel like “the only disabled girl” who was left to wonder if sex and intimacy were “ever going to happen” for her, she now finds herself in a place where she is sexually satisfied and able to speak openly about her needs and desires, feels a sense of belonging and acceptance within the disability community, and feels hopeful about her future as a sexual being.

Advice from Jane for those who read her narrative

Participating in this research was a deeply personal, emotional, and at times challenging process for Jane. When asked what she hoped others would gain from her openness she shared:

I want people to take away [from this narrative] that disabled people are sexual beings and overall just human. We all want to be wanted and appreciated and loved. I experience many things similar to that of an able bodied person. I do not want people to feel sorry for me or inspired when reading this. I hate that. I am not an inspiration. My journey doesn't make me an inspiration. I am just me. I just live my life with the hand I was dealt, so to speak. I just want people to walk away with an open mind and perhaps a different perspective.

Chapter 5.

Discussion

“Oppressed people resist by identifying themselves as subjects, by defining their reality, shaping their new identity, naming their history, telling their story.” (bell hooks, 1981, p.43).

This research seeks to develop an understanding of the lived experience of physical disability and sexuality. Using a retrospective narrative, this project is a case study of Jane, a young woman born with cerebral palsy and her experiences navigating an ableist sexual world where disability is made invisible. The discussion consists of two parts: In the first section, the major themes will be examined together with the literature. In the second part the strengths, limitations, and implications for research and counselling will be discussed.

Significant Findings

There is a long journey of discovery that many women with physical disabilities go through to acknowledge their value and their womanhood (Nosek, Howand, Rintala, Young & Chanpong, 2001). Analysis of Jane’s narrative revealed three key processes through which she came to understand and acknowledge her value and womanhood: the sexual identity formation process, the relationship formation process, and the process of finding a community and sense of belonging. The theme of erasure and its consequence silencing, were present within all three of these processes. Erasure in this context is considered a social phenomenon by which one is excluded, ignored, or blocked from a realm of human existence that is regularly afforded to others. For Jane, this erasure resulted in silencing, or an inability to address or explore the realm of human sexuality in a safe and open manner. This chapter will discuss how the theme of erasure showed up in Jane’s narratives, how she navigated these processes, and how she resisted the silencing, eventually coming to find her voice.

Erasure

Erasure within the Media

Understanding and appreciating one's own sexuality is a complicated and arduous process for many youth. This is especially true for individuals who may not see their sexuality represented in societal norms and the media. This was true for Jane as both a disabled and bisexual woman. As individuals attend to and interpret sexual content in the media, they also evaluate and may or may not incorporate what they see into their own developing sexual identity (Brown, 2002). The media Jane was exposed to included stereotypical heteronormative portrayals of same sex desire. For example, she saw mainstream portrayals of lesbian sexuality was represented as a source for straight men's arousal, which contributed to her realization that she lived in a "heterosexual world." This reality led to a sense of confusion around whether same sex attraction was "normal" or something that should be shamefully kept a secret. Individuals with disability were also excluded from these depictions of sexuality. Individuals with disability are largely ignored in mainstream media. A study of diversity in television conducted by GLAAD found that only one percent of regular characters on American broadcast TV had one or more disabilities, compared to 12 per cent of the U.S. and Canadian populations (GLAAD, 2017). The underrepresentation and invisibility of individuals with physical disabilities in all forms of media further contributes to marginalization.

As a young girl navigating her sexual identity, Jane spoke about the impact of the media on this process. Representations of women's sexual behaviour in television and film provided Jane with messages and images that formed the basis for her understanding of same sex desire and sexual practices. These media representations precipitated Jane's first sexual experience and provided her with a script of how women engage in sexual behaviour together. The impact of media on early sexual exploration and expression is well supported in the literature on adolescent sexual development (Gruber & Grube, 2000; Brown, Steele & Walsh-Childers, 2001; Bond, 2014; Ragsdale, Bersamin, Schwartz, Zamboanga, Kerrick, & Grube, 2014). Adolescence is a critical time in an individual's life when the process of developing an identity is most salient. As adolescents come to understand who they are, they begin to incorporate notions of their sexuality into their identity (Bond, Hefner and Drogos, 2009).

The Media Practice Model (Steele and Brown, 1995) posits that adolescents build on and transform the shared social and cultural understandings available through the media as a way to make sense of their identities. This is accomplished by selecting media, evaluating the significance of the mediated messages through their own lived experience, and applying those meanings to their everyday lives (Bond, Hefner and Drogos, 2009). Early adolescent girls (age 11-15 years old) attend more to media sexual portrayals when they are seeking information about relationship norms, strategies for establishing relationships, and tips on how to be sexually attractive (Brown, 2002). This use of media as a source of sex education was reflected in Jane's narrative. The sexual scenes portrayed in film and television dramatically shaped Jane's sexual expression from an early age. As a young adolescent, scenes in the film 'American Pie' provided Jane with her first exposure to same-sex sexual behaviour, peaking a curiosity about women that precipitated her first sexual experience with a member of the same sex.

The media's influence stretched far beyond simply providing Jane with examples of sexuality that peaked curiosity. Jane cited the media as the basis for her understanding of sexual preoccupation, or the importance of sex in a person's life. This includes her sexual self esteem, which is characterized by one's understanding of being a good or bad sexual partner. Further, her sexual satisfaction, which characterizes the level of satisfaction or dissatisfaction with one's own sexual life, was also framed by the media.

Media exposure has also been shown to be related to motivations to self-compare with mediated characters, which increase the social comparison process and, in turn, lowers body image perceptions (Eyal & Te'eni-Harari, 2013). There is clear evidence suggesting that the media's typical portrayal of women in advertisements for example, has a negative effect on the way women feel about themselves and their bodies (Grabe, Ward & Hyde, 2008; Groesz, Levine & Murnen, 2002; Perse & Lambe, 2016). It is well known that sexual identity and body image are very important to overall psychological wellbeing and life satisfaction for all human beings, but these aspects of the self are particularly important for women with physical disabilities. Recent research comparing sexual identity, body image and life satisfaction among women with and without disabilities has demonstrated that women with physical disabilities have the same sexual needs and desires as women without disability, but their body image, sexual self-esteem, sexual satisfaction and life satisfaction are significantly lower (Moin,

Duvdevany & Mazor, 2009). Furthermore, for women with disabilities, low body esteem is related to higher levels of depression and an increased risk of vulnerability to intimate partner violence (Hassouneh-Phillips & McNeff, 2005).

Erasure within Sexual Education

Erasure and silencing showed up once again during Jane's sexual identity formation process in the sex education that Jane received within her educational and family spheres. Sexual identity has been defined as an awareness of one's self as a sexual being and characterizes a person's collective or social identity (Moin, Duvdevany & Mazor, 2009). The term narrative identity refers to one's personal evolving story of the self that is created both consciously and unconsciously in order to link together different aspects of the self (McAdams, 2006). The creation of a coherent narrative identity is critical for various developmental outcomes (McLean & Jennings, 2012). As the development of a narrative identity is often situated within relational contexts, it becomes important for adolescents to develop strong relationships with peers (Hellenga, 2002; McLean & Jennings, 2012). Within the safety of peer friendships, adolescents are able to self-disclose personal information about sensitive topics that help them construct sexual identities and an understanding of sexual practices. It is within the context of these intimate friend conversations that much of the narrative identity develops (McLean & Jennings, 2012). Jane's experience of erasure amongst her peers developed as a result of her feeling like she was "the only disabled girl" and the perceived message that no one wanted to discuss sexuality with her. This erasure left Jane confused and without a voice when it came to exploring or expressing her sexuality in a healthy manner. The silencing that Jane faced meant that she was unable to make meaning of her experiences through the construction of life stories told to another person, a process which would have allowed her to understand how past events led to or influenced other events or aspects of her sexual self (Habermas & Bluck, 2000 as cited in McLean, 2005).

The erasure that Jane faced when it came to discussions of sexuality with her family and peers effectively blocked access to important sex education sources. Research on the sexual education of individuals with disabilities shows that the odds of not receiving sexual education or sexual counselling services among women with disabilities are two times greater than among their male counterparts (Tilley, 1996).

Negative assumptions surrounding the sexuality of women with disabilities have often found their way into the literature on sexuality and disability. For example, books and articles aimed at addressing sexual education for individuals with disabilities sometimes include statements about the disabled woman's passive role in sexual acts resulting in a lack of literature aimed at female directed education (Tilley, 1996). Research by Nosek et al., (2001) revealed that both women with and without disabilities learn about physical aspects of sex at about the same age, 13 years old. However, only 59% of the women with disabilities believed that they had received adequate information about how their disability affects their sexual functioning (Nosek et al., 2001). While most able bodied individuals receive sex education from parents, friends and other sources, disabled individuals are most likely to receive their sex education from "other" sources (McCabe, 1999). Individuals with disabilities are more likely to receive their sex education from the media or formal sex education classes only (McCabe, 1999). This lack of openness around discussions of sexuality means that they are less likely to be able to check the accuracy of the information they receive and are less likely to discuss with others their thoughts, feelings, experiences and needs in relation to sexuality (McCabe, 1999). The whole topic of sexuality is less likely to be normalized due to this silencing. This lack of discussion by family and friends around topics of sexuality may convey negative messages to people with disability about their own sexuality. Indeed, for Jane the silence when it came to discussions of sexuality amongst friends and family translated into a belief that no one expected her to be a sexual person, which in turn contributed to confusion in regards to her sexual competence. Many women with disabilities who receive information about sex believe that because of their disability, this information does not apply to them (Nosek et al., 2001).

Both sexual and body esteem in women with physical disabilities are important factors that affect self – esteem and mental health. Sexual esteem refers to one's sense of self as a sexual being, which ranges from being sexually appealing to unappealing and sexually competent to incompetent (Moin, Duvdevany, & Mazor 2009). Research on sexual esteem and disability has found that high degrees of physical impairment is often associated with lower sexual and body esteem in women with physical disabilities (Taelporos, Dip, & McCabe, 2002). While Jane did not discuss sexual and body esteem specifically, her experience of erasure from the media and within the sexual education she received effectively erased her from the realm of sexuality. This experience left her

wondering whether her body was even capable of having sexual intercourse at a young age. This confusion, combined with the erasure and silencing that came from having no one to discuss this with, undoubtedly impacted her sexual esteem and lowered her view of self as sexually competent. While everyone around Jane was exploring dating and intimate relationships, Jane felt this was never going to happen for her. This feeling is likely shared amongst many women with physical disabilities, reflected in their increased difficulty forming and maintaining intimate partner relationships than non-disabled women (Gill, 1996).

Erasure within Intimate Relationships

The adolescent period is an essential time for human sexual development, physical changes, onset of masturbation, dating, beginning intimate relationships and sexual experiences all occur during this developmental time period (Wiegerink, Roebroek, Bender, Stam & Cohen-Kettenis, 2011). Jane experienced silencing and erasure during the formation of her early intimate relationships. She also experienced significant sexual dissatisfaction and described instances of being controlled in her relationships which are consistent with patterns of emotional abuse. Jane described her early intimate relationships as sexually dissatisfying and lacking in reciprocal pleasure. Jane felt unable to discuss her dissatisfaction with her partner out of fear that he would label her as a burden to his own sexual satisfaction. Furthermore, Jane described not knowing what sex was supposed to *feel* like. The lack of discussions around sexuality in all realms of her life left her unable to discern whether her experiences were unusual or not.

Lack of confidence and uncertainty often play a role in the early sexual experiences of young people without physical disabilities. However many young people with cerebral palsy have additional hurdles to overcome including developing positive relationships with their bodies, learning to negotiate their own physical limitations and needs during intimacy, and being able and willing to discuss all of this with a partner (Wiegerink et al., 2011).

The erasure that Jane experienced in her early intimate relationships meant that she was unable to negotiate these hurdles, and instead remained silent out of fear of losing her partner. This silence led to an increase in sexual dissatisfaction as Jane was

unable to communicate her needs to her partner. Research by Taleporos, Dip & McCabe (2002) has shown that sexual esteem, body esteem and sexual satisfaction are strong predictors of self-esteem for women with physical disabilities. Women with disabilities who report being sexually satisfied and feeling good about their sexuality and their body, are more likely to have high levels of self-esteem. Feeling good about their bodies and being sexually satisfied also results in lower levels of depression (Taleporos, Dip & McCabe, 2002).

Low sexual esteem combined with a strong desire to have an intimate partner has been shown to increase women's vulnerability to getting into and staying in abusive relationships (Hassouneh-Phillips & McNeff, 2005). Women with physical disabilities who have poor body and sexual esteem also report lowered expectations and standards with regard to selection of intimate partners and an increased willingness to tolerate a certain level of abuse rather than be alone (Hassouneh-Phillips & McNeff, 2005). Jane's experience of being required to dress provocatively and to remove her body hair by a former partner is an example of emotional abuse, characterized by the power and control Jane's partner had over her bodily autonomy. Despite Jane's preference to dress modestly and to keep her pubic hair, Jane felt that she did not have a voice in this relationship, and conformed to her partner's expectations that she remove her body hair and dress provocatively.

This *silenced* woman stood in stark contrast to the outspoken and confident woman that I interviewed. When asked about this difference, Jane believed that she did not speak up out of a fear of being alone, stating that she "wanted to be wanted". Indeed, for some women with disabilities, there is an increased tolerance of abuse in intimate partner relationships which stems from fear that no one else will want or care for them (Hassouneh-Phillips & McNeff, 2005). It is also possible that Jane's lack of education about intimate partner relationships had a role in her silencing, as healthy relationships and bodily autonomy were never discussed with her while growing up as a result of her erasure from the realm of sexuality.

Erasure within the Medical Community

Sexual health is recognized as being a particularly difficult topic for doctors to discuss with patients for reasons including discomfort, feeling inadequately trained, and

fear of “opening the flood gates” (Humphrey & Nazareth, 2001 as cited in Hinchliff, Gott & Galena, 2004). For individuals with physical disabilities, there are even more barriers to accessing sexual health information. Information on birth control methods and their consequences are often withheld from women with disabilities, particularly those who have been institutionalized. It has often been thought that because women with disabilities are not sexually active, they do not require the internal examinations that are routine in the lives of able bodied women (Tilley, 1996). Jane sought out cervical cancer screenings, but found that the physician she went to was unable to conduct a routine pap smear due to spasming of her vaginal muscles. The fact that the physician did not know how to conduct a pap smear on a woman with cerebral palsy, once again left Jane feeling erased as “the only disabled girl,” and resulted in her leaving the physician’s office without receiving a common and necessary routine examination for all women.

Inadequate training and education about disability represents only one of many barriers to receiving adequate health services for women with physical disabilities. Social barriers also make access to adequate healthcare difficult for women with disabilities, such as the attitudes and behaviours of healthcare professionals who may not recommend or offer internal examinations or cancer screenings for women with disabilities (Yankaskas et al. 2010).

Stereotyping and myths pertaining to women with disabilities by health care professionals may also lead them to view women with disabilities as genderless or asexual and therefore not in need of routine screenings (Armour et al. 2009). Physicians’ feelings of discomfort have been found to be associated with a reluctance to provide or offer cancer screenings to women with disabilities (Verger et al. 2005). Buckley et al. (2012) found that clinicians believed that patients with severe and moderate disabilities may have limitations that might preclude or impede cancer screening. As a result of these barriers, women with disabilities are less likely to have routine breast cancer screenings than women without disabilities, despite having the same or increased risk of having breast cancer (Peters & Cotton, 2014). For Jane, these social barriers had such a negative impact that it would be many years before she would request another pelvic exam, putting her at an increased risk of having undetected pre-cancerous or cancerous processes in her cervix. Women with disabilities are less likely to receive pelvic exams within the recommended guidelines (once every two years) (67%) compared to women without disabilities (73%) (Nosek et al., 2001).

There are also numerous physical barriers to health care including lack of access to adequate parking, transport, buildings, rooms, assistance, and equipment (Peters & Cotton, 2014). Jane's experience of being denied access to health care is not unique. A national study conducted at the Center for Research on Women with Disabilities revealed that thirty-one percent of the women with physical disabilities who participated in the research were refused care by a physician because of their disability (Nosek, et al., 2001).

Resistance

Resistance through “Coming Home”

One of the first ways in which Jane sought to resist the erasure she experienced as “the only disabled girl,” was to move to a larger urban community. It was within this community that Jane began to develop her identity as a disabled woman. Identities help individuals to make sense of different or distinct aspects of the self (Oyserman, Elmore & Smith, 2012). For individuals with disabilities, having a disability identity allows for guidance towards what to do, what to value, and how to act in different circumstances where disability is a salient quality (Dunn & Burcaw, 2013). Olkin (1999 as cited in Dunn & Burcaw, 2013) defines three distinct disability identity groups: (1) those who “pass” as non-disabled; (2) those whose disability is linked to their overall self-concept; (3) and, those who identify as disability rights activists and characterize disability as a social construct and a civil rights issue. For Jane, being “the only disabled girl” meant that she fell into the second group. Disability was linked to her overall self-concept – but its valence was negative. During this time Jane described wanting to be able bodied, preferring to surround herself with individuals who were able bodied in an attempt to be more able bodied herself. It was not until Jane changed communities and identified herself as a member of a larger disability community that Jane came to develop a disability identity that she was comfortable with. Gill (1997) refers to the identity development that occurs as a result of integration with the disability community as “coming home” and describes it as being characterized by a level of connection that is unique to relationships within the disability community. This integration allows individuals to develop a sense of disability community, culture, or family and often occurs when one seeks out disability related services or information (Gill, 1997). Jane found a sense of

home, family, and connection through the disability community that she became a member of when seeking out an adaptive yoga class. It was through the individuals that Jane encountered in her class that she came to develop healthy and satisfying friendships and an intimate relationship. It was also within this disability community that Jane came to develop a sense of disability pride that she would come to proudly express through her clothing.

Resistance within Intimate Relationships

Jane resisted the silencing and erasure she faced within her romantic relationships with able bodied individuals through the development of a romantic relationship with a peer who also has cerebral palsy. Although initially hesitant to date another person with cerebral palsy due to the stigma associated with dating someone with a disability and the loss of practical support she received from her able bodied partners, Jane described this relationship as the healthiest relationship she had ever experienced. Within this relationship, Jane no longer felt like her body was a burden. This allowed her to develop a voice and a sense of sexual agency. The World Health Organization (2011) defines sexual agency as a basic sexual right which includes the right to have one's bodily integrity respected and the right to choose – to choose whether or not to be sexually active, to choose one's sexual partners, to choose to enter into consensual sexual relationships, and to choose whether or not, and when, to have children. Others have argued that sexual agency includes the right to be able to seek knowledge and assert sexual desires (Froyum, 2010). The fear that Jane experienced around being abandoned by her able bodied partners due to the perceived burden her disability placed on their relationships acted as a tool of silencing that prevented Jane from speaking up about, or asserting, her sexual desires. When she believed her body was no longer viewed as a burden, Jane was able to speak about her body's limitations as well as her needs and desires in a way that allowed for open and safe sexual communication with her partner. Jane could not recall why sexual communication came so openly and easily in this relationship, just that it had been that way from the beginning. Although not identified as such by Jane, research would suggest that the level of sexual communication exhibited by Jane and her partner in their relationship is important to her level of sexual satisfaction and sexual wellbeing (MacNeil & Byers, 2009).

When Jane was silenced in her previous relationships, she experienced significant sexual dissatisfaction. Was the satisfaction she now experienced a result of her open sexual communication? Or was her willingness to engage in open sexual communication a result of finally feeling sexually satisfied? Byers (2011) suggests that individuals who self-disclose more about their sexual preferences to their partner report greater sexual wellbeing and satisfaction. It is through this instrumental pathway between sexual self-disclosure and sexual satisfaction that individuals are able to negotiate mutually pleasurable sexual scripts with their partners. An increase in sexual self-disclosure leads to a greater partner understanding of our sexual preferences. This in turn leads to engaging in a sexual script that includes more pleasurable and fewer dissatisfying sexual activities and, a more pleasurable sexual script results in an increase in sexual satisfaction (Byers, 2011).

Implications for Counsellor Education and Training

For individuals with physical disability, problems with depression and self-esteem are closely linked to concerns around feeling positive about their bodies, their sexual selves, and their sexual lives (Taleporos and McCabe, 2002). As such, researchers and clinicians who are concerned with the psychological health of individuals with physical disability should give due attention to issues pertaining to sexuality. Not only do counselors need to be adequately trained about the physiological and emotional aspects of sexuality, they also require training on how to communicate about sexuality and how to teach these communication skills to their clients (Bridges, Lease & Ellison, 2004). Jane's story also suggests that counsellors should raise questions about power in relationships and willingness to communicate. Counsellors and other helping professionals have an important role to play in supporting women with disabilities' efforts to express their sexuality. A lack of attention to and knowledge about the sexuality of women with disabilities, coupled with the reluctance to acknowledge sexual desire represents a major barrier when it comes to creating safe spaces that allow for open discussions with these women (Drummond & Brotman, 2014).

Counsellors and other helping professionals who work with the parents of young people with disabilities are in a unique position to be able to provide support that will help parents develop the skills necessary for quality interpersonal conversations about sexual issues important to youth sexual development (Byers, 2011).

Counsellors working with young people with physical disabilities need to be aware that the marginalization experienced by these youth is not tied most closely to their identity as young people, but due to the social stigma experienced as a result of having a physical disability. Not only do young people with disabilities never see themselves reflected in media representations of dating and sexuality, but they are often never asked about sex or their ideas related to dating, intimacy, or their bodies (East & Orchard, 2013). Counsellors can play an important role in the lives of the youth they work with, through the acknowledgement of such erasure and an opportunity for resistance through open, non-judgemental conversations about sexuality. Furthermore, counselling graduate programs would benefit from providing education that will allow and encourage counsellors to be proactive in asking about sexual issues and have the skills to provide effective interventions (Byers, 2011).

Implications for Future Research

Much of the limited research conducted on sexuality and identity development amongst youth with disabilities is dated, quantitative in design, and focused on the experiences of youth with cognitive disabilities (East & Orchard, 2013). Much of the existing research on the sexuality of women with disabilities is focused on sexual self-esteem and social attitudes on sexuality, not how women negotiate sex/engage sexually (Kattari, 2015). Research on sexual communication amongst couples with cerebral palsy is non-existent, a review of the literature shows that sexual communication research has focused primarily on acquired illness and disability that has resulted in a sudden loss or decrease in sexual functioning (Foley, LaRocca, Sanders & Zemon, 2001; Ussher, Perz, Gilbert, Wong, Mason, Hobbs, & Kirsten, 2013). Future research on sexual communication would benefit from the inclusion of individuals living with congenital disorders such as cerebral palsy, and an awareness that issues pertaining to sexuality for individuals with physical disabilities are not solely focused on sexual functioning, but also on confidence and the ability to pursue intimate relationships and think of oneself as a desirable sexual being (Talepros & McCabe, 2002). As Shakespeare (2000) argues, one of the most challenging aspects of sexuality for many people living with physical disabilities is not *how* to do it, but *who* to do it with.

Strengths

One of the strengths of this research was that it allowed for the acknowledgment of Jane as a sexual being. Much of the existing research on women with disabilities is focused on social attitudes on sexuality, not on the sexual agency of women with disabilities or how they negotiate sex/engage sexually (Kattari, 2015).

Another strength that arose as a result of using a narrative research methodology was that it gave voice to Jane's experience of disability and sexuality. When asked what it was like to engage in the process, Jane stated:

Doing something like this that is so personal you are always apprehensive at first. Able-bodied people have been writing about and speaking for disabled people for many years and it's usually done in such a way as to fit able bodied ideals or expectations or to create an element of inspiration. As long as my narrative is truthful and completely my story then I am happy.

Narrative inquiry is an established research method for inquiry into subjectivity and identity formation. Focusing on how individuals make sense of their experiences and communicate those experiences to others, the stories told are treated as primary sources of data (McLeod, 2011). Treating Jane's narrative as the primary source of data allowed her to contribute to determining the most salient themes in her story (Elliot, 2005).

Finally, I believe my identity as a scientist practitioner in the field of counselling psychology was a strength in that I was able offer empathy and a collaborative dialogue during the interview process. In preparing for these interviews my primary intention was to provide a safe and welcoming environment that would allow Jane to feel comfortable examining and sharing these aspects of her life. When asked how it felt to share her story with me, Jane described being "made to feel comfortable and accepted."

Limitations

Due to difficulty recruiting women willing to openly discuss their sexuality with me, this study is limited by the small sample size. As a result of this difficulty, this study exclusively examines the experience of one woman interviewed for this specific project. Although the case study approach allows for a rich and deeply contextualized account, it

also presents many limitations. Reporting the narrative account of only one woman means that while this narrative can be used to sensitize others to the experiences of women with disabilities, caution should be taken when applying as no one story can stand in for the experiences of a heterogeneous group.

Given that the theme of sexual communication was a key process that emerged within Jane's narrative, and given that most sexual activity occurs in pairs, only interviewing one of the individuals within Jane's relationship also acted as a limitation to understanding the processes involved in sexual communication. Future research on sexual communication in couples where both partners have a disability would benefit from the use of a method that incorporates both individuals within the relationship, such as the Action Project Method (Young, Valach & Domene, 2005).

This research was also limited by the race, class, and sexual orientation of my participant as it is likely that her experience will differ greatly from other women with disabilities who have different locations within society.

My own social position was also a limitation, given that my privilege as an able bodied, Caucasian woman undoubtedly influenced the way in which Jane's story was presented. During the process of writing this thesis I struggled greatly with my own position as an able bodied woman, coupled with the fear that I would "other" Jane, or that I was using her experience for my own academic benefit. The emphasis within narrative research methodologies on creating non exploitative and collaborative relationships helped me to balance this limitation (Riessman, 2008). I engaged in the process of reflexivity throughout the course of this research in an effort to better understand my own social position. I explored my own personal and political background and made efforts to reduce the impact my background may have on the way in which I attended to Jane's narrative. I did this by allowing her to lead and by following the advice of my supervisor, Dr. Sharalyn Jordan to "hold on to my hunches." Through better understanding of my own social position and the ways in which it impacted my relationship with Jane, my interpretation of her story, and the way in which I presented her narrative, I was able to hold awareness of the power imbalance that exists between researcher and participant. It is important to note that these attempts are not enough to *resolve* the problem of power relations within the research relationship.

Conclusion

This study sought to explore the ways in which the intersections of disability, gender and sexuality are experienced and understood by a woman living with cerebral palsy. Societal attitudes and perceptions are driven by education and knowledge, with the current lack of exposure to the issue of sexuality and disability, it is not surprising that society has a relatively narrow understanding of sexuality (Esmail, Darry, Walter & Knupp, 2010). In order to meet the needs of their clients and provide the best care possible, Counselors need to be aware of their underlying beliefs surrounding disability and sexuality (Drummond & Brotman, 2014). It is my hope that this thesis will bring new knowledge to an under researched area of study where there remains much uncertainty and misguided beliefs.

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Appendix A.

Recruitment Poster



ARE YOU A WOMAN AGED 18-35 LIVING WITH CEREBRAL PALSY?

Researchers at Simon Fraser University are interested in exploring your understanding of and experiences with sexuality.

This information will help counsellors to better understand the intersectional nature of identity and the impact of occupying multiple marginalized positions on counselling client's experiences in the world.

If you are a woman who is living with cerebral palsy, between the ages of 18-35, who is open to discussing her sexuality, we are inviting you to share your experiences in a confidential interview with a researcher. The initial interview will take approximately 2 hours and will require a follow up interview that will take place a few weeks later.

For further information or to book an interview please contact (778) [REDACTED]

Ethics Application: 2016s0059

Version March 20th,2016

Appendix B.

Phone Screening Interview

Research question: How do women with cerebral palsy narrate their lived experience of disability and sexuality?

I. Study Information

Before I ask you any questions, I want to give you a good sense of the study. The purpose of this study is to get a clearer understanding of the ways in which women living with cerebral palsy speak about their experiences of sexuality. If you are eligible for this study, I will be asking you to meet with me for a period of approximately two hours in order to have a discussion about what your experience with sexuality has been. The questions asked will explore your experiences including your sexual expression which includes discussions of your fantasies, desires, actions and feelings; the way in which you describe your identity as a sexual being, and the ways in which you feel your sexuality is perceived and responded to by others. Two to Three months after the initial interview you will be contacted for a follow up interview during which time you will read the transcript of the first interview and have the opportunity to ask any questions or request any changes.

At any time, you can change your mind and are free to withdraw from the study without any consequences. Do you have any questions or concerns so far?

II. Screening Questions

- *This study is looking in particular at the experiences of women aged eighteen to thirty five living with cerebral palsy. How old are you?*
 - If between the ages of 18-35, move on to next question.
 - If age falls outside of range, let the potential participant know the study is not a good fit for them and thank them for their interest.
- *Do you identify as a woman living with cerebral palsy?*
 - If yes, move on to next question.
 - If no, let the potential participant know the study is not a good fit for them and thank them for their interest.

- *In order to engage in a meaningful analysis of the experiences of women with cerebral palsy, it is sometimes necessary to limit the number of dimensions of diversity. This study is looking in particular at the experiences of women who identify as heterosexual. What is your sexual orientation?*
 - If heterosexual, move on to next question.
 - If sexual orientation is anything other than heterosexual let the potential participant know the study is not a good fit for them and thank them for their interest.
- *This study is looking in particular at women living with cerebral palsy's experiences with sexuality. Are you comfortable discussing topics of a sexual nature? All discussions will take place in a location that ensures privacy.*
 - If yes, let the potential participant know they are eligible to participate and move on to scheduling the first interview.
 - If no, let the potential participant know the study is not a good fit for them and thank them for their interest

III. Scheduling Interview

If you are interested in participating in the study, we can book a time for us to meet and discuss your experiences. When would be a good time for you?

Version April 12, 2016

Appendix C.

Consent Form



Education Building
8888 University Drive, Burnaby, BC
Canada V5A 1S6

TEL 778.782.3676
FAX 778.782.4203

[...][@sfu.ca](mailto:)
www.sfu.ca/education

Study Information and Consent to Participate

Study title: At the Intersection of Identity and the Body: Women's Experiences with Disability and Sexuality

Who is conducting this study?

Alexandria Parsons, Principal Investigator, [...][@sfu.ca](mailto:), [Phone number]

Sharalyn Jordan, Ph.D, Faculty Supervisor, [...][@sfu.ca](mailto:), [Phone number]

This study is being conducted through Simon Fraser University (SFU). SFU and the investigators of this study follow the strictest ethical guidelines in order to ensure the safety and comfort of all the participants in this study. This document is intended to clearly identify the nature of this study, including any possible risks and benefits, as well as the procedures involved. Your participation is completely voluntary, and can be withdrawn at any point during the study without consequences.

Why are we doing this study?

You are being invited to participate in this study because we want to know more about women living with cerebral palsy's experience with sexuality. More specifically, we want to know how your experiences and understanding of sexuality have evolved over time, as well as any key moments that have occurred throughout your life that influenced the way you view yourself as a sexual being. This information will help counsellors to better the intersectional nature of identity, and the impact of occupying multiple marginalized positions on counselling client's experiences in the world.

Voluntary participation

Your participation in this study is entirely voluntary and can be withdrawn at any point during the study without any consequence. You will not be compensated for your participation in this study. You have the right to say no to participation in this study. If you choose to participate, and change your mind later on for any reason, you can withdraw your participation at any point without any negative consequences. You do not have to give a reason for choosing not to participate, or to withdraw your participation. If you do choose to withdraw your data will be destroyed. It will not be used in the results of this study or for any other purposes.

What will you be asked to do?

If you choose to participate in this study, you will be asked to participate in an interview with the principal investigator that will explore your experience with sexuality as a woman living with cerebral palsy. This interview will take approximately two hours of your time. The questions asked in this interview will attempt to better understand the ways in which your experiences and understanding of sexuality have changed over time, as well as any key moments in your life that have impacted the way you view yourself as a sexual being. The principal investigator will ask further questions to make sure that your answers are well understood. You can refuse to answer any of the questions asked, and do not have to provide a reason for doing so. The interviews will also be video recorded in order to be transcribed and to observe body language, movement, facial expressions, and other contextual cues that cannot be observed with audio recordings only. All video recording will be conducted using Simon Fraser University's Faculty of Education's wireless disabled, password protected iPad's to ensure full confidentiality.

Within three months after the initial interview is completed, you will be contacted by email to schedule a follow up interview. During the follow up interview you will be asked to watch a videotape of the first interview and asked follow up questions by the researcher. Once all interviews are complete, you will be provided with a copy of the narrative that was developed from your interviews and will be asked to read it in the presence of the principal investigator. Follow up questions that arose for the principal investigator during the transcription process may be asked of you at the time. You will

also be given time to ask any questions or to provide any comments about what this experience has been like for you.

It is possible that you will be contacted through email during the transcription process to provide any clarification. Email is not a confidential medium. In order to protect your privacy as much as possible, any documents sent to you through email will be given a password that you will need to provide in order to open and read the documents. If you decide to participate in this study, we will come up with a password together for these documents.

What are the risks and benefits of participating?

There are low emotional risks involved in discussing the topic of sexuality. Some participants may experience negative emotions in discussing their experiences, either during the interview or after it. If you do not want to answer any question, you do not have to, and do not have to provide a reason why. If you get upset at any time, please speak to the interviewer, who can provide you with community resources for more ongoing support. The interview may be terminated at this time.

There are benefits to participating in this study as well. Some people find that it is helpful to talk about their experiences. Also, the information found in this research could provide a potentially useful new perspective regarding programs aimed at supporting women with disabilities, and may be useful in informing future practice for counsellors and other helping professionals.

Confidentiality

All information obtained during this study will be kept strictly confidential. The information you provide will be anonymized by way of a pseudonym of your choosing, and any documents containing your real name or any identifying information will be kept separately. The documents, including transcripts of your interviews, will be kept in a locked cabinet in a locked research office at the SFU Surrey Campus. Typed transcripts will be kept on a password-protected computer that is not connected to the internet.

All video recording will be conducted using SFU's Faculty of Education's wireless disabled, password protected iPads. The only people who will have access to the video recordings are the principal investigator and co-investigator. Audio will be extracted from

the video recordings and will be downloaded onto a password protected USB stick. Audio and video recordings will be kept in a locked cabinet in a locked research office at the SFU Surrey Campus. All audio and video recordings will be destroyed after transcription has taken place, however, the transcriptions will be kept and may be used for secondary analysis for future related research. A graduate level coder will also have access to the written transcripts, as they will perform a member check on these interviews. This person is bound confidentially and will have signed a confidentiality agreement to ensure that your information is kept confidential. All information gathered from participants who have withdrawn from the study will be destroyed immediately; however final transcripts will be kept indefinitely for the purposes of analysis in future related research.

The only instances in which confidentiality would have to be broken would be those required by law in Canada. This includes disclosure of intent to harm yourself or someone else, as well as possible child abuse.

Study results

The results of this study are being used for a Master of Arts thesis project, and may be published in an academic journal, or other non-academic blogs, magazines, and websites. The results may also be presented at a research conference in the future. No identifying information of participants will be included in any of these endeavors, unless the participant requests to be identified.

Who do I contact if I have complaints?

Should you have any concerns or complaints about participating in this study, please contact:

Dr. Jeffery Towards
Director, Office of Research Ethics
Simon Fraser University
Email: [...]@sfu.ca
[Phone number]

Consent

Participation in this study is completely up to you. If you do decide to take part, you can change your mind and withdraw at any time without any negative consequences. If you decide to withdraw, your data will still be kept for seven (7) years

and then destroyed, but will not be used in the results of this study or for any other purposes. If you choose to participate in this study, your transcription will be kept indefinitely and may be used in secondary analysis for future related research.

Name: _____

PRINT NAME

Date: _____

YYYY/MM/DD

Signature: _____

I agree to being contacted via email after the interview to review the information extracted from my interview. Yes No

Would you like to be contacted with the results of this study? Yes No

Version January 14, 2017

Appendix D.

Interview Protocol

Interview Protocol

Research question: How do women with cerebral palsy narrate their lived experience of disability and sexuality?

I. Study information and consent script:

As we have already discussed, the purpose of this study is to better understand women living with cerebral palsy's understanding of and experiences with sexuality. I will be asking you some questions in order to get a better sense of your experiences and the way you view yourself as a sexual being.

Sometimes when people talk about their experiences with sexuality, they can become upset or emotional. If at any point you find yourself getting uncomfortable, please let me know and we can pause the interview and have a conversation regarding what would help to ease your discomfort.

Instructions: Review consent form with participant and answer any questions. Have participant sign consent form and pick pseudonym before beginning to video record with the iPad. When recording has begun, state the date and participant pseudonym before continuing.

II. Interview Questions (Drummond, 2010)

The format of this interview is semi-structured, and uses an interview guide approach. The interview will focus on the broad question areas below, while at the same time remaining conversational and free to probe into unanticipated circumstances and responses. Keywords in brackets indicate possible issues to explore within the broad question areas.

Identity

Can you tell me the story of how you've come to understand yourself as a sexual being? (gender, sexuality, disability, changes, transformations and representations)

Expression

How do you express your sexual self? When have you felt best in your sexuality? What do you think has helped you to feel your best?
(context and location, body, desire, fantasy, actions, feelings)

Interaction

How have other's responded to your sexual self?
(lovers, sexual partners, friends, family, colleagues, disability community, health and social service professionals).

Version April 12, 2016

Appendix E.

Interview Debrief

Debrief

- What was it like to share your experience with me today?
- Is there anything you need to feel ready to continue on with your day?

Version April 12, 2016

Appendix F.

Resource List

- 1) **Qmunity**- Free Counselling Program- 604-684-5307
www.qmunity.ca/get-support/
Free counselling for members of the LGBTQ community
- 2) **Simon Fraser University Counselling Clinic**- 604-587-7320
<https://www.sfu.ca/education/centres-offices/sfu-surrey-counselling-centre.html>
Provides free counselling for adults, children, and youth. Counselling provided by students in the Master's program in Counselling Psychology.
- 3) **UBC Scarfe Counselling Clinic**- 604-827-1523
<http://www.ecps.educ.ubc.ca/cnps/scarfe-counselling-clinic>
Provides free counselling in Vancouver by counselling psychology graduate students.
- 4) **UBC New Westminster Counselling Centre**- 604-525-6651
<http://www.ecps.educ.ubc.ca/clinical-instructional-resources/new-westminster-ubc-counselling-centre>
Provides free counselling by counselling psychology graduate students.

Version April 12, 2016

Appendix G.

Member Checking Questionnaire: External Reviewers

Instructions:

Please read each narrative two times. The first reading is for you to gain an overall understanding or feel for what is being talked about, and to familiarize yourself with the story. As you read each story, please consider and briefly respond to the following questions:

1. Is this a coherent story? Does it flow? Do you get a sense of what the story is trying to get across? Do you get a sense of the person the story is about?
2. Is this a pragmatic story? Would it be useful for others to hear this story? Would it be useful to present this information at workshops and conferences to help people understand women living with cerebral palsy's experiences with sexuality and disability? Would parents, educators, counsellors, social workers, health professionals and others benefit from hearing these stories?

Version June 7, 2017

Appendix H.

Member Checking Questionnaire: Participant

As you read please think about the following:

Does this narrative fit with your experience?

Is anything missing?

Did I get anything wrong? (timeline/locations/people involved)

Is there anything you would like to add?

How does it feel to read your narrative?

What would you like readers to take away from this narrative?

Version June 7, 2017