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A Narrative Inquiry into the Menopause Experiences of Women with Spinal Cord Injury

by

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We acknowledge and respect the Lək̓ʷəŋən (Songhees and Xʷsepsəm/Esquimalt) Peoples on whose territory the university stands, and the Lək̓ʷəŋən and W̱SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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A Master's Thesis:
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Abstract

Menopause presents distinct medical and social challenges for women with spinal cord injury (SCI), yet research on this topic remains limited. In this narrative inquiry I explore how disability, gender, and aging intersect to shape the menopausal experiences of women with SCI. Through four in-depth conversations with each of two participants, Kim and Nadine, I examined how they navigated menopause in the context of living with SCI. Conversations were recorded, transcribed, and analyzed alongside field notes to develop narrative accounts. Two key narrative threads emerged: *The Liminality of Menopause* and *Questioning of Self*. Both women's stories revealed how silence, uncertainty, and discrimination influenced their understanding and experience of menopause. In clinical encounters, disability was frequently treated as the primary focus, which eclipsed other important aspects of health and social experience. These findings highlight significant gaps in care and the need for healthcare providers to engage in early, inclusive, and validating conversations about menopause with women living with SCI.

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List of Abbreviations

Abbreviation	Unabbreviated
BC	British Columbia
CEE	conjugated equine estrogen
CVD	cardiovascular disease
SCI	spinal cord injury
HIV	human immunodeficiency virus
HRT	hormone replacement therapy
NAMS	North American Menopause Society
SRH	sexual and reproductive health
SSCHR	standing senate committee on human rights
STI	sexually Transmitted Infection
UVIC	University of Victoria
WHI	women’s Health Initiative
WHO	World Health Organization

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Chapter 1: Coming to my Research

Although menopause, with its varied symptoms and manifestations is widely experienced, women with spinal cord injury (SCI) encounter distinct challenges during this transition (McColl, 2002). In addition to barriers commonly faced in accessing menopause care, such as provider hesitancy and fragmented services, women with SCI must also navigate challenges linked to both the social and physiological impacts of disability alongside menopause (McColl, 2002; Kalpakjian et al., 2010). Utilizing a narrative inquiry methodology, my goal was to learn about how women with SCI understand their social and health experiences of menopause and how these experiences (which may include ableist and normative attitudes) contribute to health inequity.

Reflecting upon my journey of becoming academically, intellectually, and emotionally invested in women's health was a muddy process. Throughout this journey, I have come to realize how my experiences as a registered nurse, a mother, a patient, and a student have come together to form the foundation of my interest in the menopause experiences of women with SCI.

Professional History

My professional experience as a nurse began working in a busy, high-acuity cardiac unit. While I gained many clinical skills in this position, I realized I wanted a job where I could connect with patients beyond the realm of physical care. I savored the rare moments in this acute setting where I could sit with a patient and support them through their experience. I soon decided that the cardiac unit was not the right fit for me and moved into community nursing. In 2012, I began working for a youth sexual health clinic. This new position allowed me to utilize my clinical and interpersonal skills while attending to my patients' physical *and* emotional needs.

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While continuing to work at the youth sexual health clinic, I also gained experience working in various community settings: a clinic that supported people living with HIV, a supervised injection site, an inpatient mental health and addictions facility, and a primary care center for populations who are structurally marginalized. The experience of working with people who faced so many barriers to achieving health and safety in our society prompted me to develop a strong interest in social justice and equity. So, when a position became available to work as a clinical research nurse with women involved in sex work and women living with HIV, it seemed like the perfect opportunity to blend my passion for sexual health with a position where I could learn more about social justice issues.

Throughout my five years of working with women in this research project, I was able to provide care that the traditional healthcare system did not provide. I had the privilege to get to know many women well, to be trusted (sometimes this took years), to be let into their lives, to learn from them and to share knowledge. I developed a nuanced understanding of the sex work industry and began to learn about the broad spectrum of feminist views on the issue. Sadly, I also saw firsthand the colonial legacy of the child welfare system in BC, and how this impacts Indigenous mothers. I saw the devastating impacts of stigma and criminalization of drug use and mental health issues on a daily basis, sometimes feeling defeated. But I also felt great satisfaction when I could tailor care to my patients, improving their health and trust in nurses.

Several memories of working with women in this role are still very fresh. For example, I remember supporting Laura[1] through a new HIV diagnosis. When Laura received her diagnosis, I had been working with her for a couple of years and built a level of trust in our relationship. In most clinical scenarios, the provider-patient relationship ends when the appointment is over (or is

[1] Pseudonym used to protect identity of patient

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fractured over a series of appointments and framed within the time/space requirements of the healthcare system). In my experience with Laura, I was able to provide care on her terms, which meant sometimes meeting in her home, having a coffee, and accompanying her to initial appointments with HIV specialists. I also remember Gina[2], a woman who required syphilis treatments, but feared for her safety if her partner found out. We were able to arrange meetings in our outreach van in a back alley, at a time outside typical clinic hours when her partner would not question where she was going. Delivering care in non-traditional ways allowed me to make a small impact by tailoring my care to the needs of the women I worked with.

During my time in this position, I was afforded the opportunity to see what equitable health care can look like. We provided gynecological and sexual healthcare to women in innovative ways, and it worked. For example, pap tests were sometimes completed using headlamps in massage parlors. I will never forget when Katie[3] returned to our clinic with tears in her eyes. Unfortunately, she had received a diagnosis of advanced cervical cancer. However, she came to me with thanks – for 'nagging her' to get her pap test and for providing the opportunity to receive the care she wanted and deserved. Unfortunately, the only reason these women received the type of care they *required* was because the primary investigators of the research project had an ethical obligation to do so. After working in this position for five years, I became pregnant and went on maternity leave, taking with me a strong belief and value that all women (especially those facing additional barriers) deserve equitable, safe healthcare that meets their unique needs.

[2] Pseudonym used to protect identity of patient
[3] Pseudonym used to protect identity of patient

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Personal Encounters with Reproductive Health

My pregnancy went smoothly, and I continued to work until one week before my due date. Unfortunately, I had a difficult labor and delivery, resulting in blood loss that left me weak and anemic, requiring an extended hospital stay. Despite this, I was in awe of my daughter and loved spending time with her. At the same time, I struggled. I developed post-partum anxiety, had difficulty sleeping, was losing more than my baby weight, was teary, and simply did not feel like myself. I knew about the "baby blues" and was well-educated in mental health. However, I had a new identity as a mother and wondered if that included an obligation to bear the emotional and psychological burdens that came along with it. After all, everyone says this time of motherhood is hard.

Looking back, I wish I had asked for what I needed sooner instead of assuming I simply needed to get through it. I was aware that hormonal shifts occurred post-partum that contributed to depression and anxiety, but I hoped it would pass. At the same time, I wonder why so many healthcare providers did not ask me more directly about my mental health -- when I arrived at a follow-up appointment exasperated in tears, I was given instructions on breastfeeding, when I called my provider with complaints that I was not sleeping, I was given suggestions for herbal remedies. Exasperated and worried that my level of fatigue was becoming unsafe, I went to a walk-in clinic, telling the physician that I simply could not fall asleep, even when the baby was sleeping. She looked at me blankly, asking me, "What is it that you want me to do?" Being a nurse, I researched what medications I needed. Eventually, I got back to feeling like myself – perhaps with a little less faith in the ability of our healthcare system to meet the reproductive needs of women. Reflecting on my care journey is not done with the intent to cast blame on any provider. What I can see now, with some distance from the experience, is how our societal views

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on what is normal for women to go through, combined with stigma, can impact the care we receive and our own understanding of our health in a very real way.

Expanding my Experience and Integrating Values into Care

When I was ready to return to paid work, I wanted to continue working in sexual and reproductive health (SRH). I was fortunate to find my current position supporting people with disabilities and chronic health conditions with their SRH care needs. While patients who come to see us have a wide range of diagnoses, most have spinal cord injury (SCI). When I started in this role, I was nervous and aware that I did not know much about the health and social issues important to this population. What I came to know I learned through books, documentaries, conversations with patients, and studying disability history. I learned that access to healthcare and equity in social and economic life were major barriers for people with SCI, not so unlike the women I had worked with in my previous role. It was frustrating to see how the medical system and society often failed to reach beyond the very basic healthcare needs of patients. However, working with people through these experiences helped me develop strong values that guide my patient care. For example, I believe that our healthcare system and research institutions have a responsibility to collaboratively support the unique health needs of populations facing barriers to care. I value quality of life and view health as more than just the absence of illness--it is about reaching one's full potential and engaging in a meaningful life.

When I saw women with SCI who were considering pregnancy or were already pregnant, I encouraged them to be aware of postpartum depression and anxiety and normalized the importance of seeking help. I provided resources and opened the conversation so they would not feel like these experiences were normal parts of motherhood that they had to endure alone without medical, psychological, or peer support. My care and health care work for women with

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SCI was guided by the disability rights movement ethos, 'nothing about us without us'[4], which asserts people with disabilities should lead in decisions and processes about their care. After seven years in this role, I became more confident in my clinical practice and better at identifying SRH health issues that are caused by inequities.

One of the most obvious areas where I saw inequity was in the resources and education available to women, transgender, and non-binary people compared to men. In my clinical practice, I have noted a gap in care for sexual pain, adjusting to gender-affirming interventions, vaginismus, and menopause. Pelvic floor physiotherapy, a primary treatment for many female sexual issues, is generally not covered by the medical services plan in British Columbia (BC). Some specialty clinics for women's sexual issues exist, but wait times for specialists are long. For example, at the time of writing this document, the BC Centre for Vulvar Health reports a wait time of between six and eight months (e.g., https://www.bcvulvarhealth.ca/healthcare-professionals/referral). Experts in the field of gynecology and sexual medicine have attempted to fill this gap in care by creating online resources to guide primary care providers in care and treatment (e.g., https://www.vulvodyniatoolkit.com/). Although this is a commendable and positive step, in my clinical experience, supporting patients with sexual health problems is time-intensive and requires interdisciplinary expertise, two assets rarely available to primary care providers. The BC Centre for pelvic pain and endometriosis has a current wait time (Nov 2024) of 4-5 months and requires a gynecology consultation as a condition for acceptance. Gynecology referral wait times in BC are approximately 18.2 weeks (Moir et al., 2023). This example further

[4] 'Nothing about us without us' is a slogan and ethos of the disability rights movement, which was popularized by James Charlton's' (1998) book of the same name. In Charlton's book, he recalls hearing the phrase from South African disability activists who themselves adopted it from Eastern European activists.

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exemplifies the need for more resources to support women's (or anyone with a uterus and ovaries) sexual and reproductive health.

After years of working in sexual health, I could see that many women were left to deal with sexual issues on their own. In recent years, my clinical practice has revealed that as women age and approach menopause, formal medical consideration for their reproductive and sexual health becomes sparser. Globally, there has been a focus on maternal health while neglecting other reproductive and sexual health issues, including endometriosis, vulvodynia, dyspareunia, and menopause (Ghebreyesus et al., 2024).

Menopause and Gender Identity

When discussing menopause, I acknowledge that not all who experience it identify as women. Trans men, non-binary individuals, and people with variations in sex also go through menopause. Furthermore, not all women experience menopause. I would agree with Toze and Westwood (2024) when they describe menopause as a biopsychosocial life transition, normatively understood as a female experience (Toze & Westwood, 2024). In Toze and Westwood's thematic analysis of the menopause experiences of trans and non-binary people, their participants clearly highlighted interactions between menopause and gender identity. The menopause experiences of gender-diverse populations deserve their own attention and care. When I use the word 'women' in reference to menopause, I do so while acknowledging that gender-diverse populations may encounter some of the same experiences during menopause while also having their own unique considerations.

When my workplace started receiving inquiries from women with SCI about managing their unique health concerns during menopause, I began to research the topic. A thorough review of existing literature on menopause and SCI revealed limited resources or helpful information.

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This made me uncomfortable and, in retrospect, frustrated. It seemed unfair that women with SCI, already facing additional health challenges, had to navigate menopause without appropriate guidance. After discussing this with colleagues well-versed in SCI care, it became evident that a lack of guidelines and evidence on the interplay between menopause and SCI acted as barriers to care. When I had the opportunity to hear from women with SCI about their experiences seeking menopause care from primary care providers, the lack of evidence-based information was bothersome to them. However, providers who displayed normative and ableist sentiments were more distressing. This aligns with data from Dillaway and Lisack's (2015) study on the experiences of women with SCI seeking reproductive healthcare. While interpreting the qualitative data, the authors assert,

> the lack of education and training seemed like their primary barrier, almost more important than exam table barriers, because the lack of education and training impacts how they are treated as human beings and as bodies, and affects the everyday interactions they have with providers and their staff. (p. 21).

In this narrative inquiry study, I explored the everyday and medical experiences of women with SCI who are navigating menopause. Specifically, I wondered:

1. How do women with SCI understand their experiences of menopause?
    a. How does this intersect with their disability experiences and needs?
    b. What does help seeking for their menopause look like and entail?
2. What role do health care practitioners, and the healthcare system play in shaping and organizing people's experiences and understandings of menopause, and how do these contribute to health inequities?

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3. Where and how do ableist and normative ideas about bodies and aging come into play in people's menopausal experiences?

Asking the right questions is a foundational skill for healthcare providers. A clinician with knowledge of the health and social issues impacting their patient population can often use foresight to anticipate patient needs, including bringing up topics that can be difficult or 'taboo' to speak about. Unfortunately, people with SCI are routinely instructed that if they want good care, they ought to become experts in what they need (Dormire et al., 2006). In other words, they are told that because they are not able-bodied, they cannot trust their healthcare provider to be competent in the care they require. The following excerpt from Dormire et al.'s 2006 article on menopause and SCI illustrates how when women with SCI enter menopause, the expectations for their expertise expand to include their menopause care,

> A unique element of a collaborative relationship between an HCP and a woman with disabilities is that the HCP is not the expert in the woman's needs. Rather, it is the woman herself who is the expert on disability and its effect on her life. The woman with a physical disability generally knows more about the disability than the primary care provider. She must actively define the strategies for her health promotion during the menopausal transition, which should be tailored to her special health needs and health resources. (p. 43)

Although I appreciate some benefits of treating patients as experts in their own care, clinicians must be aware of the potential for this to become burdensome. I wonder how it feels to have the responsibility of being an expert in both disability *and* menopause placed upon you? I wonder if women with SCI expect their clinicians to be competent in managing their menopause care, and if not, how do they manage this uncertainty? Moreover, how do women with SCI feel

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about the lack of quality research in this area? These are some of the questions that arose and were part of my research puzzle.

Although I remained open and curious about what came forth as I continue to explore menopause and SCI, it was important first to identify and explore the roots of oppression often associated with being a woman and a person living with a disability. While doing so, I respect that not every woman or every person with a disability is situated in a permanent state of oppression or identifies as being oppressed. In my following literature review, I discovered that the tension and duality arising from discussions of oppression as a collective identity is not new. James Charlton eloquently explores the paradoxes of disability oppression in his 1998 book, "*Nothing about us without us: Disability oppression and empowerment",* utilizing dialectics to examine oppression as a condition that is constantly in flux, experienced individually and collectively, and as a catalyst for emancipation. Charlton's (1998) nuanced discussions on these topics align closely with my feelings on the concept and remind me of patients and colleagues: women living with disability who find strength and solidarity in who they are as individuals and the experiences that bond them with others while also encountering systemic oppression and inequity.

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Chapter 2: Literature Review

In the following literature review, I draw on disability and feminist scholarship to examine how inequity and oppression shape sexual and reproductive health (SRH) issues for women with spinal cord injury (SCI), with a focus on gaps in menopause research. Additionally, I will provide a brief overview of menopause in the general population. The history of forced and coerced sterilization in Canada will be reviewed, as these practices are an important part of the broader context of SRH for this community and may influence how women with disabilities engage with the healthcare system today. The medical model of disability will be discussed as a contributing factor to inequity. The social model of disability, along with crip theory, and feminist disability theories will be positioned as alternative lenses to address inequity issues. Because menopause is primarily a woman's experience, I will also explore oppression and inequity as social phenomena and posit that women and people with disability face common barriers to achieving reproductive health equity. The state of SRH inequity for women will be reviewed, focusing on the evolution of menopause research and care and the notable gap in current research regarding menopause management for women with SCI.

Menopause in the General Population

The menopause foundation of Canada (MFC) released a 2022 report titled, *The Silence and the Stigma,* which outlines the inadequate state of menopause medical care and the impact on work-life for women in menopause. In a survey of 1023 Canadian women, four in 10 reported feeling alone through their menopause experience (MFC, 2022). Menopausal symptoms were reported by 95% of women surveyed, with an average of seven symptoms reported. Most women reported an overall low level of awareness of the diversity of menopausal symptoms (there are more than 30). Although women reported their family physician as their most trusted source of

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information, less than one-quarter had their family physician proactively discuss menopause with them. Of the 41% of Canadian women in the general population who sought out menopause advice, 72% found that advice to be not helpful or only somewhat helpful. Furthermore, four in 10 (38%) women felt their symptoms were undertreated. Finally, this survey also revealed that two out of three women feel unsupported by their employer during this stage of life (MFC, 2022).

Women with SCI may encounter many of the same difficulties in accessing menopause care as the general population, with the addition of barriers arising from the social and biological impacts of disability. To better contextualize the menopause experiences of women with SCI, I will first review the state of SRH in women with disabilities.

Sexual and Reproductive Health in Women with Disabilities

Statistics Canada (2023) notes that the number of people with disability is increasing (in 2017, 27% of Canadians aged 15 and older had a disability[5]). Compared to men, women are 4% more likely to have at least one disability and more likely to have a severe disability (Statistics Canada, 2023). Disability is the outcome of the interaction between individuals with a health condition (e.g., cerebral palsy or depression) and personal and environmental factors such as negative attitudes, inaccessible transportation and public buildings, and limited social support.

While women with disabilities may share similar experiences of oppression, bias, and discrimination, they are a diverse group with unique functional, physical, sensory, and neurodivergent abilities. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) was ratified in 2010, guaranteeing the fundamental human rights

[5] Person with disability is defined by the United Nations as having long-term physical, mental, intellectual or sensory impairments. These impairments interact with barriers, preventing full and effective participation in society on an equal basis with others (United Nations Convention on the Rights of Persons with Disabilities, 2006).

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to physical, social, and psychological health, and recognizing that disabled women are disproportionately impacted by the effects of discrimination. Women with disabilities in Canada form a substantial and varied demographic, facing both common and unique challenges related to discrimination and access to health rights (WHO, 2022). Compared to women without disabilities, women with disability face disproportionate rates of gender-based violence (WHO/UNFPA, 2009) and sexual abuse (Tomsa et al., 2021). In a study examining rates of intimate partner violence in women with SCI, more than half (55%) of the 175 women had experiences with physical, sexual, or disability-related violence (Robinson-Whelen et al., 2023).

Pregnancy and Birth Outcomes

A large Canadian study on disability and pregnancy revealed that one in eight pregnancies occurs in females with a disability (Brown et al., 2024). This same landmark study on equity and inclusion in pregnancy care, one of the largest in Canadian history, revealed serious and concerning health disparities for individuals with disabilities from preconception throughout all stages of pregnancy. For example, females with disabilities in this study were more likely to experience uncommon yet serious physical health complications, as well as mental health conditions and interpersonal violence during pregnancy. Birth outcomes were also affected, showing increased rates of preterm birth and infants small for gestational age. Qualitative data on the experiences of women in the study highlighted that the pregnancy care system in Canada remains inaccessible to many people with disabilities.

Sexual Health Education in Schools

Davies et al. (2023) highlight that sexual health education in Canadian schools largely fails to address the needs of youth with disabilities despite numerous studies showing increased risks of negative sexual health outcomes. For example, Brennand and Martino's 2022 study on

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the link between disability and sexually transmitted infections (STIs) found that Canadians with functional disabilities face a higher risk of STIs, with women being disproportionately affected. As with other sexual health risks associated with disability, it is crucial to avoid viewing disability itself as a risk factor for STIs, which would wrongly medicalize disability. Instead, the focus should be on addressing the significant gaps in sexual education for people with disabilities (Brennand & Martino, 2022).

Despite damaging societal myths and narratives, women with disabilities are sexually active, become pregnant, have children and families, and experience menopause. Their SRH relies on access to tailored information and care, enabling them to make informed decisions. Unfortunately, a long history of discrimination and paternalism by those without disability has resulted in barriers to sexual and reproductive autonomy and for some, has eroded trust in the healthcare system (DiMatteo et al., 2022).

The Legacy of Forced and Coerced Sterilization

Although SRH issues exist among people with disability of all genders, women with disabilities face additional injustices, most notably forced and coerced sterilization (Standing Senate Committee on Human Rights [SSCHR], 2022). Other marginalized groups, such as Indigenous and racialized women, are also disproportionately impacted (SSCHR, 2022). Acknowledging historical harms experienced by women with disabilities within the healthcare system is necessary for understanding the current context of SRH healthcare for this population. The healthcare system was a key player in the eugenics movement in Canada (SSCHR, 2022). Between 1930-1970, Alberta and British Columbia passed the Sexual Sterilization Acts, legislating those deemed ‘mentally defective,’ containing ‘undesirable elements,’ or belonging to part of ‘unfit groups’ to be sterilized without consent (SSCHR, 2022). Over 3000 Canadians

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were sterilized over this period. Forced and coerced sterilization is still a pressing issue for the disability community and its advocates. The SSCHR (2022) released a report stating that "this horrific practice is not limited to history but is evidently still occurring today," and issued an urgent call for action directed at the Canadian government (p. 27). The eugenics movement contributed to an ableist schema that has become entrenched in social systems and practices such as coerced contraception, sexuality education for people with disabilities that emphasize risk while minimizing discussion of pleasure or intimacy, and discriminatory child welfare interventions (McConnell & Phelan, 2022). The history of forced and coerced sterilization of women with disabilities has influenced negative attitudes toward disability, leading to ongoing harm and a loss of bodily autonomy, dignity, and humanity.

Factors Contributing to Inequity and Barriers in Care

A wide body of international research reveals that women with disabilities face attitudinal, structural, and informational barriers in accessing SRH care (Gibson & Mykitiuk, 2012; Kalpakjian et al., 2020; Taouk et al., 2018). The WHO (2022) has established equitable[6] access to SRH for women with disabilities as a human rights issue that enables biological health and social inclusion. Despite this formal recognition, many barriers are deep-rooted.

The mechanisms underlying and perpetuating inequities in SRH for women with disabilities are complex. Viewing inequities in SRH for women with disabilities through an intersectional framework helps deconstruct and make visible contributing factors. Intersectionality, a term initially coined by the legal scholar and black feminist Kimberlé Crenshaw emphasizes the barriers experienced by women with disabilities who navigate multiple

[6] Achieving health equity for people with disabilities means removing barriers to health and ensuring fair opportunities for well-being. It recognizes that some may need more resources to achieve equal outcomes while respecting their rights to autonomy, participation, and decision-making that affects their lives.

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forms of marginalization (Crenshaw, 1991). The inequity in SRH for women with disabilities is often compounded by the fact that they face ableism *and* sexism, two forms of discrimination heavily steeped in paternalism.

Ableism is rooted in systems of social power that devalue the bodies and lives of individuals with disabilities (Fletcher et al., 2023). For instance, when women with disabilities cannot be examined during a medical appointment because of inaccessible equipment, this is a manifestation of ableism. Excluding women with disabilities from research samples is also an act of ableism. Research funding structures that consistently overlook women's health issues or conduct studies without considering sex as a variable are mechanisms of sexism. When sexism intersects with ableism, these overlapping forms of social exclusion and bias create a complex web of disadvantage and power imbalance. The healthcare experiences of women with disabilities vary based on their individual identities and circumstances.

Attitudinal Barriers

Misperceptions, ignorance, and negative attitudes toward women with SCI influence health system policies, research, healthcare provider practices, and the quality of life for this population (Dillaway & Lysack, 2015; Gibson & Mykitiuk, 2012; Kalpakjian et al., 2020; Hampton et al., 2011). Healthcare providers often assume women with SCI to be asexual, or the care received by women with SCI is limited via narrow conceptualizations about disability and sexuality (Sharma, 2021). For example, in a study examining the barriers to breast cancer screening for women with disabilities, it was found that healthcare providers focused on the medicalization of disability instead of the health conditions women were facing (Barile, 2004; Brown et al., 2022). Perinatal care for women with disabilities is significantly impacted by ableist attitudes about who is capable and fit to parent (Brown et al., 2022).

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In Dillaway and Lysack's (2015) study on the experiences of women with SCI seeking gynecological care, a participant named Terry explained how negative attitudes about the lives of people with disability act as a barrier to care, Terry declared, "The barriers [to care] are 'stupid people'. Just people that believe [that] because my legs don't work my mind doesn't work or [that] my hearing is bad. I'm always trying to figure out how they are related!" (p. 17). Several women with SCI in this study lamented that they encounter poor treatment nearly every time they seek healthcare. A general discomfort with disability is prominent among healthcare providers, deterring women from receiving comprehensive care (Dillaway & Lysack, 2015). Even in the context of rehabilitation, Giurleo et al. (2022) found healthcare providers often make assumptions about the importance of sexual health based on disability and age.

Gender Bias

In 2019, Craven and Musselman (2019) called attention to the "many sex and gender disconnects in the field of SCI rehabilitation, which may be contributing to conscious bias, unconscious bias, or both, in the service delivery of spinal cord injury care and rehabilitation" (p. 1). In recent years, gender bias in SCI research and care has drawn increasing attention (Craven & Musselman, 2019; Piatt et al., 2022; Sharma, 2021; Stewart et al., 2020; Thomas & Murphy, 2019). Sex is rarely considered a biological variable, limiting evidence-based research on women with SCI and thereby contributing to inadequate health care and poor SRH outcomes (Piatt et al., 2022; Thomas & Murphy, 2019).

Additional Barriers

Disability activists have been advocating for universal design for many years. Women with SCI face barriers to accessing SRH services due to inaccessible offices, exam tables, scales, and breast mammography equipment (Angus, 2012; Mele et al., 2005; Rajan, 2013). The barriers

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to mammography are particularly concerning because women with mobility disability may have a higher likelihood of breast cancer diagnosis (Agaronnik et al., 2022).

Systems-level policies that do not accommodate longer appointments for women with complex care requirements or mobility issues also present barriers. For example, Angus et al. (2012) found that providers assigned low priority to health promotion for women with mobility impairments in these circumstances. Fragmented SRH medical care also contributes to difficulties in navigating the healthcare system (Brown et al., 2022; Fletcher et al., 2023).

Studies indicate that women with disabilities often face limited access to SRH information because of healthcare providers' lack of knowledge and competence (Dillaway & Lysack; Gibson & Mykitiuk, 2012; WHO, 2009). Informational barriers also arise from ableist attitudes and bias in health research. Dillaway and Lysack's (2014) study on the experiences of women with SCI accessing gynecological care highlighted insufficient education and training among healthcare providers as the main barrier faced by these women. In addition to medical knowledge on disability, McColl (2002) recommends that healthcare providers consider how the personal, social, and environmental contexts in which women live may alter the effectiveness or feasibility of traditional medical practices impacting menopause care. A lack of evidence-based education about menopause in all women also stems from widespread misunderstanding of research data from the Women's Health Initiative (WHI), a large, randomized study launched in the 1990s to explore health issues affecting postmenopausal women.

Women's Health Initiative and Public Perception of HRT

Hormone replacement therapy (HRT), a common treatment for menopausal symptoms, has a complex history that still influences treatment decisions today (Panay et al., 2024). The original WHI study included 3 randomized control trials (RCTs), an observational study, and a

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community prevention study (WHI, 2021). Participants included postmenopausal women between the ages of 50 and 79 (WHI, 2021). Two arms of the NIH study that included women on HRT were cut short between 2002-2004, and a startling press release indicated that HRT was related to an increased risk of invasive breast cancer, coronary heart disease, stroke, and pulmonary embolisms. (Avrum et al., 2023). Years of intense debate in academia and the media on the benefits and risks of HRT have led to significant uncertainty for healthcare providers and left women feeling disempowered (Avrum et al., 2023; Panay et al., 2024). Critics of the WHI state that statistically insignificant data was construed as meaningful and data was misrepresented (Avrum et al., 2023; Panay et al., 2024). In a white paper released by the international menopause society board president, Panay et al. (2024) describe the impacts of the WHI:

> Although the absolute risks of MHT on health outcomes in the WHI were rare to very rare by common standards, the data were alarmingly presented as percentage changes rather than absolute numbers by the media, and the risks were said to apply across all age groups. The fall in prescribing, especially in primary care, resulted in many women 'suffering in silence' and seeking other solutions for their symptoms. Numerous subsequent WHI publications following the initial report demonstrated that the problems were mainly in the older age groups [26], and probably due to the particular types and doses of hormone therapy used in the WHI. Yet many women and their prescribers were still too anxious to return to use of MHT. (p. 3)

The WHI now recognizes that HRT is the most effective treatment for managing menopausal vasomotor symptoms, genitourinary syndrome of menopause, and preventing bone loss (Avrum et al., 2023). Using conjugated equine estrogen (CEE) alone *lowers* the risk of

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breast cancer by 23% and reduces breast cancer mortality by 40% (Avrum et al., 2023; North American Menopause Society [NAMS], 2022). The main question that remains is whether the combination of CEE with medroxyprogesterone acetate increases breast cancer risk and, if so, whether that risk outweighs the therapy's many benefits (Avrum et al., 2023). A full discussion of HRT is beyond the scope of this paper however, NAMS (2022) states that the benefits of HRT lead to improved quality of life with low absolute attributable risks for women in the 50- to 59-year-old age group or within ten years of menopause onset.

Globally, there is an urgent need for accessible, evidence-based information and safe, effective treatment options for those requiring care. Ongoing advancements in healthcare provider training and the education of women in midlife will enhance both individual and societal health, boost productivity, and help alleviate the growing burden of chronic disease (Panay et al., 2024).

Menopause in Women with SCI

There is a significant lack of concrete research on the potential unique medical and social considerations for women with SCI experiencing menopause. This gap in knowledge poses a significant challenge for healthcare providers, who are left without clear guidelines to effectively support or even understand the unique needs of this population. As advances in care have led to increased life expectancy for women with SCI (Furlan et al., 2023; Hosier et al., 2012), there is a growing need to understand how they experience menopause. The SCI population in Canada now includes a growing number of older adults, particularly those over 60, due to the increasing number of falls (Noonan et al., 2012; Pickett et al., 2006). This has created a bi-modal age distribution, with peaks at 30 and 60 years of age (Noonan et al., 2012; Pickett et al., 2006).

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There is currently no clear consensus on whether SCI impacts the average age of menopause in women with SCI. Some studies report menopause onset to be 43.3 years old compared to 45.5 years for those without SCI (Hosier et al. 2012; Jackson et al., 1999), while another found no significant difference in age of onset (Kalpakjian & Quint, 2009). In Jackson et al.'s 1999 study, they found that 7.9% of women with SCI had permanent cessation of menses after SCI.

Without appropriate support, menopause can negatively impact not only health, but overall quality of life. This is an issue of particular concern for women with SCI who already contend with systemic barriers to healthcare, employment and social inclusion. Understanding menopause in the context of SCI is essential not only for younger women aging with SCI but also for those who sustain injuries later in life.

Menopausal Symptoms and Quality of Life in Women with SCI

Menopause has the potential to impact nearly every aspect of health for women with SCI. (Kalpakjian et al., 2010). Differentiating menopausal symptoms from other health issues in any woman can be challenging for clinicians (Menopause Foundation of Canada [MFC], 2022). This becomes even more complex for women with SCI (Kalpakjian & Quint, 2009). Women with SCI have elevated risks for specific health conditions and symptoms that menopause may exacerbate (Kalpakjian & Quint, 2009). These include cardiovascular disease, metabolic syndrome, osteoporosis, sexual dysfunction, sleep disturbance, depression, urinary tract infections, and skin breakdown (Kalpakjian & Quint, 2009; McColl, 2002). HRT can play a significant role in mediating many of these same disease processes and symptoms (MFC, 2022), however no clear guidelines for HRT in the SCI community exist.

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As McColl (2002) emphasizes, to fully understand the unique consequences of menopause on SCI, they must be situated against a background of pre-existing medical complexities, psychosocial contexts, and potential caregiving issues. Kalpakjian and Quint (2009) hypothesize that women with SCI experience a greater severity of symptoms. For example, because women with SCI have difficulty with temperature and blood pressure regulation, vasomotor symptoms of menopause (e.g., hot flashes) may be more severe. Furthermore, the authors point out that a hot flash in women with SCI could trigger complications such as bradycardia or tachycardia, shortness of breath, or headaches.

In the general population of people with SCI, the prevalence of cardiovascular disease is 17.1%, compared to 4.9% in those without SCI (Cragg et al., 2013). Metabolic syndrome (a cluster of symptoms including diabetes that increase risk for heart disease) is also prevalent among people with SCI. Szlachcic et al. (2014) note that prior to their study on atherosclerosis, in women with SCI, no studies had evaluated cardiovascular health in this population. Accelerated atherosclerosis in older asymptomatic women with SCI (mean age, 43) is a clinically significant condition deserving attention (Szlachcic et al., 2014). A 2015 Cochrane review by Boardman et al. (2015) of randomized control trials on HRT revealed an overall reduction in risk of cardiovascular disease and all-cause mortality for women who started HRT within 10 years of menopause (Boardman et al., 2015; Hodis & Mack, 2022).

Osteoporosis, once thought of as an inevitable part of aging is now recognized as a significant chronic illness which impacts quality of life and independence (Bauman et al., 2015). Women with SCI are at high risk for osteoporosis and fractures due to reductions in bone mineral density exacerbated by reduced weight-bearing activity (Garland et al., 2008; Khong et al., 2005; McColl, 2002). In addition to weight bearing, estrogen is one of the most critical determinants of

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bone health (Slade et al., 2003). Fractures in SCI often occur due to falls from a wheelchair, transfers or even low-impact activities, such as performing range-of-motion exercises (Bauman et al., 2015). The Women's Health Initiative study showed HRT reduced the risk of fractures by 34% in women who were at low risk for fractures, when compared to placebo (Lorentzon et al., 2022). Health Canada and the FDA have approved the use of HRT for preventing osteoporosis, but not as a treatment for osteoporosis once it has been diagnosed, making early education for women crucial in preserving bone health (Khan et al., 2022).

A reduction of estrogen at menopause contributes to a loss of collagen, diminished vascular perfusion and skin changes that can have a significant impact on quality of life for women with SCI if skin breakdown occurs (Dormire and Becker, 2007). Furthermore, post-menopausal weight gain has the potential to make transferring more difficult and increases the risk of skin breakdown or falls. This may increase caregiving or equipment needs, adding to financial or psychological stress.

Pre-existing sexual function concerns in women with SCI, such as diminished sexual response, autonomic dysreflexia, or spasticity, may be compounded by other sexual issues related to menopause, such as vaginal dryness and decreased sexual interest (Kalpakjian et al., 2010). Because of the potential for more severe health consequences than their peers without SCI, Dormire et al. (2009) suggest that healthcare providers should provide menopause assessment and education earlier than usual. The imperative to further understand and address menopause and SCI will not decrease; rather, it will become more important over time. As more women survive their injuries and go on to lead extended, healthy lives, we must do more to respond to their evolving needs adequately. I agree with scholars who suggest that viewing

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disability or menopause solely as biological conditions defined by deficits is harmful (McRuer, 2006; Thomas, 2006; Leng, 1996; McColl, 2002).

The Risk Benefit Ratio of Hormone Replacement Therapy in Women with SCI

The use of HRT in women with SCI is significantly understudied (Welner et al., 2002, Yang et al., 2006). Use of HRT in a study of women with mobility impairments from 2006, revealed 22.3% were using HRT (Yang et al.). No published intervention studies examining the use of HRT in women with SCI have since been conducted (as of November 2024). Older research discussing HRT in the context of women with mobility impairments weighs benefits such as osteoporosis prevention and cardiometabolic protection against risks, particularly thrombosis (Becker et al., 2009; Kalpakjian & Quint, 2009). Becker et al. (2009) state that SCI predisposes women to thrombosis, making HRT potentially risky. On the other hand, Welner et al. (2002) argue that women with SCI who have no history of thrombosis could theoretically be considered low risk, but there is no data to support this. Of note, thrombosis risk is most prominent within the first six months of SCI, reducing significantly thereafter (Mackiewicz-Milewska et al., 2016). More recent research on HRT reveals the route of delivery and type of progestogen used contribute to clotting risk (Morris & Talaulikar, 2023). The first pass metabolism of both estrogens and progestogens in the liver leads to increased production of clotting factors (Morris & Talaulikar, 2023). However, progestogen formulations such as oral micronized progesterone and dyhydrogesterone do not increase clotting risk (Morris & Talaulikar, 2023). Similarly, transdermal estrogen (unlike the oral equine estrogen studied in the WHI) has no increased risk for thrombosis compared with nonusers (Morris & Talaulikar, 2023). Considering the recent science on the safety and health benefits of HRT, a more balanced clinical discourse on HRT in women with SCI is required. This dialogue would contribute to clinician

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confidence in the realm of menopause treatment for women with SCI. One of the most significant factors influencing a woman with mobility impairment's decision to pursue HRT is an awareness of healthcare providers' views on the treatment (Becker, 2009). Furthermore, women with mobility impairments desire more information on the use of HRT in menopause (Becker, 2009).

Background on Sex Hormones and SCI

Women with SCI have unique sex and gender-based considerations for rehabilitation, living with SCI, and treatment (Furlan et al., 2005; Garland et al., 2008; Soldin & Mattison, 2009). Literature on the impact of sex hormones on SCI recovery, health maintenance and long-term health is beginning to emerge, partly in response to a 2015 National Institute of Health Initiative to investigate sex as a biological variable (Stewart et al., 2020). To date, most SCI guidelines have been developed from research that neglects sex-based differences (Stewart et al., 2020). The existing research supporting sex-dependent effects after SCI focus on motor outcomes and white matter sparing[7] while neglecting secondary complications that significantly impact quality of life (Stewart et al., 2020).

During the menopausal period, estrogen decreases. Understanding the full spectrum of estrogen's role in health is beyond the scope of this paper. However, here I will highlight research regarding estrogen that may be particularly relevant to women with SCI. Evidence is growing that the higher prevalence of estrogens and progesterone in females is neuroprotective (Garcia-Ovejero et al. 2014; Lee et al., 2018; Roof & Hall 2000; Sengelaub et al., 2018; Stewart et al., 2020). For example, a body of work (Aminmansour et al., 2016; Roof & Hall, 2000; Stein & Hoffman, 2003) revealed that when high-dose estrogens or progesterone are used for

[7] White matter of the spinal cord helps conduct, process and send nerve signals

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neurotrauma treatment, outcomes persistently improve. Furthermore, Storch et al. (2005) found that premenopausal women with SCI had better protection against adverse lipoprotein profiles and cardiovascular disease risks compared to men with SCI, likely due to their estrogen levels. However, the study did not include peri- and postmenopausal women and mainly focused on the risks for men with SCI. Unfortunately, Stewart et al. (2020, p. 3) point out that the influence of female hormones on recovery from neurotrauma has led to an appraisal that inclusion of females adds too much variability to data due to the fluctuation of estrogens and progesterone during the estrus cycle, which scientists use as an argument to exclude the use of females in most pre-clinical research. Estrogen plays a significant role in modulating the immune system, exerting anti-inflammatory and antioxidant properties after acute SCI (Stewart et al., 2020). Whether these benefits continue into the chronic SCI period is unknown (Stewart et al., 2020).

In addition to researching how estrogen and progesterone impact SCI outcomes, another consideration is how SCI impacts hormones and the endocrine system. During the acute phase, SCI induces estrus cycle dysfunction (often interrupting menses for a short period during acute SCI). Robust research is lacking on whether hormones are impacted in the longer term for women with chronic SCI. However, Stewart et al. (2020) suggest that SCI contributes to chronically reduced circulating levels of sex hormones, resulting in long-term health consequences, including disproportionate losses in bone density compared to men (Garland et al., 2008). A decrease in sex hormones during menopause results in unique sex-dependent considerations for women with SCI (Stewart et al., 2020).

The Intersection of Feminist and Disability Studies

Feminist and disability studies have become closely intertwined and offer a framework for understanding and addressing the experiences of women with disabilities. Both feminist and

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disability studies fall under an umbrella of identity-based studies that share a deep history and further our understandings of subjugated knowledge, oppression, emancipation, and activism (Garland-Thomson, 1997; Thomas, 2006). Before these fields converged, women with disabilities were often overlooked by disability advocates and those studying women's issues (Asch & Fine, 2009). Garland-Thomson (1997) describes the link between feminist and disability studies in the following passage,

> Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both the female and the disabled body are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority. Indeed, the discursive equation of femaleness with disability is common, sometimes to denigrate women and sometimes to defend them. (p. 119)

Stereotypes that depict women and people with disabilities as passive, dependent, and needy have perpetuated a historic lack of academic and scientific inquiry into the population (Asch & Fine, 2009).

The history of rehabilitation medicine reveals an evolution of male-centric care, funding, and research within this field. Asch and Fine (2009) recount how rehab medicine grew in a time of war when wounded veterans (inevitably male) returned home, requiring reintegration into society. The social narrative at the time equated disability with childlike helplessness, the antithesis of masculinity – further propelling societal efforts to rehabilitate veterans. In other words, the imperative in rehab medicine was rehabilitating the male population (Asch & Fine, 2009). Social constructs that depicted women as innately docile, emotional, and passive aligned with stereotypes of disability, thereby reinforcing apathy towards rehabilitation efforts for

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women with disability (Asch & Fine, 2009). Many would argue that rehab medicine continues to be biased towards supporting male populations. (Craven & Musselman, 2019; Gibson, 2012; McColl, 2002; Piat et al., 2022). Although increasing attention is being drawn to the needs of women with disabilities, the SRH needs of aging women with disabilities remain under-studied and under-resourced (Fletcher et al., 2023). This remains true for all women, regardless of disability status (Panay et al., 2024).

Ontological Tensions in Defining Menopause

Evolving academic discourse regarding menopause has led to tensions regarding how menopause is defined. The biomedical model defines menopause through hormones (Leng, 2006). Early research on menopause treatments took place during the 1930-1960s when medicine was heavily patriarchal. Shortly after synthetic estrogen was released as a treatment in the 1960s and hailed as a fountain of youth, feminists organized in opposition, arguing that medicalization was perpetuating the social ideology of women as sex objects and reproductive organs (McCrea, 1983). A heavy biomedical focus on menopause created tensions within feminist discourse on the medicalization of menopause (Bell, 1987; McCrea, 1983; Utian, 1997). Many feminists believed that menopause was a social phenomenon requiring social solutions and that medicalization disempowered women, situating them against authoritative physicians and rendering them passive and dependent (Bell, 1987; McCrea, 1983).

Feminist scholars demonstrated that the stigma and silence surrounding menopause are related to society's historical attempts to erase aging women from cultural and social life (Orgad & Rotterberg, 2024). Feminist menopause politics came with criticism. Leng (2006) calls out the boundedness inherent in the valorization of a 'natural female body'.

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> As we have seen, there are two positions available to menopausal women in the feminist literature: they can either submit to the biomedical paradigm (accept HRT) or resist it (reject HRT). But these two positions quickly reduce to one real position: the subjectivity proper to menopause is resistance since to accept HRT and medicalization implies passivity and victimization. This resisting menopausal body then becomes the privileged site of feminist discourse and in this privileging, feminist politics itself becomes a totalizing narrative of menopause. My point is that this menopausal body, a body uncontaminated by patriarchal intervention, is no less constructed than the biomedical definition of menopause as deficiency or syndrome. Nature, and the normal body, are quite simply not to be trusted as foundations for anything. (p. 44)

Over time, feminist and medical literature evolved, offering diverse perspectives of women's experiences of menopause, including those that are positive and neutral (Brown et al., 2018; Hyde et al., 2010; Utian, 1997). Heightened media attention has pushed menopause into popular culture, with high-profile women such as Michelle Obama, Halle Berry and Naomi Watts speaking publicly about menopause experiences (Onculer & Onculer Yayalar , 2025; Orgad & Rottenberg, 2024). Since the latter part of 2010, commercial growth of menopause products and services has also mirrored an increase in public and academic interest (Onculer & Onculer Yayalar, 2025).

Medical and sociocultural aspects of menopause have been widely debated for decades, bringing a new wave of women who are demanding evidence-based information, autonomy in decision-making, and societal acknowledgment of the worth of aging women (Alspaugh et al., 2021; Orgad et al., 2021).

Ontological Underpinnings of the Medical Model of Disability

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Since the 1800s, the medical model of disability has prevailed within societies, viewing disability as objectively abnormal, undesirable, and requiring repair (Zaks, 2023). This model often overlooks complex, intersecting experiences of identities. For example, care provided through a medical model of disability would treat disability and menopause as separate medical conditions rather than recognizing the combined impact on physical and emotional well-being (McColl, 2002). Furthermore, as researchers, our ontological schemas of disability matter. They heavily influence our epistemic approaches and subsequently, patient care (Doane, 2008). By focusing solely on managing symptoms or 'fixing' the body, the medical model disregards the social, environmental, and psychological factors that shape experiences. This narrow perspective can lead to inadequate care, marginalization, and a lack of comprehensive, individualized support.

The comparative and evaluative nature of the medical model creates a climate that Shuttleworth (2007) states has created a "moral edict that exerts tremendous influence on disabled people's body images" (p. 145). In other words, by juxtaposing disability next to the taken for granted 'normal', functional differences are devalued and ableism is born. The medical system is constantly seeking to measure and gather knowledge on people with disabilities, but it raises the question: what epistemologies are best suited to improve SRH outcomes for this population?

Epistemic Inadequacy of Medical Model

In attempts to normalize people living with disabilities, the medical model primarily focuses on gathering biomedical knowledge. In viewing disability through a narrow biomedical lens, the medical model imparts a knowledge gap, as other types of subjugated knowledge (such as phenomenological or qualitative) are left out of the conversation. Doane and Varcoe (2008)

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point out that knowledge/practice gaps are "fostered by the kinds of knowledge that are *assumed* to constitute valid theory or evidence and on which practice is subsequently based" (p. 285). A biomedical epistemic focus often sidelines research and support for the types of issues people with disability really want addressed. Take for example, this quote from renowned disability feminist, activist, and scholar, Barbara Waxman (1991)

> the disability rights movement has never addressed sexuality as a key political issue, though many of us find sexuality to be the area of our greatest oppression. We are more concerned with being loved and finding sexual fulfillment than in getting on the bus. (p. 23, as cited in Shuttleworth, 2007).

Ontological Underpinnings of the Social Model of Disability

In the latter half of the 20th century, the social model of disability emerged alongside the civil rights movement, aiming to address social justice concerns and challenge the medical model of disability (Zak, 2023). Various social models of disability (the North American minority group approach, the social constructionist approach, or the Nordic relational model) share the same goal of the British social model; to improve the lives of people with disability by promoting inclusion and removing oppressive barriers (Shakespeare, 2014).

The social model of disability illuminates a broader picture of why women with disabilities face inequities in accessing SRH. Developed by activists like Paul Hunt and Vic Finkelstein in the 1970s, this model asserts that disability results from societal barriers, not an individual's impairment (Thomas, 2006). The social model is rooted in constructionism, where "meanings are constructed by human beings as they engage with the world they are interpreting" (Crotty, 1998, p. 43). Constructionism has the potential to move society beyond a narrow biomedical focus on disability, allowing us to question the structural and social factors at play.

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Crip Theory

In opposition to the medical model of disability, ‘crip’ models of disability have also emerged from the intersection of queer theory and disability studies (McRuer, 2006). The ontology of able-bodiedness as a non-identity is challenged by McRuer (2006) when they state, “able-bodiedness, even more than heterosexuality, still largely masquerades as a nonidentity, as the natural order of things” (p. 1). The author further frames this concept by explaining that “this system of compulsory able-bodiedness in a sense produces disability (p. 2). Crip theory subverts notions that disability is inherently negative and instead opens space for acknowledging and validating diverse sexualities within the disability community (McRuer, 2006). Reeves et al. (2023) explain that “to 'crip' a construct is to illuminate both the disruptive and generative potential of disability—troubling taken-for-granted ideas of what it means to be a normative person and sparking opportunities for shifting and expanding constructs" (p. 320).

What makes ‘crip’ theory particularly useful is its potential to be utilized as both an analytical lens and a tool for approaching social justice issues. For example, when translated into clinical practice, crip theory challenges traditional appointment times that are often insufficient for those with disabilities. When utilizing ‘crip’ theory and constructionism in research, narrow biomedical epistemic approaches can be replaced with post-positivistic methods of inquiry, such as narrative inquiry. Knowledge gained from this type of inquiry is likely to unveil societal myths regarding disability that have perpetuated harmful outcomes for this population and prevented appropriate interventions.

This literature review revealed that menopause and SCI have both received attention in academia, albeit as distinct and separate areas of inquiry. Critical disability studies contribute to a nuanced understanding of disability that situates deficits as resulting from environmental

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barriers. Similarly, feminist studies oppose the notion that menopause is purely a biological condition steeped in deficit and encourage us to examine how sociocultural influences contribute to understandings and meanings of menopause. Although feminist paradigms of menopause are omnipresent in the literature, they are too often built upon politics that valorize the natural, 'normal' female body, thereby situating medical intervention as an intrusion of patriarchy (Leng, 1996). This paradigm can stigmatize women who require or desire medical intervention for menopause (Leng, 1996).

Justifications for Research

My motivations for approaching this research puzzle have evolved as I continue to learn about the state of health inequity for aging women, particularly for women with SCI. The Women's Age Lab [WAL] (2024) points out that the National Institute of Health (NIH) only recently began requiring the inclusion of women and older adults in research studies. Before the 1990s, women were often excluded, and it wasn't until 2019 that older adults were systematically included (WAL, 2024). The authors explain that a lack of diverse representation in research created a concerning data gap, making it difficult to understand how conditions affect women and older adults specifically. Recognizing this issue, the Canadian Institutes of Health Research (CIHR) started requiring researchers to consider sex, gender, and age in their grant applications in 2006. Despite this, only 5.9% of grants in Canada and the United Kingdom focus on female-specific outcomes. When looking at grants that consider the health of older women, the percentage of research decreases further (WAL, 2024).

My social justifications are strongly rooted in a belief that women with SCI deserve SRH health equity and that fostering a contextual understanding of their experience through narrative inquiry will support this goal. My values align with pragmatist feminism, which embraces

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activism and situates experience as "radically contextual and relational. In acknowledging the constant flux of life and collapsing the theory/experience divide, pragmatist feminists are interested in the particularities of each situation and the connections between" (Lake, 2020, p. 30). Pragmatist feminism, as described by Lake (2020), encourages a commitment to reflexivity, prompting me to consider my part in sustaining SRH health inequity and directing me to consider how I can support positive change.

My justifications are also situated against a backdrop of experiences and stories previously recounted. Because of my interest in health equity, I am drawn to consider how women with SCI experience menopause care. Along with colleagues in my workplace and stakeholders, conversations and meetings have begun on how to approach the knowledge gap in menopause care for women with SCI. For example, while attending meetings with representatives from BC Women's Hospital and women living with SCI, I listened attentively to the recommendations of my colleagues with lived experience. Further, I sat in on two education sessions on menopause and SCI, led by a woman with SCI who was in menopause herself. Attending a small working group on menopause and SCI provided me with additional opportunities to hear various perspectives on the topic. All these experiences contribute to the proposed inquiry, shaping my research puzzle[8].

Research Puzzle

When I reflect upon my personal justifications, questions arise, such as what are the expectations of women with SCI regarding what menopause care should look like. For example, I begin to wonder if their providers have proactively addressed the topic of menopause. How did

[8] Unlike other qualitative methodologies, narrative inquiry is unique because it does not utilize a research question (Clandinin & Caine, 2013). Instead, a research puzzle is composed, consisting of many inquiries and informed by the researcher's personal, practical, and social justifications (Clandinin & Caine, 2013).

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these conversations, if any, make them feel? I am also curious about the impact of menopause on their quality of life. How do women with SCI experience changes in quality of life during menopause, if at all? Do societal assumptions about their quality of life, as people with disabilities, influence the support and attention they receive during this transition?

From a practical standpoint, I feel strongly that, as a medical community, we need to do better in providing proactive quality menopause education and care to women with SCI. Clinically, I am aware of the unique health considerations of women living with SCI who are impacted by the menopause transition. For example, I have seen first-hand how a fracture due to osteoporosis or a wound due to fragile skin or weight gain can restrict a woman's freedom of movement, interrupt her social and economic life, and negatively impact her mental health. A better biological and medical understanding of the menopause process in women with SCI could help alleviate gaps in standards of practice and improve the quality of life for this population.

I have further questions about how it feels to navigate what is normatively understood as a female phenomenon in a medical system built primarily with males in mind. I also wonder if the feminist dialogue, so strongly positioned in the literature, shapes conceptions of menopause for women with SCI. Furthermore, I am curious if and how the fallout from WHI has shaped menopause care for women with SCI. These are some of the questions that build my research puzzle.

Turning toward a Methodological Approach

Employing a methodology that allows for a nuanced and deep understanding of how intersecting identities contribute to the experiences of menopause and SCI will be essential for informing future research and care. Narrative inquiry provides a vantage point to cast aside rigid

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paradigms and ontologies and instead explore how the complexities of disability and menopause show up within time, place, and context in the lives of women with SCI.

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Chapter 3: Methodology

This research is a narrative inquiry study. Narrative inquiry is a methodology that honors the nuance in complex research questions, making it ideal for exploring the experiences of menopause and SCI. Epistemologies and ontologies that bracket complex human experiences in biomedicine or other restrictive constructs rarely go unopposed (Komearoff et al., 1997). Just as disability can be situated in a medical or social model, the experience and meaning of menopause can vary greatly depending on the ontological viewpoint. Leng (1996) reminds us how our positionality as researchers contributes to shaping the narrative of menopause, "menopause is animated by the discourses and practices that construct it as an object for study. These discourses and practices - whether biomedical or feminist - are themselves locked into particular social and historical conditions" (p. 40). To avoid displacing knowledge that reflects the experiences of women with disabilities, we must resist approaching the subject with rigid or binary ontologies and instead listen closely to women with openness and curiosity.

Exploring the Ontology of Experience in Narrative Inquiry

Narrative inquiry is a relational methodology that focuses on experience and encompasses the three dimensions of time, place, and sociality (Clandinin & Caine, 2013). By centering context in this way, space is provided for rich and layered narratives to arise (Clandinin & Rosiek, 2007). Narrative inquiry frames experience as the central unit of analysis, allowing participants and researchers to explore personal, social, and political experiences that reflect our past, present, and anticipated future events (Clandinin & Rosiek, 2007). This methodology draws on pragmatist scholarship, including Jane Addams's (1902) feminist work on social ethics.

Addams (1902) believed that knowledge is derived from experience. She argued that ethical will and, subsequently, ethical actions are motivated by immersing oneself in the

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experiences of communities we wish to understand. In her book *Democracy and Social Ethics*, Addams underscores the idea that our ethical obligations arise from personal experiences and relationships rather than some external moral code. In speaking about moral dissatisfaction in society and the difficulty in developing moral obligations outside our family unit, she says:

> We may indeed imagine many of them saying: “Cast our experiences in a larger mould if our lives are to be animated by the larger social aims. We have met the obligations of our family life, not because we had made resolutions to that end, but spontaneously, because of a common fund of memories and affections, from which the obligation naturally develops, and we see no other way in which to prepare ourselves for the larger social duties. (p. 7).

By suggesting that a "common fund of memories and affections" fosters a natural sense of duty, Addams (1902) highlights the interconnectedness of individuals and the importance of our relationships in providing frameworks for developing and understanding our ethical commitments.

John Dewey, another pragmatist scholar, also greatly contributes to the ontological underpinning of narrative inquiry (Clandinin & Rosiek, 2007). Dewey’s theory of experience (1976) situates experience as the starting point for all inquiry (Clandinin and Rosiek, 2007). Clandinin et al. (2018) point out that narrative inquiry takes Dewey’s (1976) transactional approach to experience (we experience the world to know the world) and translates it into a relational approach, focusing on “the relationship between knower and what is known, between knowing and action, between how one knows what one knows” (Clandinin et al., 2018, p. 18).

When considering the construction of Dewey’s experience, Clandinin and Connelly (2000) note that continuity and interaction are at the forefront. The continuous nature of

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experience emphasized by Dewey (1976) is also reflected in the narrative methodology by recognizing that narratives collected during research are situated with a larger series of enmeshed and unfolding experiences that do not end when the research study concludes (Clandinin & Rosiek, 2007). In this way, Dewey's theory of experience informs the contextual focus (the three dimensions of temporality, sociality, and place) of narrative inquiry (Dewart et al., 2019). As Clandinin and Connelly (2000) note, Dewey (1976) guides us to place attention upon contextuality and the non-linear nature of experience. Finally, Clandinin and Rosiek (2007) explain that knowledge is rooted in our lived experiences and must be validated by returning to those experiences.

World Traveling

Mary Lugones' (1987) metaphor of world-traveling is a framework embraced within narrative inquiry for its ability to guide us in *coming alongside participants,* an empathetic approach to connecting with and understanding the experiences of those outside our culture or community (Dewart et al., 2019). Lugones (1987) prompts us to consider the shift in identity occurring when we immerse ourselves in another world and how these shifts in identity impact our ability to connect with others. Lugones (1987) suggests embracing a non-traditional conception of playfulness that centers curiosity and openness, therefore fostering the ability to set aside arrogance and assumptions about another's world. In the following quote, Lugones (1987) focuses on accepting uncertainty and ambiguity in her version of playfulness (which they also refer to as loving perception), "the playfulness that gives meaning to our activity includes uncertainty, but in this case the uncertainty is an openness to surprise. This is a particular metaphysical attitude that does not expect the world to be neatly packaged" (p. 16). Dewart et al. (2019) posits that the risk of approaching relationships with arrogance is particularly prominent

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in research. The metaphor of world traveling provides a language and lens to understand the dynamics of relationality within the narrative inquiry methodology (Dewart et al., 2019).

Relational Ethics

In the previous section, I introduced Addams' work on social ethics, which contends that knowledge is derived from experience. I also identified Dewey's (1976) and Lugones's (1986) contributions to narrative inquiry's moral and philosophical grounding in experience. In addition, relational ethics is another essential grounding for narrative inquiry (Clandinin & Caine, 2013). A relational ethics approach supports relational knowing and understanding (Clandinin & Caine, 2013). This ontological stance prompts the researcher to look inward and turn the gaze, "upon who we are and are becoming throughout the study of our experience alongside the experiences of participants" (Clandinin et al., 2018, p. 16). Furthermore, relational ethics facilitates the emergence of a research space and relational world that are places of belonging for the researcher and participant (Clandinin & Caine, 2013). Relational ethics also prompts the researcher to be attuned to reciprocity, care, and mutual vulnerability during the research process and beyond (Clandinin & Caine, 2013).

Vulnerability in Relational Ethics

In contrast to traditional Western philosophy, which often views people as self-sufficient and autonomous, relational ethics emphasizes a reliance on the connections between people (Koggel et al., 2022). Although the most common approach to medical ethics, as discussed by Kenney et al. (2010) involves a principle-based approach focused on autonomy, this approach becomes problematic in situations where larger social contexts are at play:

> Where traditional bioethics treats persons as self-contained, self-interested, and self-directing creatures, relational ethics insists that persons be treated as the social,

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> interdependent beings that they are. Relational persons develop and deploy their values within the social worlds they inhabit, conditioned by the opportunities and obstacles that shape their lives according to the socially salient features of their embodied lives (e.g., their gender, race, class, age, disability status, ethnicity) (p. 10).

A relational ethics perspective acknowledges that individuals are shaped by and act within relationships rather than existing as isolated entities (Koggel et al., 2022). In discussions of relational ethics and vulnerability, Mackenzie (2014) suggests that negative connotations of helplessness or neediness should be replaced with the notion of universal vulnerability (a concept derived from legal ethics). Universal vulnerability endorses the notion that there is no other "non-vulnerable" population; being human means being vulnerable and relying on institutions and social structures (Mackenzie, 2014). Further extending this concept, Kittay (2011) states that relational ethics prompts us to "acknowledge how dependence on another saves us from isolation and provides the connections to another that makes life worthwhile" (p. 57). A relational ethics perspective challenges the notion that menopause concerns of women with SCI are solely due to biological complexity or some inherent personal vulnerability (Kenney et al., 2010), guiding us to consider the relational threads of ethical issues.

Feminist Beginnings of Relational Ethics

Feminist relational theorists reorient us away from the autonomous individual and moral rules, and towards the importance of social and relational factors in shaping human identity and experience (Koggel et al., 2022**).** The feminist beginnings of relational ethics are particularly relevant because menopause is normatively understood as a women's issue. In the 1970s and 1980s, feminist relational theorists began to position relationships as the central feature of analysis in moral and political applications, including care ethics (Koggel et al., 2022).

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Hamington (2001) points out that feminist care ethics employ various philosophical assumptions but share a focus on connection and interdependence. When reflecting upon the evolution of care ethics in feminism, Hamington (2001) asserts that Addams' was an early adopter of relational ethics, with a focus on an *active* embodied ethic of care. This differs from other more passive care ethics such as Noddings' (1984) because Addams' positions experience as a precursor to morality (Hamington, 2001). I would agree with Blix et al. (2019) when they position Addams' social ethic of care as a useful framework and tool for addressing wider social issues.

In contrast to Western individualism, Koggel et al. (2022) highlight that feminist theory can situate relationships at the center of ethical discussions. For example, menopause, often framed as a private individual experience, can be influenced by societal structures and relationships. Feminist relational ethics offers a valuable framework for understanding the interconnectedness of gender, disability, and health. The authors also note that from a feminist relational view, we can better understand the effects of oppressive systems on individuals and groups with the assumption that we are all embedded in a network of personal, public, and institutional networks (Koggel et al., 2022). Therefore, relational feminist ethics lends itself to examining oppression, power, social justice, and emancipation (Koggel et al., 2022). My research was approached through a lens of relational ethics, in order to remain attentive to my responsibilities and obligations to participants.

Recruitment

Purposive sampling with a networking approach was utilized. Posters were placed in the common spaces of an accessible gym in an outpatient spinal cord centre (see appendix A). Digital recruitment was completed with support from Spinal Cord Injury BC who circulated information about the study in their newsletter. Individuals who expressed interest in the study

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were offered a meeting to discuss the study's focus, the nature of co-composition in narrative inquiry, and the associated time commitments.

Participants

The participants for this study were women with SCI who self-identified as being in menopause. To be eligible for this study, participants were required to be English speaking, self-identify as being in menopause and living in the lower mainland, BC. Exclusion criteria included current or previous recent patients of mine (past 2 years). Both participants identified as middle class, financially secure, white women. Participants were selected on a first come first serve basis after a phone conversation to discuss the study process in depth. I met with each participant for 1.5 hours on 4 occasions in their homes and on video conferencing. During these meetings, participants were invited to tell their stories, and to co-compose and negotiate narrative accounts. An honorarium of $25 was provided to participants for their time and to cover potential costs that may have been incurred throughout the research process.

Ethical Considerations

Ethical approval was obtained from the University of Victoria Research Ethics board (25-0458). Participants were provided with information on the nature of narrative inquiry and the associated time commitments. Participants were permitted to withdraw from the study at any point without consequence. Furthermore, they were informed that they could decline to answer any questions or discuss topics they were uncomfortable with, also without consequence. To minimize potential harm, participants were offered the opportunity to review and edit transcripts of their interviews. Subsequently, during the narrative writing process, participants were re-engaged to co-compose narrative accounts, ensuring the research texts aligned with their interpretations and comfort levels.

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Theoretical and Practical Considerations of Field Texts

Field texts (referred to in most methodologies as data) are composed of "conversations, interviews, participant observations, as well as artifacts" (Clandinin & Caine, 2013, p. 172). Examples of artifacts include photographs, artwork, and documents. A distinct feature of narrative inquiry is the acknowledgment that separate experiences (those of the researcher and participant) interact, giving voice to rich, layered, and ongoing narratives (Clandinin & Caine, 2013).

The conversations with both participants took place in their homes and also through video conferencing. Field texts were composed over four 1-hour conversations with each participant. An open, non-directed conversational approach was implemented to support the sharing of stories (Clandinin & Caine, 2013). Examples of questions used to initiate conversations include: Can you speak about what menopause means for you? How has your SCI impacted your menopause experience? (see Appendix A)

In order to capture contextual details of our meetings and conversations, I kept field notes which focused on inner thoughts, emotions, and moral responses. Field notes were developed over multiple sessions, spanning time and attending to earlier life experiences (Clandinin & Caine, 2013). As I enter the field, I foregrounded Lugones's (1986) conception of playfulness, inviting participants to lead conversations, which meant I had to stay open to unknown narratives that may arise. I used Whisper transcription software to transcribe all conversations. Transcripts were securely stored on the UVIC Microsoft Onedrive.

From Field to Interim and Final Research Texts

When we transitioned from field to interim texts, participants and I considered how the research experience relates to the initial puzzle. Blix et al. (2019) emphasize that in narrative

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inquiry, experience is not sitting idle, simply waiting to be uncovered, instead, narrative inquiry facilitates experience through "the active, dynamic and dialogic co-construction of forward-looking stories that have the capacity to change all involved." (p. 920). Field texts were read and re-read with attention placed upon temporality, place and sociality (Clandinin & Caine, 2013). As part of the interim field texts, I co-composed a narrative account of each participant and my experiences alongside them. The narrative accounts were negotiated with participants. The intent of the negotiations was to ensure that participants were comfortable with the experiences shared with others as part of this research. The narrative accounts also reflect my positionality in the inquiry in relation to participants (Clandinin, 2007).

Once the narrative accounts were negotiated with attention paid to the three common places (Clandinin & Caine, 2013), I met with my supervisory committee to discuss what resonant threads had emerged amongst the narrative accounts (Clandinin & Caine, 2013). The resonant threads are a significant element of the 'final' research texts which will continue to evolve and unfold as life and our stories continue (Clandinin & Caine, 2013).

Response Community

Throughout the process of this narrative inquiry, I engaged with a response community composed of trusted peers. The purpose of a response community is to support reflexivity and engagement in dialogue about how the inquiry is unfolding (Clandinin & Caine, 2013). A response community is guided by relational ethics and supported me as I revisited my personal, practical and social justifications (Clandinin & Canine, 2013).

In the following two chapters, I will share the narrative accounts of Kim and Nadine. Each of these accounts was negotiated with them. Following the narrative accounts is a chapter with a publication that focuses on narrative threads.

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Chapter 4: Narrative Account of Kim

Kim became aware of my research through a colleague of mine and reached out by email expressing interest. In her email response, Kim informed me she would try her best to spread the word to other potential participants. I would soon come to be familiar with Kim's constant advocacy within the SCI community. While negotiating details of our first meeting, Kim offered to make a trip from her city to come meet me, which was rather far away. I declined her generous offer and instead drove to her home after my workday. I certainly had a lot to think about on the drive to Kim's. This was my first research interview and naturally I wanted everything to go smoothly. Would conversation flow naturally? How would I contribute to the narrative? I reminded myself that thinking about hypothetical problems is rarely helpful. I summoned principles of mindfulness along the drive, arriving relatively calm and ready to listen. I wondered how the experience of engaging in research conversations might be different from my clinical practice. Would my experience as a nurse help or hinder the narrative inquiry process? In conversations during my nursing practice, I allowed space for what might come forth but typically ended up steering the interaction – providing education, asking questions, and gently working to create rapport – an essential ingredient of the sexual health appointment. Being in my role now for several years, I wonder if my familiarity with this process would foreclose opportunities to engage with Kim as a researcher. I knew that my role with Kim was different. I tried to remind myself of this as I arrived at Kim's single-family home late in the afternoon. Kim's bungalow was in a quiet suburb, with an accessible van and a camper parked in the front driveway. Seeing the camper parked in the front made me wonder about the places Kim would travel to.

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As I entered Kim's home, I noticed how cozy and accessible it was. Kim offered to take me for a tour, pointing out renovations such as a roll-in spacious closet that was formally a bedroom. Just down the hall, a large, dedicated shower room with a bench made me wonder why more homes didn't have this feature. Kim's bedroom was at the back of the house with warm wooden beams on the ceiling and large windows looking out onto a forested area in the backyard. *I love this room,* Kim remarked. She described how she would go outside on sleepless nights, finding the calm air and sounds of nature soothing.

coming back to, to who I used to be
I looked out the window, and there was deer
just breathe[9]

As we turned to leave Kim's room, she looked up and pointed to the ceiling and told me, "If I ever need a lift, this room is designed to install one." Kim's comment reminded me that the need to anticipate and plan for future changes in independence is an acute reality for individuals with SCI and something I have witnessed over the years in my nursing practice. Kim led me down the hall to her kitchen where her husband was busy preparing some food for dinner. I felt fortunate to be introduced to Kim's family. After a quick introduction we discovered that Kim's husband used to live in my neighborhood. We talked about how the neighborhood had changed, and he left for their workshop in the backyard. While Kim and I settled at her kitchen table, we

[9] This found poem was created using fragments of Kim's words excerpted from conversational interview transcripts. Found poems throughout this narrative account are represented in Courier New Italic Font.

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reviewed the consent form. I scrambled to get my audio recorder going as she started to recount some of her past research experiences, both good and bad.

Kim recalled a particular time when she declined to participate in a study and yet was pressured to do so. She wondered if she should have reported the situation to an ethics board but feared repercussions for other clinicians involved, whom she knew and was fond of. In one of our later conversations, Kim revealed another negative research experience. The study Kim was taking part in involved taking home a blood pressure cuff for overnight monitoring. This was a significant request, as Kim would need to wake up several times during the night to take readings. Here Kim explains how she noticed in the clinic, that the cuff would fall off while transferring, prompting her to ask the researchers for assistance and direction,

> *When I was at the Blusson building that day and it kept falling off...I'd go back to the researcher I'd say it's falling off... well long story short is I tried to tell them it's not going to work because I have to transfer I have to move my body about and this blood cuff monitor is probably going to keep falling off it already fell off how many times when I was in your building I've told you about it and you still don't want to do anything about it*

When Kim returned the blood pressure monitor to be analyzed the next morning, she was informed she would need to repeat the procedure due to interruptions in readings. She declined this request. When Kim told me her stories of being treated poorly in a research environment, I momentarily felt a wave of guilt. I wondered how my relationship as a researcher would unfold alongside Kim. I remember that this called me to contemplate how I might create a space safe

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enough for Kim to disengage from this past research. I thought about how a constant request for data, time, stories, biologic information, must grow burdensome. Everyone always *wanting* to know something about you. However, Kim also spoke of positive research experiences. It was a researcher who went out of her way to help forge a friendship between Kim and another woman with SCI who lived in her city. This connection was significant for Kim, helping her through a difficult time of her life.

This internal dialogue, however, was quickly replaced by Kim beginning to speak about her professional history as a social worker. The work of caring for others, Kim explained, provided her with an insider's viewpoint on ethical matters in healthcare. Afterall, she had once been responsible for decision making that impacted others' wellbeing and therefore, understood what ethical conduct should look like. Becoming a social worker was a landmark in Kim's life. Kim reminisced about doing her practicum at a community neighborhood house, a gathering place where parents could bring their children. I realized that I used to take my daughter to this same place when she was a baby. I shared with Kim how I valued the programs there, especially the opportunity to make friendships with other parents. We came back to Kim's journey becoming a social worker. This achievement, Kim explained with pride, was completed within five years of sustaining a life altering spinal cord injury (SCI) resulting in quadriplegia, *I knew that I had to get a job. I had my whole life ahead of me. Like, I need to get a job. It wasn't an option for me. A life without a job just wasn't a life that I wanted for so many reasons.*

Kim's SCI occurred just two weeks after high school graduation. Those caring for her were unsure that she could reach any sort of independence. I was curious about Kim's injury. What happened? Who was there? What helped her get through it? What did this injury interrupt? While I would come to learn the answers to some of these questions over our time together,

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unexpected stories would also come forth. One of these stories begins with a mystery of stolen coins,

> *when I was a kid um I had an interest in coins there weren't as many varieties back in the 70s when I was a kid um now if you look at your coins you'll see so many varieties (. . .) I came home [from the hospital] I went in one of my drawers and they were all missing so that was that really hurt a lot that added insult to injury somebody took them while I was in Vancouver fighting for my life (. . .)*

I wondered about who took the coins from Kim's room and where those coins were now. Kim describes her childhood home having a constant stream of people in and out and shrugged her shoulders while recognizing she will likely never know who took them. I imagined the sadness and betrayal Kim must have felt when she discovered the coins' disappearance. Kim's coin collecting hobby slid away for many years as she focused on rebuilding her life. Many years later, however, this hobby would return to her, grounding her through a time of upheaval. I was grateful to learn so many things about Kim during our time together.

Missed Opportunities and going Crazy

After Kim provided me with brief outlines of her history, we turned to the topic of menopause. I decided to begin with the question of why Kim chose to participate in this research? Kim paused, looking thoughtful, and then responded, *My first thought to be honest-- this is not my favorite subject I'll be honest it's probably not everybody's anybody's or everybody's favorite subject, but I also know that there aren't as many women who step forward.* Kim associated menopause with negativity and yet felt an ethical obligation to come forward. I

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was intrigued by her response and how she linked this to an ethical obligation. Kim reflected and made visible that women are a minority population in the SCI community and are often left out of research activities. Later in our conversation Kim shared something that I was never able to articulate so simply but witnessed in my nursing practice many times:

> *...it was all about men and their ability to have children, erections whatever so I guess because in theory women could still be sexual and still have children oh well maybe you guys are okay because you know,*
>
> *what's wrong with you? you can still have sex, you can still have children*

I wondered, why are women deemed 'okay' if they can biologically conceive children and engage in the act of receptive intercourse? Is that what really matters to women? What about pleasure, autonomy, knowledge, strength, choice, confidence, independence? I remembered an article by Asch and Fine (2009) that I read during my thesis proposal. This article argued that social constructs which depicted women as innately docile, emotional, and passive aligned with stereotypes of disability, perpetuating apathy towards rehabilitation efforts for women (Asch & Fine, 2009). I wanted to tell Kim all about the article, but I would wait for another time.

When I nudged Kim to expand on her feelings about menopause, she recounted how others around her would speak of the experience,

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I hear people talk about it but mostly I just hear them talk about being hot um but I mean some people say they're more irritable or whatever or maybe it's the people around them that say that yeah or that they're for lack of better words crazy or whatever

The adjective ‘crazy’ came up several times over our conversations. When remembering her mother in-law's experience of menopause, Kim recounts, *my mother-in-law apparently, she kind of went* crazy or whatever. I wondered what drove these women Kim spoke of to ‘go crazy’? What conversations are we missing out on when we label women who are in menopause as crazy? While I know this is a common association; I wonder how Kim understood the term crazy. Was it an experience of physical symptoms? An experience of mental well-being? Or was crazy associated more with absences? Absences of explanations, education, support, understanding, camaraderie, treatment. At the very end of our final conversation, Kim rejects the label of crazy when concluding that a particularly difficult summer of mental health impacts was largely caused by poor provider communication and medication changes, *I'm not crazy - it was him [the doctor]*.

the mind and body are connected

I would go for a walk maybe to the end of the street

I tried to over overcome this myself

my best wasn't enough

Early in our conversations, I found myself reaching for concrete information about Kim’s biological experience of menopause and asked her about when her period stopped. Like many women, Kim found her menstrual cycle to be a nuisance, especially in the context of SCI when

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bladder and bowel management also require consideration and time. In her 30s, Kim began continuous hormonal contraception to cease her menstrual cycle and therefor was not able to track menopause via changes or cessation of her period.

> *I didn't want to deal with the period all the time so at some point my doctor gave me um pills so that I wouldn't have a period and I don't know whether that's healthy or not or whatever but it made my life easier*.

When I asked Kim about whether she remembered a discussion about menopause treatment or hormone therapy with her doctor, she replied,

> *they offered it to my husband's mom so I was just wondering when my day was going to come but it didn't and my doctor's actually really good too, [she] spends a lot of time with, but she kind of tiptoed around things quite a bit there in my 40s because I was not in a good place*

I imagined where a discussion about menopause between Kim and her family doctor may have led. Did her provider know about the connection between menopause and mental health? These unanswerable questions challenged my desire for clarity and certainty. I continued to think about the role silence and silencing plays in the experience of menopause.

The topic of children came up several times in my conversations with Kim. She had expressed a fondness for children. Due to fertility reasons, children were not in the cards for Kim and her husband, however they did enjoy close relationships with nieces and nephews,

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I always wanted [kids] I mean I even named my kids before they were even born but um you know I kind of just we could have adopted but I ended up getting nieces and nephews

At times, menopause acted as a reminder for Kim of missed opportunities for having children,

even now I'm coming to terms with it it's like oh wow I'm not young anymore certain ships have sailed for me now, it's too late, so having children...once in a while I still wish...

Kim thought not only about her missed opportunity for children but also about the broader community of women with SCI. In my conversations with Kim about progress in social and sexual health care for the SCI community, she points out,

people with spinal cord injuries, having children, working, et cetera. I haven't seen a lot of progress... But again, I think a lot of it has to do with the barriers. If people didn't have to be in poverty, if 50% of the population of spinal cord injured people weren't in poverty, I think a lot of those other health issues would be much better as well.

I thought about absences of financial support, employment opportunities, social support, education, and how these result in missed opportunities. It is difficult to measure or make visible

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the harm or impact in absence. It is easy, however, to attribute social or medical issues to spinal cord injury and disability in general.

Since Kim's family doctor did not have an accessible exam bed, her gynecologic health care was often provided at the access clinic, a specialized facility for women with disabilities. During these gynecology appointments, Kim recalled feeling that clinicians were primarily focused on gathering information from her, which she believed was due to her being part of a minority population, *at BC Women's they would ask all kinds of questions like that too so I think it was more just because there aren't very many of us and maybe they used it for their research or whatever*. I imagined Kim on the exam table, answering a series of questions by an unfamiliar provider. I thought about the experience of feeling othered. This reminded me of the importance of transparency when assessing patients; explaining why we are asking the things we are asking. I was then brought back to the beginning of our conversation where I similarly wondered about the experience (and possible burden) of being inquired about, examined and questioned.

Kim's spoke further about access to reproductive health for women with SCI, pointing out that one single accessible exam table for the province of BC was not ideal for many women,

> *I know some women...don't even get that test done at all, ever [pap test]_.... it's nobody's favorite thing to do. But I think the added layer is just finding a place that's accessible and maybe they're not comfortable with a stranger. Maybe they're more comfortable with their doctor.*

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In Giving we Receive

Kim's SCI and resulting experiences as a healthcare consumer led her to become an advocate for women's healthcare and a committee member on several patient-led initiatives. In the 1990s, Kim was part of a committee called 'fair access to healthcare'. This committee worked to improve accessible healthcare for people with disabilities. In addition to her formal advocacy work, Kim's everyday life demanded additional self-advocacy work that often grew burdensome.

Kim remembers a recent experience where she was on her way to a mammogram at the hospital in her city when her phone rang. A key detail of this story is that Kim had been to this hospital for a mammogram before. It was a receptionist for the mammogram clinic who noticed on Kim's chart that she was a wheelchair user. The receptionist informed Kim that the clinic would need to cancel her appointment due to accessibility issues. Confused and frustrated, Kim protested, telling the receptionist that she had been there before, and accessing the equipment was not a problem. After some back and forth, the receptionist insisted that the appointment could not be accommodated. Thinking back upon the experience, Kim wonders,

> w*hy did anybody write that on my chart at all. I was already offended that they wrote that on my chart and now they're using it as a reason to say I can't come for a mammogram.*

I felt angry for Kim, that her own knowledge of her body was dismissed and undermined, I thought, here she was telling someone – I can do this, I have done it before, and still she is denied the healthcare she deserves. Looking back on the transcripts, I wondered if

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Kim felt her status as a wheelchair user was something that, when in the wrong hands, could be unjustly weaponized against her. I felt from my conversations with Kim that she was not ashamed of her disability. I imagined how frustrating it must feel to have healthcare professionals (or anyone else) make decisions about your care, based on false assumptions about your ability. I also wondered, how can this discrimination be prevented in the future? I thought about how power, bias and privilege played out between Kim and the healthcare system. In my knowledge of outpatient clinic operations, the decision to deny Kim care likely involved many individuals in positions of power, spanning years, and culminated with the receptionists' decision that day.

Kim further reflects on the mental and emotional toll of constantly educating others on her needs and abilities, *going back and forth for so long you get tired of the advocacy and educating people (...) I just got fed up and sometimes you just don't want the hassle.* I could see where Kim was coming from and was in awe that she continued to act as an advocate and educator for the SCI community despite the constant microaggressions and outright ableism that she faced. After Kim hung up the phone with the receptionist, she forged forward in her advocacy. She wasn't able to make progress with management at the clinic that cancelled her mammography appointment, so she instead contacted the manager of the BC Women's accessible mammography clinic to inform them of what occurred,

> *so I told her about it and I said you know they can't start sending everybody to you [the accessible mammography clinic] from the lower mainland that was another thing I wanted to say because I knew she'd get on the horn after that so she seemed to care I*

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gave her the name and number but I don't know if she followed up or if they stonewalled her as well

As a clinician who often refers to the 'access clinic', I have always thought of these specialized resources as valuable accommodations for women with disabilities. Although this may be true for some, Kim provided me with another perspective,

why do I have to go all the way to BC women's (. . .) to get my mammogram, now the other exam [pap tests] I get that okay but I mean they have a special [bed} whatever yeah that you can go up and down, I get that that we can't have that everywhere but they should at least have something in every city

Kim's comment made me wonder, are these specialized, segregated healthcare clinics really the answer to help bridge inequity? Do they perpetuate the lack of universal accessibility via tokenism? Shouldn't all medical facilities have equipment that accommodates a variety of abilities? Kim's advocacy work reached beyond health issues directly impacting her and extended to unjust policies affecting the broader SCI community,

yeah and of the advocacy that you need to do for your own health care all the time it's ridiculous now I'm working on another campaign with our group 'free to pee' campaign so people don't have to pay for catheters frankly I got my I get mine covered but I'm just trying to help other people

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I thought about the inhumanity of charging someone to pay for catheters when they are required for a basic bodily function. I hoped Kim's campaign would bring change. I imagined Kim on the phone with multiple clinics, fighting so that women like her could get a mammogram. I imagined all the hours Kim spent arguing her case, joined together with her peers on multiple committees, fighting for basic accessible healthcare. I admired Kim for her integrity and steadfastness but wondered what else could fill this time if she lived in a world where accessible healthcare was prioritized. I praised Kim for her advocacy work, and she replied, *in giving, we receive, right?*

Although Kim saw the benefits of her advocacy work, she was also aware of the risks for burnout,

> *yeah those of us who are strong enough to help it's a lot of work and I have to be careful about how much I take on too but I do have the skills and I do a lot of advocacy but I mean there's not that many of us who do*

A strong sense of justice, pride, and the satisfaction of helping others, sustain Kim in her advocacy work. She jokingly referred to her achievements as 'bragging rights' and pointed out that she had secured accessible parking spots at two popular outpatient medical buildings. Kim's sense of justice made her aware of disparities in the distribution of research funding. She noted,

> *People are beginning to understand the need to include the broader society, not just able-bodied white men. I think change is happening, but it's slow—very slow. Men,*

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especially white men, hold more power in society, and that power extends to research funding. Things need to change, and these conversations are essential.

While reflecting upon the absence of discussion and awareness of menopause, Kim reminded me of a virtual education session on menopause and SCI that we both had attended before she was a research participant in this study. Kim remembers that although the facilitator was engaging and well informed, she felt that the content was too advanced for most of the participants, *she did a great job, but she was way ahead of most of us way ahead*. After thinking further about this education session, Kim remarks with surprise, the *group didn't talk much do you remember that? yeah nobody said much at all, I don't know if you remember but that was the quietest group I've ever been with*. At this point in my discussion with Kim, I too could feel a silence. I felt myself reaching for something tangible, a way to outline the shape of Kim's menopause experience. I wondered about my expectations. If Kim didn't have hot flashes or talk with her friends about the change of life, what story were we telling? I would soon come to learn that for Kim, menopause went unnamed in her story.

Within the first few minutes of our conversation, Kim shared with me that a serious accident at age 40 had triggered mental health challenges for her, casting a shadow over 10 years of her life. She was struck as a pedestrian while in her wheelchair. She was out on a walk with her husband. *I was really injured like I was thrown out of my wheelchair I mean that was uh within 24 hours full on PTSD*.

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Kim's Disappearance

I kept yelling yelling yelling and he kept coming

I thought I was strong enough

I just disappeared

who knows whether that was PTSD or menopause

While describing the accident, I noticed how Kim left out details about her physical injuries and emphasized the mental health impacts which subsequently infiltrated the next ten years of her life. Referring to her mental health struggles that unfolded in the years following, Kim states, *that was more debilitating than breaking my neck*. It was a struggle for Kim to tease apart and put labels upon her experiences that spanned those ten years, *I guess you know I was actually just really depressed but I didn't really know I was that depressed... [it was] an array of emotions that just kind of crippled me physically and emotionally.* The fact that Kim's mental health concerns were more debilitating than her SCI was not all that surprising to me. I have seen the resilience of patients with SCI as they adapt to a new life with determination and hope. For Kim, physical challenges were surmountable with persistence and determination. This was not the case for her mental health challenges during those years.

As I thought further about Kim's struggles to address her mental health concerns, I remembered my own struggles after the birth of my daughter, and the frustration of feeling no control, the unbearable experience of feeling not like yourself. In recent years, I also witnessed a friend who was seriously impacted by mental health concerns. Those four tumultuous years were marked by cycles of mental health crises and short periods of recovery. Ultimately, my friend lost her life to the disease. As I listened to Kim tell her story over three different meetings that

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spanned 4 weeks, I experienced empathy and discomfort as difficult memories of my own were called forth. These emotions were also accompanied by a sense of relief that Kim had managed to move through this difficult time to a place of safety, where she was able to enjoy life and advocate for others within the SCI community.

As Kim began to unravel those difficult ten years, she describes how her mental health challenges presented. *My 40s were the toughest time of my life yeah I mean I was suicidal I was anxious I was afraid of everything everywhere I wouldn't leave my house*. In addition to her fear of leaving her home, Kim completely lost her appetite. Despite weekly counseling with her therapist, Kim's progress was slow, and at times she felt at a standstill. *The doctor, my doctor and psychologist, after two years of counseling, they basically said why can't you just eat?* During one of our later conversations, Kim thinks back to her struggles with appetite, wondering how emotional stress may have played a role. Kim remembers a similar situation during her hospitalization as a teenager after her SCI. She struggled with persistent vomiting and was easily triggered by the scent or site of food. I thought about how her experiences across her life blend and share key aspects.

> *I think what the problem was I think it was just too much stress for my body um my parents were fighting a lot my mom and dad were divorced and long story short um my mom blamed my dad and his wife for my accident and oh my gosh security had to throw them out of my room at one point or whatever they were fighting and I couldn't even move at that point I couldn't even breathe on my own so my theory is probably that was just too much stress for me to handle and I just couldn't stop throwing up*.

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Prior to the impactful accident at age 40 Kim had also been involved in a car accident after stopping for an ambulance. She described her quick recovery after this accident, *I ended up with panic attacks after that one, but I went to counseling, and it was amazing I did really well after about six months*. I was curious about the difference in Kim's mental health recovery after these two accidents. Her most recent accident at age 40 resulted in a much more prolonged and severe mental health impact when compared to her prior accident, or the accident causing her SCI. I wondered aloud if a hormonal shift associated with menopause might have exacerbated her depression and anxiety. Kim responded, *I think there was a lot of confounding variables yeah so who knows maybe it made it worse* Immediately after my comment, I internally questioned my line of thinking and knew that my speculation may be biased and reaching; I was searching for evidence that would unveil a clear menopause focused narrative. I could hear myself saying: aha! It was menopause that contributed! Menopause is part of the story all along! In retrospect, I could see that I was foreclosing the possibility for a different understanding and perhaps a different approach to care.

During those ten years. Kim experienced a variety of health concerns investigated by specialists,

> *and then another doctor at St Paul's diagnosed me with celiac but I don't I don't have celiac (...) I went to quite a few specialists one diagnosed me with that rare sun disease I don't have that*.

These misdiagnoses left Kim feeling confused and frustrated,

> *I think I'm still afraid of ending up there again um I didn't know I'd get better that lasted a really long time in my life and it was coupled with all those physical symptoms we*

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talked about too so I mean most of the time it felt like one step forward two step backwards one step forward two step back

Beyond her medical concerns and misdiagnoses, Kim faced discrimination and insensitive care, making everything feel even worse,

I mean I went to see ICBC psychiatrist, he was a nasty nasty man I remember I came in my wheelchair and he, this adds to a lot of stress too, he was sitting there in a chair that was lower than me maybe like you are now [points to my chair] I might be a little higher than you, but anyways I was considerably higher than him, he was a small man and he wanted me to sit in a chair lower than him and I said it's too hard for me to transfer onto that chair. Oh he wouldn't take no for an answer, so anyways I got really stressed out about it and I ran out of the office... for whatever reason he was trying to bully me

Kim also struggled with symptoms of insomnia, sensitivity to light and sensitivity to noise, *I couldn't stand light or any kind of noise, so I just remember spending a lot of time in my bedroom*. During this time, Kim describes the communication between her healthcare team as fractured and problematic. Here she described her frustration in trying to have one of her specialists communicate with her family doctor, *I knew it was his responsibility to write to my doctor I shouldn't have had to tell him tell him twice and ask his secretary, okay that's three times and he still didn't [write my doctor].* The lack of a cohesive team approach led to a serious incident where Kim was abruptly removed from a nerve pain medication, gabapentin. Kim remembers the summer when she was removed from this medication as being particularly bad,

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I couldn't figure out what was wrong with me that summer, but we knew something was wrong, not just wrong, extra wrong for lack of better words (. . .) I was messed up I was really suicidal (. . .) I know I had PTSD but now I want to jump off a bridge for real

When Kim was removed from this medication abruptly, her mental health took a turn for the worse, and nerve pain prompted Kim to rub or dig her nails into the top of her left thigh. While Kim was recounting memories of this particularly bad time, I noticed her rubbing the top of her thigh. At one point during our conversation, she pointed to a worn and pilled area of her pants on the left thigh -- this habit she explained, was once much worse, *I actually rubbed my leg so much that I created a wound here and there's still a little bit of a scar*. Worried that our conversation was causing Kim stress, I asked Kim if we should pause, but she reassured me she was okay. Thinking about past interactions with specialist healthcare providers over those years, Kim concludes they caused more harm than good, *the over medicalization actually was very harmful absolutely like oh my god they put me through so much trauma.* I wondered how a different approach to Kim's care may have improved her quality of life over those years.

Finding a way back; Curling, Missions in the Park and Coin Collecting

Despite Kim's struggles with her health, she continued to make efforts to find herself, and to find a way back to the life she once knew.

I was in a the bottom of a well
I climbed up and made some progress
something to look forward to

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the well dropped down

a devil on one side, to end that pain,

it'll all be over soon

I'm not crazy, it was him

I'm still here to talk about it and I got better

it's dangerous for us to walk on the road

but sometimes we have to

Kim pinpoints a milestone in her recovery as the day she worked up the courage to attend t an accessible gym,

when I went there I didn't go by myself my husband came with me he drove, I mean I was as nervous as could be...I thought everybody was staring at me and long story short as I met a friend there I got involved with research...I don't know how we came up with this but we said let's try curling together...that would be good for me because if I curl it's going to make me leave the house

I imagined how difficult it must have been for Kim to push herself outside of her comfort zone. I thought about how valuable social support was in Kim's recovery, *having a team made me more accountable (...), it was just really hard to make that extra effort to leave the house.* Curling has become a significant part of Kim's life; she plays on a competitive team that has reached the national level while also mentoring others. I contemplated the feminist scholars who argued that menopause was a social phenomenon that required social solutions (Bell, 1987; McCrea, 1983). Kim's recovery demonstrates the healing powers of recreation or any

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relationship building activity. While thinking about the support she received from loved ones during her difficult years, Kim reflects, *when you think you have nothing left to give or you can't go on it's the people that make the difference, the people who love and care about you.* I recalled how my own loved ones and wider social networks supported me during my own time of difficulty. I vividly remember debating whether to attend a parent and baby group while sitting in a rocking chair with my daughter, feeling exhausted and alone. Looking back, I can see how instrumental this group was in normalizing my experience. The relationships I formed with others in this group helped bring me back to myself.

Becoming more comfortable with leaving the house was also nourished by Kim's relationship with her nephews. When I suggested that Kim might bring sentimental objects to one of our conversations to prompt memories, she pulled from her bag a turtle carved from soap and a smooth shiny heart shaped rock. Her eyes became brighter, and a smile appeared on her face as she remembered the day when her twin nephews appeared at her bedside offering her these items as gifts,

> *I was really having a hard time right after the accident, my one nephew he was only six and he said I got this for you auntie Kim. Then the other nephew...he made this for me (a turtle carving). So, you know what, I just always have kept it on my night table and I never take them away because...it just reminds you how much you're loved*

Over time, a make-believe game evolved between Kim and her nephew in which they would go for secret 'missions in the park'. They made up code names – Kim's was turtle. This became such a well-established game, that Kim even had military-style dog tag necklaces

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engraved with their code names. Reflecting upon these outings with her nephew, Kim recognizes the reciprocal roll this relationship played in her recovery, *he was helping me as much as I was helping him then back then.*

During my third conversation with Kim, another story came forth. Kim doesn't quite remember what prompted her to revisit her passion for coin collecting, but one day, she thought about her missing 1973 horse quarters and 12-sided nickels, *I went back to replace the quarters and the nickels to...a coin dealer ...and he had all these coins and I was like...a kid in a candy store I just wanted to replace what I had lost (. . .) I remember just how excited I was to see all these coins and it reminded me of how I felt when I was younger.* I wondered perhaps if Kim was looking for a way to rebuild her identity? I thought about how reclaiming this familiar hobby might help her feel safe and grounded.

I just wanted to replace what I had lost
a reason to wake up in the morning
I'm going to be fine
there's still a little bit of a scar

Remembering back to her early coin collecting days as a youth, Kim explained that it was a sacrifice for her to save the special coins (a few cents would buy you a handful of candy at the store back then). One morning, although Kim was feeling hesitant to leave the house, she learned that Canadian portrait artist Susanna Blunt (she designed the portrait of Queen Elizabeth II on former Canadian coinage) was making a special appearance at the Royal Canadian Mint. Kim had to attend a doctor's appointment anyhow and was eager to get a signature from the artist, so she decided to make a stop. Kim remembers her trip to the royal Canadian mint going

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well, however, on the way back to her car, while passing by the art gallery, she recalls a crowd quickly forming. A protest for working conditions had brought teachers and the media together, along with flashing lights and loud noises.

> *I didn't like lights or noise or anything or big crowds and all of a sudden, all these people just converged on me there it was it was crazy before I knew it there was a huge crowd and I couldn't get out of the crowd and then there were journalists in the trees lights action everywhere*

Kim described eventually getting to her car and arriving at her doctor's appointment. When Kim's appointment started, she uncharacteristically started to cry,

> *I don't know I was just crying and crying and she knows I don't cry look I know I've never cried before with her but she just said she was very calm she says we have all the time you need - just let it out she was amazing and I cried for a long time and then then it was a little bit better*

As Kim started to feel more settled at her appointment, she informed her family doctor (who she spoke of fondly) that she discontinued gabapentin upon the advice of a new psychiatrist,

> *I said he gave me this new medication and took me off of the gabapentin and then it was dead silence in the room she just stared at the floor, I think there was smoke coming out*

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of her ears (. . .) then she looked up after about 60 seconds which was a long time and she said don't you ever let any doctor take you off of medication without checking with me first

This memory prompted Kim to consider the emotional support she received from her family doctor and the safety she felt in her presence, *maybe I just felt safe there yeah like because I just started to cry, that's so important isn't that amazing that I have such a good doctor.* After hearing about several of Kim's negative healthcare experiences, I was relieved that she had a good relationship with her family doctor. Near the end of our last conversation, Kim pondered her healthcare experiences and wondered, *is it just a coincidence that the one good health care practitioner was my female doctor? She was the best.* I wondered about how the experience of being a woman might show up in a healthcare providers care approach. As a healthcare practitioner, I would like to believe that the gender of a healthcare provider has no bearing on the care provided. Of course, there are many non-female doctors providing excellent healthcare to women. But I also know that women have different life experiences than men. Furthermore, education on menopause, or other female-specific health concerns has historically been scarce within medical training.

Bigger fish to fry

With so many health issues in Kim's life, menopause was not on Kim's radar. While remembering the mirage of health issues she experienced between the ages of 40-50, Kim comments on the experience of appointment fatigue and how this acted as a barrier to seeking out medical care

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I had so many medical problems back then it just seemed like one after the other after the other...I feel tired even talking about it...if I went running to the doctor or emergency every time I had a medical problem...

Kim's stories brought to light how those with complex medical needs might be disempowered in a healthcare system of 'one problem per appointment' doctors' visits. I thought about a concept I had heard about that emerged from disability studies called, 'crip time'[10]. I wondered how Kim's experience may have been different in a healthcare system that accommodated her needs. I was curious about whether menopause came up as a topic of conversation amongst Kim and her peers, when I inquired about this, Kim responded, *even our female group doesn't talk a lot about female-specific issues (...) what I think is a good explanation for that, is because whether you're male or female, we have bigger fish to fry in our lives.*

I wondered how women identified 'bigger issues' from those that may be related to menopause. Especially if they haven't received education on the potential impacts of menopause beyond hot flashes. I recalled Kim mentioning, the *women I know who have spinal cord injuries or disability who are about my age, they mostly talk about bone health, that seems to be their biggest issue.* I thought about the role of estrogen in bone loss during menopause, I wondered how many women with SCI were aware of this relationship. Furthermore, Kim spoke about the experience of her peers whose quality of life were profoundly impacted by wounds, urinary incontinence, and shoulder pain/injury (other issues likely impacted by menopause). Even as a

[10] crip time is a concept derived from the field of disability studies. Crip scholars argue that the normative notion of time is not a universal way of existence. Samuels, Ellen. 2017. "Six ways of looking at crip time." Disability Studies Quarterly 37(3): n. DOI: https://doi. org/10.18061/dsq.v37i3.5824

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healthcare professional, I knew very little about menopause up until a few years ago. As my interest in menopause grew, I read books, listened to podcasts by experts in the field, and even attended a documentary on menopause. Eventually I recognized language emerging among this content to describe the amorphous experience where many little things start to change, making life feel more challenging: a loss of resilience. In writing this account, I debated, am I inserting my own narrative of menopause into Kim's story? Does it add anything to make guesses at an unanswerable question? I decided it would not be transparent or reflexive to leave my inner dialogue out. Here, in the following passage, is where Kim reflects on being puzzled by her inability to recover from the accident,

> *at first I tried to over overcome this myself for two years without medication (. . .) I was still kind of embarrassed that I couldn't do this on my own yeah see when I broke my neck with willpower and perseverance and hard work I was able to get my life back but what I found very perplexing with the PTSD is no matter how hard I tried I couldn't I just couldn't do it I couldn't get back to where I was and I was less resilient*

Kim recalled her resistance to taking medications for her mental health. I was reminded about my own hesitation to take medications when I struggled with anxiety after the birth of my daughter. I remember thinking, many women have done this before, and yes, it is hard, but I should be able to do this too. I wondered if Kim had similar thoughts, if she also felt she was failing to meet some type of expectation. Despite having conversations with her doctor, it was Kim's friend who supported her decision to try medications for her mental health,

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> *we were in yale town at a Thai restaurant (. . .) she said it matter of fact like and as a friend and I'm like okay well this is a friend and who's telling me that I guess I need to take the medications, there was no judgment there whatsoever about taking the medications and probably in her own way she was in a nice way trying to support me by doing what she knew was probably best*

Near the end of our last conversation, Kim reflected on those ten years, *I think I'm still afraid of ending up there again, I didn't know I'd get better. That lasted a really long time in my life.* I thought about Kim's words, *I didn't know if I'd get better*. I imagined the difference it could have made if Kim heard from other women during that time. Women who validated that this time of life can be difficult for a lot of women. Especially in the midst of everything else happening in life. Women who could tell Kim, yes, this feels extra tough, this is a time of change, biologically, and socially. Our brains are changing, our bodies are changing, and it can make everything feel harder than it should be. We aren't crazy, but it's okay to feel like it some days. We deserve to know what is happening in our bodies. We deserve to understand how medical treatments and social interventions can support our journey.

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Chapter 5: Narrative Account of Nadine

I initially met Nadine outside the context of our research relationship, during the development of educational videos for a course on sexual health and disability, in which she portrayed a patient. My role for the day was mostly in the background, ensuring the day went smoothly. This encounter occurred several months prior to the commencement of participant recruitment for my study, at a time when I was finalizing my thesis proposal. I distinctly recall that the day I first met Nadine was also the day I met with my thesis supervisory committee. Nadine arrived on location at BCIT that day, and while I didn't have much time to speak with her, I remember her openness and willingness to participate in the video development despite many things happening in her life. The day before, Nadine had accidentally burned the heel of her foot and was frustrated that she couldn't wear the shoes she had planned. Nadine laughed it off and showed me her 'modified' converse sneaker with the heel cut off to accommodate her injury. As I looked at her burn, I wondered if she pushed herself to come when she may have felt better resting at home or having it checked at the clinic. At the same time, I was grateful that Nadine had come as it had taken weeks of planning to arrange the filming.

A few months later, when I heard from Nadine during the recruitment for my study, I was excited to learn that she was interested in participating. We scheduled a phone call, during which Nadine shared an overview of the many challenges she had faced while navigating menopause. I felt disheartened to hear about the extent of her struggles, but I was also curious to learn more. Nadine was honest when we first met that it was a very busy time in her life and briefly hesitated about whether she could fit our meetings in her schedule. Not only was Nadine in the middle of renovations and a move, but she was also planning for her (large) wedding that upcoming

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summer, all while working full-time. I was so grateful when Nadine decided that she could participate.

We decided to first meet in the atrium of the Spinal Cord Centre. This building, built for accessibility, has a large open meeting space with tables, chairs, and even a fireplace. The atrium is surrounded by windows with a beautiful concrete spiral ramp hugging the interior sides of the building. As I was waiting for Nadine, I thought about our initial conversation. She provided small snippets of medical history in an urgent tone, providing me with the sense that the topic of menopause was very important to her. I had a strong sense of anticipation and was eager to hear about Nadine's story. I wanted to learn more about how women with SCI experienced menopause.

Putting things into Context

Nadine and I greeted each other warmly, settling down at a table. We spoke briefly about the business of life, and I was thankful that Nadine had shared her time with me. I started our conversation broadly by inviting Nadine to share her experience of menopause, along with any stories that seemed important to her. Nadine moved forward quickly by providing sweeping accounts of her family and medical history. Fractured pieces of Nadine's story were coming forth, and I could sense the significance of context and interconnectedness in her story. Nadine had come to expect that most people would shape her story based off stereotypes of being a woman and someone with disability. During our second conversation, Nadine shared a metaphor about being a wheelchair user that was helpful for her public speaking work,

> *When I do like talks in high schools and elementary schools, I sort of teach like, imagine wearing whatever the worst thing in your life was around your neck on a piece of paper.*

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> *My dad died yesterday. I have Parkinson's. I have MS. I have depression. My boyfriend left me. Um, I broke my leg. Like whatever it is, imagine wearing that on your chest. That's my wheelchair. Like people look at that and they immediately see that and immediately have this preconceived set of notions in their head of what that means.*

I thought about how stifling the experience of feeling unseen, underestimated, or prejudged in this way would be. I hoped that in working together, Nadine could reclaim a small piece of her story.

Personal and Family Health History

Nadine's mother went through menopause early around the age of 33 (Nadine wasn't sure of the cause). Although Nadine's mother was not one for lengthy conversations about sexual or reproductive health, she made sure to share with Nadine the fact she went through menopause early. I wondered if Nadine's mom was hoping to prepare or protect Nadine for this in some way. Looking back upon memories from her youth, Nadine recalls, *I'd always had really, really bad periods to the point of like kneeling over and like wanting to faint, and we just chalked it up to my grandma. My dad's side had very bad periods.* I thought about the influence of our family history on what we perceive to be normal in reproductive health. I wondered if Nadine's symptoms were dismissed because, if her grandma got through it, she could too? At times, Nadine would be questioned about the legitimacy of her menstrual pain, *people are like, oh, you're T1 complete, how do you feel period cramps? I'm like, I don't know, but I do*. This disbelief at Nadine's experience became a theme in stories to come. Medical professionals commonly overreached their positions of power to challenge Nadine's bodily autonomy and knowledge. Shortly into our first conversation, Nadine brought up her history of anxiety and

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depression. She wondered about the role menopause played in these symptoms, *now they're thinking [the anxiety and depression] are either from menopause or, or perimenopause, I should say. But I'm definitely past perimenopause now.* As Nadine provided me with her medical history, I could sense that she was doing so to provide context, to make sure things weren't misinterpreted, that I was getting the whole picture.

Nadine's story wouldn't be complete without understanding the familiar backdrop of fatigue associated with her longstanding sleep disorder. Nadine's SCI occurred when she was 14 and fell asleep while skiing. Medical investigations cleared her of narcolepsy, and although her symptoms have somewhat improved, fatigue is still something she struggles with regularly. In university Nadine became known as *that girl that was in the wheelchair that would fall asleep in class.* I could tell that Nadine was trying to make light of the situation and yet also heard the frustration in her voice. This sleep condition placed an enormous burden on her life. Incongruously, Nadine also struggled with insomnia. She wondered if a fear of falling asleep in dangerous situations had conditioned her to have difficulty falling asleep at will. After Nadine provided me with these grounding details, we moved forward into her experiences with reproductive health which were closely tethered and overlapping with her experience of menopause.

Endometriosis

Around the age of 30, Nadine started experiencing nerve pain in her left leg that radiated up to her abdomen. After four years of trying various painkillers that not only didn't help, but made her feel, *crazy [sic]*, it was Nadine's gynecologist who suggested the nerve pain could be related to endometriosis,

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> *I had always said that I had this weird nerve pain on my left leg that went into my stomach, and I'd always had really bad period cramps... my gynecologist was like, you know, I think you have endometriosis, but we'd have to do a surgery to figure it out. Anyway... So they did surgery, and they're like, you are riddled with endometriosis.*

Fortunately, the surgery helped ease some of Nadine's pain. She appreciated the open-minded, and comprehensive care she received that led to her endometriosis diagnosis,

> *wow, someone is thinking outside of the box and listening to my symptoms and actually listening to me. And I wasn't even specifically asking her about it. 'Cause I was just like, I don't get why my leg's hurting. And I certainly didn't connect the two. Like, why would I think I have this weird pain in a leg that I can't even feel?*

Given Nadine's atypical symptoms of endometriosis, I was relieved and somewhat surprised that Nadine was finally able to receive a diagnosis. When thinking back upon how her symptoms presented, Nadine wondered how many other women with SCI were living with undiagnosed endometriosis.

Undiagnosed Genitourinary Syndrome of Menopause

As Nadine continued recalling her timeline of events, she remembers that it was after the endometriosis surgery, that she started experiencing recurrent bladder infections, *it was doctor after doctor, urologist after urologist, um, studies at ICORD that introduced me to new urologists, which were helpful, but I probably saw four urologists.* Between the ages of

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approximately 33-43, this relentless recurrence of UTI's had a major impact on Nadine's physical health and quality of life.

> *At about 32, 33, they came back and lasted for about nine, 10 years. And I went to doctor upon doctor, and they told me I was cathing wrong. They told me my catheters were dirty. They told me, like, all of these things that I needed to change. I tried everything to the point of, like, there was this one theory that you could use this. It sounds awful. It sounds like the COVID theory of, like, using bleach. But it was this, some sort of thing they used with horses. But it was, like, this cleaning agent ... I was like, okay, should I try that? But there was, like, I tried different catheters. I tried everything you can think of.*

I was stunned at this portion of Nadine's story. I wondered how she could manage her daily activities, work, and social life amidst the appointments and symptoms that came along with recurrent UTI's. The burden of these constant UTI's took a heavy toll,

> *literally I would stop an antibiotic. I'd have a week without one. And then I'd have to do a test. And then I'd have to fight to get a requisition that was, like, standard. Like, instead I'd have to call the doctor. And then finally I got a standard requisition that I could go in and get a urine test whenever I had symptoms.*

Feeling overwhelmed, and perhaps in attempts to bring order to the chaos the infections were causing in her life, Nadine turned to a tried-and-true method of organization,

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> *I would tell people I was having...on average 14 to 17 a year. And then I'm doing my math in my head. And I'm like, that's more than two a month. How is that possible? ...but I'm pretty sure that's right. And then I always question if I'm being accurate and I don't want to stretch the truth or lie... I took an Excel file and I went through my, um, life labs requisitions to mark how many infections I had in a year. I don't know if I still have that file, but I'm like, I'm not crazy.*

I thought about how Nadine's previous experiences with the healthcare system had led to her almost reflex like assertion that she was *not crazy*. I was frustrated for Nadine, and for all the women who had to approach the healthcare system with a preemptive defensive stance, as if to fend off being labelled in such a way that would harm future care.

As Nadine navigated the healthcare system, she would eventually find a solution to her recurrent UTI's by chance—menopause hormone therapy (MHT). Nadine's story of learning she was in menopause will come later, but it's important to note that MHT was prescribed in response to diagnostics – objective numbers on paper reflecting Nadine's minimal ovarian reserve, not in response to her subjective symptoms, including recurrent UTI's. After Nadine connected the dots, and learned how MHT supports bladder health, she was motivated to share her knowledge with whoever would listen, to prevent more needless suffering,

> *I ended up seeing a urologist probably about six years ago now. And I was telling him my journey. Cause I always want to say if other women are in menopause, that could be why they're having all these infections...and he looked at my vagina and was like, um, yeah, it's obvious that you're in menopause. Like the color is different and it's like atrophied.*

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And he just was like, they should have known that by looking at you, which is also frustrating.

After starting MHT, Nadine's incidence of UTI's dropped to one or two per year. Although this was positive, I could sense the frustration in Nadine's voice as she remembered many of her healthcare interactions. At some point during ten years of relentless UTI's and a lack of compassionate care, Nadine decided her best option was to pay for a private primary care clinic,

I ended up paying to go to Copeman Clinic, which is now TELUS, because no doctors would believe me...I'd lost my primary caregiver because she stopped her practice. And then, like, I just couldn't find a doctor and I couldn't find anyone who would listen.

Now that she is on systemic MHT, Nadine rarely experiences urinary tract infections, however, continues to struggle with negotiating an approach to treatment,

But she's [the doctor] like, I don't believe that you still have an infection because I'm pretty sure this would have gotten rid of it... Anyway, so then I had to wait three days feeling like utter shit. Excuse my language. And then do my sample again...just them not ever believing that your symptoms and your feelings are actual infections.

When I called on Nadine to remember what she was feeling while navigating her life amongst these infections, she replied, *I was exhausted. I was working full time. I was like playing tennis three times a week and I was utterly exhausted.* At this point in our conversation, I felt Nadine

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begin to shift in the way she was telling her story. The details surrounding her experiences became more precise. I took this as a sign of trust that I would hold these stories gently and portray them with accuracy.

Premature Menopause, Premature Assumptions

Nadine had many stories of reproductive health encounters that unfolded into each other. In the stories Nadine shared, I imagined her with that imaginary sign she felt so encumbered by — 'I broke my back'. Her healthcare experiences reflected the ableism so present in our healthcare system. Here, Nadine remembers an encounter with a gynecologist who was assessing her pain related to endometriosis,

> *[she] was actually quite rude. And she said, okay, well, with your pain, with endometriosis, we're going to remove your ovary...we're going to do an oophorectomy. And I'm like, okay, well, can I still get pregnant if you do that? I was 37, okay. And she said, well, you're single and 37, and you still want to get pregnant? And I'm like, I don't know that that's your business. But I'm asking if it's scientifically possible if you take away one of my ovaries.*

I was dismayed at the forthright, narrow-minded and discriminatory response of this healthcare professional. Perhaps I had been living in a bubble. I could see now that the open-minded and inclusive healthcare professionals I worked with in rehabilitation care were not necessarily reflective of the broader healthcare provider population. In this moment, I gained a newfound appreciation for the extent of ableism faced by patients navigating the healthcare system.

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The dismissal Nadine faced regarding her inquiries about fertility reminded me of Kim's, comment on the lack of social change that would support women with SCI to become parents. Nadine's story was a perfect example of a missed opportunity; one where the gynecologist could have provided support, information on cryopreservation, and realistic hope. However, this interaction with the gynecologist didn't end there. Here Nadine explains that the gynecologist was so taken aback at her question about fertility, that she insisted Nadine attend therapy,

> *[the gynecologist] was basically...saying, you're crazy, you need to go to therapy. Like, how do you think you're 37 and still want to have kids? So, yeah, that was awful. Anyway, the therapist is like, you can go home.*

Nadine described internal tension about attending the therapy appointment. While she did not perceive a therapy appointment as necessary, she was hesitant to assert her autonomy due to concerns about potential repercussions for disregarding the gynecologist's recommendation. After the meeting with the therapist, Nadine felt validated that the therapist saw no need for an appointment; there was nothing abnormal about a 37-year-old woman undergoing an oophorectomy to have questions about fertility.

Navigating MHT

After a few years of taking estrogen and progesterone via hormonal contraception, her healthcare providers made the call to switch to MHT. Finding the right medication regime was difficult,

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> *I've been on every single combination you can think of... the first combinations for about 3 years, I would like literally bleed without stopping...So, then they had to try different ones... I literally have tried probably 19 combinations of MHT to get to where I'm at.*

When Nadine was experiencing heavy periods during perimenopause, her gynecologist referred her to a colleague to have an endometrial ablation. Unfortunately, there were some complications with this procedure,

> *I remember going in and then coming out and the woman saying, the doctor saying, you had an AD (autonomic dysreflexia) attack. Um, so we had to take you out, like artificially out of the anesthetic. Um, and we weren't able to do the ablation because the wand that they used didn't fit. And I don't understand because I'm a pretty good advocate for myself. Um, so I went back to my gynecologist, and I was like, what happened? And she's like, I don't understand it. Like, I've never heard of a wand not fitting. Like, there's also different sizes.*

This experience stood out to Nadine as another facet of diagnostic overshadowing. When something unexpected occurred during a medical procedure, connecting the problem to Nadine's SCI, without adequate inquiry into other contributing factors was easy. While sharing this story, Nadine's tone was calm and disappointed, signaling the fact that this type of medical situation was (unfortunately) not unexpected in her life.

Nadine's experience brought me a further understanding of how one's identity as a person with SCI is made to take blame for the shortcomings of the medical system, personal

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errors, and general limits of medical knowledge. During subsequent appointments, Nadine continued to ask her gynecologist why the endometrial ablation couldn't be performed but did not receive a clear answer. I could see that Nadine had faced many challenges in her reproductive health experiences, and also wanted to share the positive, or sustaining forces that supported her throughout menopause. Nadine spoke highly of many healthcare professionals who made her feel seen and provided excellent care.

You're Not Crazy

Nadine praised the gynecologist who supported her through trials of numerous combinations of MHT. When that gynecologist retired, she was referred to another gynecologist who she also had a positive experience with, *I just felt really seen. She's a lovely, lovely, lovely woman.* I thought about what it means to feel seen as a patient in healthcare. I remembered my own experience of feeling seen by my primary care provider during a difficult time, yet it is hard to describe. I remember being thankful while feeling safe. During this particular interaction, my healthcare provider was professional, but I also felt the hierarchical nature of patient-provider power dynamics fade. Nadine also described an interaction where she felt her gynecologist was able to engage in an authentic way by employing humour. Here Nadine recalls dealing with some rare side effects from a new medication,

> *I went on these anti-depression medications...I had sent her an email and said, hey, I'm having some really weird symptoms, she set an appointment and she's just like, Nadine, in my 40 years of doing this, I have read that it's possible. I have never seen it... if there's a symptom, you get it. You are definitely special.*

Nadine felt validated and humanized by her gynecologist's approach to communication and clinical care,

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> *she did my pap test and she just made me feel super comfortable which my current GP does not at all...she's just relaxed and [when] you come up with something that could be like a Google search, and you think might be crazy.... she's just like, you're not crazy. Like, I get where you're coming [from] with this. And she really answers your questions...she's...willing to, to try it with you.*

I thought about how the care from this provider left Nadine feeling 'not crazy'. Shouldn't we all be afforded medical care that will NOT make us feel crazy? Nadine's concerns were taken seriously and her provider worked with her to negotiate a treatment plan. This seemed like a basic level of care that should be afforded to all women. However, women's health has been misunderstood since ancient times, resulting in medical gaslighting and healthcare bias (Micale, 1995). Nadine's gynecologist listened to her concerns; she provided rationale for her clinical decision making and she validated that Nadine had a very *complicated case of menopause.* Finally, Nadine thought back to her family doctor who had retired, explaining how her honesty, curiosity, and willingness to learn from her patients was of great value, *I wish she didn't retire. Um, she would just always say, like, if I don't know something, I'm going to go research it or like figure it out.* As a healthcare provider, I understood how difficult it can be to admit when we don't know the answer. Nadine reminded me that it is not the holding of knowledge that makes a great healthcare provider, it is the asking of questions, and the willingness to seek out answers and resources.

Although Nadine found comfort in the shared experiences of her friends who were also wheelchair users, she also felt sadness that they also faced discrimination and barriers to healthcare,

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> *it's nice to be able to lean on the fact that you aren't the only one. It's also shitty that you aren't the only one because you don't want it to happen to anyone else. But then you're like, okay, I'm not alone.*

Family support also played a positive role in Nadine's life. In particular, she had a female family member with chronic illness who really understood Nadine's unique challenges. I was glad that Nadine had people in her life to soften the difficulties she had encountered.

Murky Waters

Nadine's experience of menopause was anything but straightforward, however over the years she has learned that menopause is not just about hot flashes, and in fact, framing it this way can mislead women such as herself,

> *if I mentioned menopause, people are like, oh, hot flashes. And I've never had a hot flash. I mean, I've had AD flashes where you get extremely hot. I don't typically get that symptom from AD anymore. So I know what it possibly would feel like, but I've never had a menopause hot flash.*

I wondered if Nadine's lack of hot flashes delayed the relief that MHT eventually brought her. I also wondered, even if she were to experience hot flashes, would it be labeled as autonomic dysreflexia? Discomfort with uncertainty presented itself throughout my conversations with Nadine,

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> *as a human, you just want answers. It's like, you just want to know, it's like, you watch the shows about murder and you're like, if I just knew who did it, who killed my wife, how is that going to make you feel better? Your wife's still dead, but I don't know. Answers sometimes help.*

Although I laughed a little alongside Nadine's murder mystery metaphor, I had also been a nurse long enough to see the emotional anguish, social ostracism, and financial consequences of undiagnosed health conditions.

Uncertainty about menopause also created discomfort in my clinical practice. For example, Canadian menopause guidelines[11] speak to the benefits of MHT in preventing osteoporotic fractures but only suggest MHT for women who are *also* seeking relief from symptoms of menopause. This type of guidance rests upon the assumption that menopause symptoms are somehow a clear objective phenomenon that women will confidently be able to identify. Bone health is very relevant for women with SCI, however if they do not identify symptoms of menopause, discussing the role of estrogen in bone health becomes complicated. I found myself wondering about the rationale in the guidelines, what was it about the presence of menopause symptoms that tipped the risk/benefit ratio? Where these guidelines created with consideration for women who experienced menopause in a more nuanced way?

The Snowball Effect

During our first meeting, Nadine and I shifted conversation while stopping to eat some Thai food. I forgot to order the rice for our meal and while apologizing, Nadine reassured me

[11] Khan, A. A., Alrob, H. A., Ali, D. S., Dandurand, K., Wolfman, W., & Fortier, M. (2022). Guideline No. 422g: Menopause and Osteoporosis. *Journal of obstetrics and gynaecology Canada : JOGC = Journal d'obstetrique et gynecologie du Canada : JOGC*, *44*(5), 527–536.e5. https://doi.org/10.1016/j.jogc.2021.09.013

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that the missing rice was just one less carb calorie to worry about, *the weight gain in menopause is insane...it's been horrible.* Despite drastically reducing her calories, Nadine continued to gain weight throughout menopause. Like many, Nadine felt societal pressure to stay within a certain size range, but she was more concerned about how the weight could impact her quality of life, with *spinal cord injury... like five pounds is a big difference when you're lifting your body. But I'm 30 pounds more than I was when I was like 30.* I thought about some of my patients over the years and remembered several scenarios where weight significantly impacted level of independence. As Nadine and I discuss mobility, she wonders if the problems she is having in her shoulder are due to SCI or menopause,

> *It's likely part of being in a chair. But then my physio is like, how old are you? And I'm like 48. She's like, you know, frozen shoulder and the shoulder problems you're experiencing are very common in menopause.*

This lack of clarity about whether a particular health issue is attributed to menopause is common in my clinical experience. What is becoming increasingly clear, however, is that the difference lays in the potential consequences of menopause symptoms – a frozen shoulder is a very big deal when your arms act as your source of transportation and independence. As such, the considerations, patient-provider communication, and urgency around treatment must also be re-adjusted to match the significance of potential consequences. Nadine also relied on her shoulders for playing tennis, this activity provided her with a sense of competence, fun, and was a major form of stress relief,

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> *my shoulders screwed. So like, I don't have that exercise outlet either. I played tournaments in France and Australia and, and I was playing like minimum two to three times a week. So it's a big change for my brain and also for my body...*

Nadine remembers a recent conversation with her physiatrist (rehabilitation doctor) where he agreed to redirect her referral for surgery as she was facing a one year wait to have treatment for her shoulder pain, *at that point, I was in tears every day, and I couldn't even wheel myself*. Nadine felt overwhelmed by the complexity of navigating the healthcare system for her shoulder and arm pain, *every part of the arm is a different doctor, and you're just, like, a little bit overwhelmed with doctors and diagnoses and then fighting.* When Nadine finally saw a surgeon for the troubles with her shoulder and remembers him informing her, *we're going to try a cortisone shot in the long head of the bicep. And if that works, then we're going to cut the bicep tendon.* Nadine came away from this appointment feeling uneasy. She didn't fully understand the treatment plan and wasn't convinced the surgeon understood her lived experience or the potential consequences to her quality of life should her shoulder lose function,

> *I said...I need you to understand how important my shoulders are to me. Like, I, they're my legs, they're everything, and if you're going to cut my bicep tendon, like, I really need to understand what you're doing, and I'd like a fuller picture of what else is going on in my shoulder.*

Several other issues such as a missed referral for an ultrasound guided cortisone injection, left Nadine feeling fatigued and unheard, it's

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> *...just another thing, adding to, like, everything you're doing. And you're trying to navigate your own health experience, and then you're pushing because doctors really don't listen to you.*
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> *I've always gotten in and out of a tub. And I have, I'm T1, so pretty high. And, like, now I just, it's sort of touch and go. I had carpal tunnel surgery on this hand in 2020 and this hand, um, last September, so a year and a half ago, um, which significantly decreased what I was able to do...then it just kind of snowballed.*

So often, the experience of menopause, and aging as a woman in general can be ill-defined, without contours. When a health issue is hard to diagnose or its cause is unclear, a healthcare provider can still help ease a patient's distress by validating their experience. Simply feeling seen and acknowledged can offer comfort, even in the absence of clear answers.

Work Life

Nadine has a diverse professional background but has been a producer for most of her career. Previous work roles also include public speaking for an injury prevention organization, peer support coach with Spinal Cord Injury BC, work in radio broadcasting, in visual effects and animation. She also played a key role in promoting disability inclusion as a lead member of her workplace's inclusion committee. In recent years, finding employment in her industry was tough and Nadine was out of a job for a year and a half. At times, Nadine felt her employment may be fragile. Menopause related brain fog was a significant symptom for Nadine. Fatigue also hampered Nadine's professional life, *I just remember sitting at the desk and just being really*

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overwhelmed and being like, I cannot... It's just that my body was so heavy. I couldn't function. Like I just couldn't function.

As a woman with a visible disability, she was already navigating assumptions of incompetence and felt a need to prove her capabilities in the workplace,

> *the brain fog is very serious... I have worked in visual effects and animation most of my career...you're often starting a new job, um, and then trying to, well, with a spinal cord injury, I find that you're already trying to prove yourself. And then now, like every time you meet new people or start a new job, you have to sort of prove your ability or your skills. And if you're sitting in a meeting and you can't think of words and you're trying to like get a thought across... it's very hard when you also have this thought about what everyone else is thinking... people have that preconceived notion that someone who's disabled is not a contributing member of society.*

At the time of my research with Nadine, the political rhetoric coming out of the United States was largely prejudiced. For example, Nadine pointed toward recent narratives investigating the cause for a plane crash, *look at Donald Trump, he just blamed DEI (diversity equity inclusion) for a plane crash.* I had been following this story in the news and was disturbed by the storyline but had the privilege of turning my attention away. Nadine could not turn away from discrimination, and had multiple experiences of being labelled incompetent because of her SCI,

> I *went to the doctor once...they took forever and I was getting a physical and this nurse was examining me and I'm like, excuse me. She was actually also being quite rude. And I*

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> *said, do you know how much longer we have? Cause I have to get back to work. And she goes, YOU work in a wheelchair? And 'm just like, well, I physically sit at my desk in my chair. So yes, I guess I work in a wheelchair.*

Nadine's motivation to prove this narrative wrong, pushed her to continue moving forward, even when she knew she needed rest,

> *My brain was buzzing and exhausted. And I felt like I was floating and I just felt like I needed to continue. I needed a job. Um, you know, I watched people around me with SCI that are like, oh, I'm on income assistance. And I'm like, oh, I couldn't live off of income assistance. And, you know, you have, um, you have ableist comments all the time and you're just like, okay, I just have to keep going. I just have to keep going.*

Nadine's comment – *I have to keep going*, reverberated within me. Our conversations revealed the fact that she was determined to succeed in her career and other realms of her personal and social life. But at what cost? Why did Nadine feel that she needed to keep going? What would it mean if she stopped? What was she pushing up against? The answers to these questions are likely complex, however when Nadine spoke of her peers who were living in poverty, and the additional barriers that existed for employment, I gained a clearer understanding of her motivations, *this is a horrible thing to say, but my life and career is probably in the top 30% of people with spinal cord injury. Like there's a lot of people who don't work.* The amount of stress Nadine faced as she juggled prioritizing her health with upholding her professional duties was immense,

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going through all those bladder infections and I'm trying to get time off work to like, go get a sample. And then I'm trying to like tell work and trying to sneak out of work, which added that extra layer of stress...I'm missing, you know, four hours a week, just doing a sample. And how am I going to get there?

Research Ethics

After living with depression for many years, one of Nadine's healthcare providers came across a research study for a transcranial magnetic stimulation and suggested that it might be a good option for her. Nadine was hopeful that this novel treatment could work for her, however it would turn out to be a very negative experience. Nadine diligently filled out the assessment forms, completed the consent, and underwent a baseline MRI. The experience of getting into the MRI was the first red flag,

the people that were doing it were treating me really badly and I'm super claustrophobic and they were like pushing me and pulling me. And I'm like, I can't move. Like, could you just stop and let me help direct you? Like I've done this millions of times.

After the MRI, Nadine heard nothing further from the research team.

all of a sudden, it was like radio silence. I'd done everything they'd asked me to, um, and they kept asking me, can you transfer into a chair? And I'm like, yes, I can transfer into a

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> *chair...Long story short, the guy, the psychiatrist who was overseeing the study assumed, even though I'd said I could, that I couldn't transfer into a chair and he didn't want me as part of his study.*

Nadine was exasperated with this series of events, *it shouldn't matter if I can or cannot transfer. You should be able to do this study. This is discriminatory.* Nadine decided to speak with her rehabilitation doctor to discuss and validate her concerns. Her rehab doctor encouraged her to engage with ethics. Instead, Nadine contacted the primary investigator to have a conversation about her experience. Nadine explained that the primary investigator was a non-native English speaker, Spanish being his mother tongue, here she describes her attempts to shift his perspective, *I said, well, how about if I had discriminated you because you did not speak English as a first language?* After hearing this part of the story, I was proud of Nadine for speaking out and hopeful her concerns would be validated and addressed. I thought about how often medical providers and research don't get the feedback required to grow, change, and reflect on their biases. Nadine continued in her conversation with the researcher, informing him of her long history of taking part in research studies. Finally, Nadine brought up the fact that she had previously spoken to one of her doctors about this situation, and pointed out that he was encouraging her to contact ethics,

> *all of a sudden, like 180 total change...and he got very, very defensive, like very defensive. And I took a step back and I said, there's really no need to get defensive. These are my rights to do this. Like I was, I was actually probably too nice. And I said, let's take a step back and really think about what's happening here because you're*

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> *basically telling me I can't do this study. I've told you I can get in a chair, but you keep asking me if I can. And I keep giving you the same answer. That answer is not going to change. Yes. I can transfer into a chair. I have scaled a building in downtown Vancouver in my wheelchair. And you're telling me that I can't transfer in a chair. I said, how about we try it?*

In the end, Nadine ended up taking part in the study which spurred further grievances and advocacy on her part. Even after the study was completed, the researcher would not inform her about whether she was part of the treatment or placebo arm. Accessible parking was an issue, requiring time and patience on Nadine's part to get sorted,

> *the parking for wheelchair accessibility was more expensive than what they were reimbursing you. And I had to fight to get reimbursed. And then I had to phone... I called UBC parking and they were actually doing renos to that building. And they were like, Oh, that's good. We'll put a spot up here...The amount of advocating you have to do for everyday life in a chair is overwhelming.*

As Nadine's story of menopause but also of life began to twist and turn, it was easy to lose sight of her initial intention; her desire to gain insight and a possible solution to her mental health concerns. Nadine never ended up filing an ethics complaint. There was just too much in life to do, and she was under too much stress already, she explained. I could see clearly what she meant.

That's because you have a Spinal Cord Injury

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For many years, Nadine was plagued by pain in her neck and shoulders. By 2018 she could no longer tolerate it and underwent a breast reduction, *it had gotten so bad. I thought that like I was willing to sort of do anything to reduce that pain.* Unfortunately, after Nadine's surgery she noticed a complication and returned to her surgeon for assessment.

> *I even went to my doctor because where she'd done the incision, [it] had puckered...I went to my doctor and I'm like, am I being silly? ...she's like, no, no, that's not right. So I went to her (the surgeon) and I'm like, is there something we can do about this? And she said...well, what do you expect when you go through MSP? ... And she said, well, you know what I mean? And I'm like, no, actually, I don't know what you mean. Are you telling me that if I had paid you privately, my breasts would look better?*

As Nadine told this story, her body language, and tone of voice revealed the tension this memory called forth. I could also see the confidence and conviction within Nadine as she recalled her story — I was glad that Nadine didn't shy away from confrontation in this experience. The lack of empathy and callousness in this doctors' response was astounding to me, but this story didn't end there. After her breast reduction, Nadine developed significant pain, *then I had this horrible pain every time I touched this nipple. Like I had no idea why, just horrible...I went to her...and she goes, oh, that's because you have a spinal cord injury.* Nadine wasn't satisfied with this response that she had heard so often before, so she spoke with her rehabilitation doctor who was familiar with SCI, I *went to Dr. K and I'm like, so I'm having this pain. And then the surgeon thinks it's because I have a spinal cord injury...And he [Dr. K] goes, absolutely not.* Thanks to

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her self-advocacy and the support from her rehabilitation doctor, Nadine underwent a surgical revision to address the puckering, however her pain continued for several years.

Nadine was on vacation in Victoria when she developed a significant rash on one of her breasts and an area of her surgical scar re-opened. As she was telling me this story, she interjected, I *have photos. Not that you need to see photos, but I'm like, I'm not crazy*. After all she had been through, I understood how Nadine was expecting to be met with incredulity. I thought about how burdensome it must be to have your credibility, or even your sanity questioned every time you had a medical issue. As Nadine was away from home in Victoria, she found a doctor at a walk-in clinic to provide antibiotics for the rash and re-opened portion of the incision. After completing antibiotic treatment, the breast pain that plagued Nadine for years disappeared. Nadine wondered if the pain had been related to an underlying infection all along. Reflecting upon her experience with the breast revision, Nadine wonders if it was worth it, and contemplates how this procedure altered her body image.

Body Image, Microaggression and Self-Identity

The topic of body image emerged throughout our conversation. As someone who had lived with SCI for all her adult life, Nadine was confident in her wheelchair. In years past, when she noticed strangers looking her way, she would wonder, is it because they think I'm cute, or is it because I'm in a wheelchair? Menopause, her breast reduction, and aging in general, had changed this experience for Nadine in a way she didn't expect, a*ll these things they talk about when you're young and you're like, oh, it's fine. And then you reach that age and you're like, oh, wow.* When reflecting on her experiences with aging and menopause, Nadine was reminded of a former colleague and supervisor who had bullied her at work. This supervisor was someone who placed a high value on her appearance and the social status that came with it.

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> *she felt that with age, she was disappearing, and she was no longer seen. And this was the way she was reacting to disappearing into society, and no longer having a place, and no longer turning heads...even though I think she was an absolutely horrific person, I understand where she was coming from in terms of being a woman and disappearing...she was horrible, but she was really struggling.*

I thought it was reflective of Nadine's thoughtful and kind nature that she was able to extend empathy towards someone who treated her so badly. Furthermore, I hoped that Nadine was able to find support in her connections with other women while navigating her own experience of aging.

As our conversation about body image continued, Nadine reflected on how her breast reduction changed the shape of her body, *I'm essentially a quad with hands as they say. So now like I lean back for balance...my stomach now sticks out more than my breasts do, which was never the case. And it just makes me feel very insecure.* In addition to the impact Nadine's breast reduction had on her body proportions, she also felt the procedure created a disconnect for her, *I still don't feel like my breasts are part of me.* I wondered how much of her negative experience with the surgeon was related to how she felt about her breasts. Once again, I recognized the disproportionate impact that a symptom of menopause could have for a woman with SCI. I would argue that body image issues, and weight around the midsection are often pre-existing issues directly related to social and biological factors associated with SCI. Menopause added yet another layer.

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Body image wasn't the only factor associated with self-identity that Nadine struggled with. As a woman living with SCI, Nadine faced constant microaggressions and yet felt pressure to represent her wheelchair user community in a positive light,

> *[having a SCI], it's kind of like being an actor, um, or an athlete or someone of high profile that is always on. Like you can't be negative. If you are, you're going to be caught. That's going to be out there. That's going to be like your demise...it's overwhelming the amount of times that you have to be on as someone just like going through society, whether it's going to a doctor, whether it's going to a theater...you have to explain and advocate for yourself. You have to educate. You have to respond to people who are like, Oh, why can't you walk? Or what happened to your legs? Or what's wrong with you? And, you know, all you want to do is punch them in the face and say, I don't know what's wrong with you? But if you do, you're going to feed that stereotype of negativity.*

What struck me about Nadine's experience is the potential impact this experience could have on her sense of self-identity, and sense of belonging. Nadine spoke about how social prejudice was often hidden in the form of microaggressions,[12] and thus more difficult to conceptualize. She sent me a video[13] that she came across at work which likened microaggressions to mosquito bites. I thought this was the perfect metaphor. Microaggressions were often embedded into age old and taken for granted language used by healthcare professionals. At one point during our conversation, Nadine pulled out her cell phone and began scanning through photos. She faced

[12] Microaggression is a term coined by psychiatrist and Harvard university professor Chester M. Pierce to convey the subtle and covert insults arising from unconscious negative attitudes toward a social group (Pierce et al., 1978).
[13] Fusion Comedy (2016). How microaggressions are like mosquito bites. Retrieved from https://youtu.be/hDd3bzA7450?si=IBKbfw_8F0az0sZq

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her phone toward me, showing me a photo of her medical chat from a recent hospitalization after fracturing her leg,

Past medical history: T4 spinal injury

Allergies: sulfa drugs

Social history: Wheelchair bound

I thought about the connotations this language brought forth. Nadine wondered, *what does social history say for an able-bodied person? And why are we using wheelchair bound?* The language of *wheelchair bound* connotates the wheelchair is a negative influence, restricting and immobilizing. Many people I know with SCI grow to see their wheelchair as either an extension of their body, offering them freedom of movement, or as a useful tool to navigate the world. This experience reinforced Nadine's fear of being in the shadow of her wheelchair.

Safety in Acute Illness; Being Cared for

The concept of psychological safety emerged throughout my conversations with Nadine. I surmised that for Nadine (and likely most everyone), safety stemmed from the experience of being believed, validated, and cared for. These experiences allow for a metaphorical softening, letting go, a shedding of armor. Towards the end of our conversations, Nadine reflected upon a psychology appointment where she was guided to consider her experiences of feeling safe,

> *I had to think of somewhere that I felt safe... the other place I felt really safe was my hospital bed. This was probably now 10 years ago... that stands out for me...I felt*

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> *comfortable sort of being taken care of in that way. And then I didn't have to worry. I don't know. I really don't have an answer as to why*

I thought about the contrast of the attitude and care Nadine received during the acute stage of her injury when she was just 14 years old versus her current life stage as an adult menopausal woman with chronic SCI. As a teenager, Nadine's physical injuries were clear, she had broken her back, a severe injury, affording her great care and concern. Loved ones fawned over her, bringing her treats and a collection of stuffed animals. Medical professionals tirelessly investigated her sleep disorder with a barrage of diagnostics and went out of their way to meet Nadine's social emotional needs as well,

> *I had this one nurse, I'm going to cry...every time he worked, he went to the laundry room and...looked high and low to find us a gown that was not blue or green. So we'd get pink or yellow or just like the little things like that.*

Nadine remembers another nurse who made an impact when she was going in for spine surgery,

> *she stayed with me because they wouldn't allow my parents to come in the pre-waiting room. And I had this stuffed cat and she put one of my, um, name bands on him as a collar. And then she stayed with me in the pre-waiting room...she got off at seven in the morning and she stayed till 10 holding my hand till I went into surgery.*

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In her school community, great lengths were gone through to ensure Nadine was included; her high school installed an elevator. I get the sense that when Nadine looks back upon her time in the hospital, she doesn't locate herself as someone who was up against the medical system but rather as someone who was embraced with great care. I wondered when this changed? Living with chronic SCI as an aging woman offered a different picture, *half the time my needs have been negated and pushed aside... I do have a fear of a doctor thinking I'm over exaggerating or being silly.* Nadine was experiencing the intersecting identities of being a person with a disability, a woman, and an older person. As Nadine navigates the world as a menopausal woman with SCI, she describes a lack of empathy, paradoxically wondering if she created the conditions to nurture this dynamic,

> *sometimes I'm like, I just want some empathy, like just a little bit, you know? ... I'm not very good at being vulnerable with people that I care about...Especially when you're trying to seem capable and independent....so then I think I've sort of taught my friends and family to believe that I'm fine. And when I'm not, they're like, oh, you'll get over it.*

I recognized that Nadine had experienced being labelled as someone who is less capable, someone who needs help, and was constantly working to prove this stereotype wrong. I was aware that many women struggled during menopause under pressures to fulfil family, work and social obligations, however, Nadine's experience as a wheelchair user further compounded this phenomenon. I considered the conditions (economic, political, social) that pathologize dependence and valorize independence. I could see how these conditions would make it difficult

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for anyone to feel safe in vulnerability. Nadine also reflects on the experience of uncertainty with aging in SCI,

> *then you're told your life expectancy is less, although they believe that that's not to be true anymore, though they still tell you those things. They put all these restrictions on what you can and can't do. And then they really downplay the experiences that you're going to have. And also, then they maybe embellish isn't the right word, but embellish the risks and the negative experiences that you're going to have. And I fully believe that it's how you choose to approach those negative experiences.*

I wondered how hearing these predictions might impact a woman's choices as she ages. How much of what we predict for patients is based upon evidence, and if it's unclear, are we being helpful in painting a picture of an uncertain future?

Nadine's experiences have motivated her to help other women identity the symptoms of menopause and access treatment in a timely fashion,

> *being a storyteller at heart, I try to tell my story to others and especially [those] with SCI that, Hey, your bladder infections could be because of menopause. Like, how old are you?*

When I asked Nadine for any last comments about what to remember when moving forward in my research and clinical care while working with women with SCI, she stated,

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> *I find that people have a fear of things that are unknown and [I suggest] to approach something with curiosity and empathy and approach it in a way of learning and not be scared to ask questions or make mistakes because you don't have to know everything.*

As Nadine and I wrapped up our last conversation in her living room, we looked out her window at a beautiful sunset and commented on the migration of crows across the harbor and the park below. I was so grateful for the opportunity to learn about Nadine's life and menopause experience, and to take this knowledge forward into clinical practice and education for patients and clinicians.

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Chapter 6: Publication

Manuscript For Submission to: Qualitative Health Research

Wordcount: 8,000 words or less excluding the abstract, references, and acknowledgements.

Title: The Experience of Menopause for Women living with Spinal Cord Inquiry: A Narrative Inquiry Study.

Authorship: Nicoletti, R., Caine, V., & Albert, K.

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Abstract

Menopause presents distinct medical and social challenges for women with spinal cord injury (SCI), yet little is known about the lived experiences of this population, in part due to gender bias in SCI research and care. This narrative inquiry explores how disability, gender, and aging intersect to shape the menopausal experiences of women with SCI. This study involved two participants, Kim and Nadine, each of whom took part in four in-depth interviews exploring how they navigated, understood and experienced menopause while living with SCI. Conversations were recorded, transcribed, and analyzed alongside field notes to develop narrative accounts. Two key narrative threads emerged: *The Liminality of Menopause* and *Questioning of Self*. Both women's stories revealed how silence, uncertainty, and discrimination shaped their understanding and experience of menopause. In clinical encounters, disability was frequently treated as the primary focus which eclipsed other important aspects of health and social experience. These findings highlight significant gaps in care and the need for healthcare providers to engage in proactive and validating conversations about menopause with women living with SCI.

Keywords: menopause, perimenopause, spinal cord injury, paraplegia, narrative inquiry,

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The Experience of Menopause for Women living with Spinal Cord Inquiry: A Narrative Inquiry Study.

Although menopause, with its varied symptoms and manifestations is widely experienced, women with spinal cord injury (SCI) encounter distinct challenges during this transition (McColl, 2002). In addition to barriers commonly faced in accessing menopause care, such as provider hesitancy and fragmented services, women with SCI must also navigate challenges linked to both the social and physiological impacts of disability alongside menopause (McColl, 2002; Kalpakjian et al., 2010). Historical and contemporary literature on reproductive health among women with disabilities highlights a persistent pattern of systemic oppression and health inequities experienced by this population (Brennand & Martino, 2022 ; Brown et al., 2024; (DiMatteo et al., 2022; Gibson & Mykitiuk, 2012; Standing Senate Committee on Human Rights [SSCHR], 2022). Studies in women with disabilities accessing reproductive healthcare have found that healthcare providers often focus on the medicalization of disability rather than addressing the specific health needs the women were facing (Barile, 2004; Brown et al., 2022). While the relationship between menopause and SCI is underexplored, existing literature suggests that women with SCI may experience intensified biological and social impacts stemming from pre-existing medical complexities, psychosocial contexts, and potential caregiving issues (Dormire & Becker, 2007; McColl, 2002).

Utilizing a narrative inquiry methodology, I[1] engaged with women living with SCI to understand their social and health experiences of menopause. This narrative inquiry provides a unique opportunity to understand the menopause experience of women with SCI through life stories, drawing forth intersubjective meanings and understandings. Specifically, I wonder: How do women with SCI understand their experiences of menopause? How do these experiences intersect with their disability and needs? What role do health care practitioners, and the

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healthcare system play in shaping and organizing people's experiences and understandings of menopause, and how do these contribute to health inequities?

Women with SCI contributed stories and co-constructed narrative accounts detailing their medical, social, and everyday experiences of menopause. These accounts prompt a critical examination of dominant and less visible societal narratives, particularly those shaped by silence, power, and responsibility, which were visible in the narrative threads. This narrative inquiry also invites reflection on practical implications and opportunities for change.

Background

Menopause in Women with SCI

Academic discourse on menopause has shifted from a predominantly biomedical framework, focused mainly on hormonal changes (Leng, 2006), toward more comprehensive perspectives that view menopause as both biologically and socially constructed. (Brown et al., 2018; Hyde et al., 2010; Utian, 1997). Feminist scholarship challenges the portrayal of menopause as merely a biological deficiency, highlighting the importance of sociocultural contexts in shaping how menopause is understood and experienced (Bell, 1987, McCrea, 1983; Orgad & Rottenberg, 2024). Heightened media attention has pushed menopause into popular culture, with high-profile women such as Michelle Obama, Halle Berry and Naomi Watts speaking publicly about menopause experiences (Onculer & Onculer Yayalar , 2025; Orgad & Rottenberg, 2024). Since the latter part of 2010, commercial growth of menopause products and services has also mirrored an increase in public and academic interest (Onculer & Onculer Yayalar, 2025).

Despite this growing attention, there remains a notable absence of research on the specific medical and social dimensions of menopause for women with SCI. This gap in

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knowledge poses a significant challenge for healthcare providers, who are left without clear guidelines to effectively support or even understand the unique needs of this population. As advances in care have led to increased life expectancy for women with SCI (Furlan et al., 2023; Hosier et al., 2012), there is a growing need to understand how they experience menopause. Without appropriate support, menopause can negatively impact not only health, but overall quality of life. This is an issue of particular concern for women with SCI who already contend with systemic barriers to healthcare, employment and social inclusion. Understanding menopause in the context of SCI is essential not only for younger women aging with SCI but also for those who sustain injuries later in life.

Identifying and distinguishing menopausal symptoms from other health concerns such as sleep disturbances, mood changes or muscle and joint pain, is often difficult for clinicians (Menopause Foundation of Canada [MFC], 2022). For example, a woman with mood changes and sleep disturbance may be treated for depression and insomnia without consideration of menopause as an underlying cause. To fully understand the unique consequences of menopause on SCI, these effects must be situated against a background of pre-existing medical complexities, psychosocial contexts, and potential caregiving challenges, given their possible impact on daily functioning and overall well-being (McColl, 2002). Women with SCI are already predisposed to conditions worsened by menopause, such as osteoporotic fractures, skin breakdown, weight gain, urinary tract infections and mental health changes, all of which can significantly impact their ability to live independently and maintain a good quality of life.

These same disease processes and associated symptoms may be mediated by hormone replacement therapy (HRT), which can play a significant role in mitigating their impact (MFC, 2022). However, no specific guidelines on considerations for HRT in the SCI community exist.

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In their editorial on menopause and SCI, McColl (2002) utilizes the metaphor of a 'house of cards' to describe the state of maintaining independence while aging with SCI, "precariously balanced but easily brought tumbling down" (p. 372). These interconnected challenges highlight the need for a better understanding of menopause care in women with SCI—one that explores not only biological changes and challenges, but also the broader physical, emotional, and social factors shaping health and independence.

Access to Sexual and Reproductive Healthcare

Women with disabilities face attitudinal, structural, and informational challenges in accessing sexual and reproductive health (SRH) care (Gibson & Mykitiuk, 2012; Kalpakjian et al., 2020; Taouk et al., 2018). The WHO (2022) has established equitable[2] access to SRH for women with disabilities as a human rights issue that enables biological health and social inclusion. Despite this formal recognition, many barriers are deep-rooted and the mechanisms underlying and perpetuating inequities in SRH for women with disabilities are complex. Intersectionality, a term initially coined by the legal scholar and black feminist Kimberlé Crenshaw (1991), is analytically helpful for uncovering the barriers experienced by women with disabilities who navigate multiple forms of oppression and marginalization. Viewing inequities in SRH for women with disabilities through an intersectional framework helps deconstruct and make visible contributing factors.

The inequity in SRH for women with disabilities is often compounded by the fact that they face ableism *and* sexism, two forms of discrimination heavily steeped in paternalism (Asch & Fine, 2009). Stereotypes that depict women and people with disabilities as passive, dependent, and needy have perpetuated a historic lack of academic and scientific inquiry with the population (Asch & Fine, 2009). In 2019, Craven and Musselman called attention to the "many sex and

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gender disconnects in the field of SCI rehabilitation, which may be contributing to conscious bias, unconscious bias, or both, in the service delivery of spinal cord injury care and rehabilitation" (p. 1). Although increasing attention is being drawn to the needs of women with disabilities, the SRH needs of aging women in this population remain under-studied and under-resourced (Fletcher et al., 2023).

As more women survive their injuries and go on to lead extended, healthy lives, the imperative to further understand and address menopause and SCI will not decrease; rather, it will become more important over time. During this inquiry, the menopause narratives of two women with SCI were foregrounded and interwoven with their experiences of navigating life, and the healthcare system as a woman living with a disability.

Turning to the Research

Methodology – Narrative Inquiry

This study utilized narrative inquiry, a relational methodology that focuses on experience and encompasses the three dimensions of time, place, and sociality (Clandinin & Caine, 2013). Narrative inquiry is a methodology that honors the nuance in complex research questions, making it ideal for exploring the experiences of menopause and SCI. This methodology draws on Dewey's theory of experience (1938) and pragmatist scholarship, including Jane Addams's (1902) feminist work on social ethics. Narrative inquiry frames experience as the central unit of analysis, allowing participants and researchers to explore personal, social, and political experiences that reflect our past, present, and anticipated future events (Clandinin & Rosiek, 2007). Data sources in narrative inquiry are referred to as field texts (Clandinin & Caine, 2013). Field texts collected in this study included transcripts of conversation with participants, notes on my internal thoughts and observations, as well as artifacts.

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Narrative accounts were co-composed alongside participants, introduced below. Kim consented to using her first name in this study, while Nadine chose to use a pseudonym. Resonant threads, commonalities drawn from narrative accounts, revealed broader sociocultural narratives reflective of participants' ideas and lived experience (Clandinin et al., 2019). Ethics approval for this study was obtained from the University of Victoria (REB# 24-0548).

Recruitment and Participants

Participants were recruited using purposive sampling with a networking approach. Recruitment posters were placed in the common spaces of an accessible gym in an outpatient spinal cord centre. Digital recruitment was done with support from Spinal Cord Injury BC (a peer-led organization) who circulated information about the study in their newsletter. Individuals who expressed interest in the study were offered a meeting to discuss the nature of engagement in narrative inquiry and the anticipated time commitments. Participants were eligible for inclusion in the study if they were English speaking, self-identified as a person with SCI being in menopause and lived in the lower mainland in British Columbia, Canada. The first author, who worked with participants, is a Registered Nurse providing care to people with SCI, therefore, exclusion criteria included current or recent (within 2 years) of being a patient of the first author. Given the in-depth engagement, two participants were recruited for the study, which is appropriate for this methodology (Clandinin & Caine, 2013). Both participants identified as middle class, financially secure, white women.

Field Work

A distinct feature of narrative inquiry is the acknowledgment that separate experiences (those of the researcher and participant) interact, giving voice to rich, layered, and ongoing narratives (Clandinin & Caine, 2013). The setting of this narrative inquiry was negotiated with

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participants and conversations took place in their homes and also via Zoom video conferencing. Field texts were composed over four conversations with each participant between January 28th and May 6th, 2025. Conversations averaged between 60 to 90 min. Written informed consent was obtained from participants prior to data collection and reaffirmed at subsequent conversations. An open, non-directed conversational approach was implemented to support the sharing of stories (Clandinin & Caine, 2013). Participants were invited to share artifacts (objects or photos of personal significance) in order to elicit memories. To capture contextual details of our meetings and conversations, I kept field notes which focused on inner thoughts, emotions, and moral responses. This process held space for temporality as field notes were developed over multiple sessions, spanning time and attending to earlier life experiences (Clandinin & Caine, 2013). Field texts were read and re-read with attention placed upon temporality, place, and sociality (Clandinin & Caine, 2013).

From Field Texts to Interim and Final Research Texts

Moving to interim field texts involved co-composing narrative accounts with participants as a way to represent their experiences and the relational nature of meaning-making. Narrative accounts were negotiated alongside participants to ensure the narrative interpretations accurately represented their experiences, our relationship, and the stories they shared. Once the narrative accounts were negotiated with participants with attention to the three common places of time, place, and sociality, (Clandinin & Caine, 2013), the first author met with the other authors (to discuss resonant threads that had emerged (Clandinin & Caine, 2013). The resonant threads are a significant element of the final research texts which will continue to evolve and unfold as life and stories continue (Clandinin & Caine, 2013).

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Meeting Participants

The following narrative accounts were negotiated with participants and introduce the lives and stories of Kim and Nadine.

Meeting Kim

Kim, a longtime disability advocate and avid curler, sustained a SCI resulting in quadriplegia just two weeks after graduating from high school. This life-altering injury required intensive rehabilitation; however, Kim took pride in regaining her independence and completed her education to become a social worker within five years of her injury. After her injury, Kim also met her husband and became an aunt to twin boys who motivated her during difficult times. Around the time of expected menopause, her busy life was interrupted when she was struck by a car while out in her wheelchair. This accident contributed to mental health struggles that spanned 10 years from ages 40 to 50. Reflecting upon this time of life, Kim asserted, *that was more debilitating than breaking my neck*. It was a struggle for Kim to tease apart and put labels upon her experiences that spanned those ten years -- *I guess you know I was actually just really depressed but I didn't really know I was that depressed [it was] an array of emotions that just kind of crippled me physically and emotionally.* In addition to her mental health struggles, Kim was frequently misdiagnosed during this period of time for a variety of physical symptoms,

> *I had so many medical problems back then it just seemed like one after the other after the other [...] I feel tired even talking about it [...] if I went running to the doctor or emergency every time I had a medical problem...*

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In her 30s, Kim began continuous hormonal contraception to cease her menstrual cycle and therefore was not able to recognize menopause via changes or cessation of her period – a common way to signal the onset of menopause for many people. Kim and her healthcare providers had minimal discussion about menopause treatment or hormone therapy,

> *they offered it to my husband's mom so I was just wondering when my day was going to come but it didn't and my doctor's actually really good too, [she] spends a lot of time with me, but she kind of tiptoed around things quite a bit there in my 40s because I was not in a good place*

This was also a time when Kim's experience of reproductive healthcare, such as screening for breast cancer, was fraught with environmental, systemic, and attitudinal barriers, taking a mental and emotional toll. Here Kim describes her frustration when being told she could not receive a mammogram at her local hospital

> *I was still trying to be really nice and educate them [healthcare staff], going back and forth [advocating for your own care] for so long, you get tired of the advocacy and educating people [...] I just got fed up and sometimes you just don't want the hassle.*

Kim had mixed feelings about the sole accessible clinic for reproductive healthcare in her province, *they [the accessible clinic] have a special bed that can go up and down, I get that that we can't have that everywhere, but they should at least have something in every city.* Despite Kim's challenges navigating an inaccessible and dysfunctional healthcare system, she was

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persistent in advocating for her needs and appreciated a supportive relationship with her family provider.

Meeting Nadine

Nadine, a busy professional and peri-menopausal woman with SCI, entered our research relationship in the midst of wedding planning, renovations, and a move. Despite this busy time in her life, Nadine was motivated to share her experiences of menopause in hopes of helping others. Nadine's SCI occurred when she was 14 years old and fell asleep while skiing. Medical investigations cleared her of narcolepsy, and although her symptoms of excessive sleepiness have somewhat improved, fatigue is still something she struggles with regularly.

Nadine's experiences with accessing care for and enduring reproductive health issues were frequent and started in her youth. Looking back upon memories from her youth, Nadine recalls, *I'd always had really, really bad periods to the point of like kneeling over and like wanting to faint, and we just chalked it up to my grandma. My dad's side had very bad periods.* At times, people questioned Nadine about the legitimacy of her menstrual pain -- *people are like, oh, you're T1 complete*[3]*, how do you feel period cramps? I'm like, I don't know, but I do*. This disbelief at Nadine's experience became a theme in stories throughout our conversations. Medical professionals commonly overreached their positions of power to challenge Nadine's bodily autonomy and knowledge. Around the age of 30, Nadine began experiencing nerve pain in her leg that radiated toward her abdomen. She was eventually diagnosed with endometriosis. In the approximately 10 years following, Nadine started experiencing frequent recurrent bladder infections, having a major impact on quality of life. The frequent appointments for these ongoing issues also interrupted her work life.

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> *At about 32, 33, they came back and lasted for about nine, 10 years. And I went to doctor upon doctor, and they told me I was cathing [catheterizing] wrong. They told me my catheters were dirty. They told me, like, all of these things that I needed to change. I tried everything.*

As Nadine navigated the healthcare system, she would eventually find a solution to her recurrent urinary tract infections by chance: Menopausal Hormonal Treatment (MHT). Nadine discovered she was in early menopause while undergoing testing related to her endometriosis. Despite her menopause 'diagnosis,' Nadine remained uncertain about whether a range of other health issues were attributed to menopause, her SCI, or something else.

Nadine experienced discrimination, medical gaslighting, and bias during many of her healthcare and encounters. As she shared, *half the time my needs have been negated and pushed aside (...) I do have a fear of a doctor thinking I'm over exaggerating or being silly.* Nadine frequently pushed back against discrimination in her experiences accessing healthcare and as a research participant. For example, when being screened for a study that involved a treatment with potential to improve her mental health, she was almost excluded based on assumptions about her physical ability. In the following excerpt, Nadine described a conversation she arranged with the researcher to discuss her concerns,

> *you're basically telling me I can't do this study. I've told you I can get in a chair, but you keep asking me if I can. And I keep giving you the same answer. That answer is not going to change. Yes. I can transfer into a chair. I have scaled a building in downtown Vancouver in my wheelchair.*

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However, Nadine also spoke highly of many healthcare professionals who made her feel seen and provided excellent care. Nadine's story is marked by her determination to defy stereotypes by maintaining her independence both economically and physically. Paradoxically, she wondered if this attitude sometimes worked against her. When I asked Nadine for any last comments about what to remember when moving forward in my research and clinical care while working with women with SCI, she stated,

> *I find that people have a fear of things that are unknown and [I suggest] to approach something with curiosity and empathy and approach it in a way of learning and not be scared to ask questions or make mistakes because you don't have to know everything.*

Narrative Threads

Narrative threads are commonalities that converge across individual narrative accounts (Clandinin et al., 2019). Two central narrative threads emerged within and across Kim and Nadine's narratives, 'the liminality of menopause' and 'questioning of self'. The stories that Kim and Nadine chose to share contribute to a nuanced understanding of menopause that is often obscured by normative, ableist, and dominant representations of this life transition.

Narrative Thread: The Liminality of Menopause

Throughout my time with Kim and Nadine, stories unfolded within a context of ambiguity and uncertainty associated with change. Liminality, a concept originated by Arnold van Gennep (1909) and further developed by Viktor Turner, can be used to describe being neither here, nor there -- those who "elude or slip through the network of classifications that

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normally locate states and positions in cultural space (...) Liminal entities are neither here nor there" (Turner & Abrahams, 1969, p. 95). Van Gennep (1960) conceptualized liminality as a transitional phase associated with rites of passage; transitions associated with changes in place, state, social position and age.

Experiences of liminality arose in various ways within their narrative accounts, raising questions about the role of healthcare providers in validating menopause as a biologic and social transition. This resonant thread is imbued with ethical questions of who, if anyone, bears responsibility or obligation to bring menopause forward in healthcare conversations for women with SCI. The construct of temporality alongside liminality must also be considered in Kim and Nadine's stories, as minutes, hours and days bled into years of healthcare seeking, enduring of discomfort and advocacy work. Kim and Nadine's experiences with liminality prompt us to reimagine how healthcare could play a more proactive role in menopause education and to question what assumptions about menopause underly the deflated or absent animation of menopause conversations within their healthcare seeking experiences.

The Disability | Menopause Binary

On multiple occasions, when Kim and Nadine had symptoms that welcomed a discussion inclusive of menopause, a discussion of disability dominated instead. This phenomenon of focusing on disability as a unitary concept has been recognized for decades; Asch and Fine (1988) describe it as a harmful practice that eclipses other dimensions of social experiences. In both Kim and Nadine's healthcare narratives, disability was present as a visible and tangible biomedical construction that could account for a myriad of health concerns. Kim and Nadine arrived in their healthcare experiences as menopausal women living with disability, however, it was rare that these two identities (among others) were integrated into a pluralistic approach to

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care. For Nadine, her SCI was superimposed by practitioners upon her other identities to such an extent, that she often made deliberate efforts to identify her SCI as a non-offender in her physical, emotional or mental health concerns, here she speaks of an introductory meeting with a counselor,

> *I've prefaced things (...) I don't care about my chair [wheelchair]. Like, I know that shaped who I am, but that's not what I'm here to talk about. And they [healthcare providers] always go to that (...) that's not why I'm here.*

In this experience of seeking mental healthcare, Nadine was prevented from addressing her concerns during a time of transition and turmoil.

It may be difficult for anyone to identify symptoms of menopause given the wide array of "symptoms" associated with it, and living with secondary symptoms of SCI can make it even more challenging. Without an awareness of how menopause impacts health in covert asymptomatic ways, women may not realize that significant health concerns are being shaped by menopausal changes. For example, when Kim spoke of having *bigger fish to fry*, she downplayed menopause as a significant factor, locating aspects of health such as osteoporosis and skin integrity outside the arena of menopause entirely. When I asked Kim whether the topic of menopause came forth in conversations with peers who have SCI, this sentiment arose again when she stated, *the women I know who have spinal cord injuries or disability who are about my age, they mostly talk about bone health.* In my experience as a nurse, most women with SCI are aware of their risk for bone loss, metabolic changes, urinary symptoms or cardiovascular disease related to SCI. However, there is a notable absence of healthcare conversations that explore how

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hormonal changes, particularly those related to menopause, play a role in these conditions. This type of silence forecloses the possibility that menopause is at play, for Kim and Nadine, as if to say, you can be disabled or menopausal, but not both. Here, the liminality – the sense of being neither here nor there – is explicit in their narrative accounts.

When Menopause Goes Unnamed: Ethical and Discursive Silences

Menopause silences within Kim and Nadine's experiences played several roles, sometimes prompting action, resistance, and at other times maintaining a status quo—one in which healthcare providers do not offer education about menopause unless prompted by the patient. Analytically, recognizing silences welcomes an examination of underlying power structures and the excluded or dominant discourses that are spoken instead. Neither Kim nor Nadine presented healthcare professionals with typical symptoms of menopause such as hot flashes and changes to menstrual cycles in part due to the role of continuous hormonal contraceptives for menstrual management. One could argue that the absence of these normative biomedical indicators of menopause simply precluded menopause from being recognized or discussed within Kim and Nadines healthcare encounters. However, Kim and Nadine's experiences also raise questions of if and how sociocultural discourses might have been operating within the background of their stories. For example, what does it mean to be empowered in the landscape of menopause care and does this narrative work to serve women with SCI?

The women's health movement of the 1960s contributed to a shift from women as patients, to women as healthcare consumers which Sulik et al. (2008) points out "drew attention to individual rights and also, by extension, to individual choice" (p. xii). This shift feels particularly relevant when considering how women with disabilities are often framed within

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narratives of empowerment through notions of ‘self as expert’. However, viewing women with SCI in menopause as consumers, further shift an uneven axis of responsibility. As Sulik et al. (2008) explain, “‘Patients’ rely heavily on health professionals for information, decision-making and care. In contrast, ‘consumers’ actively seek optimal care by choosing providers, obtaining information, serving as their own advocates” (p. xii). Embedded within this neoliberal framing of patient as consumer is an assumption of privilege—namely, that individuals have the time, education, energy, and access required to navigate complex health landscapes like menopause. When dominant cultural paradigms have the potential to further disadvantage populations who already face systematic bias in the healthcare system, they must be examined.

Murtagh and Hepworth (2003) discuss this complex issue through an ethical lens in the context of primary care for menopausal women. They point out that healthcare professionals play a role in the construction of self for menopausal women. Further, they argue that by employing autonomy as the central ethical principle in decision making for menopausal women, personal choice has been co-opted as a mechanism of constraint,

> The management of women at menopause, first using discourses of femininity and more recently discourses of risk and prevention, produce women as subjects of medical and self-scrutiny that acts as a mechanism of control. Clearly there is room for resistance in such a description but when mechanisms of control are constituted in discourse that have previously been set out as the form of resistance, i.e. the women’s health movement’s concern with women’s autonomy and freedom, spaces for resistance are in turn also limited. Rather than ethics as freedom or emancipation in this instance it is precisely the practice of freedom that acts as a mechanism of governmentality. (p. 1646)

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Murtagh and Hepworth (2003) argue that previous discourses of empowerment are no longer serving women in the contemporary menopause landscape, a compelling argument that aligns with Kim and Nadine's experiences. For example, at one point in our conversations, Kim reflected on how an absence of information limits choice and autonomy in decision making about MHT,

> *I think it needs to be pointed out to people. This is what's going to happen for sure. Or almost for certain. So you have to weigh which, which road you want to travel based on all the information and facts. And that's not happening, not with menopause at all. That's way down on people's list of priorities, but it might be because they don't know, um, what the benefits might be. They're not aware of how much their quality of life might improve. We don't know. I don't know. Everyone's different, but you don't know unless you try or at least get that information to make that decision to try.*

Kim's comments speak to tensions that arise when women with SCI, often cast as self-managing subjects, are underserved in clinical contexts of menopause care. Kim and Nadine's narratives illustrate a troubling gap: they were not given enough information to recognize themselves as menopausal, and physicians were not forthcoming in providing education on how menopause may be contributing to their health concerns. Their experiences suggest a need to critically reexamine how autonomy is constructed and enacted in menopause care, especially for women with SCI.

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Being prepared to age with SCI

During my conversations with both Kim and Nadine, they spoke of an awareness of life expectancy, aging, and overall health prognosis for women with SCI. At times, Nadine felt alienated from a future of aging in good health, wondering how a different approach could look,

> *... you're told your life expectancy is less, although they [physicians] believe that that's not to be true anymore, though they still tell you those things. They put all these restrictions on what you can and can't do (...) they maybe embellish isn't the right word, but embellish the risks and the negative experiences that you're going to have.*

Nadine illustrates the power dynamics involved in negotiating who shapes expectations of aging with SCI, and how those expectations impact care decisions and experiences of transition.

In reflecting on the role of clinicians in aging and health promotion, Jane Addams' (1902) view of social ethics offers a compelling lens. Addams emphasized the importance of active engagement prior to confrontation with moral dilemma**s**, arguing for a model of ethics grounded in deliberate, relational action rather than passive response (Hamington, 2001). In this context, health promotion for women with SCI should not be reactive or narrowly risk-focused but instead rooted in early dialogue, inclusive of menopause that affirms possibilities for aging well.

Despite the potential compounded consequences of menopause for Kim and Nadine, little care was taken to prepare them in advance or even during menopause. For example, when Kim struggled with severe mental health concerns for a decade, she was unaware that in the general population, menopause was a contributing factor to depression even after accounting for other

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factors such as recent stressful life events (Joffe et al., 2020). Kim had a history of mental health concerns, and awareness of menopause as a contributing factor could have enabled her to put support in place for early intervention and care, such as HRT. The absence of menopause as a construct in Kim's narrative erased the possibility to bracket her experience with the temporality associated with this life transition. In bringing menopause into the conversation, it may have reframed the experience, as something to get to the other side of. Here, Kim expresses her sense of hopelessness without any end on the horizon, *I think I'm still afraid of ending up there again, I didn't know I'd get better. That lasted a really long time in my life.*

While menopause is rarely marked by culturally recognized ceremonies or transitions, it can often follow a trajectory similar to Van Gennep's (1960) classic model of rites of passage: separation, transition, and incorporation (de Salis et al., 2018). Menopause can be experienced as a transformative process involving loss, change, liminality, and eventual renewal, with this sense of renewal often facilitated by "liberatory cultural imagery and feminist-inspired emancipation" (de Salis et al., 2018, p. 535). Turner and Abrahams (1969) suggest that such liminal experiences may foster a sense of communitas, or shared connection, among those undergoing similar transitions. In contrast, when menopause lacks social acknowledgment, this may contribute to experiences of stigmatization, stagnation, isolation, or uncertainty (de Salis et al., 2018). In the cases of Kim and Nadine, a lack of dialogue about menopause limited their opportunity to explore both clinical solutions and social processes that might foster a sense of solidarity and help frame their experiences as a transitional journey.

Narrative Thread: Questioning of Self

Kim and Nadine's narratives were fraught with healthcare seeking experiences that included discrimination, tension, unease, and uncertainty. Although their experiences of

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menopause differed significantly, both women expressed self-doubt as they navigated changes in their health, often questioning their own clarity, reasoning, and decision-making. Their narratives revealed repeated encounters that not only shook their confidence in the healthcare system but also, at times, in themselves.

While Nadine had a definitive diagnosis of menopause, her questioning of self was most pronounced in the stories leading up to this diagnosis, often surfacing in overt ways—such as wondering, *am I crazy*? This theme also emerged more subtly, as illustrated in a story about her efforts to cure recurrent UTIs. Nadine questioned whether her inability to improve was a reflection of her own mindset: *maybe if I'm positive... maybe because I'm negative, it's not working.* After considerable emotional and physical turmoil, Nadine was eventually able to address some of her biological symptoms after a diagnosis of menopause and initiating menopause hormone therapy. Reflecting on Nadine's narrative, I began to see how menopause could serve as a way for making sense of both diagnosed and undiagnosed symptoms, as well as more intangible experiences related to aging and shifting self-identity. Throughout our conversations, Nadine repeatedly questioned whether menopause might be contributing to new changes she was experiencing in her health. When she used her "murder metaphor"—to describe comfort in identifying a killer—I began to theorize that being able to name menopause as a possible culprit offered some relief amid uncertainty. By positioning menopause as a suspect, the more damaging internal narratives—*I'm crazy* or *I'm not resilient enough*—seemed to lose foothold.

In Kim's case, the absence of sociocultural and medical discourses on menopause may have contributed to her confusion about her persistence of symptoms. As Kim recalled her

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difficulty with appetite during her years of depression, she remembers the frustration that accompanied a lack of explanation behind her symptom,

> *about two years in, even the doctor and the therapist, they got frustrated and they both [said] why can't you just eat [...] they can see I'm an intelligent person, the therapy's going well I'm following all of their directions like I'm doing everything [...] I'm frustrated too!*

Instead of wondering why their approach was ineffective or what else may be at play, Kim's providers questioned her – what was it about *her* that made their treatments ineffective? This type of approach is arguably dangerous, as subverts one's sense of autonomy, agency, and confidence. As Kim struggled with her mental health during her menopausal years, she looked inward, searching for some personal inadequacy,

> *I found very perplexing with the PTSD is no matter how hard I tried I couldn't I just couldn't do it, I couldn't get back to where I was and I was less resilient (...) I had really hard time understanding how could I get over breaking my neck and going through a year of rehab and all the pain that involved - managed to do pretty well after about a year (...) yet two years into this PTSD I was still where I started*

Kim questioned her resilience, wondering why this particular time of life was so difficult to move through when compared to her previous responses to traumatic situations. It's possible that these difficulties were in part due to changes that accompany menopause. Without menopause

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being taken into consideration, the efforts towards her mental health and other health issues were not being fully supported and possibly even mismanaged.

In response to Nadine's experiences of UTIs she too looked inward -- surveilling her symptoms, tallying in a spreadsheet, the frequency of infections and antibiotic use. In doing so, Nadine was reifying her symptoms into something concrete to bring forth evidence of the legitimacy of her experience. Experiences of discrimination and medical gaslighting eroded Kim and Nadine's sense of power in their relationships with healthcare providers. Nadine recalled one such incident during a visit to a walk-in clinic for a respiratory infection:

> *I said to him, I have a high-level spinal cord injury, and I don't have the muscles to cough. So I'm hoping to get, um, like a nasal spray to help break up [the mucus]. So it's easier for me to cough. And he looks at me and he goes, you have a high-level spinal cord injury? [sarcasm]. I said, yes, it's T1. And he goes 'as if', and I'm just like, I'm sorry?!*

Encounters like this understandably foster an adversarial stance toward the healthcare system—one where the patient must arrive armed with evidence, as though preparing for a cross-examination.

Kim echoed this sentiment when she described losing trust in her own ability to be taken seriously, prompting her to bring her husband to an appointment, *I finally went back with my husband because I wanted him to vouch for me that this is serious.* Although Kim and Nadine shared the experience of feeling a loss of agency and autonomy, they also had healthcare providers who garnered a feeling of safety and empowerment. Kim's family doctor showed her that it was possible to validate the experience of mental health struggle and grief while also de-

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problematizing the patient and thereby shifting the experience into a more neutral territory of human experience, *she's the only one who took the time to listen to let me cry and we sorted it out it wasn't a big mystery just give me some time.*

Discussion

Kim and Nadine's stories highlight how medical complexity produces or contributes to inequities within a neoliberal landscape of menopause care. In this environment, women are often expected to self-educate and self-advocate amid a constantly changing and sometimes contradictory field of menopause treatment. When healthcare providers opt out of providing menopause education for women with SCI, their silence can send numerous messages, including: that menopause is inconsequential, that the responsibility for navigating this life transition is a personal one, that aging in good health is a luxury for someone else, or that living with a disability renders menopause irrelevant or so complex that it is not worth addressing. When viewing menopause through a lens of disability equity, it is important to note that individuals with the most complex medical histories are likely those who could benefit the most from proactive menopause conversations. The stories of Kim and Nadine revealed a variety of social and political mechanisms that contributed to experiences of inequity and medical mismanagement while navigating aging with SCI.

Inequity

The context of ableism and discrimination was omnipresent in the help seeking stories Kim and Nadine shared. The choice to share stories of personal and structural discrimination in their healthcare experiences shows the potential for narrative inquiry to serve as a political tool (Çalışkan, 2018). Sometimes, the inequity was obvious, for example when Kim was unable to access screening for breast cancer or when Nadine was almost excluded from participating in a

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research study. At other times, the inequity was less visible, but not less significant. Consider for example, the toll taken over the ten years Nadine spent seeking care for her UTIs. Nadine took time away from work, suffered emotionally, experienced physical discomfort, and stress. These experiences foreclosed her opportunity for an improved quality of life during this time. When Kim was required to travel to a specialized clinic for reproductive healthcare because her doctor did not have an accessible bed, continuity of care was interrupted. Furthermore, Kim was not able to choose to stay with a well-known healthcare provider in an area that was geographically more accessible.

Despite the inequities that shaped Kim and Nadine's narratives, both women responded to oppression through acts of resistance—transforming their experiences of discrimination into advocacy. This work brought a sense of empowerment, accomplishment, and a renewed sense of self. Yet, it also raised important questions: Does the time and energy devoted to advocacy come at the expense of other forms of self-expression, self-exploration, or personal growth—be it social, economic, or otherwise? In addition to managing their health concerns, Kim and Nadine's experiences demanded the tedious and bureaucratic process of advocacy for self and others along the way. Here Kim speaks about her difficulty in coping with these demands, *I had so many medical problems back then it just seemed like one after the other after the other I probably even though now that I'm talking to you, I feel tired even talking about it.* Nadine also suffered from healthcare fatigue – often feeling obligated to undergo treatments and examinations that she knew were futile, *you get to a point where you've tried everything and you're like, okay, I'll try it again. And you're doing it to placate them [healthcare providers].* As Kim and Nadine navigated systemic bias in their healthcare experiences, they described alternating between moments of asserting their autonomy and moments of exhaustion and surrender. Their journey reflected the

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ongoing struggle to balance self-advocacy with the emotional and physical toll of seeking care in a fractured and discriminatory system.

Recommendations for Practice

The narrative threads of 'the liminality of menopause and 'questioning of self' are closely connected and offer several considerations of practical significance in shaping future menopause care for women with SCI. Because women with SCI are navigating a discriminatory and inequitable healthcare system, it is particularly important for healthcare providers to have proactive conversations about menopause and treatment options. These conversations should go beyond routine clinical assessment and include open ended questions such as, 'What is important to you as you age?' and 'What do you know about menopause?' This type of opening encourages relationality and provides the opportunity for clinicians to understand the social, biological, and cultural forces shaping the needs of their patients. Clinicians should not assume that because their patient has not brought forth questions of menopause, that this has no impact on health or wellbeing. By stepping in and offering a discussion, education, and resources about menopause, choice and a broadening of autonomy for women with SCI are opened, not only in relation to medical choices, but also social understandings.

Nadine's story of chronic recurring UTI's highlights the need for clinicians to be aware that menopause symptoms can mimic or exacerbate sequelae of SCI. Education, screening, and treatment for genitourinary syndrome of menopause can be implemented by any provider, however women with SCI often have yearly urology appointments which would be a convenient source of specialty care. Similarly, other specialists working with women with SCI should consider if and how their approach to care may be impacted by the role of menopause in this population. Even in the absence of medical treatment, healthcare providers can encourage

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women with SCI who are menopausal to remain engaged in community activities which may buffer negative psychosocial impacts common during this time.

The narratives of Kim and Nadine show that women with SCI may have a relationship with the healthcare system shaped by bias and discrimination. Therefore, it is particularly important to foster an environment of trust by listening to and validating patient experiences. Menopause care for women with SCI must include practices that uphold equity such as providing extra time for appointments to discuss issues primarily related to disability, *and* life stage health concerns such as menopause. Clinicians should not assume that 'specialized services' for women with disabilities are preferred or ideal. Kim's narrative revealed that segregating healthcare services for women with disabilities is not always a preferred or acceptable solution. To reduce the burden of self-advocacy for women with SCI, clinicians should address structural or environmental barriers in healthcare workplaces, striving for universal accessibility.

Study Limitations

While the strengths of narrative inquiry lie in its capacity to attend to temporality, sociality, and place—offering a rich and nuanced understanding of experience, these same features act as limitations; Kim and Nadines narratives are not generalizable to all women with SCI. Both Kim and Nadine identified as white and financially secure, which limits the demographic diversity of this study. In Kim's experience, menopause remained unnamed, an omission that reflects a reality often absent from dominant menopause discourse yet also leaves many aspects of her story unanswered and ultimately unknowable. Additionally, this study did not include the perspectives of healthcare providers, which could have offered valuable insight into the relational dynamics of menopause care for women with SCI and enriched the overall understanding of these interactions.

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Conclusion

Menopause presents distinct medical and social challenges for women with SCI. This narrative inquiry sheds light on the complex interplay between disability, gender, and aging in shaping the menopause experiences of two women with SCI, Kim and Nadine. Their stories revealed how discrimination and silence, framed within a neoliberal healthcare context, contributed to inequity in their menopause experiences. Kim and Nadine's experiences of navigating specialist appointments with multiple healthcare providers raise questions about where menopause care for women with SCI fits in the healthcare landscape. For example, is menopause care for women with SCI specialist care? Who should initiate menopause hormone therapy or menopause related interventions? How can these healthcare providers effectively communicate and share their expertise to develop a coordinated care plan for aging women with SCI?

The narrative threads of 'the liminality of menopause' and 'questioning of self' provide insight into the importance of proactive and affirming menopause conversations for women with SCI. The findings of this study encourage additional investigation into clinicians' perspectives on delivering menopause care for this population.

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Chapter 7: Contemplating the Significance

Narrative inquiry is a relational methodology, providing space to remember and make sense of experience through stories. Narrative inquiry holds strength in its methodological ability to reveal participant narratives (shaped by primary experience) while also exposing sub-narratives, which are shaped organically by *how* participants tell their stories, what stories they choose to tell, and who appears within them. The narratives shaped during my inquiry with Kim and Nadine reflect the contributions of my relational stance, and the benefits of a relational ontology in exposing nuance and multiple truths. My responsibility as a narrative inquirer prompts me to take pause; to consider the personal, practical, and social justifications of the work.

Revisiting my Narrative Beginnings

When I think back to my narrative beginnings, I am reminded of the professional dilemma which motivated me to begin this work: I wanted to provide good care for women with SCI, and a paucity of research prevented me from doing so. My imperative to learn more about this topic was also prompted by conversations with colleagues who have SCI, as they spoke of their frustration in navigating menopause care. While undertaking the narrative inquiry process, my personal justifications strengthened and evolved.

Although I am not yet menopausal, I remember my own experience of navigating shifting hormones after pregnancy. My experiences during this time taught me the importance of societal and cultural narratives that run as undercurrents within our stories. For example, I recall my uncertainty about my identity as a new mother, and how this impacted my relationship with the medical system. Working with Kim and Nadine as a narrative inquirer deepened my understanding of how healthcare inequities grow when providers overlook health promotion or

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fail to plan for life stage transitions. Menopause is just one example. Liminality is also experienced in other life stages such as puberty, parenthood, and while coping with grief or loss. The active engagement of a healthcare provider during these times of potential distress, creates a relational opening and space for conversations to unfold. In my clinical practice, I have a deeper understanding about the importance of approaching patients with curiosities and questions that may open pathways for new understandings. From Kim and Nadines stories, I saw how much harm can happen when healthcare is only reactive. Important needs are missed and people feel unseen. These lessons have changed how I show up in clinical settings and in my personal life too. When supporting friends or family who are having a difficult time physically or emotionally, I am more thoughtful about the context of what transitions may be happening in their lives.

As a new researcher, this narrative inquiry has taught me that being at peace with uncertainty is an effective approach to allowing silenced narratives to arise. As I was developing my research puzzle, I had fears that somehow, my curiosities were unfounded; that I would come up against a metaphorical void with nothing to discover. Yet, over time and in conversations I learned that even in blank spaces there is something to be said, and further questions to be asked. Looking back, being able to embrace this stance allowed me to engage with participants in a less directive and more authentic way. I began to understand that narratives are not always told in words but sometimes come forth in how and why participants tell the stories that they do.

Professionally, I this narrative inquiry experience benefits my perspective as an advanced practice nurse. Delivering quality patient care depends highly upon the context of the lives of those who access it. Coming to know Kim and Nadine through multiple in-depth conversations and having the time to think deeply about their experiences has provided me a nuanced understanding of the value in building patient-provider relationships that extend beyond a

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discussion of biological concerns. Their experiences reminded me of the importance of seeing patients as people first, and not people with SCI. I will continue to approach discussions from a place of curiosity and be more confident in bringing the topic of menopause up in the context of menopause preparedness or health promotion discussions.

As a nurse who has been working in an accessible and inclusive rehabilitation context for many years, Kim and Nadine's stories of barriers to care in other realms of the medical system reminded me that systemic bias remains a significant issue for many patients. As I move forward in my career, their stories will motivate me to use my position of power to call attention to and address environmental, structural, or attitudinal barriers to care alongside them.

Shifting Practice

This narrative inquiry has taught me that menopause preparedness cannot rest with any single clinician and should be enacted through a systemic healthcare approach. In my clinical experience, the lack of SCI specific guidelines has contributed to a general silence and neglect of menopause among healthcare providers working with this population. Those with expertise in SCI often feel uncertain about managing menopause, while those knowledgeable about menopause may lack confidence in addressing the complexities of SCI. Interdisciplinary teams are well positioned to bridge this gap, which should include psychologists or psychiatrists. Interdisciplinary care is necessary to optimize physical function and overall well-being, while also addressing emotional, vocational, and social needs. One potential solution is to collaborate with specialized menopause clinics (such as the complex menopause clinic at BC Women's hospital) to provide targeted workshops for providers like physiatrists, who typically maintain close, long-term relationships with individuals with SCI. This approach could improve physiatrists' ability to recognize how menopause intersects with common secondary conditions

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in SCI, such as urinary tract infections, autonomic dysregulation, and skin integrity issues. Finally, physiatrists could work with primary care providers to discuss menopause treatment options and assess how treatments might impact functional outcomes.

In a research context, I am currently engaged in another research project on menopause and SCI in my professional role as a Registered Nurse. This study aims to learn about the questions people with SCI and healthcare professionals have about perimenopause and menopause to determine priority areas for research, care, and education. Through my work as a narrative inquirer, I have come to understand that while women with SCI may share some overlapping biological factors related to menopause, their needs and preferences are shaped by a wider range of experiences and identities. Although this next research project is not a narrative inquiry, my work with this methodology has provided insight into the importance of remaining attuned to the contextual factors and life stories shaping participants' experience, desires, and needs.

One of the sub narratives that reverberated through Kim and Nadine’s stories, was the connection between health, menopause, aging, and quality of life. While aging is a time of adaptation for many, most women with SCI have already undergone significant adaptation at the time of injury, and many will still be in the process of adapting physically, socially and emotionally to their injury. Without proper support during menopause, a woman's quality of life, not just her health, can suffer. This is especially significant for women with SCI, who already face barriers to healthcare, employment, and leisure activities. Recognizing how menopause impacts quality of life can help drive forward and shape research and clinical care for this population. For example, a woman who relies on her arms for mobility may experience joint pain and stiffness due to declining estrogen levels. In such cases, proactive physiotherapy or other

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evidence-based strategies could help preserve function and support independence during menopause. By anticipating and addressing the health needs of women with SCI as they age, we can better support their independence, participation in leisure and work, and overall quality of life.

Social Significance

Although many of the stories that were called forth in this inquiry centered around healthcare experiences, the wider social implications are made visible through the stories shared. Through Kim and Nadine's narratives, it became clear that equity regarding menopause must be addressed not only in clinical settings but also in everyday interactions within communities.

While the negative impact of menopause symptoms on work life for the general population has been documented (Brotto et al., 2024), Nadine spoke explicitly about the compounded effects as a person with a disability. Unfortunately, Nadine did not feel confident that her employer would accommodate her needs related to menopause and SCI and feared she could lose employment. These experiences speak more broadly about the value placed on productivity and our tolerance to accept and accommodate variations from normative standards. In other words, women with disability are operating in a workforce where health and well-being come second to productivity. An important first step in improving workplace conditions for women experience menopause is awareness and recognition of adverse menopause symptoms among employers. Although symptoms such as hot flashes are most commonly associated with menopause, interestingly, a recent study of midlife working women identified that it was psychological symptoms which most greatly impacted workplace attendance (Faubion et al, 2023). Kim's narrative of persistent mental health symptoms during her years of menopause, combined with her lack of cohesive healthcare, speak to systemic issues of a disconnected form

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of healthcare delivery which further disadvantages those who require multiple specialists. Formulating benefits and sick leave plans that take disability into account by allowing extra time off for medical appointments or symptom management is an important action to address workplace inequity. This type of shift in how we think about equity in the workplace has the potential to benefit not only those with disability or women going through menopause, but also anyone else who encounters health issues during their working life.

In becoming a narrative inquirer, I have learned the significance of remaining attentive to context while undergoing research, calling forth sentiments from the social model of disability, which is rooted in constructionism (Crotty, 1998). For example, when considering the current lack of awareness or clinical attention to menopause and SCI, it is essential to examine the broader factors that contribute to this void. While it might be easy to assume that menopause is a low priority for women with SCI, Kim and Nadine's narratives reveal how systemic bias contributes to a healthcare environment that is often unresponsive or dismissive, requiring women with SCI to engage in a great deal of self-advocacy to have their needs met. When viewing the lack of clinical attention to menopause and SCI in this way, it is clear that there are complex structural and social factors underlying this gap. In storying the experiences of Kim and Nadine, we see how silence can operate as a mechanism of power in healthcare experiences.

Conclusion

This narrative inquiry explored the menopause experiences of two women with SCI, uncovering two closely related narrative threads, 'the liminality of menopause', and 'questioning of self'. Experiences of inequity, which stemmed from discrimination, contributed to a context in which menopause was often a silent actor, resulting in uncertainty and, arguably, unnecessary suffering. Kim and Nadine's stories also uncovered the burden of navigating a neoliberal

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healthcare context which values independence but negatively impacts quality of life. As menopause becomes a topic of increasing prominence in medical and academic discourse, it will be important to ensure that women with SCI and other disabilities are included in these conversations. Healthcare professionals such as nurses and physiatrists, who consistently work alongside women with SCI, are well positioned to advocate for collaborative relationships with menopause specialists. In doing so, steps can be taken to ensure that women with SCI are consistently receiving accurate information, which will thereby enable them to make choices about menopause and aging.

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Appendix A

Guiding Questions

- Can you speak about what menopause means for you?
- How has menopause impacted your experience of having a SCI?
- How has your SCI impacted your menopause experience?
- What are your expectations about menopause and aging?
- How have your relationships with others been affected by your experiences with menopause and SCI?
- How have your relationships impacted your menopause experience?
- What memories do you have about menopause from family, friends, the media, or otherwise?
- How have healthcare providers addressed your concerns and needs related to menopause?
- What support or resources have you found helpful in managing the symptoms of menopause?
- How have your experiences with menopause and SCI impacted your sense of resilience and self-worth?
- How have you coped with any physical, emotional, relational, or psychological challenges of menopause?
- What are your experiences of aging as a woman with a SCI?

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Appendix B

Research Poster

Spinal Cord Injury (SCI) and Menopause

AN EXPLORATION INTO THE MENOPAUSE EXPERIENCES OF WOMEN WITH SCI

A University of Victoria Nursing Research Study

WHAT DO WE KNOW?

- Women with SCI may face barriers in accessing sexual and reproductive care
- Women with SCI have higher risks for some health problems and symptoms that menopause could worsen (ie., osteoporosis, cardiovascular disease, urinary tract infections, skin breakdown).
- Menopause can impact nearly every aspect of health for women with SCI but little research exists

WHAT DO WE WANT TO KNOW?

- How do women with SCI understand their experiences of menopause?
  - How does this intersect with their disability experiences and needs?
  - What does help seeking for their menopause look like and entail?
- What role do health care practitioners and the healthcare system play in shaping and organizing people's experiences and understandings of menopause, and how do these contribute to health inequities?
- Where and how do ableist and normative ideas about bodies and aging come into play in people's menopausal experiences?

WHY DOES THIS MATTER?

- A significant lack of research on the topic has led to a gap in knowledge
- This research can help inform menopause education for healthcare providers and women with SCI
- This research can shed light on future areas of menopause research that are important to women with SCI

HOW DO YOU HELP?

We're looking for participants to join us in this research

We would like to speak to you if you:

- Are a woman with SCI
- Have experiences of menopause
- Are willing to engage in 1-hour conversation over 3 to 5 months, at least 3 times
- Live in the lower mainland of British Columbia

CONTACT

If would like to volunteer to participate, want more information, or have any questions, please contact:

RACHEL NICOLETTI
rnicoletti@uvic.ca
778-834-7224

Participation is voluntary and confidential

Along with refreshments, you will be provided a $25 honorarium for each conversation.

This study was approved by the Research Ethics Board at the University of Victoria on January 8, 2025
The study title is: A Narrative Inquiry into the Menopause Experiences of Women Living with Spinal Cord Injury

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Appendix C

Dorothy J. Kergin Endowment Fund Award 2024 Budget

Item	**Justification**	**Timeline of Expenditures**	**Costs**
amazon gift card	$25 honorarium for each meeting x 9	January-May 2025	$225.00
Supplies	Digital voice recorder (Sony 4GB Digital Voice Recorder with Built-in USB).	January 2025	$73.00
Total Funds Approved			**$298.00**

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Appendix D

Information Letter and Consent Form

Information Letter and Consent Form

Ethics Study Number: 24-0548

Study Title:
A Narrative Inquiry into the Menopause Experiences of Women Living with Spinal Cord Injury.

Research Investigator:
Rachel Nicoletti
3800 Finnerty Rd.
HSD Building Rm A402
University of Victoria
Victoria, British Columbia
Canada V8P 5C2
Email: rnicoletti@uvic.ca
Phone: 778-834-7224

Supervisor:
Dr. Vera Caine
3800 Finnerty Rd.
HSD Building Rm A402
University of Victoria
Victoria, British Columbia
Canada V8P 5C2
Email: vcaine@uvic.ca
Phone: 250-721-6463

Background
You are being invited to participate in a research study/workshop entitled *A Narrative Inquiry into the Menopause Experiences of Women Living with Spinal Cord Injury*. This study is conducted by Rachel Nicoletti and supervised by Dr. Vera Caine from the School of Nursing at the University of Victoria. The results of this study will be used in support of my master's thesis.

Purpose
This study aims to explore the menopause experiences of women with SCI. For example, participants will be invited to discuss how menopause experiences intersect with disability experiences and needs, experiences of help-seeking, the role of the healthcare system in shaping experiences and understandings of menopause, experiences of health inequities, and experiences that may reflect ableist and normative ideas about bodies, aging, and menopause.

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Study Procedures
If you choose to participate in this study, you will be asked to have at least 3-5 audio-recorded conversations with me over a 3 to 5-month period. Each conversation is estimated to take about one hour. The conversations will be unscripted but facilitated with guiding questions inquiring about your understanding and experiences of menopause. We will meet in public places, such as restaurants and cafes, or in places that work best for you. Virtual meetings are also an option. I hope to meet you once every one to two weeks for a total of five to six conversations. The conditions for meeting will be negotiated between us.

As a participant, you are welcome to talk freely about your past and current life experiences. All the conversations will be audio-recorded and transcribed. I will invite you to share your experiences through writing, art, photographs, or any artifacts that may help me better understand your experiences. Artifacts may be described in final research texts, but visual representations will not be included. The focus is on creating reflective spaces that speak to your experiences. All items shared will be returned to you during the conversations.

You are eligible to participate in the study if you:

1. You are a woman with SCI
2. You have experiences of menopause
3. Are English speaking
4. Live within the greater Vancouver area

Benefits
You will be given an opportunity to tell your life stories within a safe relationship with the researcher. You might gain insights into your experiences of menopause. By telling your stories, you may become more aware of your life history, identity, belief/value, and strengths. You may also obtain a clearer understanding of how your life experiences are shaped by various familial, cultural, social, and political backgrounds. However, it is important to note that there might be no direct benefit to you.

Payment or Renumeration
Participation for this study is voluntary; however, I will provide refreshments, and you will receive a $25 honorarium at each conversation.

Risk
As you tell your experiences of menopause, you may encounter memories and feelings which could be distressing or discouraging to you. Also, you may perceive frustrations and limitations which could be stressful to you. It is acceptable to express negative emotions during the conversations, but if it is difficult for you, you are not obliged to tell me everything. You will be given a copy of the conversations guiding questions in advance and may decline to answer any question at any time. In addition, you may choose at any time during any conversation to skip questions that may make you uncomfortable.

You have permission to take breaks from the conversations at any time and meetings may be rescheduled if necessary. I will offer frequent opportunities for debriefing difficult conversations or help you to call someone you trust for support and stay with you until they arrive. If unidentified issues surface during our conversations, I can direct and connect you to appropriate support or resources.

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Voluntary Participation
Participation in this study is voluntary. Should you choose to participate in this study, note that you are under no obligations. Additionally, if you volunteer to be in this study, you will have the opportunity to read through, edit, and withdraw information included in the final narrative account. You may withdraw at any time before you give consent to the final narrative account. You will not be able to withdraw your narrative account after you consent to and finalize the narrative account.

You may also refuse to answer any questions or talk about experiences. You can request to stop the audio-recording at any time. It is important to note that you will not be able to withdraw from this study once you review your narrative account. Narrative accounts will be analyzed for narrative threads that resonate across the accounts. Removing one of the narratives will impact the soundness of the analysis.

Confidentiality & Anonymity
The information obtained in this study will be used in the writing of my master's thesis. It will also include various presentations or research papers. The findings of this research might also be shared to wider audiences through plain language reports, including brochures, or handouts. To avoid any personal identification the use of any names or places will be modified and you will be given a pseudonym. I will encourage you to choose your own pseudonym. You will also be able to remove any information from your narrative account. Before information is disseminated, I will share the narrative account, which reflects your story, with you.

Please note that for a minimum of 5 years after the completion of the study, all the data will be stored securely within the University Systems secure storage that can only be accessed from on-campus and over the internet. No identifying information will be kept on the data. My supervisors and I are the only ones who will have access to the original data. You can ask for a copy of reports or publications on research findings at any time.

Further Information
If you have any further questions regarding this study, please do not hesitate to contact Rachel Nicoletti at 778-834-7224 or rnicoletti@uvic.ca.

The plan for this study has been reviewed for its adherence to ethical guidelines by the Research Ethics Board. If you have any concerns or questions regarding your right as a research participant, you may contact the Human Research Ethics Board at 250-472-4545 or ethics@uvic.ca. Thank you for considering being a part of this research. I very much look forward to working with you.

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Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

_____ _____

Participant's Name (printed) and Signature Date

_____ _____

Name (printed) and Signature of Person Obtaining Consent Date

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Appendix E

Ethics Certificate of Approval

University of Victoria
Office of Research Services | Human Research Ethics Board
Michael Williams Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

Certificate of Approval

PRINCIPAL INVESTIGATOR:	**Vera Caine** (Supervisor)	**ETHICS PROTOCOL NUMBER:** Expedited review - delegated	**24-0548**
PRINCIPAL APPLICANT:	**Rachel Nicoletti** **Master's student**	ORIGINAL APPROVAL DATE:	08-Jan-2025
UVIC DEPARTMENT:	**Nursing NURS**	APPROVED ON:	08-Jan-2025
		APPROVAL EXPIRY DATE:	07-Jan-2026

PROJECT TITLE: **A Narrative Inquiry into the Menopause Experiences of Women Living with Spinal Cord Injury**

RESEARCH TEAM MEMBERS:
Katelin Albert - Supervisory Committee Member, UVic

DECLARED PROJECT FUNDING:
Dorothy Kergin Graduate Award,

DOCUMENTS INCLUDED IN THIS APPROVAL:
Re permission to post flyers.pdf - 18-Nov-2024
Re SCI-BC for recruitment.pdf - 18-Nov-2024
tcps2_core_certificate.pdf - 18-Nov-2024
spinal cord injury and menopause (1).png - 18-Nov-2024
Guiding Questions.docx - 19-Nov-2024
Rachel.Nicoletti.Proposal.2024.pdf - 22-Nov-2024
Jan. 6 Consent.R.Nicoletti.docx - 06-Jan-2025

Conditions of approval

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Amendments
To make changes to the approved research procedure in your study, please submit "Amendments" or "Annual renewal with amendments" form. You must receive research ethics approval before proceeding with your amended protocol.

Renewals
Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures
When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria's policies for research involving human participants.

Dr. Sandra Gibbons
Chair, Human Research Ethics Board

Dr. Cindy Holder
Vice-chair, Human Research Ethics Board

Certificate Issued On: 08-Jan-2025