Intersecting and embodied identities:

A queer woman's experiences of disability and sexuality

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ABSTRACT/RESUMÉ

This study explores the ways in which the intersections of sexuality and identity are experienced and understood by a queer woman living with a disability. Through a narrative account of critical moments and turning points in the participant's lived experience of disability, sexuality and gender, this study examines the ways in which intersecting identities both shape and are shaped by context and experiences of the body as both complex and fluid. The participant's narrative provides a rich account of her experiences embodying multiple marginalized and intersecting social locations. The points at which her queer and disability identities intersect and diverge illuminate findings important to gaining a deeper understanding of the ways in which sexuality, queer identity and disability interact to produce particularized experiences of health, agency and resistance in daily life. The participant articulated how pain, visibility/invisibility, and the changing body contributed to her understanding of her own identity as queer and disabled. Agency and resistance were important lived concepts for her, particularly with respect to interactions with health care providers and systems and among communities in which she both located support and challenged hegemonic practices of gender presentation and discrimination. She described how support, knowledge and faith in her body, control and experimentation helped her maintain strength. This research provides insight into areas for future study, as well as recommendations for social work practice and social policy.

ABSTRACT/RESUMÉ

La présente étude se penche sur la façon dont la sexualité et l'identité s'entrecroisent et sont intimement vécues et comprises par une lesbienne présentant un handicap physique. À travers un compte rendu des moments clés et des tournants du vécu de la participante, cette étude examine de quelle façon le croisement des identités détermine et est déterminé par le contexte, l'expérience et l'intériorisation des concepts d'infirmité, de sexualité et d'identité à travers un corps à la fois malléable et récalcitrant. Le récit de la participante fournit une riche description de ses expériences en tant que marginale ayant été amenée à endosser de multiples identités et à incarner différents rôles en société. À la croisée des chemins de ses identités gay et handicapée -qui se recoupent et se séparent- ressortent des conclusions significatives dans l'optique d'une compréhension plus profonde de la façon dont les identités sexuelle, gay et handicapée interagissent pour donner lieu à une expérience intime unique des notions de santé, d'autonomie et de résilience au quotidien. La participante dépeint comment les notions de douleur, de perceptible et d'imperceptible ainsi que les transformations imposées à son corps par son handicap l'ont menée à une meilleure compréhension de sa propre identité en tant que lesbienne et handicapée. Sa force de caractère et sa capacité d'adaptation furent des tuteurs de résilience importants, tout particulièrement en ce qui concerne les nombreuses interactions avec le système de santé et ses différents acteurs ainsi que dans la vie communautaire en général. Elle affirme y avoir trouvé le soutien nécessaire pour combattre l'hégémonie et les préjugés liés à l'orientation sexuelle et lutter contre la discrimination subséquente à ceux-ci. Le soutien des pairs, l'acquisition de connaissances, l'expérimentation et la créativité dont elle a su faire preuve pour reprendre possession de ce corps indocile sont autant de facteurs lui ayant permis de rester forte et courageuse tout au long des épreuves. Cette étude fournit des pistes intéressantes pour la recherche future, ainsi que des recommandations utiles à la pratique du travail social, à l'application des politiques sociales et au développement de ressources destinées aux personnes handicapées.

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Carry It With You

Everything we knew
begins in the body
a thousand years
of history
repeat repeat repeat
our veins a tangled map
of knowledge
the course charted
long before
memory speaks

I honor the voice
of my parents
their parents'
language
I no longer understand
words
a fine filament
between us

Hold all this
carefully
every memory
carry it with you.

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CHAPTER I

Introduction

1.1 I*ntroduction*

Twelve percent of Canadians experience some form of disability (Statistics Canada, 2006). According to Statistics Canada, disability is defined as “the relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors” (Statistics Canada, 2001). Women are overrepresented in the population of people living with disabilities. Although women make up 51% of the Canadian population, they represent 54% of the population of Canadians living with disabilities (Statistics Canada, 2006). This can be attributable to the fact that women outlive men and rates of disability increase with age (Government of Canada Document, 2008). In Quebec, 13-16% of the female population is made up of women with disabilities (Barile, 2003). The number of queer[1] people in Canada is difficult to estimate because of the ambiguities of defining sexual orientation, the reluctance of individuals to openly self-identify, and the lack of population-based studies incorporating measures of sexual orientation. Data from the United States suggests that the lesbian, gay and bisexual population ranges between 2% and 8% (Fredriksen-Goldsen & Muraco, 2010) while others believe approximately 10% of the general population is made up of queer people[2]. Although there is no research documenting the demographic characteristics of queer people with disabilities it can be deduced from the estimates of the general population that similar proportions of women with disabilities are queer.

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[1] Queer is an umbrella term that includes a multiplicity of sexual orientations and gender identities such as gay, lesbian, bisexual and transgender. The word queer has been re-appropriated from it’s traditional pejorative use, and resists heterosexist oppression (Brotman & Ryan, 2003)

[2] The 1948 and 1953 studies by Alfred Kinsey found that 10% of males were exclusively homosexual, while females ranged between 2%-6%. The findings from Kinsey’s studies have since been re-analyzed and widely criticized, however 10% has remained a popular figure in estimations of queer population. See The Kinsey Institute: http://www.iub.edu/~kinsey/resources/bib-homoprev.html

It has been well documented that people living with disabilities, including chronic illness[3], experience considerable barriers to full participation in society (Shakespeare, 2008). Criteria for many disability benefit and financial assistance programs define disability in such a way that many of the chronic conditions and forms of disability more often experienced by women render them ineligible for help (Gilmour, 2008). This aggravates already high levels of unemployment, poverty, and low income among women with disabilities (see Statistics Canada, 2006). Women with disabilities are also more likely to be single parents, less educated than non-disabled women, and living apart from their family (Statistics Canada, 2006). All of these factors make an already challenging position in society that much more difficult.

All this to say is that barriers produce health disparities. It has been documented that such factors as poverty and unemployment contribute to mental and physical health challenges among all women with disabilities. Lesbian women in general face economic, social and health access barriers that have contributed to higher rates of morbidity (Cochran, 2001). Minority stress experienced by lesbian women has been associated with higher rates of substance abuse, addiction and mental health problems (Aaron et.al, 2001; Anderson, 1996; Hershberger, Pilkington & D'Augelli, 1996; Bradford, Ryan & Rothblum, 1994). Increased health risks occur for lesbian women who refuse or delay seeking treatment because of exposure to discrimination by health care providers (Harrison & Silenzio, 1996; Sinding, Barnoff & Grassau, 2004) Queer women with disabilities are at risk for health disparities' because of both marginalized social locations of disability and queer identity.

Sexuality and sexual expression are important to women's health, however this subject is often disregarded in health and social services geared towards all women with disabilities (Melby, 2003), including queer women. The World Health Organization (2004) makes links between sexual fulfillment and health and mental wellbeing. In their definition of mental health they state that individuals "have a right to pursue a satisfying, safe and pleasurable sex life" (WHO, 2004). Women with disabilities have more difficulty accessing romantic, sexual and intimate relationships

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[3] Disability is understood within this study as broad, and includes conditions and illnesses that are chronic, temporary and/or transient.

due to barriers presented by poverty (Shakespeare, 1996), and the impact of isolation and depression, common secondary health concerns for this population (Thierry, 1998).

What we don't know is how the intersections of queer identity, health, disability and sexuality play out in the context of queer women's sexuality among queer women living with disability. There have been very few studies addressing this issue, which constrains the capacity of communities and health service organizations to respond appropriately to the needs, experiences and realities of this population of women (O'Toole, 2000).

Women with disabilities, including lesbian women, need to have access to a safe, satisfying and pleasurable sexual life. Understanding women's experiences of disability, sexuality and identity can aid in improving women's lives through the establishment of better programming initiative and policies that are inclusive of concerns, improving access to sexual health care, contributing to advocacy efforts in women with disability communities, women's health organizations and queer health organizations and communities. This thesis addresses these important issues through an exploration of the experience of sexuality, disability and identity among queer women. In particular it focuses on the relationships between multiple, intersecting and embodied identities as experienced and understood through the eyes of one queer woman with a disability.

This research is based in an understanding of identity as fluid, shifting and embodied. Exploring the intersections between sexuality, gender and disability is important in developing a deeper understanding of how these identities are marginalized, intersecting, interacting and both shape and are shaped by lived experience. This can highlight the impacts of intersecting and marginalized identities on health for queer women with physical disabilities.

This study explores the ways in which the intersections of sexuality and identity are experienced and understood by a queer woman living with a disability. Through a narrative account of critical moments and turning points in the participant's lived experience of disability, sexuality and gender, this study examines the ways in which intersecting identities both shape and are shaped by context and experiences of the body as both complex and fluid. The central research question for this study asks: "What is the lived experience of disability and sexuality among queer women with disabilities and how does this experience shape identity?"

In order to develop a deep rich contextualized account of lived experience, which stays true to voice, I chose to interview one queer woman living with a disability on several occasions over the period of one year between 2009-2010. A narrative method was used, as it is well suited to this type of research. Narrative methodology values the knowledge produced in everyday life (Creswell, 2007). This method requires in-depth interviewing in order to uncover chronology, turning points and critical moments in the participants lived experiences. The primary objectives of this study are to address gaps, give voice to experiences of sexuality and disability that have been marginalized, and gain insight into the lived experiences of one queer woman with a physical disability, in order to improve social work practice, and contribute to research and social policy.

This thesis has been divided into five chapters- *Introduction and Theoretical Framework, Literature Review, Methodology, Findings,* and *Discussion and Conclusion*.

This first chapter, *Introduction* provides the reader with an overview of the goals of this study. Chapter two, *Theoretical Framework,* explains the different theoretical lenses and key concepts that are used. This study uses the theoretical lens of feminist disability studies and intersectionality to understand the narrative of a queer woman with a physical disability. I also explore the contributions of the social model understanding of disability, as well as justify how particular components of queer theory contribute to an understanding of lived experience and queer women's identity. Additionally, concepts like sexual citizenship, visibility/invisibility, and embodiment are used to grasp the participant's experiences and understandings of her intersecting, multiple and marginalized identities, and how her social location impacts her access to sexual citizenship, her sense of embodied identity and negotiations of visibility and invisibility.

The review of the literature in chapter three provides an overview of the themes that emerge across the empirical research on disability, chronic illness, queer identity and sexuality. I then explore the available literature on queer women with disabilities.

In the fourth chapter, *Methodology*, I elaborate on the purpose of the study, the narrative method and the details of my research process. I describe my research questions, participant recruitment strategy, data collection and analysis. I include a reflexive piece examining my social location and the impact that this may have on the research process and my relationship with the research participant. I discuss the ethical considerations related to this study, the steps I took to ensure trustworthiness and credibility, as well as the benefits and limitations of this research.

Chapter five, *Findings*, includes a visual diagram of the participant's chronological narrative, a description of the diagram as well as "Josie's Story" which provides context for her narrative. The two overarching themes that emerged from the study are presented, including multiple sub-themes. This chapter includes attention to the chronology of the participant's experiences, turning points, critical moments and epiphanies. Chapter six, *Discussion and Conclusion*, provides an overview and discussion of the findings in relation to the literature, as well as to the theoretical perspectives and concepts important in this study. In conclusion I discuss the implications for social work research, policy and practice.

CHAPTER II

Theoretical Framework

2.1 Theoretical framework

2.1.1 Models of disability

Competing theoretical positions in the field of disability studies emerged historically through debate between professional and experiential perspectives on the nature of disability, as either a purely medical dysfunction or as a socio-cultural identity. Within the last two decades disability has been increasingly understood as having a political dimension, including recognizing the role that the environment plays in creating a disabling society. During the 1970's, as other social movements were gaining momentum in the United States, the Disability Rights Movement began to take shape (Shakespeare, 2008) in response to the prevalent medical model[4] understanding of disability. People with disabilities worldwide fought for control over their bodies, better services and a new approach to understanding disability (Charlton, 1998). The notion of the normal body as non-disabled had dictated the social and physical structure of the environment, which, it was argued, created barriers to full citizenship in society for individuals with disabilities (Oliver, 1996). New perspectives emerged, such as social constructionist understandings of disability, which perceived external factors as disabling (Donoghue, 2003). These new conceptions of disability were

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[4] The medical model locates disability as a problem within the individual body (Human Resources and Social Development Canada, 2004), as solely impairment (Siebers, 2008; Dewsburry, Clarke, Randall, Rouncefield & Sommerville, 2004; Clare, 2001; Oliver, 1996) while ignoring the reality of context and environmental factors (Siebers, 2008). The medical model of disability sees disability as a personal tragedy (Oliver, 1983; Finkelstein, 1980), an illness or functional loss (Rothman, 2003), as something to be fixed or cured (Oliver, 1983) so that the person with the disability can be restored to normality (Siebers, 2008; Brisenden, 1998; Watson, 1998; Oliver, 1990). This model of disability has been informed by biologically-rooted perspectives, essentialist discourses and practices within the medical establishment and sociological theories of deviance (Meekosha, 2004; Donoghue, 2003), and is further reinforced by social and cultural expectations of 'normality' (Siebers, 2008). The medical model of disability is informed by, and informs, normative notions of the body, gender and sexuality (Meekosha, 1998).

referred to as the social model[5] of disability (Dewsburry et al., 2004; Gabel & Peters 2004; Barnes, 2003; Oliver, 1986).

Prior to the 1980's (when funding for the disability movement began to wane) people with disabilities were starting to examine the social construction of their sexual identities and experiences, and began to think of themselves as a sexual minority group (Bullard and Knight 1981 as referenced in Fiduccia, 2000). People with disabilities experience sexual oppression as demonstrated by low rates of sexual knowledge, low partnering rates, lack of privacy and access to reproductive health services, as well as sterilization (Fiduccia, 2000). Shakespeare (2007) discussed the need for a social model approach to the topic of sexuality and disability. He elaborated on the social and psychological barriers within the environment that impact the sexual life of people with disabilities. Internal and external disabling attitudes create barriers to sexual expression (Ostrander, 2009). For example, people with disabilities may not receive the same information or education about sex and sexuality, have the same opportunities to meet sexual partners, and may deal with unique confidence, self-esteem and body image issues (Shakespeare, 2006; Hassouneh-Phillips & McNeff, 2005; Taleporos & McCabe, 2003; Vansteenwegen, Jans & Revell, 2003; O'Toole, 2000; O'Toole & Bregante, 1993).

The social model of disability continues to offer important ways of understanding disability. But this model (as well as the medical model) neglects to emphasize the different experiences of women with disabilities (Lloyd, 1992; Fine and Asch 1988) and the intersectional nature of oppression (Oliver, 1996). In its rejection of the medical model, and the word impairment itself, the social model lacks the complexity for understanding realities that include both society *and* bodily impairments as disabling (Hughes, 2007, 2009; Clare, 1999, 2001; Schriemf, 2001;

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[5] The social constructionist perspective underlies the social model of disability. Social construction takes its roots in the work of Berger and Luckmann (1966). Social constructionism describes the process of persons and groups interacting, over time in a social system, establishing habitual representations of each other leading to the playing of certain roles. In short, it is argued that social reality is socially constructed because of imbedded conceptions and beliefs held by these interacting persons and groups (Berger & Luckmann, 1966).

Thomas, 1999, 2001; Corker, 1999; Meekosha, 1998; Shildrick & Price, 1998; Asch & Fine, 1992, 1997; Crow, 1996; Morris, 1992, 1996; Wendell, 1996; French, 1993; Finger, 1992; Lloyd, 1992; Fine & Asch, 1988).

The social model has primarily looked at modes of economic and social discrimination as defined by men, while excluding issues of sexuality and sexual identity; subjects that disabled women have been concerned with (Lloyd, 1992). Sanders (2007) noted that when sexuality is discussed in the literature, it is most often the sexuality of disabled men. This is reflective of the common assumption that disabled women are asexual (Londsdale, 1990).

Applying the social model of disability to understanding the experiences of a queer woman with a physical disability is helpful in some respects. Acknowledging the role that the social and physical environment play in the oppression of people with disabilities highlights the ways that power operates in society to privilege some bodies and identities while marginalizing others. This way of looking at disability, as well as sexuality and gender, illustrates the ableism, homophobia and sexism that are woven into the social and physical world. Although the social model offers these important elements to the discussion of queer women with physical disabilities, it lacks an intersectional analysis of the particular experiences of queer women. These issues with the social model have been taken up by feminist disability studies.

2.1.2 Feminist disability studies

Feminist disability studies emerged out of second wave[6] feminist discourse and in response to the gaps in the social model of disability. Feminist disability studies developed to problematize the idea of the normative body, and locate the body as a site of resistance. The emancipatory potential of women having power over, and through, their sexuality is one way in which the body can be a site of resistance. The feminist agendas of the past, whose focus revolved around gender difference, neglected to include the experiences and concerns of women with disabilities (Fine & Asch, 1988;

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[6] The second wave of the feminist movement occurred between 1960 and 1979. Second wave feminists focused on antidiscrimination and achieving gender equality. The second wave has been criticized for emphasizing male oppression rather than female empowerment, and excluding the concerns of women from diverse social locations. For example, women of color, lesbians and women with disabilities (Freedman, 2003).

Schriempf, 2001). Concerns of women with disabilities have also been neglected in the disability rights movement (Ferri & Gregg, 1998). The omission of women with disabilities in feminism, and the social models' neglect of issues of the body, fueled a feminist disability studies approach, which attempts to highlight the importance of uncharted areas between the social model and individual model of disability, and between areas of personal experience and private life.

A feminist disability studies perspective concerns itself with inclusion and the value in many points of view; Zola (1994) explores the places between the two models to examine disability from different perspectives. “Zola persuades us to see it is possible to be politically engaged while remaining free to explore people’s experiences” (Wendell, 1996).

Feminist theorizing on disability has encouraged a more inclusive social model, one that acknowledges the reality of pain and bodily limitation that can be an experience of disability (Clare, 2001; Schriempf, 2001). For example, Meekosha (1998) takes a feminist perspective in her work on regulated bodies and violence against the female disabled body. She critiques both the social model and the medical model of disability for grounding a complex subject in what she sees as a dualistic framework. In it’s focus on the disabling effects of a prejudiced and discriminatory society and the need to change institutions, beliefs and practices, the social model “leaves the impaired body as untouched, unchallenged: a taken for granted fixed corporeality” (Meekosha, 1998, p.175). However, the interactions between the body, gender and other social locations produce experiences and identities that are far more complex than either of these two models have acknowledged. Neither the medical nor social model adequately address the different experiences of disability for women, and both fall short in addressing sexuality.

Although able-bodied society and it’s structures are disabling, so too can be symptoms of chronic illness and disability. Disabled feminists, including Morris (1991, 1996), French (1993) and Crow (1996), have argued that the personal realm is denied by ignoring impairment (Watson, 1998). Thompson (1999, 2001) has critiqued the social model for disregarding the personal and emotional experience of disability and impairment. Disregarding the multiple factors involved in disability, such as biological, psychological and socio-political, renders the view of disability as disembodied (Shakespeare & Watson, 2002). Some feminists have advocated for a return to "impairment" as a way to acknowledge the reality of the body (Crow, 1996; Morris, 1991). In bringing impairment back, alongside and equal to the social models' conception of disability, there is a perception that a renewed social model can be created (Crow, 1996). This renewed model sees impairment and biological realities of the disabled body as a feminist issue, one that has been ignored by the social model. However, this return to the body has been criticized for failing to look at and challenge "the implications inherent in the term 'impairment' as 'biologically factual', it does not succeed in addressing the complex relations of biology and social construction within the concepts of impairment and disability" (Schriempf, 2001, p. 7). While others worry that this approach may be a slippery slope backwards towards the medical model of disability. Schriempf (2001) argues for an interactionist paradigm, similar to frameworks adopted by others in their approaches to disability and its intersections with other identities (see Whitney, 2006; Clare, 1999, 2001; O'Toole, 2000; Axtell, 1999; Corker, 1999, Shildrick & Price, 1998; Wendell, 1996; O'Toole & Bregante, 1993; Lloyd, 1992). This intersectional or interactional model incorporates both the reality of pain and the experiences of impairment within the context of a disabling society (Schriempf, 2001). Clare (2001) describes the importance of including the lived bodily experience of identity and oppression in our attempts to 'refigure the world' (p.364):

> In defining the external, collective, material nature of social injustice as separate from the body, we have sometimes ended up sidelining the profound relationships that connect our bodies with who we are and how we experience oppression (p.359).

2.1.3 Embodiment

Theories of embodiment have their roots in an understanding of the body as separate from the mind, this demarcation is associated with Plato and Descartes (Leder, 1990), and is responsible for the modern separation and elevation of the mind (or soul) above the body (Grosz, 1994). The Cartesian tradition, which continues to influence modern thinking on the body, is one that sees the body in ways that limit feminist theories of embodiment, as Cartesianism regards the body as an object or metaphor, likening it to a vessel, a machine, a tool or instrument (Grosz, 1994), but doesn't allow for an exploration of the complexities of the lived body. Merleau-Ponty addresses the problems with dualist understandings of the body, and elaborates an understanding of the body as it relates to space and perception, including an analysis of the lived body (Leder, 1990). Leder (1990) makes important contributions to this discussion by expanding Merleau-Ponty's idea of the lived body to include an exploration of the way that pain disrupts embodiment. Similarly, Mackenzie (2009) explains the effect of bodily change (for example due to illness or disability) on one's embodiment, or what these authors call 'bodily perspective':

> The centrality of a person's bodily perspective to her narrative self-conception, and the extent to which it is usually taken for granted as one of the background conditions for the ongoing unity and intelligibility of our lives, is made particularly clear by cases of disruption to one's bodily perspective, brought about by dramatic or gradual bodily change. Those who have undergone such change often characterize the process of responding to it as a process of altering or reconstructing one's sense of self (p.118).

These perspectives that move away from dualism, of the body as not only a physical thing, but also at the center of lived experience and the making of meaning, is expanded by including feminist theories of embodiment: "It is not enough to reformulate the body in non-dualist and non-essentialist terms. It must also be reconceived in specifically *sexed* terms. Bodies are never simply *human* bodies or *social* bodies." (Grosz, 1995, p.84). Grosz (1995) cites Kristeva and Irigaray as providing "two of the earliest feminist explorations of conceptions of sexed corporeality and conceptions of space and time, which may prove to be of major significance in feminist researches into women's experiences, social positions, and knowledges" (p.84).

In addition to a feminist perspective of embodiment that moves beyond dualistic terms, it is helpful to consider the role of power in the process and experience of embodiment. Although Foucault doesn't explicitly set out to dispute the 'nature' of embodiment, or what bodies are or aren't (McHoul & Grace, 1997), he nonetheless offers insight into the role of power in shaping identity and becoming a subject.

In order to understand embodiment, and identity as embodied, particularly what that means for a queer woman with a disability, we can look to Foucault's ideas about how humans are transformed into subjects. Specifically what Foucault calls 'dividing practices' (Foucault, 2000, p.326), which cause the subject to be either divided within herself or from others, in this case a relevant example being "the sick and the healthy" (2000, p.326). These divides bring us back to dualist ways of thinking, in this case not body/mind, but sick body/healthy body, which can be addressed by favoring an intersectional approach to looking at the embodiment of multiple identities, recognizing that 'sick' and 'healthy' can be co-occuring, shifting and overlapping embodiments.

Power operates both within and in connection to institutions, as well as relationally between subjects acting on each other's actions (Foucault, 2000). In the context of disability theory, an analysis of power can highlight the failings of the medical model of disability (for example the objectification of the subject in interaction with the medical institution, as well as the medical model's perpetuation of the sick body/healthy body divide), as well as reinforce some of the concerns important to the social model (where and how power operates in the relationships between the disabled body and a world built for able bodies). The web of power that women's bodies, queer bodies, and disabled bodies move through, and are entangled with, is another element to remember when thinking of embodiment as encompassing, as Grosz (1995) states, human, social and sexed elements.

The multiple, intersectional and interactional experiences of identity can be understood in their impact on the body, and as impacted by the body, when looking at embodiment as more than just a physical body, but as a complex and fluid material, and non-material physical and psychical 'thing' that also exchanges with environments and experiences. Grosz (1994) elaborates on the metaphor of the mobius strip to describe the way that embodiment can be understood as a continuous process that is neither inside nor outside, nature or culture, but moves beyond and is more complicated than simple dualistic categorizations. An understanding of embodiment as a process, as not only one's body, but one's interaction with their body, through their body, because of their body, and in relation to other bodies and outside influences. This fluid conception of embodiment lends itself to the exploration of multiple and intersecting identities, and the ways that these experiences of identity are written onto, into, and changed through the body. Recognizing identity as embodied means accepting that different social locations and the experiences and meanings that come out of these particular positions will impact the body, and the body will in turn shape these locations, experiences and meanings. Feminist understandings of embodiment, as well as the idea of the 'lived body', disruptions of embodiment, and the body as bound up with systems of power, provide part of a framework in understanding my research on women and physical disability and the role and meaning of the body/embodiment within these experiences.

2.1.4 Visibility/Invisibility

Within queer theory discourse, the concept of 'passing' is familiar, as are discussions about 'coming out', and the benefits and consequences of becoming 'visible' as a queer person or sexual minority (Brotman, Ryan, Jalbert & Rowe, 2002). These ideas can be applied to understanding experiences of disability and sexuality for women with disabilities and chronic illnesses that are invisible and/or temporary. In her study of 14 women with disabilities, Zitzelsberger (2005) explored the ways in which these women were both visible and invisible across "sociomaterial places" (p.389). The research found that "the participants experiences of visibility and invisibility are consequences of a narrow range of normative standards of 'acceptable' bodies that inscribe cultural meanings and values upon their embodiments" (p.393). Furthermore, when categorized as disabled or different, these women's other identities, such as sexual identities, remained unnoticed or ignored. "In acknowledging both disability and gender as discursive constructs with lived effects the women were engaged in interlocking effects of multiple and conflicting discourses of gender, disability and difference" (p.400).

Queer theory has pushed past understanding realms of life already identified as sexual. In exploring how sexuality infuses many areas of life not usually thought of as sexual, queer theory allows the study of sexuality to shed light on “ social processes, realms, experiences, and institutions…” (Gamson & Moon, 2004, p.59).

Experiences of illness and pain can become disabling on a social level as well as a physical level when they remain unacknowledged and invisible (O’Toole & Bregante, 1993; Wendell, 1996). Wendell (1996) described that the disabling physical aspects of illness, the unattainable social expectations, and an environment built for the non-disabled, are rendered even more difficult by the invisible nature of, in her case, chronic fatigue syndrome.

Wendell (1996) engaged in an important discussion of how disability is defined, and the need to include within such definitions space for those who may pass in the able bodied world to a certain extent, but whose pain and bodily impairments are a reality. The medical model defined disability as located within the body. As disability became politicized and the medical model was rejected, the definitions of impairment and disability became distinctly different from each other. Barnes and Mercer (2003) offered these definitions (of a social constructionist perspective) created by Disabled People’s International:

> **Impairment:** ‘the functional limitation within the individual caused by physical, mental or sensory impairment.’
>
> **Disability:** ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’. (DPI, 1982).

These definitions, however brief, leave space for interpretation. This space offers those with chronic illness, temporary disabilities, and invisible disabilities somewhere to locate themselves (Wendell, 1996). To be able to relate to an identity category can mean a connection to community, a way of understanding one’s experiences and a powerful tool for accessing programs and services (Siebers, 2008). Definitions of disability are also important for political purposes, such as the recognition of rights, increased accessibility and opportunities (Wendell, 1996). Many people with chronic illnesses or invisible disabilities have struggled for recognition, “people with AIDS and with debilitating chronic illnesses like ME fought within disability groups for the recognition that they too are disabled, share similar needs and struggles, and suffer similar forms of insult, discrimination, distrust, and exclusion (Wendell, 1996, p.12).” Although these categorizations can be useful, they can also be the cause of stigma and oppression (Butler, 2001; Wendell, 1996). ‘Coming out’ as disabled, and aligning oneself with a disabled identity can make visible an otherwise invisible illness or disability, while at the same time making one vulnerable to discrimination and prejudice (Siebers, 2008). This then begs the question: are those with invisible disabilities, or illnesses that can be hidden, at an advantage in the sense that they are able to pass in the able-bodied world un-noticed? How does this “masquerade” (Siebers, 2008) change when women with invisible or hidden disabilities are within a sexual context? People with disabilities who can pass as able-bodied within society “…free themselves from curiosity, prejudice, economic disadvantage, and violence…”(Siebers, 2008, p.117). At the same time, passing can be a solitary experience that can result in the worsening of existing conditions, and internalization of prejudice (Siebers, 2008). Tactics used to blend into able-bodied society can “…exact a heavy toll on individuals both mentally and physically, leading to psychological crises and secondary health problems” (Siebers, 2008, p.117).

Within intersectionality theory, the concept of “intersectional invisibility” (Purdie-Vaughns & Eibach, 2008) is helpful when looking at the experiences of women with disabilities who are queer, and navigating issues of sexuality, intimacy and relationships from a location of multiple subordinate-group identities. Intersectional invisibility hypothesizes that “possessing multiple subordinate-group identities renders a person ‘invisible’ relative to those with a single subordinate-group identity…” (Purdie-Vaughns & Eibach, 2008, p.377).

2.1.5 An intersectional approach

Feminist and queer theory have much to offer, and learn, from disability studies. Feminist philosophers and theorists have urged disability studies to acknowledge the importance of the word ‘impairment’ in describing and making room for the painful and sick body (Schriemf, 2001; Wendell, 1996). Including the notion of impairment also requires looking at the implications within this term, and its connection to the widely criticized medical model of disability. It must be acknowledged that simply including this notion of impairment alongside the social understanding of disability will not succeed in the creation of a new, and more inclusive social model (Schriempf, 2001).

Attempts to bridge feminist theory and disability studies have been made, in an effort to move past the problematic medical model and limited social model of disability, towards a more inclusive feminist disability studies that understands that disabled women's issues are different from those of non-disabled women (see Schriempf, 2001; Crow, 1991; Fine & Asch, 1988). However, some attempts to do this have used a 'double discrimination' approach that is limited (Schriempf, 2001; Clare, 1999; Meekosha, 1998). Problems arise with some feminist perspectives of identity and oppression are '"additive"' (see Hanna & Rogovsky, 1991; Lonsdale, 1990; Deegan & Brooks, 1985). This 'additive' approach sees one's situation as a woman, and as disabled, as separate identities. These oppressions are added together in an attempt to explain this experience (Schriempf, 2001).

This additive framework fails to acknowledge that a woman with a disability is not simply facing sexism and ableism as two separate experiences. Rather, her experiences of oppression are entwined with, inform, and are informed by her social location (Schriempf, 2001; Clare, 1999; Morris, 1991). The oppressions she faces are not separate entities, but instead are flowing through, folding over and interacting with each other (Clare, 1999). . "…Women with disabilities are not dually oppressed, doubly handicapped, or double whatever; instead they embody a complex of interwoven situations…" (Schriempf, 2001, p.9).

Thinking of disability as we think of race, class, gender and sexuality identities, as relational, "enables us to understand that they are not independent but rather interdependent, mutually reinforcing systems rooted in power" (Weber, 1998, 2001; Collins, 1998, 2000; Baca Zinn & Diss, 1996 as cited in Weber, 2006, p.37).

Understanding a disability identity also requires looking at its relationship to the body, culture and society, its location within and outside of these spaces, and the other identities and experiences written into particular bodies. A willingness to abandon the cleanliness of categorization, and the simplicity of an additive model of understanding, allows for the conflictual nature of disabled women's oppression to be heard. This framework allows us to be in a "position to always be examining and re-evaluating our thinking and our embodiment as we encounter and navigate the world and its inhabitants" (Schriempf, 2001, p.13).

This way of understanding experiences of identity and difference is guided by intersectionality theory. Intersectionality theory has its roots in critical race theory (Crenshaw, 1995; Delgado, 1995), and has also been part of feminist and anti-racist writing (Andersen & Collins, 1995; Bannerji, 1995; Bishop, 1994; Stasiulis, 1990). This theory has also been used in social work (Thompson, 2001; Oliver, 1996; and Carniol, 2000; Dominelli, 1997; Mullaly, 1997 as cited in Hulko, 2002) and has been applied more recently to sexual orientation identities (Van der Meide, 2002; Eaton, 1995; Gunning, 1995 as cited in Brotman & Ryan 2003) and further elaborated by queer theory (Gamson & Moon, 2004).

This intersectional analysis saw race, class, gender and sexual oppression as interlocking systems (Gamson & Moon, 2004), and has since been further elaborated by queer theory. Queer theory has pushed past understanding realms of life already identified as sexual. In exploring how sexuality infuses many areas of life not usually thought of as sexual, queer theory allows the study of sexuality to shed light on " social processes, realms, experiences, and institutions…" (Gamson & Moon, 2004, p.59). Queer theory is helpful in exploring sexuality and women with disabilities, because it argues that sexuality and power relations are inevitably intertwined (Gamson & Moon, 2004). In applying an analysis of power to the interactions between gender, disability/ability and sexuality, key points come to light. The power to construct a normative body, and the power this constructed notion has over individuals in society, is immense.

> In western cultures, women's bodies are highly marked and evaluated by gendered and sexual norms. Yet some women, such as those whose bodies are fat, older, racialized or ill, are alienated from normative ideals of female bodies (Odette, 1994 as cited in Zitzelsberger, 2005).

2.1.6 Sexual citizenship

People with disabilities are excluded from society in a number of ways (Oliver, 1996). One area in particular that women with disabilities are left out of is that the realm of sexuality (Richardson 1998, Weeks 1998). The concept of citizenship proposed by Weeks (1998) is important to the investigation of sexuality and intimacy for women with disabilities. This understanding of citizenship has evolved from its traditional definition[7]. Within these traditional discussions of citizenship there is no mention of the particularities of inclusion for categories such as gender, race, ability or sexual orientation, as Richardson (1998) points out:

> The primary focus has been on the relationship of class and citizenship, with some discussion of nation/ethnicity and 'race'. The question of the relationship of citizenship to gender has been largely absent from much of the debate within the social sciences and, …in the case of sexuality almost non-existent (p.85).

Sexuality and citizenship has been explored in relation to lesbians and gay men (Shakespeare, 2000), and in more recent discourse has also been applied to others considered 'sexual minorities' (Siebers, 2008). Weeks (1998) describes the sexual citizen as emerging thanks to the "new primacy given to sexual subjectivity in the contemporary world" (p.35). The post-modern world allows for multiple, conflicting and new identities, and it is within this context that the sexual citizen can create belonging (Weeks, 1998).

The concern for sexuality and intimacy in feminist disability studies is present, but remains under-researched and theorized. In order to elaborate on sexuality and intimacy for women with disabilities, the concept of sexual citizenship is helpful. The

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[7] Until recently discussions of citizenship have tended to follow T.H. Marshalls' definition from the 1950's. His understanding of citizenship was informed by social class concerns, and involved three elements: civil, political and social (Barton, 1993). Weeks (1998) elaborates on the historical trajectory of citizenships' definition, referring to Marshall (1950), he outlines the concepts of civil and political citizenship as emerging in the late 18th century. By the late 19th century, social and economic citizenship came to the forefront, alongside labor movements and experiences of poverty. Social citizenship referred to one's achievement of inclusion in society and the right to a life without poverty (Weeks, 1998).

concept of sexual citizenship can be used in combination with an intersectional and feminist disability studies perspective to elaborate on our understanding of experiences of the intersections of gender, sexuality and disability. Disability is a denial of citizenship (Oliver, 1992 as cited in Barton, 1993, p. 243) and women with disabilities continue to fight for inclusion, belonging, equity and rights in many areas of life, including the right to sexual citizenship.

Sexual rights are beginning to be recognized as having equal importance to all other rights for disabled individuals (Shakespeare, 2000; Fiduccia, 2000). When talking about people with disabilities, Finger (1992) explains:

> 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 (p.9).

Looking at the concept of sexual citizenship for women with disabilities makes known the need for space for the creation of new subjectivities, challenging institutional control over disabled women's bodies and sexualities, and moving from the margins into a position of rights, equity, justice and inclusion (Shakespeare, 2000; Plummer, 1995). Plummer (1995) notes when referring to what he calls 'intimate citizenship' that important to this concept is "the *control (or not) over* one's body, feelings, relationships: *access (or not) to* representations, relationships, public spaces…" (p.151, emphasis in original). Shakespeare (2000) echoes the importance of these elements. Drawing on Weeks (1998) he describes three dimensions important in the process of attaining sexual citizenship:

> First, is a demand for control: we demand control over our bodies, over our feelings, and over our relationships. Second, is a demand for access: we demand access to representations, relationships, and public spaces. Third, is a demand for choice: we demand choices about identities, our lifestyles, our gender experiences. And while this threefold approach was developed from the lesbian and gay agenda, I

> think it speaks to us here today in the disability community as well
> (p.165)

Numerous barriers to sexual citizenship are present for both men and women with disabilities, however the way these are experienced and the meaning attributed to such barriers will undoubtedly be unique depending on one's social location. Men with disabilities are faced with expectations of masculinity (Shuttleworth, 2002) while women with disabilities will have particular challenges regarding expectations of femininity and normative ideals of the female body. Women with disabilities are affected by cultural emphasis on bodily perfection (Crawford and Ostrove, 2003), and treated as less desirable than able-bodied women (Rinalta, Howland, Nosek, Bennet, Young, Foley, Rossi and Chanpong, 1997). Women with disabilities may not fit social norms of desirability and 'acceptable' embodiment (Zitzelsberger, 2005), or may not be seeing as fulfilling their gender identity and role, one that is seen as heterosexual and involves caretaking in the home and family spheres (Asch and Fine, 1992, 1997; Morris, 1991; Fine and Asch, 1988). The cultural fixation on the body, in addition to the image of the disabled body, as it has been presented and perpetuated by the medical model of disability, leads to the notion that people with disabilities are asexual (Charlton, 1998). The view that women with disabilities are dependant, childlike and asexual marginalizes their ability to participate in their sexuality (Shakespeare, 1996).

Further complications arise for women with disabilities who are lesbian or bisexual. The intersection of disability with lesbian or bisexual orientations makes the exploration of sexual expression more complex (Shuttleworth, 2001; Tremain, 2000; Butler, 1999; Morris 1996; O'Toole, 1996; Appleby, 1994; Fine & Asch, 1988). Lesbian and bisexual women with disabilities face exclusion from an ableist gay scene, and a homophobic disability community (Beckett, 2004; Butler, 2001; Langholtz & Rendon 1991 as referenced in Fraley, Mona &Theodore, 2007; Gillespie-Sells et.al, 1998). O'Toole & Bregante (1993) note that lesbian women with disabilities rarely find acceptance in either the lesbian or disability community. This rejection can cause isolation, internalized homophobia and ableism (Whitney, 2006). The absence of community, either lesbian or disabled, for lesbian or bisexual women with invisible disabilities is even more salient (O'Toole, 2000).

> The 'body beautiful' and youth culture of present-day Western society can be a tyranny for very many women, disabled and non-disabled. However many disabled lesbians and bisexual women have experienced alienation rather than nurturing and support from the lesbian and gay community (Gillespie-Sells, Hill & Robbins, 1998, p.57).

2.2 Conclusion

It is clear from the theoretical literature discussed that there are various discourses relevant to exploring queer disabled women's experiences of sexuality and identity. The social model of disability continues to offer a helpful, but limited, way of understanding the role played by society in shaping experiences of disability. This social constructivist perspective, when expanded by a feminist intersectional analysis becomes increasingly relevant to the topic being explored by exposing the complexities of identity and sexuality for a queer woman with a physical disability. These perspectives help to illuminate the ways in which society is disabling in conjunction with the oppressions faced from a multiply marginalized position and how these experiences intersect with bodily realities of disability and illness, such as pain. The concept of sexual citizenship emphasizes the importance of sexuality and intimacy through a language of rights, responsibilities and inclusion, while queer and intersectionality theory push the analysis towards questions of in/visibility. An understanding of embodiment as a continuous process that shapes the body, and one's experience of the lived body and the world inhabited by this body, is important when looking at narratives of illness and disability that are bound up with the body, and capable of disrupting embodiment. When this body is also a queer body, a sexual and gendered body, theories of embodiment that value fluidity are helpful in understanding how the body is changed by the intersections of social locations and multiple identities, and how these experiences are also changed by the body.

CHAPTER III

Literature Review

3.1 Introduction

The subject of sexuality and disability has received increasing attention over the past twenty years. A growing interest in the experiences of sexuality among people with disabilities has emerged from an understanding of the role that sexuality plays in the health of all people regardless of health status.

Within the literature available concerned with disability and sexuality two streams of work can be identified. The majority of research on this topic has looked at sexuality and disability from a medical, psychological and sexological perspective (Siminski, 2003; Fiduccia, 2000; Shakespeare, 1996), understanding issues of sexuality in terms of 'function' or 'dysfunction'. This perspective has been criticized for taking on a voyeuristic and pathological attitude (Shakespeare, 1996) that focuses on sexual problems due to impairment. For example, research into sexuality and disability has largely been from the perspective of health and health care, and undertaken by able-bodied researchers. That is, it has been *about* individuals with disabilities, rather than *by* or f*or* them (Fine and Asch, 1988). This has lead to marginalization and mis-representation of the sexuality of people with disabilities (Shakespeare, 1996). Research by professionals in medical, psychological or sexological fields has been criticized for; assuming that people (especially women) with disabilities are asexual (Whitney, 2006; O'Toole, 2000), using heteronormative models (O'Toole, 2000; Tepper, 2000), and constructing disabled sexuality as inappropriate or non-existent (Crawford and Ostgrove, 2003).

The emergence of concerns for sexuality has been slow, in part because the subject is still considered by some as taboo, which results in difficulty accessing participants for research (Gillespie-Sells et al. 1998; Shakespeare, 1997), and others feel that there are more pressing issues to address in the disability movement (Gillespie-Sells et al, 1998). The disability community's reluctance to discuss sexuality is noted by Shakespeare (1997), who found it difficult to find participants willing to discuss topics such as relationships and sexual activity. He says:

> Disabled people, in general, may lack the language or confidence to discuss matters of sex and love: this is a product of disempowerment, and a lack of effective sex education, and the minimal expectations of family, friends, carers and professionals (1997, p.183)

Within the last decade the voices of women, and discussions of sexuality have become more present in the disability and chronic illness literature. In the past, women's voices within the disability field were left out to a great degree (Wight-Felske, 1991 as referenced in O'Toole & Bregante, 1993). While there is a limited amount of research into disability and sexuality, there is less focusing specifically on the sexuality of women with disabilities. Recently, important intersections between gender, sexuality and disability have begun to be explored (see: Walden, 2009; Whitney, 2006; Fraley, Mona & Theodore, 2007; Zitzelsberger, 2005; Wilkerson, 2002; Clare, 2001; Walter, Nosek, & Langdon, 2001; Davies, 2000; Guldin, 2000; O'Toole, 2000; Shakespeare, 2000, 1996; Tepper, 2000; Axtell, 1999; Gillespie-Sells, Hill, & Robbins, 1998; Richards, Tepper, Whipple, & Komisaruk, 1997; Shakespeare, Gillespie-Sells, & Davies, 1996; O'Toole & Bregante, 1993), although queer women with disabilities still represent a population that has received minimal attention in research (Fraley, Mona & Theodore, 2007).

The research reviewed in this chapter elaborates on the numerous barriers present for people with disabilities in participating in a safe and satisfying sexual life. For example, due to prejudice and stereotypes, disabled people are denied their sexuality, and when they are seen as sexual, it is in the context of sexual deviance (Shakespeare, 1996). The disability community and the queer community have both faced sexual oppression; they have a shared history of injustice including medicalization, asexualization/hypersexualization and institutionalization (Whitney, 2006; Sandahl, 2003). Experiences and explorations of sexuality become more complicated when gender and sexual orientation are included in the analysis (Shuttleworth, 2001; Tremain, 2000; Butler, 1999; Morris, 1996; O'Toole, 1996; Appleby, 1994; Fine & Asch, 1988).

The literature I have reviewed to contextualize my research study includes work done on disability and sexuality from a social model perspective, work done by feminist disability scholars writing about women with disabilities, as well as literature that looks at the experiences of queer women with disabilities. Chronic illness, pain, temporary and transient disabling conditions are included in my understanding of disability. In reviewing the literature on disability and sexuality I have included relevant research that fits into my broad definition. The research included in this literature review was retrieved from various publications including journal articles and books. The majority of information retrieved online was found through the databases PsychInfo and SociIndex. Within these databases I searched with various combinations of the following keywords: women, gender, disability, chronic illness, pain, sexuality, intimacy, sexual orientation, lesbian, bisexual. The SociIndex database found 284 records for "women with disabilities", 143 of which were published between 1998 and 2010. Within the 284 records I narrowed my search using the following terms: "sexuality" (13 records), "identity" (16 records), "sexual orientation" (6 records), and "intimacy" (1 record). Between the years 1998 and 2010, 169 articles were found when combining "chronic illness" and "women". When adding "sexuality" 6 results remained. The PsychInfo database provided 114 records for the combination of "women", "disabilities" and "sexuality". Only 4 records were found for "women", "chronic illness" and "sexuality". I located articles and books used in key texts to locate additional relevant literature on the topic.

Themes found across the relevant literature are discussed below, these include *cultural and social representations and ideals*, *information and education*, *resistance* and *lesbian, bisexual and queer women with disabilities and chronic illnesses.* Due to the minimal literature available on lesbian, bisexual and queer women with disabilities and chronic conditions I have presented this separately from the other thematic areas, although some of the themes discussed in relation to women generally, also emerge in the research specifically looking at experiences of queer women with disabilities and chronic illness.

3.2 Cultural and social representations and ideals

Cultural and social representations of the body and sexuality position able-bodiedness and heterosexuality as the norm- ignoring or devaluing the bodies, sexual orientations and practices of many individuals (Wilkerson, 2002).

> The repercussion for those with physical disabilities, like many others, may be silence and unintelligibility, their sexualities rendered incoherent, unrecognizable to others or perhaps even to themselves, a clear instance of cultural attitudes profoundly diminishing sexual agency and the sense of self and personal efficacy (Wilkerson, 2002, p. 48).

In his research findings, Shakespeare (1996) noticed the impact of cultural ideals on disabled people's sexuality. Participants "…often reported serious problems with self-image, having been socialized to think of themselves as asexual or unattractive. Sexual confidence is so centrally about beauty, potency and independence that disabled women and men feel undermined" (p.193). Similarly, Taleporos and McCabe (2002) found that people with disabilities commonly feel that they are sexually unattractive. Silvers (1997) reported that rates of sexual depression are higher, and sexual esteem is lower in people with disabilities. Similarities arise in chronic illness literature, which elaborates on the impact chronic illness, pain, and associated fatigue and depression have on the sexual lives of participants. Kelly (1992) stated that people living with illness are acutely aware that they do not meet social norms, and an enormous effort is invested in appearing normal. Regarding patient's who have undergone ostomy surgery, Turnbull (2001) explained that "regardless of the patient's age, diagnosis, or sexual preference, ostomy surgery disrupts the high value people and society place on beauty, body, cleanliness and self-control" (p. 192).

Many barriers are identified by respondents in Shuttleworth's (2002) qualitative study of men with cerebral palsy and their experiences negotiating sexual intimacy with others. In the fourteen interviews conducted the following barriers to establishing sexual intimacy were expressed:

> Sociosexual isolation during their adolescent years, negative or protective parental attitudes, cultural ideals of attractiveness, social expectations of

> normative functioning and control, expectations of masculinity, poor body image and lack of sexual negotiation models (including disability and sexuality education) (p.114).

This research found that the claiming of sexuality by these men, “securing some kind of sexual intimacy, however defined by the individual” (p.122), in the context of cultural assumptions of asexuality, is a “paramount project of self-constitution…a bid for full subjectivity” (p.122). Some of the barriers identified in this study are also present for women with disabilities, however the way these are experienced and the meaning attributed to such barriers to sexual intimacy are unique.

While the men in Shuttleworth’s (2002) study were faced with expectations of masculinity, women with disabilities have particular challenges regarding expectations of femininity and normative ideals of the female body (Tighe, 2001; Asch & Fine, 1997; Fine & Asch, 1988).

Disabled women are largely absent in popular and cultural media, and when they are represented it is not reflective of their lives, and perpetuates damaging images (Gillespie-Sells et al, 1998) as well as negative and stereotypical messages (Kent, 1988 as referenced in Ferri & Gregg, 1998). This lack of positive representations keeps disabled women invisible, misunderstood, and without role models from which to aspire (Gillespie-Sells, et al, 1998). The invisibility of disabled women’s sexuality has also been linked to social exclusion and isolation (Gillespie-Sells et al, 1998), which makes access to a sexual and intimate life more difficult. For example, research has shown women with disabilities tend to have a more limited romantic life (Rintala, Howland, Nosek, Bennett, Young, Foley, Rossi, & Chanpong, 1997), and less opportunities for meeting potential sexual partners due to social exclusion, inaccessible bars or clubs, and exclusion from employment and therefore the financial means to go out to socialize (Shakespeare, 1996). Respondents have also noted the affect of segregated schooling, housing, and transport, as contributing to isolation and invisibility as a sexual being (Gillespie-Sells et al 1998).

In Zitzelsberger's (2005) study of 14 women with physical disabilities she explored the ways in which these women were both visible and invisible across "sociomaterial places" (p.389). The research found that "the participants experiences of visibility and invisibility are consequences of a narrow range of normative standards of 'acceptable' bodies that inscribe cultural meanings and values upon their embodiments" (p.393). Furthermore, when categorized as disabled or different, these women's other identities, such as sexual identities, remained unnoticed or ignored.

> In acknowledging both disability and gender as discursive constructs with lived effects the women were engaged in interlocking effects of multiple and conflicting discourses of gender, disability and difference (p.400).

Cultural ideals related to the body, gender and sexuality can negatively impact women with disabilities, these ideals can include bodily aesthetics, the importance of orgasm, traditional ways of touching and experiencing desire, "normal" genitals and reactions to stimulation (Guldin, 2000). Participants in Guldin's qualitative study (2000) recognized-and at times internalized, cultural ideals of the 'sexy body' and felt frustrated that their bodies did not fit into these ideals. Tighe (2001) interviewed 8 women with physical disabilities about the meaning of health and disability. Findings showed that women felt pressure to define their health by able-bodied standards, and fit their bodies and experiences into a limited social understanding of the body. The women expressed challenges posed by standards of normalcy in terms of the body and femininity.

Research on women with chronic illness mentions issues related to sexuality such as disruptions in communication with intimate partners (Claiborne & Rizzo, 2006), lack of sexual desire (Grandjean & Moran, 2007), pain (Walden, 2009; Grandjean & Moran, 2007; Moore, 2007) or fear of pain (Schlesinger, 1996); bladder or bowel dysfunction (Moore, 2007); sexual disorders and general anxieties about sexuality (Basson & Schultz, 2007; Bitzer, Platano, Tschudin et al, 2007 as referenced in Dibble, Eliason &Christiansen, 2007).

The way that much of the chronic illness literature frames the sexual experiences of women is within a framework of sexual 'function' or 'dysfunction', which is also reflected in the ways that health care professionals understand chronic illness and disability. Hall (1996) notes that health care professionals maintain understandings that fit within a bio-medical perspective. This can have implications for women with disabilities and chronic illness in reinforcing cultural and social norms, expectations and ideals related to women's bodies, sexuality, sexual functioning and sense of self (Telford, Kralik & Koch, 2006). Kelly (1992) observed that when health care professionals react negatively to women's disabled and changed bodies that patient's left the hospital with low self confidence, and tended to anticipate negative reactions from others, leading to worry and self-consciousness.

3.3 Information and education

The view that people with disabilities are asexual has implications for access to information and education about sexuality and sexual health. A factor that fuels the idea of disabled people as asexual is "the fear of disabled people joining up with other disabled people, and breeding more disabled people" (Humphries & Gordon, 1992, p.100 as cited in Shakespeare, 1996, p.200). Prejudice and stereotypes of disabled people held by others, whether parents, educators or peers, are partly responsible, according to Shuttleworth (2002), for barriers to sexual subjectivity, such as a lack of sexual negotiation models (including disability and sexuality education). Of all the women in Gillespie-Sells et al. (1998) study, 42 percent received no sex education at all and those who did receive sex education found it to be limited in its heterosexual and reproductive focus. O'Toole (2000) notes that there is limited sexuality information specific to people with disabilities, and information that does exist leaves out queer individuals. This was also found in research done by Mona, Cameron and Fuentes (2006); lesbian and bisexual women with disabilities have difficulty locating information about how impairment may influence non-heterosexual sexual activity.

Young women with disabilities felt they received certain messages about sexuality: "the general impression was that sex was for others and although this may not have been stated outright or openly, young disabled women 'understood' that sex was not for them" (Gillespie-Sells et al., 1998, p.41). Women in the study by Gillespie-Sells and colleagues expressed that a lack of sex education and information had a negative impact on their ability to form relationships, and on their confidence. Disabled women have been denied knowledge about sex and sexuality, "…left in total ignorance, not just from over-protective parents but also by the education system" (Gillespie-Sells et al.,1998, p.72).

In a comparison study between women with and without disabilities, Watson, Nosek and Langdon (2001) sought answers to questions about sex information, education and experiences. They found, through both qualitative and quantitative methods, that both groups of women learned about sexual intercourse at similar ages, however women with disabilities had their first sexual experiences much later. The researchers found a need "for parents, elementary and secondary school, and churches… to be educated and encouraged to teach disabled women that they are not asexual" (Watson et al., 2001, p.174), and that sexual education programs need to be evaluated to ensure that they are not promoting the idea that women with disabilities are asexual (Watson et al., 2001).

The need for education and knowledge about sexuality and women with disabilities extends to health care providers. It has been noted that providers lack of knowledge and confidence addressing sexuality with their clients with disabilities and chronic illness has a negative impact on potentially supportive interactions, and creates barriers to proper assessments (Dibble, Eliason & Christiansen, 2007). Health care providers need to ask about sexual issues (Grandjean & Moran, 2007; Moore, 2007). Queer women with disabilities and chronic illness are negatively affected by health care providers assumptions of heterosexuality, and limited knowledge of how minority stress impacts health (Dibble, Eliason & Christiansen, 2007). Queer women with disabilities and chronic illness face invisibility in the health care system (Dibble, Eliason & Christiansen, 2007), and report negative experiences with health care providers (Walden, 2009). These factors limit these women's access to information, education and care related to sexuality and sexual health (Walden, 2009; Dibble, Eliason & Christiansen, 2007).

3.4 Resistance

Despite the numerous barriers to a positive and satisfying sexual life described above, as well as barriers to education, and information about sexuality and sexual health, women with disabilities and chronic illness have challenged notions of 'normal' and desirable embodiment and sexuality. Guldin remarks that dominant cultural notions are challenged as participants "expand or redefine the meaning-or values-associated with them" (2000, p.234). Women with disabilities and chronic illness have incorporated self-care strategies in order to adjust, and have benefited from the support of partners, friends, family and community (Edwards, Thompson & Blair, 2007; Webster, 1997; Schlesinger, 1996). Women with disabilities and chronic illness have adopted new models of communicating about sexuality, including re-learning what is pleasurable (Claiborne & Rizzo, 2006; Fisher, Graham & Duffecy, 2006), information seeking (Crooks & Chouinard, 2006) and rejection of pathologizing psychological explanations (Webster, 1997). These activities have all been identified as important for women with disabilities and chronic illness in adjusting (Shlesinger, 1996), accepting (Edwards, Thompson & Blair, 2007; Webster, 1997), developing a revised sense of self (Charmaz 1983 as referenced in Webster, 1997), or in the creation of an "ill female self" (Crooks & Chouinard, 2006).

Due to bodily or environmental barriers, individuals with disabilities may employ more creative means of giving and receiving pleasure. For example, some participants in Guldin's (2000) study reported that their disabilities, in some ways, have made them better lovers, as they have had to explore their sexualities in ways that able-bodied individuals have not. Shakespeare came to similar conclusions: "Because people were not able to make love in a straightforward manner, or in a conventional position, they were impelled to experiment and enjoyed a more interesting sexual life as a result" (1996, p.209). Shakespeare (1996) interviewed a woman who described the positive impact her experience MS has had on her sexual life. By accepting her physical difference she became more liberated and more likely to initiate sex. Stories of resistance also characterized the women interviewed in Zitzelsberger's research. Although they struggled with normative and idealized representations of bodily capacity and appearance, "each woman also experienced moments of seeing differently through resistance to hegemonic orderings of normal/abnormal, beautiful/ugly and same/different bodies" (2005, p.399). All women interviewed by Gillespie-Sells et.al. (1998), spoke about breaking down barriers. Many of these women, through becoming more independent, found freedom from over-protective parents, and confidence in relationships. Some got married and others became mothers. Gillespie-Sells found that segregation and isolation of disabled women "crushed, restricted or denied" (1998, p.98) their sexual development. She maintains that for women to experience their sexuality fully, these barriers need to be removed through a "major change in society so that it starts taking into account the needs of disabled women" (p.98).

3.5 Lesbian, bisexual and queer women with disabilities

Research into the experiences of lesbian, gay and bisexual individuals with disabilities has been increasing since the mid 1990's. The existing research has focused on barriers to sexual relationships, sexual identity and challenges accessing community (Mona & Gardos, 2000; Shakespeare, Gillespie-Sells & Davies, 1996). Research focused on the sexual experiences of lesbian, bisexual and queer women with disabilities and chronic illness is important. The experiences of this population are different than the experiences and challenges faced by heterosexual, white women with physical disabilities and chronic illness. More recent empirical work has looked at the intersections between disability, race and sexuality (O'Toole, 2000), identity development for queer women with disabilities (Whitney, 2006), and for lesbians and bisexuals who are chronically ill (Walden, 2009; Axtell, 1999).

O'Toole and Bregante (1993) describe the multicultural lives of lesbians with disabilities, including the challenges of intersecting affiliations. While disabled lesbians have access to multiple communities, they also face multiple sources of discrimination, including homophobia, sexism, ableism and racism. The lesbian and bisexual participants in the study by Gillespie-Sells et al. (1998) and Axtell (1999) faced homophobia in addition to ableism. Participants described not fitting into a disability community because of homophobia, while also feeling that the lesbian and bisexual communities were inaccessible. For example, the social element of the lesbian and bisexual community occurs frequently in bars and clubs, where people go to meet potential sexual partners, form friendships and relationships. The bars and clubs are often physically and attitudinally inaccessible (Gillespie-Sells et al., 1998), and these barriers make it more difficult for lesbian and bisexual women to meet sexual partners (O'Toole & Bregante, 1993). "For many disabled lesbians there is a homelessness of the heart. They belong to so many separate communities, but they rarely find acceptance in any" (O'Toole & Bregante, 1993, p.261).

Numerous authors have found that lesbian, bisexual and queer women with disabilities faced an absence of community (O'Toole, 2000), rejection from both the disability and queer community (Whitney, 2006), barriers to participation in community (Axtell, 1999). Furthermore, entry into lesbian space was often mediated by ability, while entry into disabled women's groups was mediated by sexuality (Beckett, 2004). REGARD, a Canadian self advocacy organization for disabled lesbians and gay men, was created because of the heterosexism in the disability movement, and the isolation and distress caused by the multiple oppression of gay and lesbian people with disabilities (Gillespie-Sells, 1992 as referenced in O'Toole & Bregante, 1993).

Fraley, Mona and Theodore (2007) provide psychological perspectives on the sexual lives of lesbian, gay and bisexual people with disabilities. They discuss the impact of social policy, social perceptions, and environmental barriers that affect sexual expression. The two main barriers to establishing relationships that they describe are 1. Attitudes and physical appearance 2. Accessibility issues. Attractiveness and body image, for example, play a role in one's comfort in meeting potential sexual partners, and specific body type ideals may exist within certain lesbian or bisexual communities. Accessibility issues refer to barriers such as stairs or inadequate bathroom facilities in gay-specific settings or events. Strategies employed by lesbian and bisexual women with disabilities to deal with these barriers to sexuality and sexual expression are also discussed. These include alternative ways of finding romantic relationships (such as relying more on the Internet), and finding sexual partners (such as hiring a sex worker either in person, on the Internet or over the phone). Barriers to sexual expression involved beliefs (both internalized and externalized) about sexuality, which were maladaptive, negative or restrictive, and come from general society, and medical professionals. A need for more social support is one salient issue for couples when one or both partners are disabled. But this can become a challenge if one or both are struggling with coming out, and potentially supportive relationships have been affected.

3.6 Conclusion

In reviewing the literature, the complexities of disability, chronic illness, gender, and sexuality are apparent. To understand the implications of these intersecting identities, it has been necessary to first explain the shortcomings of research that has taken on a medical model approach. The emergence of a social constructionist understanding of disability as located in society has been discussed to trace the progression of the disability movement to its current-and complicated-status. The social model of disability was largely founded on the separation between definitions of disability versus impairment. 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.

As discussed in the first chapter, feminists began to articulate the ways in which the social model failed to address their concerns, and the reality of living with impairment. Feminist disability scholars, activists and women with disabilities began to investigate how to incorporate these concerns into a renewed version of the social model. Some feminists sought a return to impairment, while others hesitated at the potential for this move to erase the aspects of disability that had been politicized by the social model. An interactionist, or intersectional perspective has been offered by feminists wanting to acknowledge the experiences of women with disabilities who also exist in various locations of class, race and sexual orientation. An intersectional approach could allow disability to remain politicized while also acknowledging the impaired and painful body, the particular experiences of women, and those who are multiply marginalized.

Concerns related to sexuality and sexual expression have seen slow progress towards acceptance into the disability rights agenda. In the mid-1980's and early 1990's, a largely ignored call for the politicization of the sexual rights of people with disabilities was made by Fiduccia (Fiduccia, 1994). More recently, the sexual rights of people with disabilities have resurfaced as an issue to be addressed (Mona, Cameron & Fuentes, 2006; Shuttleworth & Mona, 2002). As evident from the literature review above, there is much more research to be done in the area of sexuality and sexual expression, especially with regards to those whose disability identity intersects with other marginalized positions, such as lesbian, bisexual and queer women with disabilities and chronic illness.

The literature addressing sexuality and sexual expression for heterosexual women with disabilities, and inquiries into the sexuality of lesbian, bisexual and queer women, exposes the numerous barriers to sexual citizenship for women with disabilities. Some of the concerns expressed by heterosexual women overlap with those of queer women, such as lack of representation and access to information. These issues, however, are experienced differently based on each woman's social location. Some issues are particular to lesbian, bisexual and queer women with disabilities, such as expectations or assumptions of heterosexuality, and difficulty fitting in to either a disability community or a queer community, because of experiences of both homophobia and ableism. The rejection faced by both communities is concerning, as a sense of community and engagement with others has been shown to facilitate self-acceptance and the realization of the global nature of oppression, for queer women with disabilities (Whitney, 2006).

Current research is needed to further investigate how a renewed, or intersectional, social model of understanding disability and impairment can be articulated. The barriers to sexuality and sexual expression need to be explored in terms of how they are experienced, embodied, and resisted. A clearer picture of how experiences of disability and illness are nuanced by the intersections of other marginalized identities is required.

CHAPTER IV

Methodology

4.1 Research Question

This work explores experiences and understandings of sexuality, gender, disability and identity. In particular the study focuses on the relationships between multiple, intersecting and embodied identities as experienced and understood by a queer woman with a physical disability. Through a narrative account of critical moments and turning points in the participant's lived experience of disability, sexuality and gender, this study examines the ways in which intersecting identities both shape and are shaped by context and experiences of the body as both complex and fluid. The central research question for this study asks: "What is the lived experience of disability and sexuality among queer women with disabilities and how does this experience shape identity?" Exploring the intersections between sexuality, gender and disability is important in developing a deeper understanding of how identities are marginalized, intersecting, interacting and both shape and are shaped by experience. This deeper understanding can highlight the impacts of intersecting and marginalized identities on health for queer women with disabilities.

The goals of this study include giving voice to experiences of sexuality and disability that have been marginalized, expanding understandings about this topic and providing insight into the lived experiences of one queer woman with a physical disability. I hope to explore these facets of identity and how they have shifted and changed over time, as well as how these social locations have shaped the participant's lived experience. In particular, I want to explore the ways in which multiple and intersecting identities are embodied by the participant, and how these identities shape her experience of sexuality, disability and health. I hope to highlight the moments in her narrative where her experiences of sexuality and disability intersect and diverge, as well as illustrate the tensions, critical moments and turning points experienced, and the meaning that the participant assigns these experiences.

4.2 Narrative Research Design

Within the disability studies field the necessity for a model of understanding that incorporates the social and environmental factors that can be disabling-rather than seeing disability as solely a medical circumstance or tragedy- has brought with it the need for research that allows individual stories and lived realities to emerge. Qualitative methods have been appropriate for illuminating real experiences of women with disabilities. According to Creswell (2007), qualitative research "…includes the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action" (p.37). In the context of my research, which looks at identities that are marginalized, and often mis-represented, these qualities of qualitative research design are especially important.

This qualitative research study uses a narrative method. There is no single clear definition of narrative, and no one established approach to conducting research within a narrative framework. Definitions of narrative are varied among researchers using personal accounts. For some scholars narrative refers broadly to an entire life story including interviews, observations and documents. However, broad approaches to narrative have been criticized for lacking in systematic analysis and detailed transcription (Riessmann, 1993). On the more restrictive end, narrative is understood as a "discreet unit of discourse: an answer to a single question, topically centered and temporally organized" (Riessmann & Quinney, 2005, p.394). Riessmann (1993), when discussing this more restrictive form of narrative, gives the example of Labov (1972), who assumes that all narratives are stories about a particular past event, and all share common properties such as a beginning, middle and end, as well as a linear and chronological sequence through time. However, Young (1987, as referenced in Riessmann, 1993) argues that one event in a narrative will order the next event, not necessarily chronologically, while others argue for events in narrative to be connected by theme rather than time (Michaels, 1981 as referenced in Riessmann, 1993).

Research in psychology and sociology tend to define narrative in a middle area between broad and restrictive definitions, as "an evolving series of stories that are framed in and through interaction" (Riessmann & Quinney, 2005, p.394) and that involve "long sections of talk-extended accounts of lives in context that develop over the course of single or multiple interviews." (Riessmann & Quinney, 2005, p.394). Elliot (2005) summarizes a narrative as organizing "a sequence of events into a whole so that the significance of each event can be understood through its relation to that whole" (p. 3), and that in this way narrative explains the meaning behind events. Elliot (2005) outlines common themes found across research that pay attention to narrative:

1. An interest in people's lived experiences and an appreciation of the temporal nature of that experience.
2. A desire to empower research participants and allow them to contribute to determining what are the most salient themes in an area of research.
3. An interest in process and change over time.
4. An interest in the self and representations of the self.
5. An awareness that the researcher him-or herself is also a narrator.

(p.6)

Narrative has been understood as being both a method, and a phenomenon of study (Pinnegar & Daynes, 2006 as referenced in Creswell, 2007). There are multiple approaches to using narrative as a method. Narrative studies can be differentiated based on the analytic strategy used by the author, or the form found in the narrative practice. These forms of narrative include biographical studies, autobiographies, life histories, oral histories and personal experience stories (Creswell, 2007). My research study uses the narrative form called a personal experience story, which is " a narrative study of an individual's personal experience found in single or multiple episode, private situation or communal folklore" (Denzin, 1989 as referenced in Creswell, 2007). The personal experience story "relates the self of the teller to a significant set of personal experiences that have already occurred" (Denzin, 2001, p.60-61).

Narratives can also be guided by a theoretical lens or perspective (Creswell, 2007). In the case of my research study, a feminist lens has guided the design. My feminist perspective has led to my interest in uncovering women's stories, especially those of women whose voices are silenced and experiences are marginalized, such as the queer and physically disabled. A feminist research approach has some of the same goals as a narrative approach. In feminist research methods, goals that overlap with those of narrative research include an emphasis on creating non-exploitative and collaborative relationships with participants, and an understanding of the researcher within the study (Olesen, 2005; Stewart, 1994, as referenced in Creswell, 2007). Narrative methods of research are relevant to social work by

> Showing how knowledge is constructed in everyday life through ordinary communicative action…narrative frameworks can honor social work values and ethics, by valuing time with and diversity among people. Participatory practice that is empowering for clients depends on relationships-a hallmark of social work and narrative. (Riessmann & Quinney, 2005, p.395)

The narrative approach shapes the research design in the following ways:

4.3 Reflexivity

The narrative method of research is inherently reflexive, in that it requires the researcher to 'restory' the information given by the respondent. The act of restorying requires an acknowledgment of the participation of the researcher in the creation of the research. The narrative approach thus involves active collaboration with the participant, and researchers must be "reflective of their own personal and political background which shapes how they 'restory' the account" (Creswell, 2007 p.57)

Reflexivity can be understood as an awareness of oneself acting in the social world. In the context of research methodology, Elliot (2005) explains

> …The notion of reflexivity is used more specifically to indicate an awareness of the identity, or self, of the researcher within the research process. Reflexivity means the tendency critically to examine and analytically to reflect upon the nature of research and the role of the researcher in carrying out and writing up empirical work (p.153).

A reflexive approach to research is especially prominent in work adopting a feminist methodology.

Feminist researchers have expressed concern about the potential for exploitation of women and other marginalized groups in academic research (Landrine, Klonoff & Brown, 1992 as cited in Creswell, 2007, p. 305) and thus attempt to establish collaborative, non-exploitative relationships with participants, as well as locate the researcher within the study. Emphasis is placed on making explicit the power dynamics involved in research and the representation of people (Creswell, 2007). Reflexivity is a key part of addressing issues important to feminist researchers, such as:

> …The feminist researcher as objective with insider knowledge; the need to uncover the hidden or unrecognized elements in a researcher's background; the credibility, trustworthiness, and validity of researcher's accounts; the reporting of women's voices without exploiting or distorting them…(Oleson, 2005, as cited in Creswell, 2007, p.27).

The aim of reflexivity in the context of my own research is to provide a description of my social location and discuss how that might impact my relationship with my participant, my interpretation of her narrative and the way that I present the participants story. My background has also influenced who I am as a researcher and plays a part in the topic and methodology I have chosen.

I identify as a queer woman, a feminist and someone who is engaged in social justice work, whether through political activism in the community or through my academic work. I have come to be interested in the topic of the experiences of queer women through my own life experiences dealing with homophobia, sexism and witnessing the ways that these marginalized identities impact my own life and those who are similarly situated.

I understand gender and sexuality as fluid and changeable, which comes out of my experience of, at one point, identifying and presenting to the world as a butch lesbian. I later adopted a more feminine presentation and called myself bisexual, and I currently identify as a queer femme. My interest in sexuality and intimacy stems from previous clients I have encountered in work contexts. I have been exposed, through my interactions with these clients, to the barriers that can exist for people with disabilities in terms of participating in a sexual and intimate life, and the impact that these barriers have on one's self-esteem, body image, and mental health.

Within the broader group of people that I call my queer community, I have seen a number of queer women who struggle with invisible disabilities and chronic illnesses. Fibromyalgia, multiple chemical sensitivities, chronic pain and depression are some of the various issues that women in my community deal with on a daily basis. More personally, I have struggled with depression for the majority of my life, and although I do not consider myself as disabled or see my depression as a chronic illness, the sometimes debilitating nature of my depression has impacted my life in profound ways. The invisibility of depression is both frustrating and relieving; invisibility gives me the choice of when and if to disclose my struggle with my mental health. Invisibility has also, at times, made my experience more difficult. It has meant that friends, family, and colleagues are unaware or can forget, and their expectations of me can go beyond what I am capable of giving in terms of emotional energy and my level of engagement in relationships, social and work life. These experiences have influenced my interest in disability and illness, specifically those that can be visible and invisible, as well as changeable, transient or temporary. Although I am able-bodied, my experience in the world as a queer femme woman negotiating depression links me to other women with similar social locations. I can relate to how multiple, intersecting and sometimes invisible, identities shape our experiences in the world. These experiences have influenced my research interests; my methodology and my commitment to understanding how queer women with disabilities experience and make meaning of sexuality, intimacy and identity.

4.4 Ethical Considerations

Like all research that involves human subjects, this research study requires attention to ethical considerations that ensure the participant can consent from an informed position, and that their identity will be confidential and anonymous in the research process and any dissemination of the study's findings. Research that elicits respondent stories about their experiences, understandings of identity and the meaning of their lives brings up particular ethical questions. For example, the data collection process of narrative research involves in depth interviewing, and can often result in intimate conversations sometimes akin to those that would take place in a therapeutic encounter (Lieblich, 1996; Reissmann, 1990, as referenced in Elliot, 2005). In this narrative study sensitive and personal topics are explored, it is important to recognize the potential impact that sharing these stories has on the research participant, therefore the primary ethical considerations of this study are issues of informed consent and confidentiality.

4.4.1 Consent

In order to ensure voluntary and informed consent, I provided my participant a consent form (See Appendix C), which she read and signed prior to beginning her participation in the research study. Prior to beginning the first interview I read the consent form aloud and asked the participant for verbal consent as well as the signed from that she had already provided. The consent form that the participant signed outlined the purpose of the research study and that the findings would be discussed as part of my masters thesis. The consent form described the procedure of data collection, which included the number of interviews, the length of interviews and a timeline for the data collection component of the research study. Additionally the form explained that participation in this study is entirely voluntary, and that the participant could withdraw at any time without penalty. I also elaborated on the potential risks and benefits to the participant in relation to her participation in the study, as well as describing the steps that will be taken to ensure confidentiality and anonymity. The participant was also given the opportunity to decide whether or not she agreed to have interviews audio recorded. The participant consented to have all interviews audio recorded, and agreed to participate in the research study.

4.4.2 Confidentiality

Narrative research and the in-depth interviewing of participants that is required by this method, makes issues of confidentiality and anonymity that much more sensitive. As Elliot (2005) explains in relation to the use of narrative and a focus on 'the case':

> It is the unique nature of these case histories, the specific constellation of attributes, which means that individuals are likely to be identifiable by those who know them. (p.142).

Considering the risk of this lack of anonymity it is important to discuss with the participant the possible avenues of dissemination of the completed research study. The consent form I provided the participant spoke to this and informed her that the findings of this research study would be used in my master's thesis and may be disseminated in future published papers and conference presentations. Additionally the consent form explained to the participant that every effort would be taken to ensure her privacy, and that identifying information would be disguised and a pseudonym used in place of her name. The consent form also explained that all audio recorded data, notes, transcripts and documents that identify the participant will be stored in a locked cabinet only accessible to me and will be destroyed a year after the completion of the study.

4.5 Participant Recruitment Strategy

Narrative studies often focus on one or two individuals, rather than a larger group of people. The individual to be studied needs to be accessible, willing to participate and "distinctive for their accomplishments and ordinariness or who shed light on a specific phenomenon or issue being explored" (Plummer, 1983 as referenced in Creswell, 2007).

I used a sampling strategy called snowball or chain sampling, to recruit my participant. A snowball sampling strategy is useful for identifying a case of interest within a network of people (Creswell, 2007). The narrative method requires that in sampling the "individuals need to have stories to tell about their lived experiences" (Creswell, 2007, p.128). I sought to find an individual who identified as a woman with a physical disability who considered herself part of a sexual minority community, including, for example, lesbian, gay, bisexual, and queer identities. Once receiving university ethics approval in March 2009 (See Appendix A) I created an information letter to recruit a participant (See Appendix B). The information letter described the topic and purpose of my research study, who would be eligible and what would be required of them. I explained that I was looking for a participant who identifies as a woman with a physical disability who is also part of a sexual minority community. I elaborated on the term ‘physical disability’ and explained my understanding of it as encompassing visible or invisible chronic illnesses or conditions, temporary or fluid disabilities or disabling conditions that are physical in nature. I described ‘sexual minority community’ as including lesbian, gay, bisexual, queer, and gender minority identities such as transgender, two-spirit, or transsexual individuals. I circulated an information letter about my research study over email to individuals within my own queer community in Montreal, and encouraged them to pass on this information letter to their own networks. The woman who participated in my research study had received the information letter from me, and contacted me a day later over email to express her interest in the study. The participant in this study is a 27 year-old queer woman, who identifies as someone who has experienced chronic illness and physical disability due to ulcerative colitis. I already knew the participant prior to this study, as we are both part of a small queer community in Montreal. The benefits and limitations of our existing relationship are discussed later in this chapter.

4.6 Data Collection and Analysis

Qualitative research in general tends to use semi-structured and in-depth forms of interviewing, that are relatively informal in style, much like a conversation or discussion (Mason, 2002). In addition to the above mentioned qualities of qualitative interviewing, a narrative approach also requires the interviewer to elicit participant stories which can be aided by a loosely structured interview guide that encourages a conversational dynamic and space to probe into unanticipated circumstances and responses. Prior to meeting with and interviewing the participant, I created a brief interview guide that consisted of three thematic areas for exploration, and a key question and key words relevant to each theme- in case probing was necessary (see Appendix D). I chose my key questions to prioritize the ‘how’, which is important when the research focus is on “identifying meaning making practices and on understanding the ways in which people participate in the construction of their lives”

(Gubrium & Holstein, 1997 as referenced in Elliot, 2005, p.19). The key words were selected out of a list of words I brainstormed around each broad question area.
The three thematic categories were:

1. Identity, which included the question “How do you describe your identity?” and the following key words: gender, sexuality, disability, changes, transformations and representations.
2. Expression, which included the question “How do you express your sexual self?” and the following key words: context and location, body, desire, fantasy, actions, feelings.
3. Interaction, which included the question “What is your perception of other’s responses to your sexual self?” and the following key words: lovers, sexual partners, friends, family, colleagues, queer community, disability community, health and social service professionals.

The interviews were all approximately 2 hours long, audio recorded and occurred either in the participants home or a café near her home. These locations were chosen by the participant for reasons of comfort and privacy. The original design of this research study was to collect data from three semi-structured, in-depth interviews over the course of a month and a half, as well as reflections from a journal the participant kept during the data collection process. I waited until completing all three interviews before beginning the analysis portion of the research study. I did this instead of analyzing each interview after completion, because I saw our multiple interviews as different parts of an ongoing conversation. Once I began to analyze the transcripts, I noticed emerging gaps that would require more information. I struggled for 6 months to re-story the participant’s narrative chronologically, and to highlight the meanings and themes that were most important for her as a queer and disabled woman.

Unfortunately, the data collected to this point was sparse with regards to the participants description of her queer identity, her experiences around coming out and how she felt her queer identity impacted and interacted with her identity as disabled. I also wanted more information about topics that had emerged during the first three interviews, including how the participant embodied her identity, maintained agency throughout her struggles and resisted oppression and marginalization. Given how much information I needed to create a detailed narrative of the participant's life and experiences, I set up two additional interviews. At this time the participant also told me that she had decided not to complete the journaling component of this study; the final two interviews gave me the opportunity to ask her to elaborate on this decision.

I kept a reflective log throughout the data collection and analysis process. I used this log to note feelings, observations, and questions after the interviews with the participant. These notes helped inform subsequent interviews and bring clarity to my reading and analysis of the interview transcripts. The reflective log has been a space for working out ideas and themes that emerge from the data collected, and a tool to keep me focused on the material of this thesis. The log has also pushed me to remain conscious of my role in the research process, including my interactions with the participant in eliciting and listening to her stories, and as a co-creator of the narrative presented. The reflective log has provided a space for me to flesh out my thoughts regarding the political and ethical considerations of engaging in research with marginalized individuals, the complex roles of researcher and participant, and how a narrative approach can call these roles into question.

The analysis of the five interviews was carried out in two stages. As described above, I began analysis of the first three interviews after they had been completed. I transcribed these three interviews and re-read them thoroughly to get a sense of time, or the chronology of events in the participant's life. I also looked for critical moments, epiphanies and turning points that emerged from her stories. As elaborated above, I soon realized that I required more information from the participant about certain topics that were emerging from the first three interviews, such as her queer identity, agency and resistance. Two more interviews took place and were transcribed. I then read all five interviews multiple times, again looking for chronology, critical moments, epiphanies and turning points. During this process I made notes in the margins, underlined passages and words that stood out as important, and in subsequent passes began to understand the timeline of the participant's experiences. The connections between experiences began to emerge, illustrating a complex experience of identity. To clearly understand the relationships between critical moments and events in the participant's life, I created a chart to represent her experiences over time. I struggled to combine her experiences of her queer identity and her identity as disabled onto the same timeline. I began to realize that these two identities were fluid and constantly shifting through time; there were moments of divergence as well as moments where the two intersected. I decided to illustrate this by creating two timelines, one for her queer trajectory and one for her disability trajectory. These two lines are guided through time by the participant's age, and include a space for experiences that couldn't be represented as single events on either timeline. The benefit of having a visual representation of this data is that it clarifies the timing of critical moments, and the participant's identities and experiences within a chronological as well as thematic context that acknowledges some experiences as non-linear.

Creating the visual representation of the participant's narrative was part of my analytic process of 'restorying'. Ollerenshaw and Creswell (2000) describe the process of restorying as reorganizing stories into a framework that "may consist of gathering stories, analyzing them for key elements of the story… and then rewriting the stories to place them within a chronological sequence" (as cited in Creswell, 2007, p. 56). During the process of restorying it is important to this research that the voice of the participant be present. This is accomplished by ensuring that the participants' stories are situated within her personal experiences and historical contexts (Creswell, 2007). My data analysis is intended to be a description of both the story, in the words of the participant wherever possible, and a detailed discussion of the meaning of the story.

4.7 Credibility and Trustworthiness

Collaboration between researcher and participant is an essential part of a narrative research process.

> In narrative research, a key theme has been the turn toward the relationship between the researcher and the researched in which both parties will learn and change in the encounter (Pinnegar & Daynes, 2006, as cited in Creswell, 2007, p. 57).

The participant and I collaborated throughout the data analysis process by way of member-checking, which is a technique for establishing credibility in qualitative research. Member-checking can also be understood as ‘respondent validation’ (Mason, 2002, p.192) and is a procedure that involves presenting extracts of analysis and interpretation to the participants involved in the research so that they can judge the accuracy and credibility of the account (Creswell, 2007). I presented my participant with drafts of my data analysis on two different occasions, after the completion of the first three interviews and then again after the completion of the last two interviews. The participant gave important feedback regarding what she saw as main themes emerging from her story, and explained what was missing from the chronology of her narrative. I incorporated her feedback into the second draft I showed her, which she found to be an accurate account of her experiences.

My social location as a queer woman helped to establish the credibility of this research. My insider status within the same queer community as the participant meant that I have had “prolonged engagement and persistent observation in the field” (Creswell, 2007, p. 207), which is helpful for building trust with participants in qualitative research, as well as helping the researcher make “decisions about what is salient to the study, relevant to the purpose of the study, and of interest for focus” (Creswell, 2007, p.207).

Prior to refining my focus for this research study, I engaged in numerous meetings with my supervisor as well as many informal conversations with individuals in my community who live with chronic illnesses, have experienced disabling conditions, or are friends, partners or allies to someone who has experienced illness or disability. These conversations were helpful in understanding a broader picture of disability in the lives of queer people, and highlighted the gaps in my own knowledge and experience regarding the intersections of these two topics.

4.8 Benefits and Limitations

This research gives voice to experiences of sexuality and disability that have been marginalized. Sexuality and intimacy are subjects often disregarded in health and social services geared towards people with disabilities (Anderson & Kitchin, 2000), as well as queer individuals (Brotman & Ryan, 2003). The participant's narrative offers an intimate insight into the lived experience and understandings of a queer woman with a physical disability. This research can expand our understanding, and potentially have practical implications in terms of service delivery.

However, there are limitations to the narrative method and to this study in particular. This study focused on only one queer woman with a physical disability, which has benefits and drawbacks. My feminist perspective in conjunction with the narrative methodology implemented in this research was a motivating factor in the decision to include only one participant, in an effort to give more space to the participant's voice. The limitations of only including one participant became evident during the data analysis process. Due to the large amount of detailed data, it was challenging to organize and prioritize information into relevant themes. Additional participants would have helped guide and clarify findings that stood out across narratives, creating a more organized discussion.

The narrative method relies on active collaboration with the participant (Creswell, 2007), which was challenging due to the limited energy levels of the research participant and her decision to not complete the journal component. The participant agreed to complete a journal during the course of the research study, but decided midway through the data collection process that this activity was not something that she was interested in doing. This study is limited as a result; a journal from the participant would have been an important secondary source of data, adding depth to the findings and discussion. The participant explained why she did not complete the journaling part of this study:

> I fucking hate journaling, like there is always this assumption that people love journaling, and you have this journal and organically all your innermost thoughts transcend from your mind through the pen onto paper, like that sort of thing. But really that's not how I express myself, that's not how I process my thoughts. Like, me talking to somebody and engaging is much more representative of how I think through things and am able to do things. Also I think with journaling there is this assumption that you would write something in a journal something that you wouldn't feel comfortable talking to someone about. But that's really not the case with me, I respect that journaling may work for other people it's really not well suited to how I express myself. As well I am incredibly busy, and me having to journal my thoughts is artificial, it just doesn't work with my life. It's much better that we have been able to have

> multiple interviews and that I have been able to talk to you (Interview 5, line 7-19)

The narrative method of research is a challenging approach because it requires gathering an extensive amount of data and having a clear, contextual understanding of the participant's life (Creswell, 2007). Because this research was conducted as part of a master's thesis, time constraints have influenced the depth and amount of data that could be gathered. Another limitation of narrative method is the action of restorying the participant's life experiences by the researcher. Important questions are raised addressing these issues in the collecting, analyzing and telling of individual stories:

> Who owns the story? Who can tell it? Who can change it? Whose version is convincing? What happens when narratives compete? As a community, what do stories do among us? (Pinnegar & Daynes, 2006, as cited in Creswell, 2007, p.57).

This study has both benefited and been limited by the relationship between the participant and myself. We are both part of the same queer community, share many of the same feminist understandings of the world and are both involved in academia. The existing level of comfort between us has allowed uninhibited discussions about the participant's private life, which has been beneficial due to the study's focus on sexuality and intimacy. Our shared involvement with the academic is accompanied by a specific type of language and communication we both are familiar with. This way of communicating has reduced the power imbalance that can exist, in terms of language, between "researcher" and "researched." The blurring of boundaries between researcher and participant does have benefits, as I have described, but there are also limitations. Such limitations include complications of confidentiality. In such a small queer community, those who read this thesis may, regardless of pseudonyms being used for the participant's name, recognize parts of her narrative in a way that could expose her identity. The participant and I discussed these potential complications of confidentiality before the data collection process. She agreed to participate despite these potential complications, because she feels the benefits of telling her story are very important. Despite the limitations of this study, it is an important topic to address and one that is currently underrepresented in the literature about disability and sexuality.

CHAPTER V

Findings

5.1 Introduction

Josie's experiences as a queer and disabled woman have taken her on a journey through pain, pleasure, despair and hope. Her experiences of her gender, sexuality and disability are interconnected and complicated by each other, and these fluid and shifting intersecting identities are rooted in, and have been changed by, the story of her body. Throughout Josie's experience of illness she has found support through her queer community. The radical politics she associates with being queer, and the perspectives of the body and identity embraced by the queer people she associates with, have helped her cope.

Josie's sexuality is a thread throughout her experience of illness, at points her sex life offers distraction from her reality of illness and hospitalization. At other moments, her sexuality is taken away from her-by disabling pain, self-consciousness, and more literally through the removal of her rectum, due to her illness. Once her ileostomy became permanent, experimentation with her sexual expression provided a way to come to terms with her new physical self. Her sexual and intimate life, while difficult at points, also facilitated an acceptance and pride in her queer and disabled body. Her sexual and intimate life, despite the struggles and changes that have had to take place within it, acted as, and continues to be, an avenue of empowerment, and a context in which all of her intersecting identities can be visible and celebrated.

This chapter discusses a) Josie's story, b) Josie's timeline and c) two major themes that emerged throughout Josie's story: her experience of identity as embodied, as well as the role of agency and resistance throughout her experience. Focus is placed on her own articulation of her story, in which her disability identity was most paramount. Her sexuality and queer identity helped her, over time, to see her disability identity, and "non-normative" body, in a positive way. Josie did not emphasize struggles about being queer; rather her queer identity has acted as a backdrop to her chronology of coping with her changing body, and coming to terms with her identity as disabled.

5.2 Josie's story

Josie is a 28-year-old woman who identifies as a queer femme and uses the words 'medically disabled' to describe herself as a person who has struggled with a severe experience of illness. Josie's story begins at age 14, when she came out as bisexual. Anna, a friend who came out to Josie as gay, prompted her own coming out. Josie came out first to her mother, and shortly after Josie and Anna began dating, which turned into Josie's first long term relationship of three years.

A year later Josie became ill. She had symptoms of inflammatory bowel disease, and after many tests she was diagnosed, at 15 years old, with ulcerative colitis. Her mother and her girlfriend Anna, were her main supports during this time, they helped her cope with her diagnosis and experiences of acute illness throughout high school. Josie began medication right away after being diagnosed, however she continued to become progressively sicker. She lost extreme amounts of weight, which turned into an eating disorder, was in pain and eventually hospitalized a year later.

The years that followed saw Josie struggle with illness while at the same time expanding her understanding of her sexual identity, as well as negotiating her feelings and ideas about her sick body. At 19 Josie moved to Montreal to start university. She experienced homophobia as well as prying questions about her body and her illness while living in the university residence. This new environment gave her access to other queer individuals and events through university groups and the city of Montreal in general. Meeting others who shared some of her experiences of sexuality prompted a shift in her language around the different parts of her identity. She began calling herself queer and medically disabled, and became more aware of the complex ways that her illness and her sexuality would impact her interactions with the world. Connecting with other queer people provided Josie much needed support and community. Her illness took a turn for the worse a year later, at age 19 the medication she was taking stopped working and Josie had to undergo surgery.

This period of time in Josie's life included extreme physical pain, isolation and uncertainty. Numerous complications following Josie's surgery intensified her struggle with her body and, at 23 she decided to have a permanent ileostomy created in the hopes that the pain would be alleviated. Again, complications arose, unrelenting pain lead to a critical mental health situation for Josie. Her eating disorder returned, she went through an identity crisis around her gender presentation, as well as becoming suicidal. The addition of a permanent ileostomy to her body was a huge adjustment for Josie; it impacted her relationship to her body, her sexuality, and her gender.

Receiving support from family, friends and her queer community, seeking out knowledge about her body, illness and identity, as well as adjusting her lifestyle, including her diet, and experimentation in her sexual life and gender presentation, have all helped Josie maintain strength and agency over the course of her experiences. Although she still struggles with some discomfort and certain limitations imposed by illness, she has experienced sustained wellness for the past two years. Her understanding of the intricacies of her multiple and intersecting identities, her agency and the strength she has taken from, and developed out of, her experiences of embodiment have allowed her to create a good life for herself.

5.3 Josie's timeline

Creating a visual representation of Josie's narrative was a process that I struggled with for months. I made numerous attempts to create a clear picture of how her identity as a queer woman with a disability shaped and was shaped by her experiences, and the key moments along her timeline that interacted with these identities. I found that her narrative was too complicated to display along one trajectory, as her identity as, and experiences of being, disabled did not always intersect with her sexuality and queer identity. Expressing these identities and experiences on two different trajectories allowed me to look at where and how her identity as queer and as disabled intersect and diverge. Placing these two lines on top of each other, both guided by the same timeline (in this case, Josie's age) highlights the critical moments in Josie's narrative that impact both identity trajectories. The space between the two lines represents the complex space that exists between these two parts of Josie, a space for experiences that don't fit neatly onto either timeline, and are more than moments or events, rather are forces that can be transitory, long-lasting, underlying or that don't necessarily have a beginning or an end.

The two large horizontal arrows represent her sexual and queer identity trajectory (the top arrow) and her illness and disability identity trajectory (the arrow below). These two arrows are guided through time by Josie's ages displayed at the top of the page. Arrows that run vertical mark critical moments that impacted both the queer and disabled trajectories, for example beginning university or speaking to an ostomy nurse about sexuality. Two of the vertical arrows are red, while the remaining 4 are grey. The vertical arrows that represent the temporary ileostomy, and the permanent ileostomy are red to represent the greater impact these two critical moments had on both the queer and disability trajectories.

Individual points on the queer trajectory mark moments of importance significant to Josie's experience of her sexuality and sexual identity, while points on the disability trajectory are specific to her experience of illness, and identity as disabled. For example, on the queer trajectory individual points include Josie coming out to her mother as bisexual, while on the disability trajectory and important point is her moment of diagnosis.

The visual representation of Josie's experiences over time, and in connection with her queer and disability trajectories has illuminated the complicated ways that identity intersects and diverges around critical moments and particular events. The spaces where queer and disability experiences overlap, as well as the spaces between them when they disconnect, bring out important thematic areas for exploration. The area in between these two trajectories include experiences that impact and are intertwined with her experiences of her illness and sexuality, and span over time. These experiences are represented as clouds with horizontal arrows pointing ahead in time. Clouds are varied in size depending on the importance the experience holds for Josie, and are located along the trajectory based on when the experience began, and how it relates to other experiences in this middle area. For example, after beginning university Josie had her first experiences of homophobia and ableism, represented by two small clouds. Since Josie faces both homophobia and ableism throughout her life, arrows pointing into the future are located within these two cloud shapes.

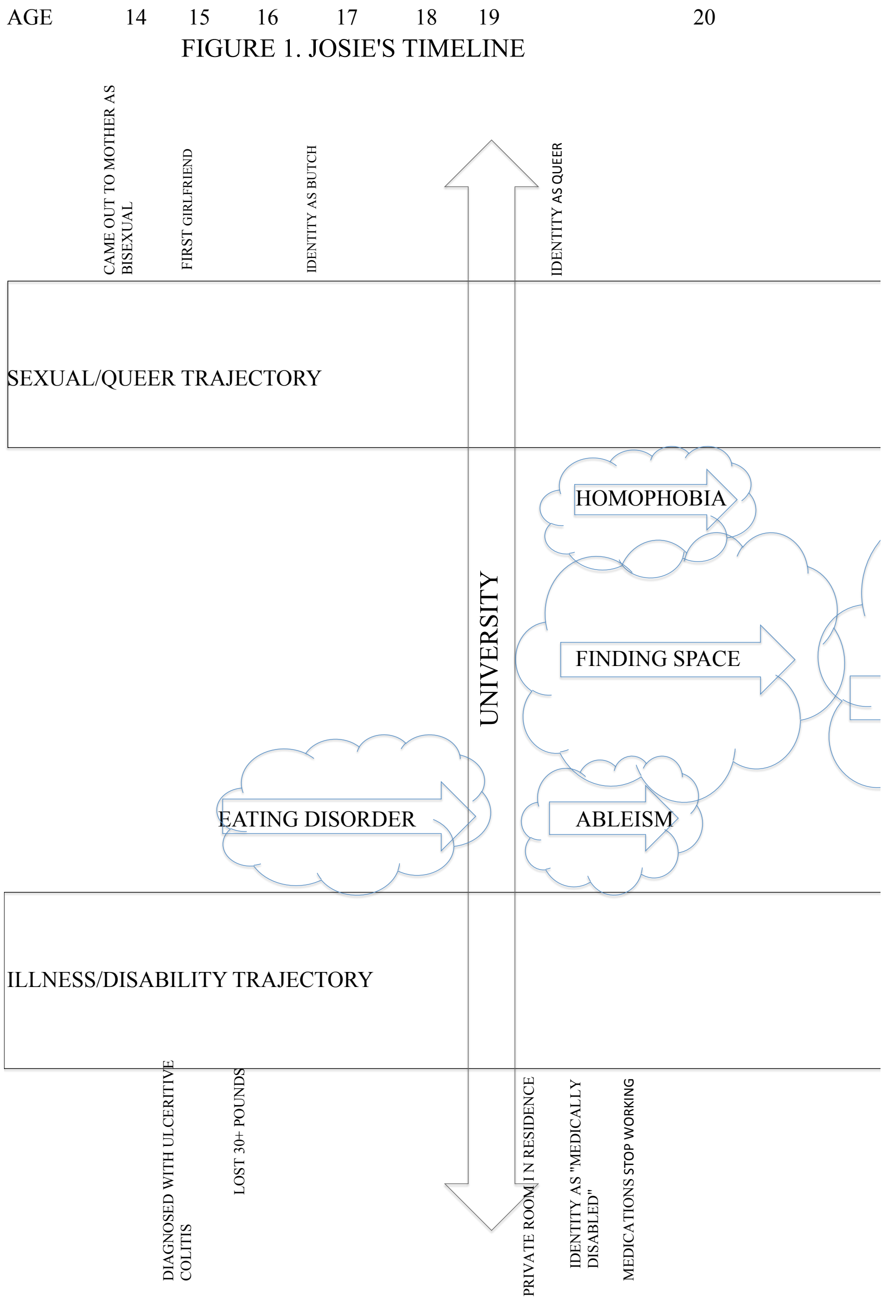
Homophobia and ableism overlap with the bigger cloud shape representing finding space. These cloud shapes overlap to symbolize the way that Josie had to find space and support in reaction and relation to experiencing oppression.

These areas can be understood as influencing Josie's experience of her sexuality and illness, and in turn are impacted and changed by her queer and disabled identities. These areas between, and connected to, linear understandings of disability and sexuality identities highlight the important themes shown in the clouds shapes, such as 'finding space', 'pain' and 'experimentation'. These themes are chronologically located in Josie's life, and although these are themes that continue to exist over the course of her narrative, they are most salient at different points in her timeline. 'Finding space' is at it's peak of importance when Josie begins university, while 'pain' is at it's most intense during Josie's early twenties. 'Experimentation' occurs at numerous points in Josie's life but is clearly embraced in the later twenties, and the present.

The middle area between the queer and disabled trajectories also contains two rectangles. These span over a specific period of time, unlike experiences represented in the cloud shapes that continue throughout time, or weave in and out of Josie's life. The two rectangles show a period in which Josie decided not to have sex, as well as a period in which she underwent multiple surgeries.

The final vertical arrow, self-acceptance, that intersects the queer and disabled trajectories has been placed overtop of the trajectory arrow points. The purpose of this placement is to symbolize this as both a critical moment in Josie's life currently and as a process carrying on into the future.

FIGURE 1. JOSIE'S TIMELINE



21 22

FIGURE 1. JOSIE'S TIMELINE

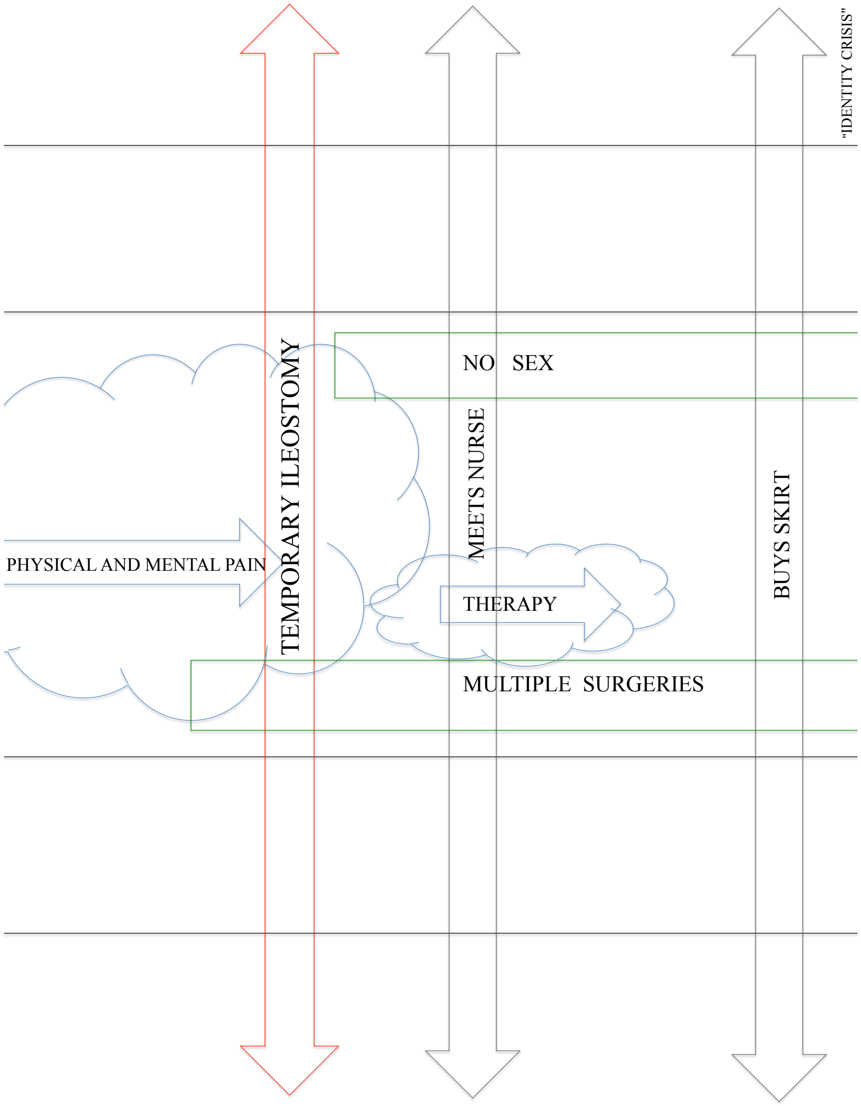
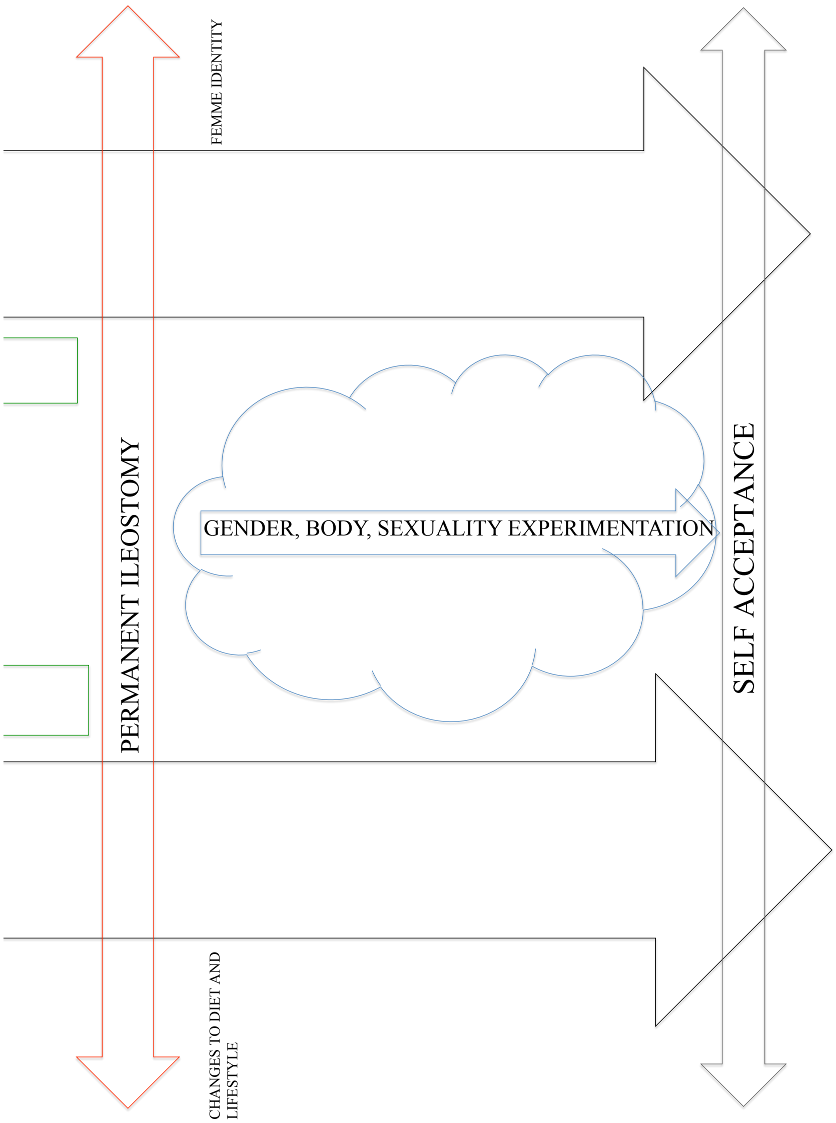


FIGURE 1. JOSIE'S TIMELINE



5.4 Identity as embodied

5.4.1 Introduction

Moving through the world, negotiating surroundings, relationships, and interactions, both within and outside of the self, begins in the body and is changed by the body. Josie's experience in, and of, the world has had an impact upon her experience and understanding of herself, and how she has come to develop and express the multiple parts of who she is. Josie is not just a woman in a sexist world, nor someone with a disability surrounded by the healthy and able bodied. She is also not just queer in an overwhelmingly straight world. She is all of the above, all at once. She is a queer woman with a physical disability, and these identities intersect, complicate and change each other within her body, and in reaction to her body. The way that Josie embodies her multiple and intersecting identities can be understood by looking at the language she uses to describe herself, the ways in which she is both invisible and visible, as well as how her changing and painful body complicate and impact her experiences of identity.

5.4.2 Understanding identity

Josie's experience and understanding of her gender, sexuality and disability have shifted and changed over time. As she developed a more complex idea of herself in the world, the language she has used to describe these identities has also changed. Over time she has chosen different words to reflect how she embodies her sexual, gender, and disability identities. At different points she has used the words sick, critically ill, chronically ill, disabled, and medically disabled. Josie explained the loaded nature of the word disabled, and how it has different meanings to different people. She related one experience when she identified as disabled to someone with a mobility disability, and was told that she couldn't consider herself disabled. Josie talked about many people that she knows who have chronic illnesses, most of whom would not consider themselves disabled, but explained that those who do use the word disabled are located within a similar academic context as Josie. Josie explained the use of the word disabled to describe herself:

> For me it's been absolutely integral to gain an education, to travel to do everything I have done in my life I have had to call it that, because that is the

> paradigm that people understand it within. And it's also been empowering in a way because when people think oh you're sick they don't really understand that it significantly impacts your life. Like it's a big big deal, a really big deal and um when you say disability there is some sort of reference point for the average person to understand what that might mean in terms of how it impacts your life. However people still don't understand, when you say disability a lot of time they are like Oh! And you know they have more questions but they don't really want to ask them. But if I actually sat down and talked about the ten major ways this impacts my life like on a daily basis like I have to go about things differently in my life then people understand why it's important to have washroom facilities then people understand why it's important to have single unit bathrooms not just like these big public bathrooms or whatever. Like it's important to have these things. Ya but you really have to have someone willing to give intimate details about their bodily function in order for average people to understand. And it should not be my responsibility but it's the only way you can get people to understand because they absolutely have no clue they have zero reference point. And I don't blame it on them, they are healthy motherfuckers, they have been really really lucky and they complain about little things and that's great for them but you know they have no reference point of what it actually means to almost die, and then not die and then figure out how you are going to live (Interview 2, line 145-167)

Josie has also related to different words to describe her sexual identity as seen in the excerpt below,

> I identify as a woman, a queer woman, I used to identify as a lesbian, I was briefly bisexual in 1993, I was a dyke for a while but if someone called me that now I would be very uncomfortable with it. Just because I don't like when other people call me things that I don't call myself (Interview 1, line 18-22)

Even over the course of our five interviews, Josie's understanding of her identity and the way she explains her queer self has shifted. When discussing her identity in the first three interviews she explained her use of the word queer, and identified as a queer woman, she saw this word as a sort of umbrella term encompassing a variety of sexualities and ways of being, that for her are linked to radical body and sexuality politics. As time passed Josie began to re-conceptualize her understanding of what queer meant to her. She explained that she still identifies as queer, however she currently sees this as a "non-identity" (interview 4, line 276). She elaborated on what the word queer means to her currently:

> Queer is about non citational life, its about an alternate relationship to time, it's an alternate relationship to capitalism it has a really radical political history. It's not actually an identity, like queer is not an identity, it's a non-identity,

> right, it's not like a stable like you're born queer or whatever, that's not what queer is. I think queer has been completely co-opted in various organizations. It's been completely co-opted, it's been stripped of all, it's not about being a good prototypical liberal subject who consumes and goes and votes. That's not what queer is, queer is not about being fucking homo normative. Homosexuality, at least in a lot of urban Canadian contexts, is completely normative. Well not completely normative, because people are still killed, beat up and disowned from their families and all these horrible things happen, but there is a move towards normativity, and a move towards having homosexuality as just like heterosexuality, that type of idea. That is not queer, that is absolutely not queer, they might call themselves queer but they have no concept of what the word means. (Interview 4, line 261-274)

This idea of a non-identity emerges from her evolving belief that "there is no stability, there is no truth" (Interview 4, line 280). She elaborated that rather than there being one truth, that there are multiple truths, multiple ways of understanding oneself and that theses truths, or understandings, change over time and are situated "historically, culturally, spatially, temporally" (Interview 4, line 284).

Josie's development of this approach to her identities can be seen as coming out of her experience of her physical body as constantly changing and shifting over time and throughout moments of illness, pain and disability. There appears to be a link between the acceptance of the changing physical body, and understanding identities such as gender and sexuality as similarly changeable. Her unpredictable physical body, and it's ability to move in and out of illness, pain, disability and relative wellness without notice, has required Josie to accept that her physical body, and it's trajectory, are not always in her control. Learning to cope with a shifting and changing physical body has, for her, meant developing an ability to understand her physical body as unstable, and unfixed.

This perspective is applicable to other areas of her experience of self, and has laid a foundation for her understanding of other parts of her identity as similar in their changeable nature, and it seems that this has offered Josie a sense of control that she hasn't always experienced when dealing with her physical body. The ability for Josie to name herself, decide what language she wants to use and when, to describe her gender, her sexuality or her disability, has offered her a way to actively engage in the creation of, and changes to, her multiple identities.

In addition to understanding her body and her queer and gender identities as fluid and changeable, Josie's worldview has also been subject to shifts and changes. The language she uses to describe and understand her multiple identities is both influenced by, and influences what she believes about the world and identity more generally. Her understanding of identity in relation to others, and to her own ideas about gender, sexuality and disability, have grown and changed significantly in the last 10 years. When looking back on her understanding of identity as a 16 year old she said:

> When I was 16 I believed that women shouldn't wear bras and that no one should shave and I believed in this second wave lesbian feminist vision of like living on a commune where you harvest wheat and you know, you have no men in your life and women were a certain way. And I believed that there were women and there were men, and that there were lesbians and that there were heterosexual people. Like I didn't believe that gender was fixed but I believed that sex was fixed and I believed that the majority of women had been duped by the patriarchy into like shaving and wearing makeup (Interview 4, line 294-301)

When Josie entered university her worldview, as expressed in the quote above, was challenged. She explained that meeting people who didn't agree with her was an important part of her development of new ways of understanding identity that are more nuanced. Meeting people who were transgendered also forced Josie to re-evaluate her ideas about gender and sexuality identities, she had to break out of what she referred to as an "incredibly soothing…ready made analysis of the world" (Interview 4, line 301-303). In expanding her analysis of the world, her ideas about the body, sexuality and gender grew into what she referenced as her body and sexuality politics. She described her body politic as including the following ideas:

> You can present however you want and that you should be able to change your body with no real authority intervening in it, and that you should be able to change it for good, change it temporarily, you should be able to be fluid, all those types of things (Interview 4, line 333-336)

Her body politics also take into account the intersectional and embodied nature of identity, highlighted by the following quote:

> There are certain points where certain types of bodies, how my experience in these different things are refracted through my body at different times. Like

> certain things might take priority. Like if I'm in a queer space one might assume that it would be my queer body that would be how I am relating to my body, however if there is only one bathroom and there are 300 people at that event then my disabled body is how I am experiencing my body (Interview 4, line 365-370)

She explained that even though she finds that there is a lack of attention, within the queer community, and queer body politics, of the disabled body, there are overlaps in experience between queers and people with disabilities.

> There is this sort of divide between um a lot of disability politics and queer politics. That is definitely not the case with all people, there are a lot of really really amazing queer people, that because of their queer experience, even if they themselves aren't disabled, they do have an insight into what it's like to have a non normative body or to experience space as an uncomfortable, having a special relationship to the world that is uncomfortable. I think that queer people and disabled people and people with chronic illness do have that in common. (Interview 5, line 29-35)

One of the ways that she explained her queer and disabled body politics intersecting is around fat politics[8],

> Unfortunately I don't think the disabled body comes into play much in queer politics, I think that's changing but fat politics and fat phobia sort of interplay as well (Interview 4, line 337-339)

She noted that in relation to her broader queer community, her ideas about the body, including her fat politics, are not necessarily a favored perspective. She explained that there is a tendency within queer body politics to include an understanding of fat politics that is simplified. She explained that the popular 'fat politic' remains un-nuanced, and takes a defensive stance in relation to any association between the fat body and the unhealthy body. Josie feels that an understanding that is more

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[8] Fat politics are perspectives found within fat activism or the fat liberation movement. This movement began in the 1960's alongside other social movements (Fletcher, 2009). Fat activists desire an end to discrimination against fat people, and criticize the idea that being fat impacts health negatively. Fat queer activism was born out of the intersection between lesbian feminism and fat liberation in the 1970's (Cooper, 2010). Within the queer feminist fat movement Nomy Lamm is an influential feminist and queer writer, performer, activist and speaker whose work has focused on ending fat oppression. See also Sander Gilman's "Fat: A cultural history of obesity" (2008), for a discussion of how obesity is a socially constructed moral panic. Important organizations include The National Association to Advance Fat Acceptance (www.naafaonline.com/dev2/index2.html), as well as the former organization called Fat Underground.

complicated is necessary, based on her experience of her body as sick as well as struggling with an eating disorder. She elaborated,

> Because I was really sick I am really committed to eating well and trying to live a good life and be active and control things that I can control. So like when people have a un nuanced or black and white approach to like fat is good or fat is always good, I think that is really short sighted (Interview 4, line 339-342)

This differing perspective is where Josie and her queer community face a disconnect. In many ways though, her understanding of her identity has been aided, and in turn has challenged (for the better) her queer community. For example, she has vocalized the importance of accessibility to organizers of queer events and in turn has helped these events become more inclusive. She noted that events put on by queer organizations or individuals are much more likely to take her criticisms about accessibility seriously. For example:

> I've always had people that I could be like "this event is inaccessible" and they will say "oh my god you are right…" you know and they will listen to me. When I've written letters of complaint to organizers of events before, of queer events, they have always responded really well, they have apologized and understand where I'm coming from or they attempt to understand where I'm coming from. So and at a lot of queer events there is a huge effort to accommodate people (Interview 5, line 36-42)

Part of her process of understanding her own identities and the ways that they intersect and impact her experience in the world has been aided by going to therapy. Josie explained that for a period of time she was meeting with a psychiatrist multiple times a week. Josie stressed the importance of being able to articulate to the psychiatrist that she wanted to remain in control of whether or not she was going to take medication for her mental health issues. She said,

> This is what I told him, because I've had so many friends who have been forced into taking psychiatric medication because their desires have been pathologized, who they are, their identities have been pathologized, like in terms of trans people and queer people like "you aren't trans you are just depressed" or whatever. So they had basically been forced to take this medication so..I recognize the over medicalization, the over prescribing, over prescribing people who are non normative, who are considered deviant (Interview 5, line 227-234)

She eventually did decide to take anti-depressants and anti-anxiety medication. In conjunction with therapy, this helped her process the impact that her illness was having on multiple parts of her life. Such as her mental health, her social and sexual life, her body image and associated eating disorder, as well as the identity crisis caused by the ileostomy and the resulting shift in her gender presentation.

5.4.3 Visibility/Invisibility

The way that Josie's multiple identities intersect have had profound effects on her experience of her body and play a role in how her identities shift between being both visible and invisible. Her gender, sexuality and disability each become more or less visible depending on how these identities are interacting, intersecting and being performed. The physical environment and the people with whom she interacts, and is surrounded by, also play a part in how and when these identities become in/visible. For example, she explained that because of the nature of her illness and it's ups and downs, she has been more disabled by it at certain points in her life than at other points, however when face to face with people who are healthy, her experience of her body has come back into focus,

> When I'm in situations around people who are really healthy, I am reminded of the fact that this will never go away. Even though I am not critically ill, and even though my health is controlled I will always have issues I need to deal with, and I have to live my life daily in a way that people who are healthy, or people who don't have an impairment or disability of some kind, um I have to live my life differently. So, you know, it takes up time, it takes up finances, emotional energy. So it takes up all those things, which definitely negatively impacts my life (Interview 1, line 33-40)

Negotiating her place in the world has often demanded that she separate herself into categories that are more easily digested by those she encounters and the places she needs to fit. For example, in order to have the university residence accommodations she needed, she had to call herself disabled, even though that was a label that she didn't feel reflected her experience of illness. Using this label meant that she would be taken seriously by the director of the residence and be able to have a room with a private bathroom, she explained:

> Access to a private, always available bathroom, absolutely essential. I could not live in a residence if I did not have this room. So I remember having this

> conversation with my mother because she obviously really wanted me to have a residence experience and I really wanted to have a residence experience and I was on the medication that kept me well for like a few years at this point, so um I was well enough to go to school but I wasn't well enough to be away from a bathroom so um she had to write this thing saying that I was disabled and I remember me telling my mother but I'm not disabled and she goes Josie you are disabled in their eyes and in order to get this room you need to tell them that you are disabled. I remember having this conversation and I was like this feels sort of like I'm lying because at this point I considered disability as being in a wheelchair, um or being blind. When obviously a blind person doesn't fucking need the bathroom, I need the bathroom! Okay? So I remember thinking it was a bit weird and then so obviously I get the room um I was the only disabled person that year who applied for it. (Interview 1, line 188-203)

She then was singled out as the only student in residence who had a room with a private bathroom. This difference and the attention it generated meant that she became more exposed for her other differences. Her visible queer identity incited homophobia and harassment from other girls on her floor. She described her experience in residence as "horrible" (interview 1, line 218) and said:

> I had a shaved head, I wore army pants, it was 2000, it was still like 90's style, I wore like doc martens and army pants, like I was very you know lesbian. Right. I also had a girlfriend who I brought to the residence, and we would say good night and kiss and stuff outside the residence on the days that she didn't come into the residence. So they knew, and my next door neighbor-the girl who lived right next to me, oh my god they made my life a living hell. Oh my god, they called me dyke, on the elevator they would whisper about me but like really loudly. (Interview 1, line 220-227)

Interestingly, her identity as disabled then became less visible as the focus had shifted to something-her queer identity-that was outwardly noticeable. Her lesbian butch aesthetic, and being seen with her girlfriend in public spaces in the residence, made her more visible as queer. Her identity as disabled was hidden, despite her special accommodations, she appeared to others as healthy.

> All the girls on my floor wanted to know why I got the room with the bathroom. So like then I have to tell them that I have a disability, and there I am, looking incredibly healthy. I'm plump, I'm you know. They don't know what the daily reality of my life is, you know?... I said that I was disabled and that I had to have a bathroom, and I remember feeling really really weird describing myself that way. Then I started using the term medical disability, because it made it so they understood there was a medical issue, and it also made it so that they wouldn't react to me with more questions. Cause when you say you have a disability, they just look confused and then you have to say

> more, and then I would be like well I'm chronically ill, that's what I would say. I have a disability and I'm chronically ill so I need a bathroom. (Interview 1, line 204-216)

This invisibility proved frustrating in that assumptions others made did not account for her daily reality and the struggles faced because of her illness. Stating her identity as someone with a disability was also frustrating because it meant becoming exposed to an array of personal questions and confused looks. This occurred because she didn't appear to fit in with assumptions held in the disabled and non-disabled communities, of what 'counts' as a disability,

> It's always kind of difficult because when people think about disability they think you have a mobility issue. They think that you can't walk or that you are in a wheelchair and then having to explain to somebody…like I ended up having to tell people details about me that is absolutely none of their business (Interview 2, line 16-20)

Josie's body has changed physically and in it's presentation, in response to the addition of an ileostomy and the pain that complications with the ileostomy have caused. For example, in order to feel more comfortable, physically and psychologically, with her ileostomy she began to shift her gender presentation-from butch to femme.

> When I figured out that I was going to have to wear skirts I was like what the fuck! I started to have like an identity crisis because the functionality of my disease necessitated a shift in my gender! Or at least my gender presentation…it was a big deal it was a really big deal. So I was like I guess I'm going to have to wear skirts and I remember going out to…buy a skirt, I remember this day, I still have the skirt actually (Interview 2, line 213-219)

This progression from a butch identity and aesthetic towards a more feminine one has impacted her visibility as queer, as well as her ability to challenge others assumptions of gender. Prior to the changes in her physical body she was able to maneuver in the world as a visible butch woman, making access to other queers and a sense of belonging easier to come by. As a result, she found other queer people and allies quickly. Without these visual markers signaling her queer identity to others, she began to move through the world in a body that despite being queer, was often read as straight. She explained that one of the reasons she dislikes summer is that she feels more exposed to, and pursued by, straight men. Despite this Josie expressed satisfaction in being able to challenge assumptions that femininity equates heterosexuality. She explained the power she has felt in being a queer femme:

> I really became invested in my femininity and the power I could wield with my femininity, like I was involved in student politics, and me being considered attractive as a woman in politics is actually very powerful and so suddenly I realized that I could actually achieve attractiveness not just in the queer community but to external people, and that's pretty fucking seductive. Suddenly having access to certain points of normativity, um it's, especially if you feel like you've been denied them, or fell short of them or didn't even want to try so you opted out because you knew you would fail, you know? So it was really powerful being this feminine, attractive, person considered attractive by straight men, and then being like well actually I'm a lesbian go fuck yourself. That's like pretty fucking amazing right, and now I'm in a situation where I would actually date them (Interview 4, line 571-581)

Her body has also been perceived as healthy, even when in the midst of critical and acute moments of illness. For example, her decision to call herself medically disabled came out of a need to assert her daily reality in the face of what is seen as a healthy body. Calling herself medically disabled meant that people would understand that there was an unseen medical issue that impacted her daily life; this also prevented them from asking personal questions about her body.

Negotiating her multiple and intersecting identities in order to access needed accommodations, or find belonging and community, has required a certain kind of balancing act, and has forced her to put parts of her identity on hold. She has been denied the experience of being perceived in the world as she perceives herself, as unique and complex. Depending on context, Josie's identities can become more or less visible, a source of stress or a place of comfort; however, more often than not she has struggled to find contexts, spaces and moments in which all parts of herself can be expressed, validated and celebrated. The tension she has experienced between her real self and projected self has been most salient in contexts that require her to embody only one of her identities, rather than being able to have control and ownership over her presentation of identity.

5.4.4 The changing body

It is challenging to pull apart the complex experience of the changing body. Multiple, shifting and sometimes contradictory understandings of identity and the body create tensions. The changing body represents both physical and mental changes resulting from illness, as well as self imposed changes to cope with illness. In addition to these factors, other forces have impacted Josie's body and her experience of it. These include external and internal pressures to conform to 'normal' visions of femininity and health.

At 15 Josie lost extreme amounts of weight due to the onset of her illness. She discovered that being thin both eased physical pain and frustration with her treatment regime. In order to cope she developed an eating disorder. Her relationship with food has continued to be one that she has struggled with on and off throughout her life. The re-emergence of her eating disorder at different times corresponds with several factors including her medication ceasing to work during university, as well as the beginning of a period of multiple surgeries to create a j-pouch to deal with complications. The creation of a j-pouch (which is an internal system to deal with waste once the colon has been removed) requires a temporary ileostomy to be put in place:

> I had the surgeries, basically there's a three-step surgery, some people have done two but if you are really ill they do the first step and then they wait 6 months or a year until your health improves. So when I went into it I was in a really critical situation so we ended up doing that. So they take out your colon first of all, they give you a temporary ileostomy-which is the bag (Interview 1, line 325-330)

While Josie had her temporary ileostomy she reduced her food intake so that she was able to avoid making as many trips to the bathroom to empty her ostomy bag and avoid painful food blockages. In this way her eating disorder allowed her more time to adjust to life with her ileostomy.

Maintaining a thin body provided comfort in the face of having to alter her gender presentation. In order to disguise the physical aspects of her disability (her ileostomy bag) she felt that she needed to wear a skirt. For Josie this meant she would be presenting as more feminine to the world.

> At the time it was helpful that I was thin because I think I would have, to buy the skirt and not have been thin, it was just a very complicated situation, a lot of things were going on. Where in my head I was like if I'm going to wear a skirt, which I need to reduce my anxiety, um I'm going to have to be feminine, but in order to be feminine I needed to be thin because my version of femininity was still wrapped up in straight culture (Interview 2, line 244-249)

The thin body that occurred because of her illness and her eating disorder played an important role-despite the difficult circumstances- in easing the transition to a more feminine gender presentation. However, the feminine body as a thin body is a perspective that Josie associates with straight culture. She notes that in the queer community there is not this same perspective, but instead a greater acceptance for different bodies, changed bodies and bodies that challenge normative ideas of gender, sexuality, and ability. Josie sees queer as more than simply whom she is sexually attracted to. For her, queer is also about one's radical body and identity politics. Despite her radical body politics, Josie has not been immune to the pressures of 'straight culture', or social and cultural discourses that dictate a particular vision of femininity, health and the body.

Being thin and more feminine made her disability and sexual identity invisible. Others assumed her heterosexuality as well as her health, because of their internalized associations linking the thin body to the healthy body. This situation complicates dichotomies such as visibility/invisibility, thinness/frailty and privilege/oppression. The more ill she became, the more positive attention she received from others who value thinness and femininity. In order to experience acceptance within the realm of feminine her struggle with illness had to remain invisible, consequently having a negative impact on her mental health. However, when acknowledging her illness she risked being perceived as frail, which is a position not afforded the same privileges as thinness.

While maintaining thinness had negative consequences for her mental and physical health, it also acted as a coping mechanism in a time of bodily transition. The transition to a more feminine gender presentation became easier for Josie because of her lower weight. Her eating disorder allowed her time to adjust to her ileostomy and avoid pain. The role that pain has played in her development of an eating disorder, and in her experience of her body in general is an important part of Josie's story.

5.4.4 The role of pain

Throughout Josie's experience of illness, pain has been reoccurring and has shaped her relationship to her body. Josie has weaved in and out of her life, and body, based on the presence of pain. During times of relative wellness, she was able to go to school, have a social and sexual life, and in an instant was pulled away from this reality by the sudden return of a painful blockage or a complication with her j-pouch or ileostomy. Pain's sudden appearances pulled her back into her body and forced her to face the limitations of illness. Pain was a barrier that disrupted her day-to-day life, and at points prevented her from participating in relationships and experiencing her sexuality, she explained:

> I was housebound, I couldn't go out I couldn't really have sex I couldn't be in a relationship, I was in incredible pain, I couldn't leave the bathroom. (Interview 1, Line 285-288)

Pain altered her body's physical appearance through significant weight loss, she talked about the disconnection between other's perceptions of her body and her own, describing the way that thinness was celebrated even if at the expense of health and confidence.

> All of a sudden I was really thin and everyone was like oh it's horrible you've been sick but at least you lost all this weight. Like literally they said that to me, like literally. Like that's verbatim what they said (Interview 1, line 611-614)

She said that even though she looked like "a dream in the modeling business" (interview 2, line 226), she did not feel confident, attractive or happy in her 100-pound body.

Pain prevented her from engaging in parts of her life, causing isolation, depression and feelings of hopelessness. She explained how physical pain created mental and emotional pain,

> It's not tolerable, it's absolutely not and that's why you go crazy because you just can't handle it, and you can't handle it for long periods of time. It's horrible. (Interview 1, Line 488-490)

The constant re-occurrence of physical pain kept her tied to her body, to illness, unable to forget about it, or have more than fleeting moments of pleasure. The uncertainty of when pain would reappear not only made it difficult to maintain structure and consistency in her life as a student, a friend and a lover, it also caused anxiety. Josie explained the anxiety that would arise when she would be in class and feel the sudden onset of a painful blockage:

> I'd be in school and then suddenly I would get this pain and I would know that in twelve hours I was going to be admitted to the hospital. I would be in school and then I would be like I need to leave now cause I may only be able to walk for another twenty minutes. It's a very distinctive pain, incredibly distinctive, I know the pain-I know it. I know exactly what's happening when it's happening and whatever I'm doing I need to try and get to the hospital. So, it was very bad, it was very bad for a very long time (Interview 1, line 467-476)

These experiences of pain lead Josie into a "critical mental health situation" (Interview 1, line 498) requiring sleep medication, anti-anxiety medication and visits with a psychiatrist four times a week. Josie explained the severity of this situation:

> For the first few years of my illness I thought this was how it was going to be forever and then obviously when the reality sets in that you can't live that way forever or you will kill yourself, like people that die from colitis die because they kill themselves. They can't handle it. (Interview 1, line 308-312)

She describes being obsessed with death, and wondered if she would ever experience life without pain, a life in which she wouldn't be trapped by her body. In order to cope with pain, Josie relied on narcotics. She described the difficulty in accessing pain relief,

> It's not actually standard practice to give you narcotics, you have to beg for them, you have to get a mental health professional to come down and tell your doctor to give you narcotics because you are going to ram your head against the wall and hurt yourself if you don't get any pain relief. (Interview 1, Line 479-483)

Josie talked about having an atypical experience of ulcerative colitis, of not being able to engage with life the same way that those around her can, and of having a non-normative body. She said:

> It's psychologically painful to be sick, even when your bowel is no longer inflamed, even when the surgery is over, even when you are no longer nauseated. Psychologically it's painful to have a body that is not normative. It still hurts to know that I can't do certain things, or that me doing certain things takes so much planning, and other people totally take it for granted (Interview 4, line 422-427)

Josie explained that because of her experience of illness she has had to live, and structure, her life very differently from people who are healthy, she said:

> I have to live my life daily in a way that people who are healthy, or people who don't have an impairment or disability of some kind, um I have to live my life differently. So, you know, it takes up time, it takes up finances, emotional

> energy. So it takes up all those things, which definitely negatively impacts my life (interview 1, line 36-40)

This has been frustrating for her because she feels that people don't understand the impact her illness has had on her daily reality. Even amongst others with ulcerative colitis, Josie has felt that her experience has been misunderstood because it has been so atypical:

> I've met people with my disease that you know have been able to manage it, like maybe they were sick for a few years, they have a had a few flare ups, they have been hospitalized a few times, you know, um and that is really shitty for them, that sucks for them, but when they tell me that you know they started meditating and they like you know do yoga and their disease is managed and maybe I should try that, it has absolutely no relevance to my life because it's very difficult to talk about my disease with other people who have had my disease because absolutely everything that can go wrong has gone wrong with me. I've been in the five percent, I've been in the one percent. I am incredibly atypical in terms of my illness. (Interview 1, line 109-118)

Josie has felt left out on numerous occasions, she talked about the sadness she feels at the beginning of every summer, when her friends organize events outside far away from a bathroom. She explained that it is frustrating to have to plan around access to bathrooms, and that often this prevents her from staying at queer events. For example if there is only one bathroom, if the line is long, or if the bathroom is not functioning, she will have to leave in order to reduce her anxiety. Although the queer community, and Josie's queer friends have played a crucial role in supporting her through her experience of illness, she has also often felt excluded.

> In the queer community there is sort of this fetishization of mobility, like oh ya I'm gonna go to San Francisco and then I'll go to Vancouver, and then I'll sleep on a couch in Portland, and then I'll go visit my friends….there is this huge primacy placed on mobility and um people that are in pain, people that have disabilities can't fucking do that. They cannot sleep on a couch, I absolutely cannot sleep on a couch, I could sleep on a couch for one night, but is the couch close to the bathroom? Right? And I need sleep, if I don't sleep my stomach..like it really affects my digestion, it really does, if I'm not sleeping my body doesn't work properly. So psychologically it's really difficult to know that people don't get it, and you are excluded from community when you can't do those types of things (Interview 4, line 428-437)

In elaborating the ways that parts of queer lifestyle are inaccessible to her, it becomes clear that psychological pain is an area where her disabled body and her queer body intersect.

5.5 Agency and resistance

5.5.1 Introduction

In order to cope with her experiences of illness and identity Josie has developed and maintained strength and agency. She has achieved this through a myriad of strategies including seeking out support from family, friends and the queer community. She has found importance and power in having knowledge about, and faith in, her body, experimenting with her sexuality and gender presentation, and resisting mainstream ideas and ideals of gender, sexuality and health. Josie has benefitted from taking control and responsibility over her own life where possible.

Throughout her experiences, Josie has strived to maintain agency in her life and to make decisions for herself whether they be about her health, sexuality or any other component of her life experience. The factors that Josie has been limited by when living as an agent in her own life include societal ideas and ideals regarding gender, ability, and sexuality. These social factors, and the way they become expressed by those that she interacts with, have had a profound impact on her experience of her intersecting identities, and have at times made her experience more difficult.

Negotiating her multiple and intersecting identities has often required her to resist mainstream notions of the body. These include the female body, the healthy body, and the sexual body. She has resisted these ideas through her alliance with the queer community, and her appreciation of bodies that are “different”. She has been open to the various ways that identities can be performed, embodied, and shifting. Josie’s complex understanding of identity as embodied and as fluid, in itself is a perspective that resists dominant and mainstream understandings. Josie’s perspective challenges the view of identity as fixed, of gender as either male or female, of sexuality as right or wrong and the body as either healthy or not.

A binary way of seeing identity is one that leaves little room for the conflicting and complicated realities experienced by Josie. Including her queer sexuality, shifting gender presentation and the ups and downs of her illness that have been more disabling at certain times than others. As discussed below many factors have helped Josie maintain agency, and given her the strength for resistance.

5.5.2 Support

The two main sources of support that stand out in Josie's narrative of illness and experiences of identity are her mother and her group of queer friends. Whether coming out to her mother as bisexual, or needing an advocate during hospitalizations, Josie's mother offered immense support. For example, when Josie was exploring her sexual orientation as a youth, her mother would drive her downtown every week for an LGBT youth group. Where her mother couldn't provide direct support, she ensured that her daughter received the resources and support that she needed.

When Josie became ill, she described her mother as her main support during this scary and stressfull time. Her mother continued to advocate for her in hospital settings, ensuring that Josie had the information she needed about her body and illness, as well as doing whatever she could to provide information on side effects of medications and engaging with doctors using medical language. When Josie was entering university and required a special room in residence-a room that had a private bathroom-her mother helped her write a letter to the director of the residence, using language, such as the label 'disability', that would ensure that her needs for a room with a bathroom would be met. Additionally her mother has helped her with the financial side of illness by paying for her ostomy bags:

> I'm lucky that my mom helps me pay for them, because I can afford to change my bag every four days. Some people financially you know have worked it out and they may only be able to afford to change their bag every 7 days. And let me tell you, 7 days and your bag smells, you don't feel fresh. 4 days is like perfect, like it's great, amazing. I don't have to worry, I can change my bag whenever I want, I don't have to worry about the finances of it (Interview 2, line 440-445)

Josie is grateful for this because as she said "Oh they are expensive, a box of 10 is like sixty bucks (Interview 1, line 380)", and expressed frustration at the lack of insurance coverage for these necessary medical supplies:

> It is incredibly expensive and it's not covered by insurance, like you can get a prosthesis-a fake boob, a fake arm, but the insurance company isn't going to buy my bag? You can live without a fake boob, I can't live without a bag! You know what I mean? It's fucked up. The government gives me 600$ a year, that covers about 5 months of my supplies (Interview 1, line 374-378)

Her mother's financial support has helped Josie to feel more comfortable with her illness. Being able to change her bag every four days rather than 7 means that she is less self-conscious and feels less anxiety in relation to her body and ileostomy.

Queer events offered spaces, (however not always accessible to Josie), to meet others with similar perspectives and interests. Josie attended these events even when she was very ill, because of the importance to her of a sense of community and belonging that she could find in these spaces. Although she mentioned that disability issues are relatively unexplored or discussed in her queer community, she found that despite this, queers have a better understanding of her needs than people in a more "normative" community might. For example she described the commonalities between queer people and people with disabilities in terms of having an experience of one's body as 'non-normative'. Having lived similar experiences on that level has meant, for her, that she has felt comfortable enough in these spaces, and with these people, to bring up issues of accessibility. When she has brought up accessibility issues she has felt respected and listened to by the organizers of such events. Having the support of the queer community in terms of taking her criticisms seriously, and working on improving accessibility to events, in turn also supports her queer identity and desire to connect with other queer people. The friendships that Josie built with other queer people have proved to be valuable sources of support during illness, she explained:

> The people that have really helped me cope with really critical illness and people who have taken care of me have been my friends who are queer and who you know who love me. Like when I was in the hospital, I used to have people come to the hospital to support me, people taking me home, coming to visit me in the emergency room, people took care of me when I was in my apartment and couldn't leave my house. (Interview 4, line 55-60)

In addition to queer events being spaces to meet friends and allies, they also provided opportunities to meet potential partners. Josie explained that since becoming ill, and because she has an ileostomy and a "non-normative" body, it is extremely important for her to be selective in whom she engages with in a sexual relationship. Meeting a potential partner at a queer event removes some of the anxiety around what kind of body and sexuality politics that potential partner might have. It becomes a little bit safer in a queer environment, and realistic to hope the potential partner will be someone who supports a positive body image. She explained that the reason she doesn't have one night stands is because she needs to ensure that her partner is going to be respectful and supportive of who she is, and how her body has been affected and altered by illness.

She explained:

> But I'm also sleeping with radical people that have good body politics. You know what I mean right? I'm not sleeping with straight men from the straight bar. These are queer people, even if they are men they are queer people you know (Interview 2, line 406-409)

5.5.3 Knowledge and Faith

Josie has found power in having knowledge-such as medical, scientific and factual information about her body, illness, medications and procedures-while at the same time holding a strong belief in the power of faith. She describes that faith as faith in herself, the power of her mind, and her body, rather than in god or a higher power. These two sources of power merge in Josie's experiences of developing agency and resistance.

Josie sees knowledge as power, and as able to demystify illness. She elaborated on the importance of having knowledge about her body and illness as a patient, and in the context of the patient/doctor dynamic. She stressed that for her, to be denied knowledge means that she is put in a position where she is not able to make decisions, in essence stripping her of her agency. She described knowledge about her body as resistance to what she sees as deferring to authority, or in this case deferral to the doctor or health professional,

> If I don't understand the way my body works than I am forced into a system of deferral. If I am denied access to knowledge then I am denied a sort of active subject position in the exchange. So this forced deferral, I have to defer to authority, I have to defer to doctors, it's really unfair (Interview 4, line 28-31)

Josie described feeling empowered by having more knowledge about her illness, the medical procedures being performed and the types of medications prescribed.

> Like being equipped with knowledge about the disease, not just talking about how it made me feel but understanding how the disease functions, and understand on an intellectual level what was happening in my body and understanding just like, just feeling powerful, being able to talk to doctors as a young person knowledgeably made me feel in control of my disease even though I was not in control of my disease (Interview 1, line 125-130)

She described how coping with her illness was helped by feeling informed about what was going on with her body, she talked about the importance of being confident and able to ask doctors and nurses questions. Since Josie's mother was a nurse and the doctors in charge of the Josie's care knew this, she described how they would speak to her and her mother using medical language, allowing her to learn about her body and her illness in a way that helped her feel in control. Additionally her mother, who Josie described as a very important support person and advocate throughout this process, also had access to information about side effects of the Josie's medications and information about her illness. Josie said she was not given information about side effects from her doctors because, as she explained, the doctors fear that if the patient knows what the side effects are they will think that they are experiencing them. This missing information caused Josie to feel as if she was going "crazy", she explained:

> So what ends up happening is that you think you are crazy because you all of a sudden you have this metal taste in your mouth and no one told you that you would have this metal taste in your mouth. You have hair growing on your back, all this fuzzy hair or something like that and they don't tell you. Or your knees start to ache and no one told you, like all this bullshit. Also the doctors they don't actually tell you all the intricacies of how they work, they think that you will be satisfied with very vague responses, and I'm not. (Interview 4, line 21-27)

Additionally, she felt that there was a lack of information being provided to her about the impact that surgical interventions for her illness would have on her body and sexual life. She explained the important role that anal sex played in her sex life up until she became ill and had her rectum removed, and her surprise that this loss was not addressed by health care professionals that were caring for her. If Josie hadn't held such agency in her life, and her right to pleasure and knowledge about what was happening to her body, she may not have had the confidence to ask for information about topics some consider taboo. Josie described asking a doctor about how her situation would impact her ability to continue having anal sex,

> I asked the doctor, I came in prepared, because I was thinking about it at home and I was like oh my god, like why hasn't anyone told me this is going to happen? Like if you were having a surgery where they were sewing up your vagina, don't you think they would tell you? Ya! They would tell you, but obviously they don't think about it in a sexual way, so I talked to my doctor about it and then I asked him if he had ever had a gay patient, I said well haven't you every had a …like he didn't really know what to say and was just like well..you should be able to have anal sex but I don't know if it would feel good because it's no longer the rectum internally it's your small bowel, which doesn't have nerve endings. So it wouldn't feel good, but then he said but I don't really know. And then I was like well haven't you ever had any gay male patients and he was like well yes of course. That was basically the just of the conversation. (Interview 1, line 539-552)

Access to knowledge, and the confidence that having this knowledge helped her build, was crucial at many points when she was hospitalized and not receiving the type of care and attention she needed. She explained one particular hospital stay when she had a severe blockage and as soon as it passed the health care professionals wanted to discharge her. Knowing her body, and the rhythm that these blockages took, she insisted that they let her stay as the blockage would return within hours, her confidence and knowledge of her body and illness allowed her to assert herself when necessary and receive the care that she needed.

This attitude of entitlement to information and knowledge has served Josie well, it has allowed her to resist the position of the passive patient, she explained her perspective:

> I do feel entitled to have information and I feel entitled to understand what's happening. Like if I'm in a situation I'm not satisfied to be a passive recipient, where I only understand one or two things, I want to understand everything. So I think my confidence to do that, to A admit that I don't understand certain things, and B to like claim entitlement to knowledge I see as being related to that dynamic being forced upon me, and that being a way that I was able to

> control my body through the situation at a very early age (Interview 4, line 12-19)

Josie's strength and agency in her life, especially when it comes to her body, illness and sexuality, acted as resistance in a sense. The lack of information provided to her during diagnosis, about medications and their side effects, about the impact surgery would have on her body and sexual life, all speak to a certain expectation of passive acceptance. Rather than putting her body completely in the hands of the health care professionals, Josie maintained her agency through asking questions, challenging doctors' notions of what is important to discuss with patients, and expected to be informed and heard. In doing this, she resisted the role of the passive/sick/weak patient, which becomes even more significant when that patient is a woman. Ideas of the passive patient are amplified when combined with notions of femininity such as being quiet, polite and dependant. She not only resisted these roles and expectations, she is open and unapologetic about who she is, and what she needs, such as her right to information about how illness is going to affect her body, whether it be side effects of medication or being unable to feel pleasure from anal sex.

Josie has described the importance of having faith in her body, in science and in medicine, rather than in some form of god or higher power. She explained that during moments of illness and hospitalization spirituality and faith in god were topics brought up by those around her. She told a story of her first girlfriend's family's reaction to her illness. They came to the hospital, bible in hand, and encouraged Josie to seek support from god during this time of critical illness. Josie grew up in a non-religious family and doesn't identify with any religion or feel particularly inclined towards spirituality of any kind. Josie was surprised when her mother began responding to her illness with discussions of spirituality. Josie responded to her mother's contemplation of the importance of spiritual faith during illness, with the following thoughts:

> I've almost died, I've been critically ill for years and I have absolutely confirmed the fact that life is about bodies that are born and bodies that die and that the whole notion of anything more than that is a complete fallacy. There is no arbiter in the sky; there is no spiritual life, that really doesn't exist. A lot of people's response to illness is spirituality, it's faith. For me it's been the absolute exact opposite (Interview 5, line 128-133)

Josie's faith in her body has helped her cope with illness and pain. She explained that when she learned that she would go unconscious if the pain was too much for her body to handle she felt calmer,

> I perceive the pain to be unbearable, I perceive the pain to be killing me, I perceive the pain to be beyond control, however if it really was all of those things I would go unconscious, like I would. So your body really only gives you as much as you can handle (Interview 5, line 176-179)

The faith she has in her body is reflected in the responsibility she takes in caring for her health. She puts emphasis on the importance, for her, of strictly managing her diet, sleep and general well being, in order to maintain a positive relationship to her body.

> If you make yourself believe that you body will take care of you, despite the fact that it doesn't work properly and that you critically ill, like if you do believe that it helps you cope (Interview 5, line 181-183)

Believing that her body will take care of her, makes it that much more important for her to take care of her body in whatever way she can. The faith that Josie has in the ability of her body to take care of her can also be understood as faith in herself more broadly. Believing in her own personal power to create a good life for herself, has meant having faith in her decisions about her body and how she structures her life to maintain her wellness.

> I believe that I have the power to create a good life for myself. I just keep that in mind, I believe I can achieve really big things and I believe I can do anything I want to in my life. Having that belief is contingent on the belief that I am responsible for my life (Interview 5, line 342-345)

Josie described her attitude of responsibility and accountability in terms of her illness, and her life more generally as a perspective that she learned from her mother, who, according to Josie, during difficult times took control of life and never complained. This way of responding is evident in Josie's narrative.

5.5.4 Control

There are many examples of the ways in which Josie's actions and decisions were influenced by a sense of responsibility for herself and a desire for control over her body, her identity, and her situation in general. Additionally it is apparent in Josie's narrative, that having a sense of control over her body, identity and situation helped her to maintain agency throughout her experience as well as the strength to resist other's desire for control over her body, mainstream and sometimes damaging notions of health, sexuality and identity.

The decision she made to reduce her food intake during the first months of having an ileostomy so that she wouldn't have to deal with the output, was a way for her to control what she could, regarding this new addition to her body, as well as changing her body to fit with her changing gender presentation. The sense of control she gained from this manifested itself further in a re-emergence of her eating disorder, however the struggle she has gone through to develop a more positive relationship with food points to the control that her disordered eating had over her.

The thin body, which she saw as more feminine, corresponded with her need to begin wearing skirts to be physically and mentally comfortable with the ileostomy. The thin and feminine body-although fraught with tensions-allowed her to feel more in control of her anxiety around the ileostomy, by reducing its visibility, pain caused by pants pressing against it, and allowing her more freedom in terms of when she would have to empty the bag.

Josie also spoke about knowledge about her body and illness, as discussed above, as important for feeling as sense of control over what was happening to her physically. She discussed the importance of feeling in control when meeting with doctors and nurses, able to ask questions and understand their responses. Interestingly when Josie spent time in the hospital she established some control over her surroundings and her experience by scheduling herself three visitors per day at specific times, and taking an active role in having her emotional and physical needs met when she could. However during times of acute illness and pain she found control through the realization that if necessary she could end her life, she elaborated:

> The reason why suicide was such a very tangible optimistic sort of possibility at this point was because there wasn't an end in sight. It wasn't like oh you are going to be sick for a year and then it's going to end and then you are going to be well. There was no sense of predictability, there was like, um I had no health in sight. Everything went wrong, everything always went wrong even though I had the best doctors in Canada, I was at the best hospital, I had the best treatment, I had the best advocate, which was my mother. I had all these things and like everything still went wrong. So in terms of gaining control and

> agency, the possibility that I could end it was really empowering. (Interview 5, line 155-163)

This is interesting in contrast to what Josie sees as other's view of suicide, which is seen as out of control, rather than an idea that promotes a feeling of control. She explained this tension in the following words:

> A lot of people think about suicide as being an irrational um response to a situation that is perhaps not controlled, or that they think oh you are only suicidal because your pain isn't adequately controlled, or you are only suicidal because you can't see that there is an end to your suffering. That type of view of suicide is perpetuated by people whose suffering has ended, and sort of denies the fact that for many people their suffering doesn't end, and that there is no end. So me knowing that I could end it was extremely empowering, really empowering. It made me feel like ok I am in control in the sense that I could end my life if I really needed to (Interview 5, line 163-171)

The strong desire within Josie to feel a sense of control in her life is in response to her experience of her body as unstable and her daily reality of illness and pain as unpredictable.

This is also evident in her approach to managing her illness currently. She talked about controlling her diet to minimize nausea and discomfort, as well as maintaining a lifestyle that allows her to be close to a bathroom, and have the necessary rest every night to ensure her body is functioning at its best, as well as strong friendships and people in her life who support a positive body image.

5.5.5 Experimentation

As has been previously elaborated, Josie's identity as a queer woman has been an undercurrent of strength throughout her experience of disability. Her queer identity and the ways that she engages with her sexuality have provided moments of pleasure, connection to community, and have facilitated an appreciation of her changed body.

Experimentation as a theme is most salient in Josie's stories around her sexual life. She struggled with pain, poor body image and mental health concerns throughout her experience of disability, however these difficult times are punctuated with positive and pleasurable sexual experiences. Even in the midst of critical illness, when Josie was first hospitalized, she maintained some elements of her sexual life:

> Granted I was so heavily medicated like I didn't have an orgasm but we really wanted to do something "radical" you know like we should have sex in the bathroom. It was my idea and she was like "are you sure?" And I'm like "Ya" and so we had sex in the bathroom listening to Ani Difranco on my fisher price cassette player. (laughing). I loved her, I loved her she was amazing, she was so great. (Interview 2, line 485-490)

Josie also maintained her dating life during periods of hospitalization,

> …Gregory that was a few years later, Ya I met him and he didn't know I was sick and we had a date planned. And I called him and was like "hi, so you know how we are hanging out tomorrow well I'm actually in the hospital but I would still love to hang out so this is my number, call me" and he actually called me back in the hospital! And he came and we hung out in my bed. Ya it was really nice, first penis I ever touched actually! (laughing), I mean I was also really high on narcotics! (Interview 2, line 511-517)

It was necessary for Josie to be open to intimacy and sexual expression taking other forms in her relationships because at certain times she was in too much pain to engage in some types of sexual expression. She explained:

> Before I used to be in pain or I was heavily medicated so having a sexual life when you are in pain is difficult…I had a long time lover in high school named Anna and then in University time I had a few really good lovers. When I was in mild to moderate pain, if I was in a lot of pain than obviously I wouldn't be having sex, but like if you are in pain a lot you still want to be feeling sexy you know? So we would do different things like my lover would just give me a massage you know? So you would still feel like you had an intimate life. But I definitely um didn't have a monogamous lover during my acute illness. I had a lover who was seeing other people, which was fine, and she would come to the hospital every day and rub my feet, and I was not interested in you know we would kiss and you know gentle and that was okay with her (Interview 2, line 462-474)

When Josie received the temporary ileostomy she decided that she would not be having sex for as long as the ileostomy was present. She talked about feeling uncomfortable if anyone were to see it, and anxiety that the bag would fall off during sex.

> My anxieties were that it was going to open, and that I was going to get shit on the person which is, how horrible, could you imagine, so horrible. Luckily it's never happened. My bag has come off once and I just clicked it back on. Luckily I empty it and change my bag right before I have sex (Interview 2, line 357-360).

At this time an ostomy nurse met with Josie, and one of the points of discussion was sexuality. Josie remembers feeling embarrassed, as well as frustrated at the nurse's assumption of Josie's heterosexuality. The nurse told Josie strategies that other individuals with ileostomies have used to make sex more comfortable, Josie explained her conversation with the nurse:

> So she was saying some people use smaller bags and some women use cumberbunds, that's like one of those man sashes that they wear on the tuxedo…To put around and they cover it. And I don't use a cumberbund, I use a fucking garter belt, obviously! Like what the fuck why would you use a cummerbund you know? And then the woman was explaining to me that she had one patient who um got a pink one that she decorated with lace. And like that is like really really sweet but why wouldn't you just buy a garter belt! It's so functional and it's already got lace! Anyways this whole thing was intensely embarrassing, I was so profoundly uncomfortable. I was young okay in my early twenties, I do not want to be talking to a 55-year-old nurse about my quote unquote boyfriend! And her pink lace cummerbund patient! So horrifying. So embarrassing so embarrassing. Cause in my mind this was temporary and I wasn't going to be having sex because I did not want anyone to see it (Interview 2, line 329-343).

Although Josie didn't have sex again until the ileostomy became permanent, when she did return to her sexuality she found ways to cover her ileostomy bag to feel more at ease. Something she needed to do to become more comfortable with her bag being seen by someone else was to make fabric bag covers. She later incorporated electrical tape to secure her ileostomy bag to her body during sex.

> So I'd have the bag cover and I'd have electrical tape and I'd tape it down, it was sort of sexy, ya sort of hot ya, and it really sort of opened, I was in my early twenties, and it really opened my mind up to kinky sexuality stuff like electrical tape you know? (Interview 2, line 370-373)

She talked about the importance of being creative. Creativity helped her discover a side to her sexuality that she hadn't been aware of before. She explained:

> I guess I had been sort of vanilla before, well all of a sudden you have to deal with this altered body, you really don't have a choice but to be creative and come up with things that work for you. I guess what I figured out with the electrical tape was like it was the best way you know to like secure my ileostomy to my body. Then um it sort of provided this really great pathway to like talking about sex with my partners (Interview 2, line 521-529).

This kind of experimentation facilitated sexual experiences that were both comfortable and fun for Josie, allowing her to regain confidence in her body and express her self sexually. Josie described that having a "non-normative" body has been beneficial to her sexual life. She explained that using electrical tape opened up the door to a more interesting sexual life by making it easier to introduce sex toys into the bedroom, as well as allowing her to see her ileostomy in a positive way.

> By sort of likening the electrical tape-which is a functional necessecity of my disability- to a fun, sexy aspect of my erotic life it makes my ileostomy an addition rather than a hindrance to the whole experience (Interview 2, line 541-544).

Josie structured her sexual life to support her needs. This has involved being selective about her partners, ensuring that whom she chooses to engage with sexually will support a positive body image. She explained that because of her particular situation she has had to develop excellent communication skills and the ability to talk about sex, her boundaries and her body with partners.

Experimentation also emerges as a theme related to Josie's presentation of her gender, identity as butch, and later on as femme. Josie experimented with her aesthetic after she first came out, she explained why this moment was important.

> In grade ten I decided I was going to cut all my hair off, I wanted a lesbian haircut. So I went to this hair salon down in the village, right at church and Wellesley and I asked the guy for a lesbian haircut, " I want to cut my hair off and I want a lesbian haircut", and I was like 15 and he was this older gay man cutting my hair whatever and I absolutely loved it, it was really short, my mother was horrified. All of a sudden I was considered attractive in the gay community. I went from being this chubby girl, that looked awkward, that was funny and smart. Then all of a sudden I'm in the queer community and I'm hot, I'm considered hot! It felt incredible, oh my god, it felt like my world had opened up (Interview 4, line 505-514).

The addition of an ileostomy to Josie's body years later prompted another shift in her aesthetic, in particular a progression from butch to femme. Josie needed to find ways to reduce her anxiety about her ileostomy bag's visibility, and discomfort caused by pants pressing against the ileostomy, she decided she would try wearing skirts. As someone who identified as butch for most of her young adulthood, wearing a skirt was something that caused confusion for her. Josie's need to experiment to find ways to cope with her ileostomy required her identity as butch to become more fluid and open to shifts.

> I love lingerie now, I didn't used to be like this, I used to be really sort of butchy, it's been this slow progression. Now I wear makeup, I do my nails, I wear high heels like I wear skirts all the time. Even if I could wear pants, okay if I could wear pants, yes I would definitely wear pants but I wouldn't wear pants to the exclusion of skirts you know? Like go big or go home. If I'm gonna be wearing skirts I might as well look damn good wearing them (Interview 2, 564-569).

Josie's experimentation with gender presentation and regarding ways of coping with the anxiety she felt in relation to her ileostomy, facilitated a progression towards a femme identity, which resulted in new sources of strength and empowerment. Over the course of Josie's trajectories of illness and sexuality there have been many moments of struggle, and more often than not these difficult experiences have also acted as turning points towards growth. Josie has developed strength and agency in her life, which she has used to cope with illness, to find pleasure and happiness and to resist oppression. As elaborated in the previous pages, Josie has used knowledge and support to help her through difficult periods, has struggled to feel a sense of control, while also allowing herself the freedom to explore, and experiment with her gender and sexuality in ways that have ultimately led her to increased comfort, confidence and happiness.

CHAPTER VI

Discussion and conclusion

6.1 Introduction

Josie's narrative has been explored by highlighting the chronology of her queer and disabled identity development, as well as looking at critical moments, turning points and thematic areas emerging from her experiences and understandings of being a queer woman with a disability. Main findings from studying Josie's experiences emerged under the themes of identity as embodied, as well as agency and resistance.

6.2 Insights from findings

The shifting language of identity, whether she used the words lesbian, bisexual, queer or sick, disabled, medically disabled, all point towards an articulation of bodily experience that is constantly in motion. Experiences of embodying identity were also dependant on context, becoming visible and invisible in response to factors such as homophobia, ableism, and other's perceptions of Josie's daily reality, body and gender presentation. As Josie's body went through periods of intense pain and changed from illness, an eating disorder and surgery, so too did her understanding and expression of her gender and sexuality. Experiences of pain had an immense impact on Josie's mental health. Depression, anxiety and suicidal thoughts were mediated by therapy, psychiatric medication, and support from family, friends and community.

Findings clearly showed a number of factors that facilitated Josie's agency within her life and resistance to dominant normative ideals of gender, sexuality, and the body. Knowledge about and faith in, her body allowed her to cope with pain, medical and other helping professionals as well as to occupy a position of empowered and knowledgeable patient. Knowledge about her body and illness also helped Josie feel a sense of control over her experiences. Feeling supported by family and her queer community helped her to maintain strength. The queer community played a big role in Josie's ability to navigate her experience of illness, whereas she associated a disability community as one in which she would be more isolated in terms of her politics, queer identity, and definitions of disability.

Experimentation in her sexual life, as well as with her gender expression, were important for Josie's confidence and integration of her multiple identities and changed body. Findings included feeling more attractive after experimenting with her lesbian aesthetic and presentation, and feeling less anxious about the visibility and discomfort of her ileostomy once adopting a more feminine gender presentation, which for her meant wearing skirts. Her sexual life became structured around her disability and thus she needed to plan ahead more so that she could have casual, or one-night stand, sexual experiences. Having to disclose her disability and 'non-normative' body to potential sexual partners meant that she sought out partners who were supportive of a positive body image, and with whom she could communicate openly. Her sexual practices became more creative in order to incorporate covering of her ileostomy bag- whether by bag covers, a garter belt, or using electrical tape to keep it secured to her body. The experimentation she engaged in to feel good sexually has meant that she has experienced a more satisfying sex life than most people she knows. This experimentation opened up an avenue of sexual practices that she had never before explored, including sex toys, and what she described as "kinky" sexual practices.

The findings make clear a process of developing and understanding her multiple and intersecting identities; how they are embodied, both visible and invisible, and fluid. Negative experiences of illness and sexual identity such as ableism, homophobia, pain and mental health issues were improved through access to knowledge, faith, support, community, a sense of control and a willingness to experiment. These factors helped to support agency and resistance as well as moving Josie closer towards self-acceptance.

Similar findings can be located within queer theory, disability and sexuality literature. Within the minimal literature addressing queer, lesbian or bisexual women with disabilities findings that are similar to those presented in this study center around identity development and community. Various authors have shown that queer, lesbian and bisexual women with disabilities face exclusion from, or difficulty accessing, queer and disability communities (Whitney, 2006; Beckett, 2004; O'Toole, 2000; O'Toole & Bregante, 1993). Ableism is often experienced within the queer community, while homophobia is experienced in the disability community. Although

Josie did not describe the queer community as ableist, she did note that she experienced problems with physical accessibility, but that upon bringing these issues up, organizers of queer events were understanding and respectful. Similarly, O'Toole (2000) explained that the lesbian community has shown a pattern of creating accessible events and dealing with accessibility problems. Josie identified with her queer community over any kind of disability community. According to Shakespeare (1992) this could be because Josie's understanding of herself as queer occurred prior to becoming disabled. His study indicated that most individuals more strongly identify with the community of their first identity. Whitney (2006) also found that women in her study saw their queer identity in a more positive light than their disability identity, and that all of the women had identified as queer before they became disabled. Axtell (1999) noted that lesbian and bisexual women, in developing their disability identity, became more involved in the lesbian community for support.

The presumption of heterosexuality is an issue discussed in the literature on queer, lesbian and bisexual women with disabilities. Josie faced a similar situation when the nurse that met with her to discuss sexuality with an ileostomy assumed her to be heterosexual. Additionally, queer women with disabilities in the literature have described their identity development as a process (Whitney, 2006), as connected to expressing the positive elements of being disabled and resisting internalized ableism (Axtell, 1999), which all have been echoed in the findings of this study.

The impact of chronic illness and disability on the mental health of women is present in the literature, as well as in this study. Walden (2009) found in her study of lesbians with chronic illness that the mental health needs expressed in the participant intake interviews were "numerous and alarming" (p.565). Walden (2009) references Livnen and Antonak (1997) who agree that the presence of psychological problems including depression and anxiety appear to be strongly linked with chronic conditions.

Literature looking at women with disabilities found expectations of femininity and the 'normal' body (Shakespeare, 2006; Zitzelsberger, 2005; Taleporos & McCabe, 2003; Tighe, 2001; Guldin, 2000; O'Toole, 2000; O'Toole & Bregante, 1993; Asch & Fine, 1992, 1997; Fine & Asch, 1988) challenging, which was also experienced by Josie in terms of her eating disorder, internalized connection between thinness and femininity, and the anxieties around her ‘non-normative’ body and ileostomy bag being visible to others. Other studies have found that people with disabilities resist notions of normative sexual expression by becoming more creative in their sexual life. In the case of Josie, she found creative ways to feel comfortable with her ileostomy in sexual situations and developed an exciting repertoire of new sexual interests because of this.

Theories of embodiment, and feminist articulations of the need for the body to be included in the social model of disability are applicable to the findings of this study. Josie’ s experiences of illness and of her queer identity were deeply connected to her body. Embodying multiple identities and coming to understand these as fluid, intersecting and interacting with her physical body was an important part of Josie’s identity development and expression. As feminist disability studies scholars suggest, the body plays a central role in the experience of disability. Josie experienced inaccessibility and ableism from the social world, both structurally and attitudinally; however she also struggled with pain, an eating disorder, depression, anxiety, suicidal thoughts and underwent numerous surgical procedures resulting in a changed physical body. These daily realities of lived and bodily experience are profoundly linked to identity and oppression (Clare, 2001). The findings of this study reinforce the need for the social model to either expand it’s understanding of the experience of disability (see: Crow, 1996; Morris, 1991), or be replaced with a new way of thinking about disability and the body. A feminist, and intersectional framework has much to offer the project of understanding disability experience (Schriempf, 2001). As shown from the complexity of Josie’s experience as a multiply situated and multiply marginalized queer women with a disability, the social model is not especially relevant to understanding the full range of social and bodily experiences, and neglects to understand the overlap and interactions between the social and corporeal (See: Hughes, 2007, 2009; Shakespeare &Watson, 2002; Schriempf, 2001; Clare, 1999, 2001; Thompson, 1999, 2001; Corker, 1999; Meekosha, 1998; Shildrick & Price, 1998; Asch & Fine, 1992, 1997; Crow, 1996; Wendell, 1996; Morris, 1992, 1996; French, 1993; Finger, 1992; Lloyd, 1992; Fine & Asch, 1988). The feminist and intersectional framework was particularly appropriate and helpful in understanding the multiple elements of Josie's experience of identity.

Where the findings of this study diverge from the literature is in regards to the theoretical concept of sexual citizenship, as well as the view that people with disabilities (women especially) are seen as asexual. Josie did not describe experiences of being perceived as asexual, perhaps this is due to existing predominantly in academic or queer circles, as well as having a largely invisible disability.

The literature discussing sexual citizenship argues that people with disabilities are not afforded citizenship, or belonging, in the sexual realm (see Plummer, 1995; Richardson, 1998; Shakespeare, 2000; Weeks 1998). In much of the empirical literature on the topic of sexuality and disability many barriers to sexual citizenship are mentioned. These include the view of people with disabilities as asexual (Whitney, 2006; Crawford & Ostgrove, 2003; O'Toole, 2000; Shakespeare, 1996; Lonsdale, 1990), difficulty accessing sexual information, education (Shuttleworth, 2002; Watson et al., 2001; Fiduccia, 2000; Gillespie-Sells et al., 1998; Shakespeare, 1996) and for queer individuals an absence of gay, lesbian, bisexual and queer specific sex information (Walden, 2009; Dibble et al., 2007; O'Toole, 2000). Social and cultural representation, lack of representation, or mis-representation, as well as cultural ideals related to attractiveness, gender and sexuality have all been previously identified as preventing the full participation of people with disabilities in a sexual life (Fraley et al., 2007; Shakespeare, 2006; Hassouneh-Phillips & McNeff, 2005; Zitzelsberger, 2005; Taleporos & McCabe, 2003; Vansteenwegen et al., 2003; Wilkerson, 2002; Tighe, 2001; Guldin, 2000; O'Toole, 2000; Kelly, 1992; O'Toole & Bregante, 1993)

In this study findings did not suggest that Josie felt denied a sexual life, or that she faced barriers to sexual citizenship. Although she did struggle with her body image, and has become more selective in her choice of sexual partners, she has, fairly consistently, maintained a dating and sexual life despite her disability. This could be due to the queer community that Josie surrounded herself with; she described these individuals as having 'radical body politics'. Additionally, because Josie's disability is invisible under clothing, a barrier to accessing partners and a sexual life is perhaps minimized. The points at which Josie did not want to participate in a sexual life were times of extreme pain, while she had a temporary ileostomy, and directly following the addition of a permanent ileostomy to her body. She speaks about these instances as clear choices on her part, rather than desires that went unmet. Josie's sexual identity was a strong and positive force that helped support her disability identity, and her sexual life was similarly powerful in leading her towards acceptance of her changed body, eventually seeing her ileostomy as a positive addition to her sexual life. Josie's comfort with her sexuality can inspire us as social workers to help others achieve positive feelings about their sexuality and sexual life.

It is interesting to explore and question the concept of sexual citizenship in light of my findings that showed minimal issues for the participant in accessing and enjoying a sexual life. This leads to questions around how one defines a sexual life, access or citizenship, and what is meant by a sexual world or realm. The concept of sexual citizenship-even though it has been drawn from the lesbian and gay scholarship and applied to disability studies-perhaps doesn't make enough reference to the multitude of sexual worlds and realms one could find, or want to find, belonging within. This illuminates the potential assumptions within the concept of sexual citizenship for people with disabilities, that belonging is sought within the heterosexual world of 'normative' sexual practices.

This study included the experiences of only one queer woman with a disability; therefore to draw conclusions applicable to a broader population would be inappropriate. However, the findings from this study can be useful for offering unique perspectives on conceptual and theoretical understandings of disability and sexuality, as well as offering considerations for social work policy, practice, theory and research.

6.3 Implications for research

Collaboration throughout the research process between Josie and myself has resulted in he findings of this study emerging in a way that is true to the voice of the participant. However useful and applicable the narrative method has been to understanding one woman's personal experiences, it offered little suggestion in regards to understanding intersecting and multiple identities. The analysis process, which involved looking for chronology, critical moments, and turning points, was especially challenging because the participant's identity trajectories were not adequately captured across one timeline. The eventual choice I made to represent her queer identity and disability identity as two different trajectories of experience occurred out of these methodological limitations of the narrative approach. The participant in this study had two chronological trajectories; her queer and disability identities came together at certain points and diverged at others. The diagram I created to acknowledge the intersectionality of her identities can offer the narrative methodology, and future researchers using this method in investigations of intersecting identities, a potentially useful tool to aid in the data analysis process.

The findings presented in this thesis offer directions for continued research. The participant in this study is a privileged white, Canadian, university educated middle class woman. These factors shape her experience of queer and disability identity in particular ways. Research needs to be done with women from varied backgrounds, and in different social locations. For example, queer women who are marginalized along lines of race and class may have very different narratives to share about their experiences of sexuality and disability. Other factors that need to be explored for their impact on the sexual life of women with disabilities include age, geographic location, rural women and women with differing types and degrees of illness or disability.

Comparison studies between women with differing sexual orientations could highlight precise areas for increased support. As the literature has demonstrated, queer women with disabilities have difficulty accessing community. Further research on this topic can contribute recommendations for community organizations. More information about the diverse experiences of women with disabilities is important to identify gaps in health care, social work practice, and social policy initiatives in order to better meet the needs of women with disabilities.

6.4 Implications for social work practice

The findings of this study have implications for social work practice and can inform service delivery. The research points out the importance of addressing heterosexism and homophobia at personal, and institutional levels. In doing so, queer women with disabilities may feel more comfortable to discuss sexuality, or other concerns with helping professionals. Practitioners could benefit from becoming more knowledgeable about the population of queer women with disabilities, and how these intersecting identities are experienced. Knowledge about the struggle for queer women with disabilities to find belonging in community is important for helping professionals to keep in mind, as access to a support network is extremely important when coping with disability or chronic illness. The connections between chronic illness and mental health remind social work practitioners that queer women with disabilities face numerous sources of struggle not only located within society but also can experience depression, anxiety and other mental health issues. Health professionals never asked the participant, how her disability had impacted her relationship with food, she noted that everyone she knew with a similar illness had also developed an eating disorder. Additionally, when investigating mental health concerns with clients, this study has shown that what may appear to be a damaging or negative behavior (for example thoughts of suicide or an eating disorder), need to be explored for what these behaviors mean to our clients, for example, are suicidal thoughts a way of feeling in control of one's situation? Is an eating disorder tied up with managing a new ileostomy?

It is necessary for helping professionals to challenge the notion that women with disabilities are asexual. Although the participant in this study did not describe being perceived as asexual, this remains an attitudinal barrier for many women with disabilities in attempting to access sexual health care, for example:

> Oftentimes, many of us do not get our annual pap tests because of inaccessible examination tables or the assumption by practitioners that women with disabilities are 'asexual' and therefore, at less risk for gynecological concerns or STIs (Odette, as quoted in Lush, 2005, p.14).

The Center for Research on Women with Disabilities (CROWD) looked at attitudes and behaviors of healthcare providers and found that women with physical disabilities are significantly less likely to receive regular pelvic examinations, and that focus tends to be placed on the disability, rather than sexuality or reproductive health issues (Thierry, 1998). In her review of the Southeastern Ontario District Health Council (SEO-DHC) and the Kingston, Frontenac Lennox and Addington (KFLA) Health Unit, McColl (2006) found that neither had explicit policy relating to access for people with disabilities. She also mentions that access to preventative services were not considered, services such as sexual counseling and family planning and there was no mention of issues around fertility or preventive health behaviors for people with disabilities. These findings suggest that health care settings and the professionals within them require further training and equipment to meet the sexual health needs of women with physical disabilities.

An overall service delivery and social work practice that is more nuanced is necessary; one that is conscious of the intersectional nature of identity, and the impacts of occupying multiple marginalized positions on client's experiences in the world. Helping professionals need to be aware of their underlying perspectives on disability and sexuality. Health care providers, and the institutions in which they work need to be inclusive of queer sexual orientations, and working to challenge discrimination and oppression of queer women with disabilities. Access to information, education and care related to sexuality and sexual health that is relevant to particular situations of disability, chronic illness and various sexual orientations is necessary. This research has highlighted some areas where special attention and increased knowledge are needed in order to effectively meet the needs of queer women with disabilities and chronic illness.

6.5 Implications for social policy

There is no Canadian public policy that directly addresses issues of concern specific to women (queer or otherwise) with disabilities and sexual or intimate relationships[9]. What Canadian disability policy does address ends up creating barriers for women with disabilities because of its limited understanding of disability. For example, the eligibility criteria for receiving Canada Pension Plan Disability Benefits

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[9] The only time public policy has focused on sexuality is around sterilization, when in 2005 the British Columbia Supreme Court approved a 450,000$ settlement between the provincial government and 9 women with mental disabilities who had been sterilized while at a psychiatric hospital between 1940 and 1968 (Henderson, 2007).

and the Disability Tax Credit state that the disability must be "severe" and "prolonged" (Human Resources and Skills Development Canada, 2007). These terms need to be amended to include cyclical and degenerative mental and physical conditions, as well as other invisible illnesses (HRSDC, 2007, Recommendation 3.3, p22.), like pain related disabilities, which affect 11.4% of women over 15 years of age in Canada, compared to 8.8% of men (Statistics Canada, 2001).

Therefore some of the disabling conditions experienced by women in Canada tend to fall outside of the eligibility criteria for income assistance programs. Without access to these programs women with physical disabilities are further at risk for ill health due to the stress and barriers created by poverty. As Shakespeare (1996) has noted, living in poverty has consequences for one's access to the social world and creates financial barriers to participation in settings and activities in which to meet potential sexual or intimate partners. Insufficient income support and exclusionary eligibility criteria hits women with disabilities the hardest, because women experience greater disability, live in greater poverty than men, and consequently depend more heavily on income support (Gilmour, 2008). "Women make up the majority of people with disabilities in Canada and typically live longer than men, making them more likely to experience health conditions associated with aging" (Government of Canada Document, 2008).

The existence of organizations for women with disabilities is crucial for support, advocacy, activism, and education, and can counter isolation and depression, which are two of the most frequently reported secondary health conditions of women with disabilities (Thierry, 1998). Sexual education and sexual health initiatives specific to women with disabilities is necessary, however the community organizations with the potential to engage in these projects require more funding[10]. Without the

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[10] Changes to disability related funding in the past decade has resulted in "less money to go around, increased competition between groups for funding, and pressures to change mandates or project foci to meet new funding requirements" (Boyce, Krogh & Boyce, 2006, p.205). Additionally, they note that provinces have less incentive to give funds to special interest groups due to the elimination of the cost-sharing program, and conservatism in many provinces results in cutbacks to social welfare initiatives and organizations

necessary funding, organizations like DAWN and AFHM[11], are unable to provide sexual information and education materials, referrals to accessible sexual health clinics and professionals, opportunities for friendship and support, discussions about sexuality and intimacy, and assistance for women with disabilities who are living in poverty.

The participant in this study experienced serious mental health issues related to her disability and benefited greatly from access to therapy, as well as a supportive group of friends, family and her queer community. These factors aided in countering isolation and depression, it is crucial that all women with disabilities have access to support. Policy should reflect this important need by increasing funding to community organizations for women with disabilities, to ensure that these services can be provided. Additionally, amendments need to be made to the criteria involved in receiving financial support. The participant in this study noted that her necessary medical supplies (ostomy bags) are not covered by provincial health insurance, and she currently relies on financial support from family in order to pay for these. During the most acute points of her illness, Josie was a student and although her studies were disrupted she was not negatively affected financially (for example had she been dependant on full time employment). Working women with disabilities that fall outside of policy definitions face potential financial struggles if their condition, illness or disability requires them to work less, or not at all.

Definitions of disability need to be broadened to include the many conditions, chronic illnesses, experiences of pain, and temporary or transient disabilities that affect women. This is necessary to ensure that women with a variety of disabilities can be eligible for disability benefits, financial programs and income support initiatives.

6.6 Conclusions

This study has presented insights into the experiences and understandings of sexuality, gender and disability for one queer woman living with a disability. The

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[11] DAWN Canada is the only feminist organization by and for women with disabilities in Canada. Its provincial affiliate, is Action des Femmes Handicapées de Montreal (AFHM). Dawn has struggled to create affiliate organizations in more provinces but has not been able to because of lack of funding (Disabled Women's Network Canada, 2006).

participant in this research has provided a narrative important to understanding the embodiment of intersecting and marginalized identities. This thesis has highlighted one woman's strategies for coping with illness, maintaining agency, and resisting intersecting oppressions. Furthermore, her narrative explains the important role that community, sexuality and experimentation can play in facilitating self-acceptance.

It is clear that the experience of intersecting queer, disabled and gendered identities is a complex and important area for continued investigation. The findings from this study provide a rich account of experiences and understandings of sexuality, illness, identity and the body. This research adds a unique perspective to the small, but growing literature on queer women with disabilities. These findings also offer important knowledge, challenges to address, and areas for future work, to individuals working in policy, practice and research.

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APPENDIX B: INFORMATION LETTER

Research Study Information Letter

Title: **Sexuality, Intimacy, Identity and (In)Visibility: Experiences of a Queer Woman with a Physical Disability.**

Dear Participant,

I am conducting the research study described for my master's thesis at the McGill School of Social Work. The purpose of this research is to explore the intersections between gender, sexuality and disability and how these are experienced and understood by women with physical disabilities. I intend to explore the meanings and themes drawn from the participants' narrative about her experiences and understandings of sexuality and intimacy.

I am looking for a participant who identifies as a woman with a physical disability, and as someone who is part of a sexual minority community. I use the term disability in a broad sense, and see it as encompassing visible or invisible chronic illnesses or conditions, temporary or fluid disabilities or disabling conditions that are physical in nature. The term sexual minority could include lesbian, gay, bisexual, queer, and gender minority identities such as transgender, two-spirit, or transsexual individuals.

There is no compensation for participation in this study but it is an opportunity to share your story as a queer woman with a physical disability. The study will involve three interviews and recording your thoughts in a journal. The findings from this study can have potential practice implications regarding service delivery, and can expand our understanding about the topic.

For more information about the study please contact the researcher:
Jennifer Drummond at 514-297-5353 or email: Jennifer.drummond@mail.mcgill.ca

APPENDIX C: INFORMED CONSENT FORM

Informed Consent Document

Title of research study: Sexuality, Intimacy, Identity and (In)Visibility: Experiences of a Queer Woman with a Physical Disability.

Investigator
Name: Jennifer Drummond
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Purpose

The purpose of this research study is to explore experiences and understandings of sexuality, intimacy, identity and (in)visibility of queer women with physical disabilities. The goals of this research study include giving voice to experiences of sexuality that have been marginalized, expand understandings about this topic and provide insight into the lived experiences of queer women with physical disabilities. This research study is part of Jennifer Drummond's McGill School of Social Work Master's Thesis.

Procedures

You are invited to participate in 3 interviews, each 2 hours long, in a private location of your choosing. These interviews will occur over a period of a month and a half. These interviews will involve discussing your experiences and understandings of sexuality and disability.
You are asked to keep a journal, during the month and a half data collection process, reflecting on topics discussed in the interviews, and thoughts about your life experiences. You will be asked to share this journal with the researcher, to be used as data within the research report.
You will be shown the researcher's preliminary analysis for comments and reflection, and are asked to participate in this collaborative process.

Your participation in this research study is entirely voluntary. You can withdraw at any time without penalty or consequences. All interviews will be audio recorded and these tapes will only be accessible to the researcher. These audio tapes will be kept in a locked cabinet and will be destroyed within one year of the completion of the study. Transcripts, and other written materials related to this research study will be kept in a locked cabinet for a duration of time as required by McGill University.

Risks and Benefits

You have been provided with an information letter explaining the study, and are encouraged to contact the researcher with any questions you may have The information you share with the researcher during the interviews and in the journal may be used in the researcher's thesis and future published articles or presentations, but no personal identifying information will be shared. Any information that might identify you personally will be disguised and pseudonyms will be used.

There is no direct benefit to you by participating in this research study.
You will have the opportunity to make comments and reflections about the researcher's preliminary analysis of the data. After the completion of the study the researcher's thesis will be available to you upon request.

It is possible that there may be a risk of discomfort from being in this study due to discussing personal and/or painful experiences.   You do not have to answer any questions that are upsetting, and are free to discontinue talking about any topic you find difficult. If needed, the researcher can provide you with referrals to professional or community services.

Conditions of Participation

- I understand that all information gathered from interviews and my written journal may be used in Jennifer Drummond's master's thesis and any future presentations or written publications related to this research study.
- I understand that I am free to withdraw my consent and discontinue my participation at any time without penalty or consequences.
- I agree to having all interviews for this research study audio recorded
  YES ______   NO_______

I have read the above information and I agree to participate in this study

Participant Name (or initials):   Signature:
Researcher Name: Researcher Signature:
Date:

Please keep one signed copy of this form for your records.

If you have any questions or concerns about your rights as a research participant in this study, please contact the Research Ethics Office at 514-398-6831.

APPENDIX D: INTERVIEW GUIDE

Interview Guide

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

-How do you describe your identity?
(gender, sexuality, disability, changes, transformations and representations)

Expression

-How do you express your sexual self?
(context and location, body, desire, fantasy, actions, feelings)

Interaction

-What is your perception of other's responses to your sexual self?
(lovers, sexual partners, friends, family, colleagues, queer community, disability community, health and social service professionals).