A Feminist Analysis of Women’s Chronic Pain Experiences in Northwestern Ontario

Jenna Scali
Lakehead University

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Abstract

This feminist research project explores women's experiences with chronic pain in Thunder Bay, Northwestern Ontario. Through an intersectional feminist narrative approach, I examine how chronic pain impacts women's sense of identity and explore their experiences in the health care system. In-depth interviews with eight women between the ages of 18-50, who self-identify as having chronic pain, were conducted to understand their chronic pain narratives. Findings suggest that women's experiences with chronic pain are deeply connected to their identity. Participants' gender, age, body size, ability, and the context of place, significantly influences their chronic pain experiences. Discourses surrounding normative ideals about femininity and bodies shape how participants experience their chronic pain, especially through their relationships, motherhood, employment, education, mobility, autonomy, and mental health. Their identities shift as they grapple with the physical limitations of chronic pain, and their taken-for-granted embodied ways of being in everyday life. Participants also struggle to navigate the health care system in Thunder Bay. They point to a lack of doctors to treat the population of Northwestern Ontario, leading to long wait times and a lack of access to specialized services. Significantly, participants' identities as women created gendered experiences in the medical system, which intersected with age, place, and body size, to cause challenges with being diagnosed and believed by medical professionals. Although they are challenged by structural barriers and biases, participants developed a resistance toward the biomedical system and took their health into their own hands by advocating for themselves and doing their own research to find alternatives for treating their chronic pain.

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Chapter 1: Introduction

Chronic pain takes many forms. In Canada, approximately one in five individuals live with chronic pain (Health Canada 2021). Chronic pain lacks a unified definition and understanding of its disabling effects due in part by the difficulty to define the experience. Chronic pain has been recognized by the World Health Organization (2020) as a disease, defining chronic pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage. Chronic pain is pain that persists or recurs for longer than three months" (p 1).

Gender is significant when discussing chronic pain. Gender is a socially ascribed identity and social practice (West and Zimmerman 1987; Butler 2006) that influences the way health and illness are experienced and understood (Lorber and Moore 2002; Hankivsky 2012; Springer, Stellman and Jordan-Young 2012). Sex and gender are different terms to explain biological and social processes, but both have been theorized as socially constructed categories that constitute masculinity and femininity on a continuum (Davis and Preves 2017; Fausto-Sterling 2000; Phillips 2005), as I will explain further in Chapter Two. For many women, chronic pain is often related to reproductive and autoimmune diseases with chronic conditions such as endometriosis, polycystic ovary syndrome (POS), fibromyalgia, rheumatoid arthritis, and lupus being common causes (Jackson 2021; Westergården, Larsson and Aili 2021). Although the etiology of chronic pain is often unknown, it can have devastating physical, social, and emotional impacts and shape how women understand the self, or their identity (Barker 2005).

In this qualitative research, I examine women's narratives detailing their experiences with chronic pain in Thunder Bay, a city in Northwestern Ontario. I interviewed eight participants between the ages of 18-50 who identified as women over the age of 18 who live with chronic pain. In this thesis, I consider how women's experiences of chronic pain are understood through their everyday experiences including their interactions with the health care system, an institution that holds great authority and power over how women experience chronic pain (Barker 2005). Specifically, I explore how participants' intersectional identities are impacted by discourses related to women's bodies and health as these are constructed through their experiences with the health care system and living with chronic pain.

The project uses intersectionality (Collins & Bilge 2016), and I take a feminist narrative approach. A feminist narrative approach grounds the analysis in women's stories and experiences, as I will discuss in Chapter Three (Fraser and Taylor 2020). Intersectionality is a feminist theory, methodological approach, and as Carbado, Crenshaw and Mays (2013) explain, "a heuristic device" (p. 303) for understanding the intersections of power and oppression within women's lived experiences (Romero 2023; Hesse-Biber 2014; Collins 1990; Collins and Bilge 2016). An intersectional approach requires paying careful attention to how women's identities are structured through gender, race, age, and social class, which are embedded in systems of power that lead to sexism, racism, ableism, and classism, and thus, different experiences (Romero 2018; Collins and Bilge 2016). Biomedicine and health care, as systems of health knowledge concerning individual bodies and the collective body politic, reproduce inequalities connected to gendered intersectional identities (Hankivsky et al. 2007; Barker 2005).

Critical health and feminist disability studies point to the problem that heterosexism and sexism, as systems of gender and sex oppression, are produced in biomedicine and health care (Garland-Thomson 2002; Gomes et al 2019; Merone et al. 2021; Barker 2005; Wendall 1996). For instance, women's experiences within health care can be overlooked because of the power and authority that is invested in the physician-patient relationship (DasGupta and Hurst 2007).

Gendered assumptions about women’s bodies and health inequalities have resulted from deeply biased beliefs that women as a group are unreliable subjects for biomedical research because of regular physiological processes such as menstruation, pregnancy (e.g. fear of harming fertility) and menopause, which led to women being systematically excluded from research (Merone et al. 2021). Moreover, throughout history, patriarchal ideologies have constructed women's illness as an inherent biological weakness (Annandale and Riska 2009; Barker 2005). An ideological mind/body dualism enforces socially constructed ideas that associate men with mind, reason, and culture; and in contrast, women have been associated with the body, irrationality, and emotionality (Bendelow and Williams 1998).

Within biomedicine, these gendered ideologies have enforced patriarchal power over women’s bodies, impacting collective knowledge and dominant discourses about women’s health. Thus, there continues to be a lack of research on women’s health issues, a reinforcement of gender stereotypes in health care, and little consideration of women’s narratives of chronic illness or pain (Merone et al. 2021; Jackson 2021; Barker 2005). This absence of research has led to a gap in our understanding about women’s experiences of the health care system, and as I bring into focus in this project, women’s experiences of chronic pain.

1.1 Women's Health in Canada

In Canada, women have access to a range of health care services through the Canadian Health Act, yet as Carducci et al., (2022) and Hankivsky et al. (2007) explain, multiple inequities continue to exist due to interlocking and intersectional structural identities. For example, Canada's purported universal health care system problematically discriminates against

Indigenous Peoples,[1] and there remains serious gender gaps across the system made more visible by the global pandemic (Carducci et al., 2022). Additionally, many services such as specialized treatments like chiropractic care, physiotherapy, and massage therapy, which are often prescribed for those living with chronic pain, are not covered through provincial universal benefits such as the Ontario Health Insurance Plan (OHIP). Individuals must secure private insurance or have the ability to pay for these services out of pocket (Hankivsky et al. 2007). This creates gaps in an individual's ability to access the specialized health services that they require.

In Canadian health policies, the social determinants of health (SDH) framework is an additive model to explain how social factors impact health, but there is a lack of attention to how these determinants intersect (Hankivsky and Christoffersen 2008). This can essentialize the experiences of women and marginalized groups as social determinants are seen as independent of each other and not in constant interaction (Hankivsky and Christofferson 2008). Hankivisky and Christofferson (2008) emphasize moving beyond SDH towards an intersectional model of understanding health in order to build tools and policies that takes into the account how structural positionalities are interlocking. For instance, one’s health experiences differ based on gender, race, ability, age, body size, where one lives (eg. urban vs. regional city), sexuality, and other factors, which effect access to health services, the type of care received, and socio-economic benefits (Hankivisky and Christofferson 2008; van Amsterdam 2013). Understanding illness experiences, health, and health policies through an intersectional analysis provides insight into the interlocking dynamics of human health experiences, which can advance our knowledge of population health and lead to better health outcomes (Hankivsky and Christoffersen 2008). As

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[1] Indigenous peoples experience structural inequality in accessing and benefiting from Canada’s universal health care system (McCallum and Perry 2008).

this thesis discusses, the concept of intersectionality is necessary for gender-based and health equity research on chronic pain.

1.2 Chronic Pain

Chronic pain has serious impacts on peoples' lives, with increased severity for those who experience structural barriers in everyday life resulting from their social positioning. For example, a loss of income or employment because of the physical impacts of chronic pain or disability will affect a woman's ability to pay for health care services not covered by private insurance (Campbell et al., 2022). In 2019, the Government of Canada created the Pain Task Force to better understand and address the needs of people living with chronic pain. They note that chronic pain has been unrecognized and ignored as a legitimate disease with far-ranging impacts. It has primarily been understood as a symptom of something else and not its own condition (The Canadian Pain Task Force 2019). The Canadian Pain Task Force (2019) adopts the biopsychosocial model of pain, recognizing the biological, psychological, and social dimensions of pain, noting that chronic pain disproportionately impacts those living in poverty, Indigenous Peoples, certain ethnic communities, and women. Chronic pain is also said to be more prevalent in rural and northern areas (The Canadian Pain Task Force 2019).

The Canadian Pain Task Force (2019) explains that chronic pain can severely impact an individual's cognitive and executive functioning, for example, reduced mental processing speed, memory, selective attention, increased fatigue, exhaustion, and sleep problems. Chronic pain causes reduced functioning in daily life and physical and social functioning, this can include school and work absence, decrease in activity, and a decrease in social connections (The Canadian Pain Task Force 2019). Chronic pain affects all aspects of life, and can alter relationships, autonomy, mobility, education, work, mental health, and identity. These considerable impacts can cause a lower quality of life, leading to higher rates of depression, anxiety, and negative emotional processes (Edwards et al. 2016).

1.3 Women and Chronic Pain

Women's experiences of chronic pain are an under-researched topic (Arman et al 2020; Hill and Harrell 2020; Umeda and Kim 2019). Jackson (2021) explains that although women have a higher prevalence of chronic pain, there is a gap in knowledge of women's pain symptoms leading to them being misdiagnosed, mistreated, and dismissed within the health care system. Emerging social research conducted by Schopflocher et al. (2011) explores chronic pain, illustrating how biological, psychological, and social factors all inform experiences of chronic pain. Chronic pain is more prevalent among women than men, where conditions such as "fibromyalgia, irritable bowel syndrome, rheumatoid arthritis, chronic pelvic pain, and migraine headache are disproportionately reported by women" (The Canadian Pain Task Force 2019:9). From the perspective of women, the experience of chronic pain has many effects as it is a "disruption of a person's ongoing life" and identity (Werner, Isaksen and Malterud 2004). Gendered stereotypes are enforced in health behaviours, where men are less likely to seek health care for pain, yet women's pain symptoms are more likely to be overlooked by medical professionals (Samulowitz et al. 2018).

Conditions specific to having a uterus and reproductive health are more likely to be overlooked, under researched, and underdiagnosed (Jackson 2021). Research in Canada on chronic pain lacks a detailed account of the specific chronic pain conditions that women experience (Campbell et al., 2022; Meana, Cho and DesMeules 2004). Chronic pelvic pain conditions such as endometriosis, adenomyosis, vulvodynia and painful bladder syndrome are chronic pain disorders that affect women, yet chronic pain research often leaves out these conditions or does not nuance their vast impacts on women (Hawkey et al. 2022; Meana et al. 2004).

A lot of research on age and chronic pain seems to explore the physical, emotional, and social aspects of pain on older adults (Schopflocher et al. 2011). Yet, women experience higher rates of chronic pain during reproductive years (18-50), and as women get older rates of chronic pain seem to level out with rates of men's chronic pain (Jackson 2021). Age and gender intersect and are important signifiers for conditions such as chronic pelvic pain, endometriosis, and adenomyosis, as symptoms usually develop when menstruation begins (Hawkey et al. 2022). Not a lot is known about young women and pain due to gaps in research, especially on the social and emotional impacts and experiences of chronic pain on young women (Finlay, Lind, and Dela Cruz 2020, Broom et al. 2015; Hill and Harrell 2020).

1.4 Women's Bodies, Pain, and the Self

Sociologists and feminist scholars have explored aspects of self, stigma, and shame in women's chronic pain and chronic illness experiences, finding that their narratives combine individual health behaviours and health and illness discourses reproducing gender and health ideologies (Werner et al. 2004; Charmaz, Harris and Irvine 2019; Barker 2005). Chronic pain and embodiment shape women's identity as they construct the self through interactions with society and cultural ideologies about femininity to inform the pain experience. Emerging social research has shown the significance of studying gendered aspects of pain (Campbell et al., 2022; Arman et al. 2020; Umeda and Kim 2019). Specifically, gender and the socio-cultural context must be considered alongside biopsychosocial factors of chronic pain to capture the complexity of chronic pain (Arman et al. 2020; Strath et al. 2021, Campbell et al., 2022).

Bendelow and Williams (1998) write that aside from the medical aspects of pain, "pain is also very much an everyday experience: one rooted in the lived structures of embodiment and the emotional modes of being and selfhood this involves" (p 199). As illness scholars explain, understanding the social and cultural aspects of chronic pain is imperative as the social conditions and environment shape the experiences of the body and its consequences (Bendelow and Williams 1998; Zajacova et al. 2021; Charmaz et al. 2019). Charmaz et al. (2019) point out that it is the self that mediates the shifting meanings of the body with the onset of a debilitating illness. Moreover, Zajacova et al. (2021) note that,

> micro-, meso-, and macro-level conditions affect risk factors for pain-inducing conditions or injuries and the likelihood of pain becoming chronic; they shape pain's psychological, social, and financial consequences; they influence how pain patients are treated by the health care and social welfare systems and society at large; and, most intimately, they shape intrapersonal perceptions and understandings of pain (p 303).

In Duenas et al. (2016) review of chronic pain literature they identify how an individual's social, professional, and family life is impacted by chronic pain, causing severe consequences for their quality of life. For women, the discourses surrounding femininity, the body, and motherhood, place additional pressures to conform to the normative feminine ideal (Parton et al. 2018; Wendell 1996). When chronic pain is added to that, it constructs difference in how women's bodies are portrayed against the norm, as ability, body size, race, class, and gender, among other social positionalities, intersect to shape women's chronic pain narratives (Barker 2005; van Amsterdam 2013).

1.5 Sociology of Illness and Illness Narratives

Sociologists have studied the social construction of illness which "emphasize[s] the relationship between ideas about illness and the expression, perception, understanding, and response to illness at both the individual and societal level" (Barker 2005:9). Sociologists have focused on biomedicine as a social institution that controls the lives of patients (Conrad 1992; Foucault 1994; Barker 2005). Barker (2005) defines biomedicine as a "medical practice based on the principles, methods, and technologies of the biological life sciences, and it has tremendous cultural authority in matters of illness" (p 10). Biomedicine has such authority over human pathology that if a disease is not represented through a biomedical category, then it does not exist, and it cannot be diagnosed or treated (Barker 2005). Sociologists also maintain that in some cases, medicalization occurs where social human experience become identified as medical where no inherent medical issue exists (Annandale and Riska 2009; Barker 2005). Medicalization puts the diagnosis, treatment, and prescription plan solely in the power of medical professionals to define and control, while limiting the autonomy of the patient and their illness narratives.

Women are particularly subject to medicalization as natural bodily processes (e.g., pregnancy, childbirth, menstruation, and menopause) become the focus of women's health in biomedicine while ignoring other factors of their health (Barker 2005:13; McHugh and Chrisler 2015). Gendered norms around health cause women's bodies to be seen as the 'other' in comparison to the normative male body causing women's illness narratives to be dismissed and discredited within biomedicine. The biomedical system does not have the tools to define or treat the complexity of chronic pain (Barker 2005). The prolonged search for medical meaning of women's symptoms is a frustrating journey as they experience their symptoms as real, but doctors find nothing wrong (Barker 2005). Yet, experiencing one's illness experience through medicalization is important because it gives legitimacy to women's experiences within a system that is characterized by gender inequality (Barker 2005). Medicalization provides women with a diagnosis, and once they have that label, they are able to be seen as credible in relation to their own experience with doctors, and within themselves to affirm years of pain (Barker 2005). It also allows them access to resources and find the care they require based on their diagnosis. Barker (2005) argues that we must focus on illness narratives, alongside biomedical explanations, if we want to understand the experience of suffering and not solely the etiological nature of the disease.

On the individual level, chronic illness and pain have been theorized as a disruption of one's normative and daily life experiences (Charmaz 1991, 1995; Bury 1982). Chronic illness forces one to reconsider their sense of identity and recreate a new self within the confines of their bodies (Bury 1982; Charmaz 1991; Williams 2000; Barker 2005). Bury (1982) theorizes the concept of "biographical disruption" where chronic illness causes a disturbance of everyday activities, a rethinking of the self, and obtaining and engaging with resources (Campbell 2021). Individuals recognize chronic illness as associated with disability, pain, suffering, and even death, which are usually seen as distant possibilities, but become illuminated with chronic illness, causing a disruption of the self (Bury 1982:169). Building on Bury's (1982) biographic disruption, Arthur Frank (1995), theorized a typology of three illness narratives: 1) restitution, 2) chaos, and 3) quest experience stories. First, he describes the restitution narratives as linear whereby someone experiences a change to their health, such as a cancer, and following treatment, the expectation is recovery and a resumption of their previous life, as it was before the illness diagnosis. Second, chaos narratives are what Frank describes as anti-narratives, in that they are unpredictable and there is no resolution. People are often stuck in their experience of illness. Finally, the quest narrative involves self-transformation. There is a recognition that illness has profoundly changed one's life, and one *comes through* the experience noting how they have gained from the experience.

More recently, Williams (2000) has suggested that one's cultural realities impact the experience of biographic disruption, where class, race, gender, and age intersect and cause differing life advantages and structural constraints, therefore shifting the illness experience. Similarly, Barker (2005) points to the experiences of gender, alongside race, class, age, sexuality, ability, and other social positionalities, as important features of women's chronic illness narratives, whereby some women's experiences remain subjugated as they navigate their new identity in a system that is not set up to treat women's illnesses. Exploring intersectional identities that impact how a biographic disruption emerges within the experience of chronic illness or pain remains largely under researched (Williams 2000; Campbell 2021). As Campbell (2021) notes, no research has used an intersectional analysis to study the structural factors impacting a biographic disruption. It is through an intersectional analysis where this study will analyze the nature of biographic disruption through women's intersecting narratives of chronic pain.

1.6 Intersectionality

As mentioned, intersectionality seeks to address and explain how multiple and intersecting systems of oppression and privilege operate through practices and institutions of everyday life (Collins & Bilge 2016; Romero 2018, 2023), including in biomedicine and health care (Hankivsky et al. 2014). Standpoint theory (Smith 1992; Harding 1991) proposes that knowledge should be developed from women's lived experiences, with Black feminist theorists and scholars of colour (Collins 1990; hooks 1990; Crenshaw 1991) arguing that women's experiences are not universal but an effect of interlocking oppressive social structures such as white supremacy and heteronormativity that lead to different experiences depending on an individual's social positionality or social location. Intersectionality therefore considers the social organization of society whereby multiple systems of oppression/privilege and the accompanying axes of power located within social institutions (legal system, health care system for example) reproduces systemic inequalities (Collins 1990; hooks 1990; Crenshaw 1991). There are recent critiques of "whitewashing" intersectionality where research re-centres white experiences and precludes Black and racialized women's experiences (Griffin, Bailey, and Lopez 2022). Research often focuses on the intersections of gender and disability, or gender and sexuality, leaving out considerations of race (Griffin, Bailey, and Lopez 2022). This is especially true in fat studies research, where the body positivity movement is grounded in Black women's resistance toward normative racial and body standards, yet white women's experiences exist at the forefront of the movement (Griffin, Bailey, and Lopez 2022).

When it comes to understanding the intersection of health, illness, and disabilities, biomedical discourses are hegemonic (Barker 2005; Carson 2018). Biomedicine and health care systems are institutions and social structures that enforce systems of power through a Eurocentric, colonial and patriarchal framework that impacts health research, education, and policy (Young et al. 2020). Biomedicine has the power to define health and what is normal versus abnormal while also creating the standards for health behaviour (Barker 2005; Carson 2018). As a result, the health care system perpetuates existing systems of power and oppression such as sexism, racism, ableism, and homophobia. Research using an intersectional perspective has shown the disparities within the health care system that disproportionately impact marginalized people (Etherington 2015; Wiklund et al. 2016; Gattamorta et al. 2020; Naqvi et al. 2020) For example, Etherington (2015) studied racial disparities among women in the United

States and found that Black women did not experience the same degree of health benefits as white women, and highly educated Black women experienced disproportionate health disparities compared to white women with similar education and resources. Additionally, Wiklund et al. (2016) studied patient perceptions in accessing pain rehabilitation where they found that access depended on the power of social factors like gender, ethnicity, social status, and the status of certain diagnosis. Women were regarded as “being less valued and holding a lower status in the health care system than men. Women were regarded as being ‘in need of someone [preferably a man] who brought their case’, whereas men were regarded as having a stronger voice and the power to access more resources and support” (Wiklund et al. 2016:np). Understanding how the health care system perpetuates gendered oppression is an imperative for acknowledging how access to care, treatment, and biases are influenced by intersections of identity.

Intersectionality is also a research approach or “heuristic device” as I will discuss more fully in Chapter Three (Carbado et al. 2013; Romero 2023). Through an intersectional lens, or applying intersectionality heuristically, we can uncover how power operates in biomedicine and the health care system, thus maintaining a system that oppresses and privileges certain groups of people (Hankivsky 2012; Carbado et al. 2013). By using intersectionality in my analysis, I will better understand how chronic pain is a multifaceted experience constructed through socio-cultural and biomedical knowledge and participant’s embodied experiences of chronic pain.

1.7 Research Question

The research questions guiding this project asks: How do women experience chronic pain, and what impact does chronic pain have on one's sense of identity? How do women draw on broader social and cultural discourses about the body and health to interpret their experiences of chronic pain? How are social differences such as race, social class, ethnicity, age, ability, and gender experienced in relation to chronic pain?

1.8 Aim of the Thesis

The aim of this thesis is to explore women experiences of chronic pain in Thunder Bay. In examining how participant's experiences of chronic pain are constructed through everyday life including through their interactions with the health care system, I will better understand how aspects of women's intersectional identities take shape and inform their experiences of health care and biomedical ideologies about bodies, health, and chronic pain.

This thesis will contribute to knowledge about women's experiences of chronic pain, as health research has often ignored women subjugated knowledges and illness narratives (Jackson 2021). It works to understand the normative discourses about femininity and the body and their impact on women's identities. The research will use women's chronic pain narratives to explore potential barriers they face in the health care system in Thunder Bay. Finally, the thesis findings can be used to inform health research on women.

1.9 Framing Myself in the Research

My interest in this research stems from my experiences as a woman who lives with chronic pain, and my interest in the feminist and sociological research on health and illness. My experience with chronic pain started about seven years ago when I was 18. I suddenly had the onset of back problems and after a few years, I had back surgery. I later developed mid-back, neck, and shoulder pain. Although I have been diagnosed with disc bulges and severe degeneration of the spine, physicians minimize my pain explaining to me that it is my body size that is the cause. Since then, I have been managing my pain in many ways by seeing chiropractors, physiotherapists, and massage therapists, and a lot of trial and error to find ways to keep my pain under control. I have had a lot of negative and positive experiences navigating the health care system in Thunder Bay, which resonated with friends and family members who are women. When sharing my own story with other women, many confided their own stories of neglect, dismissal, and ignorance through interactions with health care providers and the health care system. For this reason, I undertook an honours research project on this topic in my undergraduate degree, where I found gaps in health research and in understanding women's experiences of chronic pain from a feminist perspective. Socially locating myself and practicing reflexivity (Hesse-Biber 2014) about my position as a young, white woman with chronic pain, and also a researcher is important, which I discuss more in Chapter Three.

1.10 Plan of the Thesis

In Chapter Two I review the literature on the gendered nature of biomedicine and the health care system and the sociocultural context of women's health and bodies in Western society. I then discuss health care in Canada, with specific focus on Thunder Bay. This is followed by an overview of chronic pain research, paying particular attention to the relationship between gender, age, body size, and identity. Lastly, the literature on women's chronic pain and pain experiences are discussed.

In Chapter Three, I discuss the methodology and methods. The project takes a qualitative intersectional feminist approach, using narrative methodology as I have mentioned. In this chapter, I explain in more detail how intersectionality is used as a research approach and describe narrative research and how I have used both to guide the research process. This is followed by an explanation of my research question, objectives, sampling procedures, data collection, and data analysis. I then explain the importance of reflexivity in feminist research and how it has informed the research. Then, ethical considerations and limitations are explained.

In Chapter Four, I focus on the participant's experiences of chronic pain in relation to their relationships, parenting, intimacy, education, work, autonomy/mobility, mental health, and identity. I explore how women's sense of self shifts based on their social positionalities as they experience biographic disruptions at the onset of chronic pain symptoms.

In Chapter Five, I explore women's experiences in the health care system in Thunder Bay using an intersectional approach. Specifically, I focus on how women's narratives illustrate different barriers in the health care system due to the intersections of place, gender, age, and body size. I share women's predominantly negative experiences in the health care system in trying to access ongoing care and in some cases a diagnosis. I explore how participants resist the biomedical system by going beyond medical interventions, by doing their own research, and finding alternatives strategies to manage pain. Participants share how they value a holistic view to health care and share their positive stories.

Finally, in Chapter Six, I sum up the main arguments of this thesis. I explain how the use of an intersectional narrative approach was most useful for studying the unique experiences of women's chronic pain in Thunder Bay. Additionally, I discuss the significance of using the concept of biographical disruption through a feminist analysis to explore participants changing identities. I explore the main intersections of participants identities, and the tension in seeking out medicalization. Finally, limitations of the study are explained and areas for future research.

Chapter 2: Literature Review

In this chapter I provide an overview of the literature on the gendered nature of health care within a biomedical framing of health, paying particular attention to how gender has been understood and theorized in relation to body size, and age. I review the literature on chronic pain and gender focusing on the intersectional dynamics of gender bias in health care. I explore the intersection between gender and disability and the construction of women's bodies in comparison to the normative standard. I explore how sociologists construct the self in relation to chronic illness and chronic pain. Then, the history of gendered discourses related to women's pain is discussed, including an overview of the empirical literature and research on women's chronic pain experiences. The chapter concludes by exploring the medicalization of fat bodies and how stigma influences the care women receive when seeking health care for chronic pain. First however, I begin by providing some context on health care in the study location, Thunder Bay Ontario.

2.1 Health Care in Thunder Bay, Northwestern Ontario

As stated in the Introduction, the study is set in Thunder Bay, Northwestern Ontario (NWO). NWO covers 460,000 square kilometers of land with a population of 236,000 (Health Quality Ontario 2017). Thunder Bay is the largest populated city in NWO with a population of about 108,000 (Government of Canada 2021) and acts as a service center for the surrounding communities for health care, education, and access to travel services. The social and geographical conditions of NWO and Thunder Bay have created multiple health disparities for its inhabitants. People have a lower life expectancy, are more likely to die young, and report having multiple chronic illnesses (Health Quality Ontario 2017). Individuals have poorer health and worse access to care, which is heightened due to gender and race (Sahai et al. 2000). Many barriers exist for Indigenous Peoples, newcomers, and LGBTQ+ individuals who struggle to access culturally appropriate health care (Lin et al., 2023; Alzghoul et al 2021; Henriquez and Ahmad 2021).

The current health care crisis in Canada, emerging acutely following the global Covid-19 pandemic, has directly impacted Thunder Bay as people experience long wait times in the emergency room, accessing tests and surgeries, and has led to an overall neglect of care (Zimonjic 2023). Thunder Bay and the rural-urban mix of the region sets the city apart from the rest of Ontario because there is a lack of access to specialized health care and public health services compared to larger cities in Southern Ontario (Sahai et al. 2000). For instance, on average, the wait time for a Magnetic Resonance Imaging (MRI) test is 100 days in Thunder Bay, whereas the provincial average for MRI wait time is 73 days (Ontario Health 2023). This is similar to CT scan wait times where the provincial average is 65 days, but patients in Thunder Bay wait 110 days (Ontario Health 2023). For individuals seeking care for chronic pain, the current doctor shortage means that many people wait a long time for referrals if, and when, they are able to access a general practitioner (Zimonjic 2023).

2.1.1 Chronic Pain Resources in Thunder Bay

The Regional Health Sciences Centre and St. Joseph's Care Group operate chronic pain clinics in Thunder Bay (Government of Ontario 2022; Chronic Pain Network 2019). Services are covered under OHIP and require a referral from a doctor or nurse practitioner (Government of Ontario 2022). Through these programs, individuals can access “nerve blocks, pharmacologic therapy and other more novel forms of treatment such as radio-ablation and lidocaine infusions” (TBRHSC 2016:np), and they offer “a patient-focused, interprofessional, time-limited, goal-oriented team approach to address chronic pain via a biopsychosocial model of care” (Shojaei et al. 2022:3). As these programs see people from all over NWO, one of their main challenges is wait times. Currently, from referral date to intervention initiation, the wait time is 101.5 days at St. Joseph's Care Group (Shojaei et al. 2022). Once individuals are in the program, there are wait times to make appointments with clinicians, for example, the wait time to see the dietitian is approximately 10 months (Shojaei et al. 2022).

Additionally, long wait times, transportation issues, and financial costs create large barriers for individuals accessing chronic pain care in NWO. Although not the focus of this thesis, it must be mentioned that another challenge in Thunder Bay is the opioid crisis, and neither program mentioned above is set up to manage opioid use disorder or tapering (Shojaei et al. 2022). Thunder Bay has the highest rates of death in the province related to opioid use (Paas-Lang 2023). This directly relates to chronic pain treatment as mismanaged pain can lead to devasting social results. Shojaei et al (2022) argues that in order to improve the care for individuals, programs must continue expanding staff, extend services, increase virtual appointments for rural communities, and expand research and education, which relies on increased funding from the Ontario government.

2.1.2 Impacts of the Covid-19 Pandemic on Chronic Pain

The Covid-19 pandemic led to major physical, psychological, and socioeconomic impacts around the world, causing an increase to pre-existing social and systemic inequities (Dassieu 2021). For those living with chronic pain, the Covid-19 pandemic proliferated their chronic pain symptoms due to stress, isolation, increased mental health conditions, and reduced the ability to maintain mobility (Health Canada 2021). Additionally, access to necessary health care resources and services were disrupted (Health Canada 2021). Services such as physical therapy, chiropractor, medical appointments, and surgeries or procedures to alleviate pain were unavailable or difficult to access at certain points in the pandemic. Many chronic pain clinics across Canada ceased or significantly reduced their in-person programs and instead offered phone and virtual appointments (Lynch, Williamson, and Banfield 2020). As a result, patients were waiting longer than normal to access care or completely lost care, and experienced an increase in pain, stress, and medication use such as opioids and cannabinoids (Lynch et al. 2020).

2.2 Women and Chronic Pain

As discussed in the Introduction, women are disproportionately represented in rates of chronic pain, yet research on chronic pain often focuses on male subjects (Sorge and Totsch 2017). For example, studies understanding pain mechanisms are still predominantly conducted on men, overlooking the physiological mechanisms of women’s pain or gender/sex differences in pain (Moretti et al 2023; Mogil and Chanda 2005). Within the available literature on chronic pain conditions, such as chronic neck and back pain, men's chronic pain issues tend to be considered the norm, while women's are seen as irregularities (Samulowitz et al. 2018). As a result, women's chronic pain symptoms and conditions can be dismissed as they differ from the norm of male symptoms. Moreover, women with chronic pain frequently report being dismissed by medical professionals within the Canadian health care system, with Campbell et al. (2022) noting a gendered treatment of women’s chronic pain symptoms.

2.3 A Gendered Perspective on Health and Pain

In much of the literature, sex and gender are both understood as determinants of health whereby gender is viewed as a social construct while sex is ascribed to biology (Phillips 2005). However, feminist scholars argue that gender and sex are both socially constructed categories (Davis and Preves 2017; Fausto-Sterling 2000; Phillips 2005). Sex cannot be neatly defined through one’s biology (genitalia, hormone levels, reproductive structures, or brain structures), as there are many variations now widely recognized as intersex that do not fall neatly into the sex binary of male and female (Davis and Preves 2017; Fausto-Sterling 2000). Thus, sex and gender interact with each other to shape an individual’s experiences, including in the production of social meaning about health and illness, and gender can be understood as the “composite of both social and biological health effects” (Phillips 2005:3). Society ascribes meaning to both sex and gender and creates a binary of femininity and masculinity for how individuals understand and perform their gender. For example, due to gender roles women are expected to be the primary support to others by being responsible for the emotional well-being and health of their families at the expense of their own health (Kaufert 2010). The gendered expectations and caring responsibilities are major sources of stress and can be a detriment to a woman’s health (Kaufert 2010). These dominant gendered meanings are used to understand micro and macro-social processes related to health (Hankivsky 2012). Moreover, gender is a dynamic category that intertwines with other social positionalities such as race or social class, leading to varying outcomes of experiences that can marginalize or privilege individuals and groups (Collins & Bilge 2016).

Applying a gendered lens to health allows a perspective where “life conditions, positions in society, and societal expectations about ‘femininity and ‘masculinity’ are considered along with biology in professional encounters and relations as well as when theorizing about women and men” (Risberg, Johansson, and Hamberg 2009: 2). The socio-cultural context of society shapes its norms and ideas about gender, which impacts multiple institutions, such as health and health care. Within the health care system, individuals present themselves through a gendered self, and medical professionals interpret narratives in differing ways for men and women

(Hamberg 2008). Gender bias may then occur based on these normative narratives and how people perform their gender. Gender bias in medicine refers to “an unintended, but systematic neglect of either women or men, stereotyped preconceptions about the health, behaviour, experiences, needs, wishes and so on, of men and women, or neglect of gender issues relevant to the topic of interest” (Hamberg 2008: 237). Hamberg (2008) notes that in a large variety of conditions, such as coronary heart disease, neck pain, and arthritis, men are more extensively treated than women with the same severity of symptoms. This mistreatment is not universal across all women, but varying degrees of discrimination occur based on a women’s race, sexuality, ability, age, and other identity factors, that create barriers and biases within the medical field (Hankivsky and Christoffersen 2008). Thus, gender bias, among other biases relating to intersectional identities is prominent across Western biomedicine and health care.

2.4 Women's health

As discussed briefly in Chapter One, due to the patriarchal nature of the health care system, medical research has been predominantly conducted by male scientists on male bodies, which have then generalized the results onto women's bodies, resulting in a neglect of understanding women’s specific health issues (Merone et al. 2021). Due to the neglect of women’s health, the Western health care system has focused on women's health primarily through the breast and reproductive system, working to pathologize natural bodily processes while ignoring other considerations of women's health (Hankivsky, Morrow, and Varcoe 2007; Wenger 2004). Thus, the masculinized nature of the health care system creates a separation between what women know about their bodies versus what is deemed to be true in modern medicine (Greaves 2015).

Advances in women's health have been achieved due to steady activism that began in the late 1960s. At this time, health was in the hands of government and doctor's and women's health was not a priority for funding and research (Greaves 2015). Women were sharing knowledge about their bodies through consciousness-raising in small groups, and as women's health collectives with the most well known women's health collective publishing "Our Bodies, Ourselves", in Boston in the 1970s. Women shared knowledge about their health in accessible ways and challenged the dominant health care system to improve care for women (Greaves 2015; Boston Women's Health Collective 2011). Women's health movements and feminist health activists were prominent during this time, and advocated for women's control over their own bodies, promoting activism and research that centers women's experiences and connects social position and health (Hankivsky et al. 2007; Parker 2001). In Canada, Health Canada committed funding for women's health research through the Centres of Excellence in Women's Health Program (CEWHP) in 1995, building on the momentum and movement towards gender equality following the United Nations Decade for Women (1975-1985) and the Fourth UN World Conference on Women (1995) (British Columbia Centre of Excellence in Women's Health 1996-2001). This movement furthered women's health sex and gender-based research focusing on the diversity of identities that impact health.

Gender medicine (GM) emerged in 2006 in response to calls to fill the gaps and better understand the impact of gender/sex on health; however, recently, critiques suggest that the focus is primarily on biological sex, which enforces biological differences between the sexes, and fails to understand the effects of gender norms, gender-related behaviors, and gender-related violence on complex subjects such as chronic pain conditions (Shai et al. 2021). Shai et al (2021) contend that approaches to studying gender and health must focus on the interactions between society and biology through feminist methodologies and epistemologies in order to fully understand the complexity of gender on women’s health. This thesis attends to these calls as I focus on the gendered intersectional aspects of chronic pain using feminist narrative research, which I will describe in Chapter Three.

2.4.1 Feminist Critical Disability Studies and Women’s Health

With a critical feminist disability lens, gender and disability cannot be understood without one another (Gomes et al 2019; Garland-Thompson 2005). Illness experiences become gendered due to the oppressive nature of biomedicine to perpetuate inequalities and vulnerabilities that render women’s experiences in health care as precarious (Gomes et al 2019; Garland-Thompson 2005). Feminist disability studies makes visible how identities, particularly the identities of women with disabilities, are shaped by embodiments, as people learn about themselves and the world through their bodies and the construction of their bodies (Ahlvik-Harju 2016). Exploring participants’ narratives through this lens is necessary, as it considers the sociocultural expectations placed on women’s bodies and the normative standards expected of women.

The body is highly regulated and objectified in Western society and this creates pressure for an individual to fit into this normative standard (Ahlvik-Harju 2016). Normative bodies are bound up in the able-bodied, rational, white male subject that shapes each person’s sense of self and restricts those who deviate from the norm by pressuring them to embody the ideal (Ahlvik-Harju 2016). Feminist disability studies point out how appearance and health norms overlap to medicalize certain bodies as women and people with disabilities “have been viewed as medically abnormal, which also means that sickness is gendered feminine” (Ahlvik-Harju 2016:223). Women with disabilities are cast as inferior, lacking, incapable, unfit, and useless, and are stereotypically defined as undesirable, asexual, and unsuitable as parents (Garland-Thompson 2005:1567). This sickness narrative along with biomedicine enforces the idea that impairments are medical crises that require technological interventions, causing us to understand disability and non-normative bodies as something that is wrong with someone rather than simply one's embodiment, life, and relatedness to the world (Garland-Thompson 2005:1568). Therefore, the value of the normative body causes individuals to fear the social disadvantages of having a disability, as well as the pain, illness, limitations, anxiety, and fear of dying (Ahlvik-Harju 2016). This is even more prominent for women as the pressure of upholding the standards of motherhood and domestic duties directly contrast the sociocultural narrative of a person with disabilities, causing further anxieties and stress for women with disabilities to prove themselves (Ahlvik-Harju 2016).

2.5 The Self, Identity and Chronic Pain

As discussed in the Introduction, the onset of a chronic condition has been theorized by Bury (1982) as a "biographical disruption" whereby one's self-identity is disrupted, and the individual is forced to reconstruct the self. As Charmaz et al. (2019) state,

> A biographical disruption rips apart people's taken-for granted assumptions about their bodies, lives and deaths. This disruption separates life before illness or disability and life after its onset. A formerly unnoticed, functioning body now imposes unwelcome limits. Physical independence may be threated and with it, personal autonomy. Biographical disruptions force reappraisal and reconstruction of self and identity (p. 112).

Chronic illness and chronic pain impact on an individual's perception of their life and their relationships with others, as the individual is forced to reconsider the physical limitations imposed by a body that is functioning differently and the social expectations of others in a woman's role as mother, partner, or employee. What previously may have been ordinary activities, such as childcare, selfcare, or household activities are now contingent as chronic illness disrupts taken-for-granted notions of the self as well as daily habits and interactions that previously supported this self (Charmaz 1991, 2002). Multiple meanings become embedded in a woman's experience of chronic illness and how they make sense of themselves through the medical encounter (Werner and Malterud 2003). Charmaz (1991) writes that the meanings of self, identity, and health change with the onset of illness and its progression through time. An individual's control over their illness is then also a struggle to control how they understand their sense of self (Charmaz 1991), which Werner and Malterud (2003) contend occurs through interactions with physicians and the health care system as women seek to become credible patients.

2.6 Gender Bias and Chronic Pain in Biomedicine

Gender bias in medicine has created lasting impacts on the care women receive in the health care system (Jackson 2021). For example, in Samulowitz et al. (2018) theoretical literature review on gender bias in health care, they found that gender bias in pain treatment was prominent, impacting the interventions that doctors give to men and women for their pain. Specifically, "women, compared to men, received less effective pain relief, less pain medication with opioids, and more antidepressants, and got more mental health referrals" (Samulowitz et al. 2018:9). Doctors are more likely to offer women antidepressants and mental health referrals due to the psychologizing of women's pain, and gendered norms about illness. This connection between chronic or unexplained pain and mental illness has a long history first explained as hysteria (Jackson 2021).

Werner et al. (2004) writes that in the 19th century, medical discourses about gender and illness were constructed around notions of hysteria, which "manifested the very horizon of expectation to femininity and the woman: she was seen as (needing to be) sickly, weak, and delicate" (p 1037). The construction of hysteria continues within modern medicine. It has been redefined within diagnoses of post traumatic stress disorder (PTSD), borderline personality disorder, depression, and chronic pain conditions, where women’s specific symptoms are unknown; therefore, doctors assume symptoms are a sign of irrational behaviour rather than a specifiable condition (Jackson 2021). Women's pain seems to be psychologized; thus, when women raise complex pain issues with health professionals, they are problematically labelled through gendered language as 'hysterical,' 'emotional,' and 'difficult' (Jackson 2021; Samulowitz et. al 2018). This leads to women with chronic pain symptoms being diagnosed less, misdiagnosed, and mistreated within the health care system (Merone et al. 2021; Jackson 2021).

Westergården et al. (2021) qualitatively studied women’s experiences with chronic pain finding that they experienced barriers within the health care system as their chronic pain was not taken seriously because their pain was not visible. This caused participants to mistrust medical professionals, feel neglected, and feel alienated from their daily life (Westergården et al. 2021). Their chronic pain challenges impact their ability and autonomy to do daily tasks, their dependence on others, and increased stress levels and loneliness due to pain (Westergården et al. 2021). Similarly, Arman et al. (2020) studied the experiences of women with chronic pain, finding that “when seeking care, the women expressed lack of recognition and feelings of abandonment in their encounter with the health care system.” (p 775). This research highlights how women’s experiences of chronic pain are overlooked in the medical encounter.

A related point concerns reproductive health, as these conditions are predominantly experienced by people with a uterus, or women and thus, become gendered in the medical encounter. Specifically, gendered stereotypes lead women to being viewed as ‘emotional’ and ‘hysterical.’ For example, chronic pelvic pain is prominent among women, including conditions such as endometriosis, adenomyosis, vulvodynia and painful bladder syndrome (Hawkey et al. 2022). In research by Moradi et al. (2014), endometriosis was found to be under-diagnosed, under-reported, and under-researched, taking on average 8.1 years for women to be diagnosed. The delay of diagnosis or lack of diagnosis is a result of health professionals’ limited understanding of women’s health conditions, which as Hawkey et al. (2022) writes, “no explanation for women's pain was seemingly apparent to health care professionals, [and] the materiality of their pain was often completely dismissed as being psychological” (p 490).

Chronic pelvic pain conditions such as endometriosis have long lasting impacts to women's lives and while struggling to be believed by doctors and be diagnosed, they also can struggle with their identity as a woman. Specifically, many of the symptoms impact fertility and sexual intimacy, causing disruptions to gendered discourses about what it means to be a woman such as being a mother, and being a ‘good’ wife (Hawkey et al. 2022). Not surprisingly, Moradi et al. (2014) found that the major impacts of endometriosis on women’s lives were declining self-esteem, mental health issues, limited autonomy, and impacts to relationships, education, work, and life opportunities, all of which implicating women’s identities and beliefs about the self.

Gendered norms about femininity that construct women as over-reacting, dramatic, and attention-seeking are tightly linked with health (Jackson 2021; Samulowitz et. al 2018). Thus, when women's pain and testimony are more dismissed and ignored by physicians, they become seen as untrustworthy or not credible in relation to their own embodied somatic experience (Werner and Maltrud 2003). This is more prominent for women of colour from diverse cultural backgrounds, Indigenous women, queer women, and fat women who face intersections within their identity that create unique experiences of oppression (Hankivsky 2012). Body size is a major factor for being believed in health care settings, especially with women who have chronic pain. The intersection of gender and body size has caused fat women to experience higher rates of weight stigma and stigma associated with their chronic pain symptoms (Mensinger, Tylka, and Calamari 2018).

2.7 Body Size, Gender, and Health

Women's bodies have been regulated and policed for any divergence from the norm, with body size being a central preoccupation (Taylor and Hoskin 2023). Body size is often regarded as a signifier of health, where healthy is assumed to equate to white, thin, heteronormative bodies while fatness is viewed as unhealthy (Parker 2020). Although health is deeply connected to our cultural ideas about body size, the social meanings and cultural ideas are always shifting, highlighting how the social meanings about body size are socially constructed (LeBesco 2004; Farrell 2011). Farrell (2023) argues that gender and fatness co-constitute each other in their degeneracy, as bodies represent status, identity, and power, and women's bodies have been marked as partial, or a "second" sex in comparison to men's bodies. Moreover, the fat body in western society does not represent personhood as it is seen as degenerate (Farrell 2023). Thus, body size and gender become signifiers of one another, and fat bodies are dehumanized or considered not fully human (Farrell 2023).

Fat stigma and fat shame are linked historically with the construction of racialization and gendering (Farrell 2023). Strings (2019) traces the sociocultural and political factors that connect racism and the body where fatness is marked as "savagery" and thinness as "beauty." These contemporary markers of body size have shifted drastically since the sixteenth century, where fat bodies were seen as more desirable (Strings 2019). However, in the seventeenth century, ideas begin to change with the “philosopher’s slim ideal” and fat bodies begin to be seen as a sign of poor morality (Strings 2019:9). Strings (2019) explains that in the eighteenth and nineteenth centuries, body size became connected with race, morality, and national identity, and contributed to the sociocultural debates on the superiority or inferiority of some groups over others. This anti-Black and anti-fat rhetoric continues in present day as whiteness and thinness is viewed as a sign of national identity, while fatness, especially among Black women, is viewed as the major threat to public health (LeBesco 2004; Strings 2019).

Taylor and Hoskin write that both “fatness and femininity are constructed as soft, weak (morally and physically), and as the inferior “Other” to muscularity, strength, and masculinity” (p 74-75). This binary illustrates the relationship between patient and doctor, where when women raise complex symptoms, they are often reduced to their body size as the source of their health problems (Sedney et al. 2023). This is due to the power asymmetry rooted in medical practices and the patient/doctor interaction (Pilnick and Dingwall 2011). Doctors become the knowledge producers of women’s experiences, where a “higher social value is attributed to biomedical knowledge compared to patients’ embodied, experiential perspectives” (Kost and Jamie 2022:321). As a result, knowledge about women’s health and bodies are not produced in the context of women’s lived experiences, but through the perspective of the rational, educated doctor, leaving out major gaps in understanding women’s health. This leads to pathologizing women’s body size because of the stereotypes about fatness, and the lack of value placed on women’s experiences, therefore making it easier to blame symptoms on body size rather than an actual medical problem (Sedney et al. 2023; Mensinger et al. 2018).

In the second half of the twentieth century, the Body Mass Index (BMI) scale was used extensively as a medical model to measure “obesity”,[2] and was instrumental in constructing ideas about what constitutes “healthy” versus “unhealthy” weights (Saguy and Riley 2005; Saguy 2013; Burgard 2009). The BMI is continued to be used to label some bodies are normal and others as abnormal or problematic and needing medical care (McPhail, Lind, and Mazur 2023). This measure of obesity creates an easy way to medicalize fatness, where no medical problems may exist (Bacon and Aphramor 2911; Burgard 2009; Campos 2004).

As mentioned in the Introduction, medicalization occurs where medical processes are used to diagnose or treat nonmedical problems. By defining fatness as “obesity” and as a disease, health care professionals and medical professionals become specialists in handling and controlling the lives of fat people, and seek to define, treat, and fix fatness (Friedman, Rice and Rinaldi 2019; McPhail et al. 2023). Medicalization causes fatness to become labelled as “overweight” or “obese” using standard measurements; therefore, “to be obese, then, is to be labelled with a health condition based on body size alone” (McPhail et al. 2023:211). For example, medical professionals may advise patients to pursue weight loss, and offer weight loss medications, rather than a clinical treatment plan to address the issue of concern (McPhail et al. 2023). Fat stigma then becomes embedded within the medicalization of fat bodies as they become defined as inherently problematic, lacking self-control, and apathetic towards health (McPhail et al. 2023; Kost and Jamie 2022).

While BMI is upheld as the standard of measurement for health and body size, Burgard (2009) notes that 91% of factors impacting health outcomes have nothing to do with BMI. Measures of “obesity” create the assumption that being fat automatically means one is unhealthy,

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[2] “Obesity” is placed in quotation marks to recognize that it is a contested concept (Campos 2004).

and that individuals must lose weight in order to improve their health without acknowledging life circumstances, environmental factors, social identities, and other health conditions (Burgard 2009; Campos 2004).

Medical fat bias and weight stigma develops within the health care system as stereotypes about fat people seep into the way that individuals are treated, especially women and marginalized people, where intersections of their identities, such as gender, body size, race, ability, and socioeconomic status, create further discrimination (Kost and Jamie 2022). Research suggests that being fat has an impact on the quality of care received in the health care system (Balkhi, Parent, and Mayor 2013; Chrisler and Barney 2017) and highlights the unique barriers in health care based on body size and gender (Ioannoni 2020; Lee 2020; McPhail et al. 2016), where fat women are "less likely to receive cervical cancer screening, breast cancer screening, and colorectal cancer screening than non fat ciswomen" (Lee and Pausé 2016:2).

Additionally, ideas about normative bodies seeps into the delivery of reproductive care where anti-fat bias controls how individuals access reproductive technologies and birth control, and in how pregnancies are managed (McPhail et al. 2023). Through interviews with 59 fat women in Canada, McPhail et al. (2023) found that participants were discouraged from reproducing and having children by their doctors. They note that the main way this was achieved was through health moralism, where fatness has become associated with "bad" citizenship and fat individuals are shamed if they reproduce because of the serious risk to their health and the life of the foetus (McPhail et al. 2023). This perpetuates the "bad mother" and "good mother" stereotypes where being fat is viewed in terms of being a bad mother because the welfare of the foetus should be above that of their own selves (McPhail et al. 2023).

The intersection of fatness and chronic illness remains significant as doctors focus on medicalizing body size while dismissing women's chronic illness and chronic pain symptoms. Fatness is often used as a predictor for chronic illness without considering other factors, such as stress, genetics, discrimination, social positionality, and poverty, therefore, perpetuating weight biases. For fat women with chronic illnesses, they are blamed for their pain and suffering because of their body size, where any medical interventions to 'manage' their pain include exercising and losing weight, especially for women where dieting and weight-loss pills are more commonly prescribed (Chrisler and Barney 2017; Schlauderaff 2020). Chronic illness and pain symptoms become ignored as women seek diagnoses and pain management, causing further health disparities for fat women (Kost and Jamie 2023; Chrisler and Barney 2017).

2.8 Chapter Summary

This chapter has explored the literature on the gendered nature of the health care system and the connection between gender, body size, ability, and age and follow the advancements made in women's health due to activism. I explored the normative standard imposed on women that enforce sociocultural ideas about bodies, health, and ability. Following that, I explored how chronic pain drastically alters one's identity as it impacts their taken-for-granted notions of daily life and what they know to be true based on their life before pain (Charmaz 1991; 2002). Then, I explained gender bias in the health care system, noting that women's experiences in the medical system have been disrupted due to gender bias, where women frequently report being dismissed by medical professionals (Campbell et al. 2022). Lastly, gender and body size are connected as fat stigma is prominent for many women's experiences as healthism is upheld within the biomedical system (Crawford 1980; Mensinger et al. 2018). This is especially true for women accessing health care services with chronic pain symptoms, as they experience both pain stigma and weight stigma (Sedney et al. 2023). In the following chapter, I will explain my research methods and methodology through an intersectional narrative approach.

Chapter 3: Methodology and Methods

In this chapter, I discuss my qualitative methodology, research design, and methods. First, I describe narrative feminist intersectional methodology. This is followed with a description of the research design, sampling, and methods. Specifically, I discuss the research sample, and how I purposively sampled participants who self-identified as women living with chronic pain. As I will explain, the method of in-depth semi-structured interviews fit with my goal of wanting to hear the narratives or stories detailing their experiences with chronic pain and the health care system. This is followed by an explanation of how I analyzed the data, which includes employing intersectionality as a heuristic device (Carbado et al. 2013) to make sense of the complexity of women's experiences as they relate to their understanding of the self and identity. Lastly, I explain the importance of feminist reflexivity to frame my research project, finishing with a discussion of ethics and ethical consideration.

3.1 Methodology

Qualitative research is an interpretive methodology that works to make sense of the meanings individuals and groups have in the world (Cresswell and Poth 2016). The methodology guiding this research is narrative feminist intersectional approach (Fraser and Taylor 2020; Fraser and MacDougall 2017; Reinharz 1992). Feminist intersectional research supports social justice and social transformation to explore women's diverse situations and the institutions that frame and impact those situations (Hesse-Biber 2014; Romano 2023). Gender is socially constructed and is seen as an organizing principle that shapes the conditions of an individual's life and becomes the starting point for feminist researchers to pose their questions (Cresswell and Poth 2016). In this feminist intersectional research, the project works toward advancing social justice issues by giving my participants a place to share their subjugated experiences of chronic pain and the health care system.

3.1.1 Narrative Research

Narrative research is the most appropriate approach for this research, as it explores women's individual experiences with chronic pain. Creswell and Poth (2016) explain that a narrative approach is best suited for research that explores the life of an individual and the stories of their experiences. Narrative research collects stories from individuals and explores the social, cultural, linguistic, and institutional narratives that accompany and shape an individual's experiences (Creswell and Poth 2016). Stories are thus embedded within the participant's personal experiences, culture, and sociohistorical contexts (2016). Through exploring the stories of a small group of individuals, researchers can gain rich and detailed descriptions of their lived experiences and work collaboratively to tell their stories. Creswell and Poth (2016) write that "in narrative research, a key theme has been the turn toward the relationship between the researcher and the researched in which both parties will learn and change in the encounter. In this process, the parties negotiate the meaning of stories, adding a validation check to the analysis" (p 72). Working from the stories of participants and asking their interpretations of their experiences allows a more accurate portrayal of their stories by negotiating the meanings they provide.

Potential challenges arise in narrative feminist research through issues of power relations (Hesse-Biber 2014). As a researcher who analyzes and tells other people's stories, there are important questions to consider, such as who owns the story? Who can tell it? And who can change it? (Cresswell and Poth 2016). Within this research project, I identify as an insider in the community I am studying as a woman with chronic pain (Hesse-Biber 2014). This can mitigate power relations in telling others' stories because I may share similar experiences and insider knowledge. Additionally, working from participants' experiences will help in mitigating power relations as they will be able to assess the accuracy of their stories which "often leads to more politicized data given participants are able to talk freely about issues that affect them, and researchers are likely to analyze their responses in terms of the power dynamics they represent" (Fraser and Taylor 2020:6). Using a narrative approach, the analysis is grounded in women's experiential knowledge, as I have centred their voices, allowing for a deeper understanding of their day-to-day experiences of chronic pain. Providing an opportunity for women with chronic pain to be heard and fairly represented is a crucial social justice issue, important for intersectional and feminist narrative research, as women are often misdiagnosed, dismissed, or ignored by medical professionals.

3.1.2 Intersectional Research

A feminist intersectional methodology will enable me to deepen my understanding of the unique experiences of women with chronic pain. A key method of feminist intersectional research is reflexivity and interrogating how one's social location and domains of power interact to shape the research experience (Romero 2023; Hankivsky 2012). Intersectional feminist research explores the complexity of women's lives and creates knowledge situated in their experiences. Hillsburg (2013:7-9) outlines three axioms for researchers to follow when using an intersectional methodology. Firstly, researchers must not police the parameters of intersecting identities. Instead, researchers must allow participants to locate their own subject position by asking intersectional questions where participants self-identify as intersectional and have space to discuss the most important aspects of their identity.

In my project, I sent participants a demographic questionnaire before the interview, so they could self-identify their gender, age, race/ethnicity, and their chronic pain diagnosis (if they had one or not). During interviews, I also asked questions that would allow participants to identify aspects of their own experiences that they find important, for example, asking "Have you experienced any obstacles or barriers in the care you received within the health care system?" This allowed participants to disclose their identity without me asking them specifically about it in order for them to choose their story. Second, researchers must acknowledge that identity categories are fluid and fluctuating entities wherein "discursive categories and subject positions are made historically specific, and, while each meaning is linked to other understandings of a discursive location, these meanings and subjectivities are not fixed, nor are they necessarily consistent" (Hillsburg 2013:8). Lastly, an intersectional methodology notes that researchers must not violate the vulnerability of others. Rather than assessing the most oppressed identity and starting research from those assumptions, researchers must acknowledge that each individual is vulnerable and is located within the interlocking network of oppressions. Using intersectionality as a methodology and analytically, as a heuristic device, allowed me to study women's experiences through the stories that they share and make sense of the data through their perspectives (Carbado et al. 2013).

Adopting an intersectional approach within health research means that "aspects of social status (e.g., gender, race, socioeconomic status, and sexuality) are understood to affect health outcomes in complex, multiplicative ways that can never properly be captured by attempts to parcel out the individual contributions of single social domain" (Springer et al. 2012:1818). Multiple factors are always at play in shaping an individual's identity and health experiences; thus, women's health cannot be homogenized and must be studied through intersectionality. Using intersectionality provides a framework to understand and conceptualize the role of power in health inequities and the influences of the biomedical system on women's health experiences

(Macgregor et al. 2023). Therefore, an intersectional, feminist narrative approach is best suited for this project as it seeks to create knowledge about women's chronic pain grounded in women's unique lived experiences. Through this approach, the research explored women's narratives of chronic pain and experiences within the health care system in NWO.

3.2 Research Questions and Objectives

The literature about women's health and chronic pain emphasizes a need for research rooted in women's experiences and the socio-cultural contexts that impact these experiences. To explore this type of research I have developed several key research questions that will help to uncover the diverse lived experiences of women with chronic pain.

My research questions ask:

1) How do women experience chronic pain, and what impact does chronic pain have on one's sense of identity?

2) How do women draw on broader social and cultural discourses about the body and health to interpret their experiences of chronic pain?

3) How are social differences such as race, social class, ethnicity, age, ability, and gender experienced in relation to chronic pain?

Multiple objectives guide this research project. Firstly, a primary objective is to understand the experiences of women with chronic pain and how it is impacted by broader socio-cultural discourses created about women's bodies. Second, I aim to understand how women make sense of their chronic pain and how it affects their sense of self. Third, to generate knowledge about women’s health care experiences that stem from their actual lived stories. Fourth, to contribute to the scarce literature about the social impacts related to women and chronic pain, especially within NWO. Lastly, a goal of this research is to empower women through the process of telling their stories and having their voices are heard.

3.3 Recruitment and Sampling

Recruitment of participants began in September of 2022. Before recruiting participants, I first obtained ethics approval from the Lakehead University Research Ethics Board. In terms of sample size, Creswell and Poth (2016) recommend that “narrative research is best for capturing the detailed stories or life experiences of a single individual or the lives of a small number of individuals” (p 71). Feminist qualitative research also emphasizes a small sample size to look at the social meanings individuals give to their experiences and social context, therefore, the purpose of the research is to understand how women experience chronic pain (Hesse-Biber 2014). For this project, I interviewed eight women. I used non-probability sampling strategies through purposive sampling to recruit participants. Non-probability sampling allowed me to select a sample based on the population of interest rather than randomly selecting (Hesse-Biber 2014). Purposive sampling was used to define a specific demographic of individuals based on criteria in order to gain the most appropriate and useful information (Campbell et al. 2020).

I sought out individuals who met the sampling criteria, which included: identifying as a woman between the ages of 18-50 who has chronic pain. Given that the onset of chronic pain seems to occur during women’s reproductive years, where women experience higher rates of chronic pain than men, the age range of 18-50 is appropriate (Jackson 2021). To do this, I created a poster targeting women, between the ages of 18-50, who live in Thunder Bay, and experience chronic pain (See Appendix A). Originally, I wanted to post posters online through social media outlets, as well as post them around campus, in health centers, and women's centers. However, upon uploading my poster online to Instagram and Facebook, where it was shared by over 25 others, I immediately received fifteen emails expressing interest within a few days. I also shared the poster with my massage therapist and chiropractor who sent it to individuals they thought would fit the criteria. I followed up with participants who emailed by sending them an information letter (See Appendix B) and interested participants were then sent a consent form (See Appendix C) and demographic questionnaire (See Appendix D). The demographic questionnaire was used to gain an understanding of the overall sample.

After sending participants the forms, eight participants sent me their signed consent form and demographic questionnaire, at which point, we then were able to set up either a Zoom or in-person interview. Participants were able to choose whether they would like the interview on Zoom or in-person, and if they chose in-person, they also were asked where they would like to do the interview. It was important that participants were able to choose the context and environment of the interview as I wanted them to have autonomy in the research process and be as comfortable as possible. Two interviews were conducted on Zoom and six were in-person. All interviews took place in Thunder Bay, with participants who considered the city as their home community.

All participants identified as women. Four were in their 20s, three in their 30s, and one was 50. Seven participants identified as white, and one participant as white and Metis. Five participants identified as heterosexual, one as lesbian, and two as bisexual. This demographic information is important as it provided a diverse sample of narratives through which to explore experiences of chronic pain. Understanding the diversity of participants also helps to point out the gaps or differences between and among experiences. In this research, a more racially diverse sample would have provided further in-depth insights into women’s chronic pain experiences. Especially with an intersectional approach that is grounded in Black and Indigenous feminist thought, I should have made more of an effort to recruit more women of colour. Given the large population of Indigenous women, I could have worked with Indigenous health centres to recruit participants, such as the Aboriginal Health Access Centre.

3.3.1 Participant Demographics

Pseudonym	Self-Identified Gender	Age	Self- Identified Race/Ethnicity	Sexual Orientation	Medical Condition	Time lived with chronic pain	Work Status
1 Violet	Woman	24	White-European	Heterosexual	Undiagnosed but probable endometriosis. Chronic neck and back pain	8 years	Full time work and a student
2 Sarah	Woman	30	White	Heterosexual	Chronic sciatic nerve pain	10 years	Full time work between two jobs
3 Paulina	Woman	26	White (Irish, English)	Lesbian	Adenomyosis	10 years	Full time
4 Mia	Woman	50	White	Bisexual	Mystery illness- never diagnosed. Doctor proposes fibromyalgia	14 years	Part time
5 Charlotte	Woman	21	White	Bisexual	Occipital neuralgia	7 years	Full time student
6 Leah	Woman	37	English, Scottish, Finnish, and Metis	Heterosexual	Chronic back pain, sciatica and numbness from herniated discs during pregnancy Adenomyosis	9 years	Full time
7 Hazel	Woman	30	White	Heterosexual	Chronic lower back pain and chronic right shoulder pain	back pain- 15 years, shoulder pain- 10 years	On maternity leave but works full time
8 Shay	Woman	24	White	Heterosexual	Relapsing and Remitting Multiple Sclerosis (RRMS or just MS for the general term). migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in my lumbar spine.	10 years	Full time

3.4 Methods and Data Collection

In-depth, semi-structured interviews, with open-ended questions were used to collect data between September 2022 to November 2022. With a feminist approach, in-depth interviews explore issues concerning women’s lives and give voice to those who are marginalized with the goal of uncovering experiences that are often hidden (Hesse-Biber 2014). In-depth interviews are chosen for this project as the method "seeks to understand the 'lived experiences of the individual ... [as] We are interested in getting at the 'subjective' understanding an individual brings to a given situation or a set of circumstances" (Hesse-Biber 2014:189). This approach allows researchers to uncover the subjugated knowledge of an individual or group of people. It was important for me to be able to develop an understanding of the lived experiences of my participants as women with chronic pain from their own perspectives because women with chronic pain are often dismissed and ignored in the health care system (Jackson 2021). Therefore, data collection of the stories and experiences of my participants grounds my research in their experiences.

The goal of semi-structured interviews is to have a specific agenda in mind but allow the participant to guide the interview, going where they want to go but keeping the main topic in mind (Hesse-Biber 2014). This is ideal for the narrative approach as it gives the participant control over how they want to tell their story freely, not only through their words but also through their emotions expressed and those felt by the researcher during the interview (Fraser and Taylor 2020). Using open-ended questions gave the participants freedom in choosing how to answer the questions and create a conversational environment. Within narrative research, "researchers are accustomed to opening up the interview with a broad question and following the lead of responses, often moving in circular motions, with one story leading to another (Fraser and Taylor 2020:11). I had a list of general questions that I brought for each interview (See Appendix E). My first question asked, "what is your experience of chronic pain?" which allowed participants to begin telling their story how they would like and share as much as they would like. Semi-structured interviews allowed me some control in the sequence of questions asked and focused the content of each question; however, new questions emerged based on participants' answers and the emerging themes across their stories (Hesse-Biber 2014). The interviews were conversational as I shared parts of my experiences that connected with theirs, which helped to open them up to sharing more experiences.

In-person interviews were recorded on the memos app on my phone, and interviews through Zoom were recorded through the software. They began with me going over the information letter (see Appendix B) and explaining the informed consent (see Appendix C). I then shared my story of chronic pain with them to add to the context of the study so that they understand how I came to research the topic. Feminist narrative research emphasizes a critical but also compassionate and non-judgemental interview approach as “such care is required because it is through our relations with others that identities are formed and reformed” (Fraser and Taylor 2020:9). Building rapport with participants is a crucial strategy for narrative research, especially with potentially emotional topics; therefore, by being compassionate, open, honest, and trustworthy, I worked to demonstrate that I care about and want to listen to their stories. Additionally, disclosing my identity as a woman with chronic pain and giving them insights into my story helped to enable trust and a relationship to be built. Many of the women nodded their heads or said “yes” while I was sharing aspects of my story because they resonated with or experienced similar things to me. Several participants also connected to my story while sharing their own by saying “I also experienced that…" or “it was similar to what you described…” The interview space provided participants with an opportunity to connect with me, the interviewer, who is also another woman living with chronic pain. This opportunity enabled participants to share experiences in the health care system.

At the end of each interview, participants were given a page of resources to local mental health centres, chronic pain resources, and appropriate women's centres (See Appendix F), if they felt they needed to access support following our conversation. Many participants had already known about a lot of the resources available for chronic pain and mental health, however, a couple of participants explained they found new resources from the list. None of the participants explained needing mental health support after the interviews, but they found the list helpful for future reference.

3.5 Data Analysis

As soon as the interviews were conducted, participants were given pseudonyms to increase confidentiality. Interviews were transcribed verbatim during the interview process if conducted by Zoom, and soon afterward if they were done in-person. Although the Zoom interviews were automatically transcribed, I had to go through them again to ensure accuracy. After transcribing the interviews, the voice memos and Zoom files were deleted. The transcribed interviews are stored in a shared folder that only my supervisor and I have access to. Once transcription was completed, each participant was emailed a document of their interview to read over and let me know of anything they would like taken out, added, or changed to their document. Most participants got back to me with two wanting changes, one for taking out her saying "like" so much, and another for taking out information about her workplace. In feminist narrative research, portraying participants' stories as accurately and genuinely as possible is essential; therefore, giving participants the option to review their interview transcript enables collaboration, increasing trustworthiness of the data (Hesse-Biber 2014).

Data analysis was done using the software NVivo. In narrative research, data analysis allows me to situate participants stories within their personal experiences, such as their jobs, education, relationships; within their cultural identity; and within historical contexts such as the time and place of their experiences (Cresswell and Poth 2016). With careful consideration of the context of each participant's experiences, I began data analysis through coding in the software NVivo. NVivo is an ideal software for coding because it offers an easy way to analyze and identify patterns within the data. I uploaded the eight interview document files to Nvivo to analyze.

I began with open coding which is the first step of analysis where themes and actions are categorized within the data by labelling them with codes without any preconceived theories or notions in mind (Charmaz 2014). Coding for themes helped me to understand the context of the women's stories, including the discourses and norms that impact their experiences. Additionally, taking inspiration from constructivist grounded theorists such as Charmaz (2014), coding for actions allowed me to understand the analysis from the participant's point of view by preserving their words and actions when categorizing the data. For example, codes such as "advocating for themselves," "finding supportive relationships," and "getting a diagnosis," are all actions from the participants experiences. Charmaz (2014) writes that initial coding with actions,

> is a heuristic device to bring the researcher into the data, interact with them, and study each fragment of them. This type of coding helps to define implicit meanings and actions, gives researchers directions to explore, spurs making comparisons between data, and suggests emergent links between processes in the data to pursue and check" (p 121).

Moreover, using intersectionality as a heuristic device allowed me to explore the data from multiple participant perspectives while considering their unique sociocultural identities and environments that impacted their health experience (Carbado et al. 2013:303). Coding for both themes and actions helped me to understand the broader processes impacting women's experiences with chronic pain but also their deeper feelings, emotions, and lived stories by staying close to the data from their point of view. This is especially true within narrative research where I want to preserve the stories of women, while also illuminating the similarities and differences of their experiences (Fraser and Taylor 2020).

During this process, I was also writing memos in a notepad about major themes that were emerging and the connections between themes to later reflect on them and develop more focused coding. Memos help trace relationships within the data and how the data fits or does not fit together (Hesse-Biber 2014). Memos also aid in keeping track of the project's progress and allowed me to write my ideas down and make connections within the data (Hesse-Biber 2014).

Once open coding was finished, I started focused coding, which helped me determine which open codes were most prominent and made the most analytical sense with my data (Charmaz 2014). It helped me to create a clear direction with my research by making connections between codes and themes to capture the multitude of experiences that participants faced. Once I had gone through a stage of focused coding and began to categorically group themes together, I started outlining each of my major analytical chapters based on these themes. Then I collected stories and quotes from participants to help narrate the themes and showcase key examples from their experiences.

3.6 Reflexivity

A feminist approach to research emphasizes reflexivity throughout the entire research process. Reflexivity means being aware of one's position as a researcher and understanding the importance of one's values and beliefs within the research (Hesse-Biber 2014). Throughout the research process I reflected on the following questions proposed by Hesse-Biber: (2014:200)

1) How does your own biography affect the research process?

2) What shapes the questions you choose to study and your approach to studying them?

3) How does the specific social, economic, and political context in which you reside affect the research process at all levels?

Acknowledging my position in relation to my research project meant recognizing, examining, and understanding how my social location and assumptions I carry about my own experiences as a woman living with chronic pain impact and intervene in the research process (Hesse-Biber 2014). Participants came from different social locations and backgrounds than me, which impacts how I hear and respond to their experiences. As a researcher, it is my responsibility to be aware of the situational dynamics between me and the participants, which affects the creation of knowledge (Hesse-Biber 2014). Standpoint theory, as described earlier, and the concept of "strong objectivity" (Harding 1998:129) involved my ongoing reflection and self-critique of my position (standpoint) within the research. As Harding (1998) argues, the researcher's biases can never entirely be removed; therefore, amplifying bias and being reflexive throughout the research produces stronger objectivity.

Reflexivity is obtained by acknowledging my social positionality throughout the process. This results in transparency within the project. As a researcher, I recognize my privilege and potential bias and assumptions I bring to the research project. I am also a woman who has chronic pain, with "insider" experiences situated in similar contexts to the women I study. An "insider" in qualitative research refers to the researcher who is a member of the population of study which offers greater access to the knowledge and context of the population than someone who is not a member (Hesse-Biber 2014). I understand I may share similarities in identity with the women I interview, but I am also cognizant that a multitude of social, cultural, and historical factors such as race, ethnicity, sexuality, ability, location, among other social and structural positionalities, shape one's experiences. My lived experience will benefit the research process and allow me greater access and relatability with participants and provide particular insights useful for a feminist qualitative project. Before conducting interviews, I disclosed my identity as a woman with chronic pain to participants and shared a bit about myself and my story to build rapport. This helped participants understand my position in relation to my project and how I came to study this topic. I believe this helped the women I interviewed to feel more comfortable telling me their stories, as they did not have to justify certain experiences or emotions which they might have to do with someone who does not have chronic pain. Samulowitz et al. (2018) found that through their analysis of chronic pain research, "studies that demonstrated objectively measurable gender bias in medical treatment were less extensive and less consistent. Subjectivity in their assessment of pain makes pain experiences and pain treatment sensitive to gender norms" (p 10). Being subjective and reflexive within my research helped to create more profound and richer narrative accounts, while also being critical of my position throughout the research project.

3.7 Ethical Considerations

As mentioned prior, I received approval from the Research Ethics Board (REB) at Lakehead University, protocol #1469405. My research followed the principles of ethical research: respect for persons, concern for welfare, and justice. I used these ethical principles throughout the entire process to ensure the safety of participants. My approach from the beginning of the project was to use a feminist narrative approach which allowed me to build knowledge from the experiences and voices of women participants. Women’s stories were centered in this research, so my analysis focused exclusively on their perspectives and the themes that emerged in their experiences. It is important to me to present women’s stories as accurately as possible and provide a space for women to share aspects of their lives that they may not have been able to share with anyone else. My goal was to always center women and build knowledge in an area where their experiences are subjugated.

The accessibility of the knowledge produced from the project is an essential aspect. Often medical research is inaccessible to the public resulting in a gap in understanding health and illness. Individuals should be able to easily access health information, especially in a region where there is scarce research about the social aspect of women's health. It is important to me to offer free and accessible research to women about their health. Therefore, the research results have been, and will be disseminated in multiple ways. I presented aspects of this research project at the Feminisms at Lakehead conference at Lakehead University in April 2023, and the Canadian Sociological Association conference at York University in June 2023. After finishing this project, I plan to write an article to publish in a scholarly health journal, such as *Sociology of Health and Illness*, and create social media infographics to disseminate knowledge across social media.

Lastly, as a white woman my research process was centred around my beliefs and experiences. Given the racial homogeneity of my participants, the research project is based predominantly in white women's stories, which offers only a small insight into women's chronic pain experiences. With a more vigorous recruitment effort, and a longer timeline, this project could have considered Black, Indigenous, and racialized women's voices through further recruitment strategies to ensure a more diverse sample to better reflect the population living in Thunder Bay.

3.8 Conclusion

In this chapter, I have outlined my methods for my research project. I discussed a feminist intersectional narrative approach which frames the methodology for the research. I have outlined my methods, including the recruitment of participants, data collection, and data analysis. I explained how I employed reflexivity as a researcher and as a woman with chronic pain, and how that plays a role in my research. I described the ethical considerations of the research and potential limitations. What follows in Chapter Four will highlight how I used intersectionality to share my participants stories through their experiences of chronic pain and the impacts to sense of self, how they navigate the health care system in Thunder Bay, and their stories of resistance.

Chapter 4: Narratives of Chronic Pain on Bodies, Identity, and the Self

In this chapter, I explore the illness narratives of participants. Specifically, I focus on how participants experience chronic pain in relation to their everyday lives, including in their relationships, with intimacy, parenting, school, work, homelife, and being active. I demonstrate how women manage the sociocultural expectations of femininity placed on them as gendered bodies, following the onset of chronic pain (Barker 2005; Lorber and Moore 2002). Specifically, chronic pain changes how participants are able to maintain aspects of their prior life including their connection with others, whether in platonic relationships with family, friends or with their romantic relationships or with their levels of mobility. Participants explain how they have had to adjust to different bodily limitations as they experience symptoms of fatigue, pain, and inflammation. Participants also spoke about denying and accepting their diagnoses (or lack of diagnosis) and the mental health challenges that accompanied living with chronic pain. I employ the concept of "biographic disruption" (Bury 1982; Charmaz 1995) as the chronic pain experienced by participants imposes new experiences and feelings towards the self, as the women are forced to navigate new limitations of their physical bodies. As Charmaz (1995) and Barker (2005) explain, assumptions about one's body become shaken with the onset of chronic illness, and one's sense of self shifts, causing one to compare the differences between their present body with their past body, as they recognize a loss of self and a loss of autonomy. As mentioned in Chapter One, participants also experience the three illness narratives of restitution, chaos, and quest experience stories, at differing points in their chronic pain experiences (Frank 1995). As I illustrate, participants' concept of self and their identity shifts as they struggle to make meaning about their new experiences of pain within wider societal discourses about femininity, health, and bodies.

4.1 Chronic Pain and Relationships

Participants explained that chronic pain affects their relationships with their partners, friends, children, and other family members in both negative and positive ways, which speaks to the complexity of their experience. First, for one young participant, her relationships with friends were challenged because they could not relate and did not understand her experience of living with chronic pain and bodily uncertainty. Charlotte explained how her friends were quick to dismiss her pain, causing her a lot of hurt and sadness.

> Mentally I think what was difficult was just the almost immediate dismissal from people in your, your circle. You know, even initially mentioning- oh you know I have been having this pain everyday it's really bothering me- Oh yeah it's not really a big deal take some Tylenol and get over it. And at first, it's like whatever, but when you realize it's staying with you a little bit you just keep hearing the same thing over and over. The kind of mental effect of that was, I don't know, it was hurtful and just upsetting because no one wanted to hear about it even from the very beginning (Age 21, Occipital Neuralgia).

The lack of empathy she received from her friends impacted how she felt about her pain and her body. She explained that she felt she was a burden to her friends, and her pain made her feel more irritable and less likely to want to go out. She shared,

> And physically you know, I almost immediately was reducing the things I was doing. I wouldn't go out with my friends as much, I didn't wanna do crazy stuff, I didn't wanna do whatever I was doing when I was younger. [...] But I'm telling you that I feel pain every single day [...] its kinda like a broken record you keep talking about it but if that's your reality, and that was my reality, and I have great friends but I felt like I was almost burdening them talking about it all the time where it was annoying to them. It's like yeah okay we get it, your neck hurts whatever it sucks. It's like okay, but yeah it really hurts. I wouldn't be talking about it if it didn't hurt, I'm not trying to annoy you guys but imagine how I feel with the pain. (Age 21, Occipital Neuralgia)

For Charlotte, in her early twenties, not being able to hang out with her friends impacted her emotional and mental health. Chronic pain disrupted her normal activities as a young woman. As she adjusts to living with the chronic pain of occipital neuralgia, she is also forced to reckon with her new identity and the body of someone who has chronic pain, which then impacts how she views herself. The abrupt physical and identity changes due to having chronic pain caused a disruption to Charlottes routines, normal activities, and social role as a young woman (Charmaz 1995; Barker 2005).

Not all participants felt unsupported. Paulina shared that she received support from her partner, who was empathetic to her chronic pain. She explained,

> My relationship with my wife was definitely impacted, particularly because a lot of it deals with painful intimacy. Like there is like a huge, like she is very, very understanding and I'm very grateful, I was very lucky to have like a partner that like gets, not gets it, 'cause she doesn't have chronic pain. But like who is just so compassionate, when I say that like I'm too in pain to like do 'x' intimacy act she doesn't berate me and say you're not meeting my needs or anything like that, she's very understanding. If I'm having a flare day or whatever, like I'm usually the one who cooks dinner, but if I'm having a flare day or whatever, she's like no, no problem, like I do not care about me getting a meal, like what do you need [...] (Age 26, Adenomyosis).

Although her partner is empathetic to her adenomyosis pain, a gynecologic condition, Paulina feels guilty, and similar to Charlotte above, feels that she is a burden in their relationship. She says,

> But there is always that voice in the back of my head that's like, its kinda the voice that's like 'she could do better' you know 'you suck as a partner because you can't do the things she wants to do' like maybe she wants to go for a walk right now, I can't cause I'm in pain, or maybe she wants to be intimate but I can't cause then I'll be in extreme pain or I am currently in extreme pain. So, there's like those things, where it's just like, I know that I'm like, she says that she doesn't mind but there's that guilt that you feel where you're just like I know you say you don't mind but I feel like, bad, cause it's like something that I can't help but it's like you didn't sign up for (Age 26, Adenomyosis).

Paulina experiences tension in her relationship when being supported as she also feels guilty because her own physical limitations constrain their relationship and this weighs on her emotionally. She also describes feeling like she is holding her partner back. For participants in their twenties, their age intersects with their experiences of chronic pain, which impacts their relationships, experiences of dating, intimacy and finding a partner.

Shay explained how, after her diagnosis of Multiple Sclerosis (MS), she wanted to share with the man she was seeing that she was living with this chronic disease. She explained,

> That's another part of health that I kind of wanna bring up because being a young woman, someone who's still dating, still looking for a partner like that is also an element that you have to bring to the table that can turn a lot of people off, and can get you a lot of weird responses and can be a barrier in romance, in sexuality, and intimate connections. And I don't think that there's a right answer on like how and when you're supposed to tell someone that you have a disease [...] that guy was the first guy I had dated and I was like, I really don't know. I know that I have to tell him for myself like I want to. But like, I don't know when the right time is. (Age 24, Relapsing and Remitting Multiple Sclerosis)

She explained that once she told him, it was awkward because she found herself supporting his feelings in terms of adjusting to her lived experience of chronic illness. It didn't take long however, for them to break up, which she believes was because of her illness, even though he never explicitly stated it. This idea of disclosure is prominent within chronic illness literature where individuals weight the costs and benefits of disclosing their stigmatized identity to individuals in their lives (Camacho, Reinka, and Quinn 2020). Disclosing can yield many positive benefits such as social support and enhancing relationships, but it can also increase stigma, create unwanted treatments, and unsupportive reactions, as it did for Shay (Camacho et al. 2020). Women with disabilities are perceived as incapable partners because they depart from the stereotypical (traditional) roles constructed for them by society, as they are seen as unable to perform domestic duties (Gill 1996). Shay's experience highlights the difficulties young women face in navigating intimate relationships and the judgement they face when disclosing their invisible illnesses to partners who construct them according to society's conventions of ability and disability.

4.2 Chronic Pain and Mothering

The constraints of femininity or gendered expectations of being a mother also intersect with experiences of chronic pain or chronic illness (Hansen 2008). Four out of eight participants have children, and three of them threaded discussions about parenting throughout their narratives of chronic pain. As these participants described, caring for children places additional stressors on their bodies. As Sarah explains,

> If I carry my daughter around too long like hold her versus like push her on the stroller while we're like walking around a store- my back, I'm going to be out the next day, like I am going to be in so much pain the next day, so I try to ice myself in the evening, after I put her to bed just to help alleviate that before it comes, because I know what's coming, and that's frustrating. (Age 30, chronic sciatic nerve pain)

Sarah explains how she manages her pain using ice after the physical exertion of carrying her child, which is an expectation for mothers of young children. As Parton et al. (2018) describe, mothers will often put the needs of their children before their own, when it is physically possible, because of the societal expectations about mothering and being a 'good' mother. These authors explain that the 'good mother' is the mother who is selfless and prioritizes the needs of her family over herself, which can often disrupt the physical limitations of having chronic pain (Parton et al. 2018), which aptly describes Sarah's selfless approach to mothering.

Participants who are parents also described how their experiences of chronic pain can hold them back from what they see as their mothering responsibilities or the societal expectations of mothering because of the physical limitations they experience in their pained bodies. Leah, a mother of two, describes how emotionally difficult it was for her to imagine not be able to actively play with her children. She explained,

> I think the biggest, the biggest, I guess, upset for me was like what if like when I was really bad, I was like what if I can never play with my kids outside? You know? What if I can't play tag with them? Like that, that was a really hard time, because I'm just like you know, that's not, that's not why I had kids. It's not the type of mom. I don't want to be, being like sitting on the couch and like watching them and not being able to, you know, interact and engage with them. (Age 37, chronic back pain, sciatica and numbness from herniated discs during pregnancy, adenomyosis).

With chronic back pain and sciatica, Leah has ‘bad’ days and experiences flares or longer periods of time experiencing severe pain. She explains that at the height of her pain, it was her fear that she would never be mobile enough again to play with her children. Having a chronic illness and chronic pain disrupts the expectations women have for themselves as mothers because they can not live up the moral standards set for mothers in terms of caring and managing the household (Parton et al. 2018).

4.3 Navigating Education and Work

Participants described the impact of living with chronic pain on their education and their careers. Five participants were currently in university or had been a student in the recent past, and they shared the challenges of having an invisible disability and chronic pain while attending school. Two participants explained that they had not asked for accommodations from the university, but reached out to their professors letting them know they live with chronic pain, and that this might impact how they can manage the course. These participants describe being dismissed by their professors. Professors were not empathetic and rarely offered extensions or modifications for assignments. Charlotte shared,

> Then I started university it was the same thing. But it was more pressure because I’m like this is like high stakes. You need to be going to class, you need to be learning. Uhm, so it was difficult because there were sometimes when I wouldn’t be able to go to class because I’m in excruciating pain, or it's just so bad that it's leading to a migraine. At that point I’m not gonna go sit in an hour and a half lecture, potentially three hour lecture, if I, I can’t even think straight. What am I gonna even retain? (Age 21, Occipital Neuralgia)

The physical impacts of being a full-time university student while living with occipital neuralgia, and in constant pain profoundly impacted her ability to participate in class, yet the expectations she had for herself demanded that she keep up at all costs and affected her emotionally. She explained further,

> But then that also contributed to more negative self-talk. Maybe you’re just being lazy, maybe you should just go to class you know. Well I would love to, it's just not that simple or you know, not being able to get assignments done on time and having to take extra time. It was just tricky cause chronic pain is usually an invisible disability and so many people just don't really understand the impacts that that has, physically but also emotionally. (Age 21, Occipital Neuralgia)

Charlotte berated herself to be more productive and push through her physical pain. This strain she describes is not unusual for sufferers of chronic pain as society places great value on productivity and efficiency over mental and physical health; it is seen as a personal failure when one cannot live up to these standards (Barker 2005). Yet, there were times when she was not able to go to class because she was having a flare-up and needed to lay in bed all day, causing schoolwork to pile up as she waited for a time when her pain would be more bearable. She experienced added emotional stress beyond the physical pain because she could not meet her own expectations or the expectations of her instructors. She shared,

> So trying to explain to a teacher that yeah I didn’t get your paper done because I was crawled up in my bed all weekend cause I couldn’t move my neck. And they’re like uhm, well, maybe you could have just done it last week. And it’s like well I wasn’t really predicting that I was gonna be out of commission for three days. (Age 21, Occipital Neuralgia)

The social expectations of being a university student are in tension with the experiences of chronic illness, and this impacts how students may be treated by their instructors. Hamilton, Hulme, and Harrison (2023) undertook research with 67 university students in the United Kingdom living with chronic illness, and they found that professors were unaccommodating when students explained they would not be able to attend class or asked for extensions on assignments because of their chronic illness flare ups, even when telling their professors about their illness beforehand. As Hamilton et al. (2023: 33) explained, students’ experiences of chronic illness and impairment were not understood by instructors who retained rigid expectations for assignment deadlines. According to Hamilton et al.’s (2023), students described professors who expected that chronic illness could be controlled, which caused students to experience an exacerbation of illness.

Violet and Shay shared similar challenging experiences navigating their education with chronic pain which was made worse during the pandemic. The structure of education, with mandatory classes at set times during the week, long lecture times, extensive screentime, uncomfortable seating in classrooms, and having to sit for long periods of time to complete assignments and readings, negatively impacted their chronic pain. Violet explains,

> In university though, like the lectures can be really long and you're sitting at your desk for a long time, or especially during COVID and all of the lectures being online and just sitting at your desk all day long. Like, I definitely feel like that's aggravated my pain a lot. So I think over the last couple years it's definitely gotten worse. (Age 24, chronic neck and back pain, undiagnosed endometriosis)

Shay, another participant, detailed a similar experience, explaining that when she was in high school she started to routinely take pain medication to get through the day.

> I would take Advil and Aleve together, which no one told me I wasn't allowed to take in combination. And I would be sitting in class, like basically passing out because I had made myself stoned and not in a way that I could function. I'd be falling asleep at my desk frequently, and had to ask my parents to come pick me up from school to take me home because my headaches were too bad [...] So that disc pressure caused so many different things over the years, like extreme sciatic pain down both my legs, but then also like nerve pain localized just to my hip joints. Which was worse in university to the point where I would have to skip class if the lecture was in a certain kind of lecture theater, because I physically could not sit on the hard plastic lecture theater chairs cause I would be in way too much pain. In my hips, in my back. (Age 24, Relapsing and Remitting Multiple Sclerosis (RRMS) migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

As these participants describe, their pain increased while attending university although they pushed through it and graduated. Yet it also impacted how they saw themselves as both students and women. Delaney and Bell (2008) note that women may suppress the needs of their body and health in order to keep up with the demands of paid and unpaid work. As mentioned above, femininity is constructed around the idea of selflessness, causing many women to ignore or push past the pain they experience in their bodies, which causes their health to deteriorate (Delaney and Bell 2008). Women push their bodies and downplay or even hide their illness and pain in order to be taken seriously at school or work because of the structures of patriarchy and sexism, where women already experience barriers and precarity in the workplace (Delaney and Bell 2008).

For Paulina, who is an accountant, having adenomyosis and chronic pain means that she must navigate her workplace and the work demands of her career. She explains,

> I only have 5 sick days. And they know I am chronically ill so they know that when I take a sick day, I mean if they believe it or not that's not really my knowledge or my business, but when I say I'm having a flare up today I'm not coming in, they're understanding right. They're still expecting me to get my work done on time, and expecting me to do the same quantity and quality of work. In my field it is quite hard, just because the demands are quite significant, but with being chronically ill and being mentally disabled with autism, like it's definitely not a field that I'm going to be able to continue in. Because they kinda expect to do 50-60 or more-hour weeks. And that's not feasible when you're chronically ill [...] so I know that ultimately I am not going to be able to keep this job long term. Because it doesn't work with what my physical needs are. (Age 26, Adenomyosis)

Similar to the participants' experiences of university, for Paulina, navigating full-time employment where there are few accommodations and limited sick days, the expectation is that she must be willing, capable, and able to perform at an excellent standard all of the time. Because of this, she feels like she is going to have to find another career because she cannot keep up with the work demands placed on her as the job requirements are more than her body is able to do. As Griffiths (2020) writes, many workplace environments feel frantic and produce stressful working conditions that have become normalized. For women with chronic illness or pain, especially invisible disease, their experiences are exacerbated by the intense working environment. Co-workers and managers may not even be aware of what their employee is dealing with in terms of their invisible disability (Griffiths 2020). As Paulina describes, navigating the workplace is an ongoing struggle and one that she does not think she will be able to manage long-term. Her functional limitations mean that she may have to give up her career in order to manage her pain.

Gender socialization and chronic pain has caused several participants to reassess their career and forced them to think about their future working lives long term. Several participants spoke about having to find jobs that are flexible and do not require physical labour. As described by Mia,

> It's pretty well affected everything. I lost my job, I worked at the hospital at the time. Uhm, I had to regain my ability to work and I started working for my partner. Which gave me the pleasure of being sick for a month at a time, he needed help but I was at least privileged enough to say I can't make it in and he was good with that, there was no way I could get a job working anywhere else under those circumstances. And I'm a good worker but there are just days I can't do it. (Age 50, undiagnosed fibromyalgia)

This type of flexibility is not common in most employment contracts and Mia acknowledges her privilege in being able to work for her partner, who is understanding of her physical limitations. As Hansen (2008) writes, the structure of employment enacts multiple physical, social, and emotional barriers for women, as the regular eight-hour day, five days a week job, which can be compounded by the double-day for women with caring responsibilities, takes a personal toll on women's bodies. Mia's recognizes that her chronic pain, which is unpredictable, make it impossible to work for anyone other than her sympathetic partner. For the other participants, who all work full time jobs or are in school full time, sitting at the computer all day means they must adapt their work in order to deal with their chronic pain. For example, three participants explain that they use a sit-to-stand desk in order to move from sitting and standing throughout the day, and during breaks they will go for little walks and stretch. However, these options are not always available in their workplaces.

In terms of work, participants also shared how their income impacted their ability to access specialized care services that are not covered by OHIP. As discussed in Chapter Two, services such as physiotherapy, massage therapy, and chiropractic care are specialized services used to treat and manage chronic pain. For some, these services are covered by a private health insurer through an individual's employer benefits while others do not have access without having to pay out of pocket. Violet, who has chronic neck and back pain, has used physiotherapy and massage therapy to help manage her pain explains,

> Cause I mean, you don't choose to have chronic pain, but then to try to get a massage, that's like, it's not relaxing- like the next day you're in more pain than you were to start with, but it helps. And you can't access it because it costs so much money or like other kinds of treatments and stuff. So like that is a barrier in the negative side of our health care system, not just, just not being like comprehensive and like fully inclusive. (Age 24, chronic neck and back pain, undiagnosed endometriosis)

Violet explains that how massage, prescribed as a pain treatment, is only accessible if you can afford it. Sarah shared a similar frustration,

> I had seen a couple of doctors, and they pretty much just said like Tylenol, massage, and physio, and that'll just be that. And then, after, when things weren't repairing, they were like, well, you might just have to live with the damage and just have to utilize these services forever, and I'm like, I can't afford to do that. At the time, I didn't have benefits, I mean, how am I supposed to afford to see a chiropractor every two weeks, and go to the massage therapist every three to six weeks, like I don't, I can't afford that. (Age 30, chronic sciatic nerve pain)

Pain treatments are a financial burden unless you have extended health care benefits through the workplace. As people with chronic pain rely on these specialized services and if they cannot afford them, they are left to find ways to manage the pain themselves, which impacts on their physical and mental health.

4.4 Bodies, Loss of Mobility and Autonomy

For some participants, being active and playing sports was a huge part of their life before their pain started. Leah explains,

> The biggest challenge for me is my quality of life in terms of my physical activity. I'm a very active person. I was like an avid runner um before kids. I played volleyball. I did a lot of outdoor things, and now I'm very limited in what I can and can't do [..] so letting a lot of that go, and accepting that it's like, was the biggest, definitely the biggest challenge for me. Because like to me, that's a grief that was grief to me like losing that part of myself, because, no matter what I did, it's something I would never be able to get back. (Age 37, chronic back pain, sciatica and numbness from herniated discs during pregnancy, adenomyosis)

Accepting that she is no longer able to play volleyball, run, and be active affects how she now sees herself and she grieves her past self who could be active without pain. The onset of chronic pain causes a lot of changes with an individual's mobility and autonomy (Barker 2005). Charmaz (1991) writes about how the disruption and inability to perform routine tasks and daily activities creates existential dilemmas about one's self worth and quality of life. The loss of daily tasks and mobility symbolizes the undermining of the self, along with feelings of frustration, anger, despair (Charmaz 1991), and in some cases, complete hopelessness (Barker 2005). Leah, redefining what being active means has had to change.

Similarly, Hazel discusses that one of the most prominent changes in her life due to the pain was no longer playing sports. She wrestled throughout high school and had to stop because of her chronic pain. She explains,

> When I was young I pushed through and I still wrestled with my back pain. But, like, my mom used to get mad at me. I'd get on the mat and be like my backs killing me and she'd be like why are you on the mat if your back is killing you? Like I'd just tough it out. Uhm but as I've gotten older it's gotten worse, the shoulder pain [...] I would have loved to go to university, like come to university and wrestle on like scholarship but that just wasn't, like out of high school I was like I can't, there's no point. I'm not gonna do well because I need to sort out what's going on with my back. So that was unfortunate cause I loved

> wrestling. Uhm, I don’t participate in any sports really from the chronic pain. (Age 30, chronic low back pain and chronic shoulder pain)

She explains feeling depressed as she became excluded from her sport, and its accompanying social group. The loss of daily tasks and mobility symbolizes the undermining of the self, along with feelings of frustration, anger, despair (Charmaz 1991), and in some cases, complete hopelessness (Barker 2005). Hazel’s experiences are not uncommon, as feelings of loneliness and isolation are common among women with chronic pain, as the body feels impossible to control and they are exhausted from having pain all the time, so they stay home more, and lose interest in their hobbies and activities that they once loved (Broom et al. 2015; Råheim and Håland 2006). Despite this, Leah and Hazel are able to accept the physical limitations of their pained bodies and find alternatives to being active.

For some participants, there are periods of acute pain where they have trouble moving for a few days, to experiences of chronic pain where they are bedridden for weeks to months. Either way, their experiences of pain mean they are unable to perform daily tasks. As Shay shares,

> In grade ten or grade eleven, I threw out my back for the first time and I was essentially paralyzed on my couch for an entire March break. Like I was just doing nothing, I was getting out of a car on like the Friday night, first night of March break, and I just tweaked my back and I was in such excruciating mind numbing pain that my parents had to carry me inside. I laid down on the couch in the living room and I didn't get up for a week. Like I had to pee in diapers and it was atrocious. (Age 24, RRMS, migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

In this experience of acute pain, she experienced a radical disruption between her body and self, as a fourteen-year-old experiencing excruciating pain. She goes on to explain how she would continue to deal with chronic pain for the next several years as a university student.

> Then in university things just kept getting worse and worse and worse, and my pain overall got unbearable. My fatigue was worse than ever before. There were days, there were months actually, where I couldn't get up, I couldn't get off the couch. I spent my life in my house coat and I was just a vegetable. And it killed my mental health because I was lying there, not able to do anything. And I'm thinking, I feel like the oldest person in the

> city. I, this is not what a young twenty year old is supposed to feel like. I'm not myself, I can't go with my friends, I can't do anything. (Age 24, Relapsing and Remitting Multiple Sclerosis [MS], migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

Shay explains how she wrestled with her identity as a young woman living in what she imagines feels like an old body, and how she could not mentally reconcile her life with how she felt physically. As described already, chronic illness and chronic pain can cause individuals to feel estranged and alienated from their bodies, as they experience new constraints and impairments, causing them to deal with their relationships, mobility, and autonomy in new ways (Barker 2005; Charmaz 1995). For example, taking back control of their body by finding new ways to be active, rethinking what mobility means outside of their bodies before pain, and accepting their chronic pain as something they cannot entirely 'fix.'

4.5 Chronic Pain and Mental Health

Chronic pain has serious impacts on women's mental health and emotions due to the toll of constant pain and stress on the body (Vrekoussis et al. 2020; Molin et al. 2021; Broom et al. 2015). All of the participants shared their experience with sadness, depression, isolation, or anxiety which has had serious impacts in how they feel about themselves. Mia explained how she developed depression and anxiety due to having chronic pain for 14 years, and her constant adverse experiences with the medical system.

> I did go down a bad spiral of depression, uhm I don't think anyone could have gone through that and not been affected mentally. If you can go through that and not have it affect you that way, the more power to you but uh I ended up becoming agoraphobic for a bit. Did a complete lockdown for 18 months. That came on slow, I was avoiding, like just like my mom's whatever is coming up I'll just not go. And then I noticed my doctor's appointments, I was starting to have anxiety three days prior to the appointment which it's not usual for me. Then it got so bad that I would start to pass out as I went to the door. (Age 50, undiagnosed fibromyalgia)

She explained that it took years for her to manage her mental health and after multiple prescription antidepressants from her general practitioner, she found that these medications only made her depression and anxiety worse, but he would continue to up her dose. She ended up in a mental health crisis and was admitted to the psychiatric ward of the hospital for a short period of time. She felt like her general practitioner was making her sick with the constant pushing of antidepressants, and she wished for a new doctor, but the waitlist for other doctors in Thunder Bay was (and continues to be) so long that she did not want to risk letting him go if she needed other tests done. Otherwise, she gave up on medical interventions to help her mental health and chronic pain. She explained that she stopped using her antidepressants, and started using marijuana to help manage the pain, and also researched micro dosing on psychedelic mushrooms for her mental health, which she began to do, and it made her feel happier than any prescription her doctor gave her. She says "I looked into microdosing for mental health, and I took one pill, and I knew I found a winner. It was like the clouds just lifted, and you could have told me the worst news ever and I would have been in the perfect mental state to take it." Only after she began to manage the pain herself did her physical and mental health improve.

Charlotte shared a similar experience with her mental health. She has been diagnosed with occipital neuralgia by a pain specialist at the chronic pain clinic at St. Joes, after several years of weaving in and out of the medical system with unexplained symptoms. She explains that she has health anxiety, where she worries excessively that she has a severe or life-threatening illness, where any minor symptom seems like a bigger problem. Similar to Mia, she also developed anxiety towards the medical system. She explains,

> I'll like feel a sharp pain in my upper left side and I'm googling like okay what's exploding inside of me because obviously something is. Uhm, I have like a plethora of other health issues as well. And I have that same health anxiety but then I also have in the same sense of health anxiety, seeing health professionals now. It has almost left like a

> bad taste in my mouth from all the overwhelmingly negative experiences that I've had that now, for even something a normal person be like just go see your doctor, it's like mm I know I should and it's probably better for my health but the idea of going is also so anxiety inducing and so upsetting [...] But then the health anxiety kicks in and I'm like what if this problem is really serious and life threatening or who knows what's gonna happen down the road. (Age 21, Occipital Neuralgia)

Her anxiety about her health extended to anxiety about seeking medical care. She began to fear appointments with medical professionals because she believes they will dismiss her pain, which causes more anxiety and stress. She goes back and forth between fearing she has an unknown medical issue and wanting to seek help and fearing seeking help because prior appointments with doctors have been overwhelmingly dismissive.

4.6 Navigating a 'Disabled' Body

Most participants recognized that their mental health also impacted their relationships to their body including how they think about their body. Sarah described that at the onset of her pain experiences 10 years ago, she blamed her body for failing her and limiting her life.

> I think I went through a part of my life where I had a really hard time with my body, and I blamed my body for a lot of the pain that I was in, and I blamed my body for not like doing the things I needed it to do, and it took a long time to kind of come out of that. (Age 30, chronic sciatic nerve pain)

As she describes, before pain she could do anything, and she grieved the loss of her old, pain-free body. She explained,

> I was unstoppable then. At that point I was. I was doing everything. I was driving transports, and I was delivering bread, so I was lifting super heavy things, and I was traveling, and I had so much hope for all these things that I wanted to do, and I think there was a lot of opportunity. And then, as the pain started. I felt weaker and weaker, and I really struggled to do those types of things, and I think that ties into how it felt about my body. I feel like when the pain started. I felt like my body failed me because I felt weak. Um, and I felt like I lost a piece of something that I had hoped for, and I was grieving that at the beginning, and I think that was a really hard thing to wrap my head around, and it took a while to do. (Age 30, chronic sciatic nerve pain)

It took a long time for Sarah to come to terms with her failed or disabled body, which also caused her major mental health issues as she grieved her past self. Arman et al. (2020) found that women with chronic pain who are no longer able to trust their own bodies because of pain and develop anxiety and grief in this transition. The meaning of life changes as they adjust to the new limitations of their physical body (Arman et al. 2020; Barker 2005). As Sarah's quote illustrates, she felt a complete sense of body betrayal and it was difficult for her to accept the pain and navigate a new identity.

All participants described feeling denial at some point in their experiences of living with chronic pain. Not unlike Sarah above, others also explained how they were grieving for their past selves. The journey of denial, grievance, and acceptance of their bodies and identities was shared by several of the participants When aspects of bodily life are disrupted by illness, people are unable to control their bodies, and how they feel about themselves shifts as their view of themselves aligns with how society constructs disability (Wendell 1996). This is further compounded by how women are treated within a medical encounter, as I will elaborate on in Chapter Five, because of weight stigma and anti-fat bias by doctor's and the wider health care system. Thus, women's identity and sense of self shifts as they navigate their chronic pain in the everyday social world, including their experiences of health care.

4.7 Shifting Identities

Participants believed that their initial chronic pain symptoms were just acute episodes of pain, where they would briefly rest and then make a full recovery. Mia shares how she felt when her chronic pain began,

> I thought it was the flu. I treated it like the flu. I grabbed my Nyquil, took a swig and thought I would sleep it off for a couple days. And I remember talking to someone in my partner's office who was sick the day before me. I ran into him, I even made a joke I put

> my shirt over my face and said I can't afford to be sick right now. And I went right to him and I said what were your symptoms? And he said it felt like he fell into a prickled bush and rolled around and was on fire, so he had some kind of nerve tingling and just got better and I didn't. So I don't know what happened to me. I just got sick, and I, I'm assuming my immune system turned on me. (Age 50, suspected fibromyalgia)

Mia believed that her symptoms of a fever and widespread bodily pain were caused by the flu initially; yet after 14 years, she still does not have a diagnosis for her chronic pain symptoms. This is a common experience for women with fibromyalgia, who often search for meaning with regard to their pain symptoms for years before being diagnosed (Barker 2015:90). Mia explained that she is still in denial about being chronically ill and in pain. She shared,

> I still don't think it's permanent. I'm kind of in denial on that one, I'm slowly coming to terms with the fact that I might be handicapped I, and I don't judge anyone who's handicapped, I just think oh they're handicapped. But for some reason when it's me it's like I can't be handicapped, I don't know what that is. But uh, I am just coming to terms with that now that I'm slowly not getting better, there are days where I'm worse. (Age 50, undiagnosed fibromyalgia)

Mia explains that she does not think of herself as a handicapped or disabled person. Although she does not judge others who are disabled, she just is not able to see herself this way. Quinn and Earnshaw (2001) point to the stigma that is attached to chronic illness or pain and bodily differences. People with chronic illness, or invisible illnesses, anticipate and internalize being devalued, discredited, and shamed because of their chronic illness, based on society's preconceptions about ableism and able bodies, and obsessions towards health (Werner et al. 2004; Quinn and Earnshaw 2011). Society deems individuals with bodily differences or limitations as less than able-bodied persons, which leads Mia to deny that she has an illness or debilitating pain symptoms. Even though she is coming to terms with her new identity as someone who is disabled, she admits that there are days when she denies being ill. Given the unpredictability of fibromyalgia, an illness that is very much contested, yet what her doctor suspects she has, it isn't surprising that she is also uncertain as to whether that label accurately describes herself (Barker 2005).

A similar experience of denial was shared by Shay, who after her MS diagnosis, was in complete denial. She says,

> My sense of identity was like in a state of chaos when I, the first MS bomb was dropped because that identity was like, oh my god, I'm picturing this narrative of what I think an MS patient is, and that's not me, must not be true, but also like what the fuck's going on. So that was, at that time, it was in such intense denial because my sense of identity had been so shaken and that's why I refused to acknowledge it for such a long time. (Age 24, RRMS, migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

The way Shay viewed MS was through what she had learned in the media, and she felt detached from these representations. She felt that her identity did not match being a sick person and she was in denial about her diagnosis. Her state of chaos relates to Frank's (1995) second illness narrative whereby Shay was overwhelmed with the intensity of her diagnosis, with no time to reflect on her illness. This biographic disruption (Charmaz 2002; Bury 1982) happens with the life changing diagnosis of MS, which did not fit with how she viewed herself as a 22-year-old woman just finishing university. Initially, she had many unanswered questions about MS and her doctor did not provide her with any information. She felt like she didn't know where to begin.

Chronic illness disrupts the taken-for-granted notions of the self as well as daily habits and interactions that previously supported the old self (Charmaz 2002; Bury 1982). When patients receive a serious diagnosis, Charmaz (2002) notes that individuals may reject, challenge, attempt to negotiate, and redefine the person with a chronic illness. Diagnostic shock may occur where the patient's reality and identity become disconfirmed because they did not anticipate getting such as a serious diagnosis (Charmaz 2002). As well, patients' identity will be challenged because they lack knowledge about the illness and are only aware of it through socially prescribed norms about people with chronic illnesses (Charmaz 2002; Bury 1982).

Shay sought out second opinions from other doctors, and it was not until she went to Toronto and saw an MS specialist who talked to her for hours and allowed her to ask questions where she could finally take a deep breath. She says,

> I'm feeling great but it's for a reason though, cause I'm being taken care of with the right therapies and medicines, because I have this really big diagnosis [...and] before diagnosis, like my sense of self was completely different in a sense of like, this isn't me, you know. Especially in the years of university where I couldn't do anything and I felt so sick so sick, and crying to my doctors, like something is wrong with me. That sense of who I was, I was like, this isn't me, this isn't my life. So that was a whole other experience. Now my self worth has always been remarkable. That's my, that is my like most powerful asset in myself is that my self worth and my self-esteem is unshakeable. But my sense of how other people see me from a health standpoint is still shaky. And I think that it's, I think it will be shaky for a little while. (Age 24, Relapsing and Remitting Multiple Sclerosis (RRMS or just MS for the general term), migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

She acknowledges that her identity is a work in progress because she must come to terms with how others view her illness and how she views herself. She has only disclosed her diagnosis to her parents, and has not told extended family members or friends yet because she does not want them to see her as someone with a disability.

In terms of coming to accept their new embodied reality and self, it was helpful when participants were able to normalize the experience of living with chronic pain. For example, Violet explained, “my pain, it’s just a part of my identity now, where it’s [not] something that I’m constantly thinking about.” She has had chronic back pain, chronic neck pain, and endometriosis symptoms for over eight years, and for her, having these conditions for so long has caused her to accept the regularity of the pain and she identities as being someone with a chronic condition. Her experience of chronic pain was a process of self transformation, according to Frank’s (1995) third illness narrative, where she has accepted that her illness has changed her life and acknowledges it as a part of her identity now. She says,

> I feel like when you have chronic pain and like I have chronic back pain, you have like this other condition and you have like a whole life going on. You're going to school, you have a job [...] obviously I'm thinking about it, but it's kind of like normal. And so like, I don't always spend the time to like research into it cause I'm just like maybe… frustrated. I've dealt with it for so long, like the back pain, especially like, I don't even know how bad it really is [...] Like it's like, is it actually that bad? But, I have a pain every day. I get headaches like three times a week or more and like, that's definitely not normal. (Age 24, chronic neck and back pain, undiagnosed endometriosis)

Although she recognizes that the pain she lives with is not normal for everyone, it is for her and this is how she sees herself. She has a busy lifestyle being a student and working full-time so she does not have time to dwell on the pain. She has become accustomed to the pain, and it is part of her normal. Violet is seeking a diagnosis so her pain can be seen as legitimate, because without a label, it is easier for doctors to dismiss her (Barker 2005). All of the participants shared experiences of navigating their identities as they came to terms with their chronic pain, with or without diagnoses, which I will discuss further in Chapter Five.

4.8 Accepting Chronic Pain

Once participants begin to understand their pain, they begin to accept it and what their body is capable of (Frank 1995). All of the participants explained that they have accepted aspects of their pain and are in a more positive place in their lives now versus who they were when they first started living with pain. Charlotte shares,

> There are like good things and bad things that I discovered about myself with living with chronic pain for so long. Some of the good things are you know, I’m resilient and I’m strong and I can fight through adversity and get through things even when I feel like I can’t. [...] Like you know some people wouldn't have been able to handle it as well or might not have pursued going into university with that level of pain. (Age 21, Occipital Neuralgia)

In this narrative, Charlotte accepts her pain and sees positive aspects in her experiences. Wendell (1996) explains that for women, accepting that they have chronic pain and/or a chronic illness, they are able to recreate their sense of identity and create new possibilities within their lives.

Most of the participants described being in a better place now mentally than they were at the onset of their pain, ranging from 7-15 years ago. Paulina shared how she is slowly getting back to what she is passionate about, while at the same time, listening to her body and accepting that she cannot do what she used to be able to.

> Then there's Paulina now where, now like I'm aware of my limits and I've kind of more accepted them, I still do get a bit disheartened sometime when I realize how much I can't do in comparison to what I would like, before. I've rejoined karate and have been in karate for a few years now. I am able to mostly like work a normal 9-5, I do still need to like make adjustments and stuff. But like right now I'm living like, as far as my middle self was concerned, I'm back to like not normal, but my new normal where being on birth control has kind of reduced the pain level to like a level where I'm able to function. (Age 26, Adenomyosis)

She explains how she has adjusted to her *new* normal, which has improved her sense of self and mental health. As I will describe more fully in Chapter Five, she explains that she is feeling better now, not because of the resources she accesses locally, but because of the resources she found online including a community of women with adenomyosis who have helped her accept and manage her pain. She says,

> What's definitely helped the most, for me is finding out what the actual problem was and finding the label for it. Cause then when you have a label for it you can search like on google or on Instagram hashtag adenomyosis. And then you'll kind of find the communities that you need, and they'll kind of guide you towards the supports you need. So they'll kind of tell you like oh therapy is good stuff, or heating pad is good stuff, like they'll kind of bring you to the tools and techniques that you need […] I haven't really found a ton of local help, but I feel like that could just be due to kind of like size too. Cause I'm sure if you went to Toronto there would probably be an adenomyosis support group, but in Thunder Bay if it exists, they're not advertising well cause I've never seen it. (Age 26, Adenomyosis)

Finding an online community following her diagnosis was a significant step towards acceptance for Paulina as she found other women who share similar experiences and can give each other advice. As I will discuss in Chapter Five, getting a diagnosis is not only important in terms of personal acceptance, but it is also significant in terms of social acceptance. Once there is a label to categorize or make sense of the pain, participants can feel validated by biomedicine that they have an illness and are legitimate in the sick role.

Another aspect of acceptance is how participants feel about their body. As discussed earlier, with the onset of chronic pain, participants described feeling betrayed by their bodies. Yet several participants described coming to a place whereby they accept their body, even with its pain. As Sarah describes,

> I spent a long time working on me, and what I needed, and what I wanted. I was able to kind of recognize all the good things that my body does for me, and, and all the good things my body's done and created life and all of these things. So it took me a long time to get there, but I feel like as much as the pain is a struggle. I love the body that I have because of all the things it's done for me. (Age 30, chronic sciatic nerve pain)

As Charmaz (2002) describes, chronic illness forces a continual reconstruction of oneself as it provides an opportunity to find strength in how one responds to the loss, emotion, and pain that comes with it. Wendall (1996) explains that when women accept their chronic illness and chronic pain they lose the former self, but in its place, a new sense of identity is recreated. As I will discuss in Chapter Five, the participants found strength and resilience by taking control of their own pain and the narratives of their experiences, forging new identities in the face of difficult pain and illnesses.

4.9 Summary

Participants' chronic pain narratives reveal the pressure of sociocultural notions about femininity, ability, and the body, that participants grapple with alongside their experiences of everyday life. Chronic pain has disrupted my participants daily life, and taken for granted notions about parenting, school, work, relationships, and mobility. Their experiences are gendered as they manage traditional expectations of the feminine body and expectations of motherhood and being a" good mother." For participants, learning to live with chronic pain is a journey of denial, grievance, and acceptance of the self and the materiality of a body in pain. The onset of chronic pain disrupts how participants think and feel about themselves, ultimately changing who they are and what they are capable of in their new identities and bodies. They have reassessed their education, careers, relationships, and life passions taking the chronic pain they experience on a day-to-day basis as they renegotiate their new identities. Participants sense of self is shifted as they learn how to manage their pain, and the difficulties they encounter when making sense of the pain and dealing with their mental health. Participants have learned ways to manage their pain, and for some, they have even come to accept their pain and their chronic illness as part of who they are. Acceptance is an important aspect of their identity, as is learning to not blame their bodies for the pain they feel.

Chapter 5: Accessing Health Care: Intersectional Considerations

In this chapter, I explore participant's illness narratives in relation to the health care system and the medical encounter. I consider participants' intersectional experiences in relation to their access to care, their treatment by physicians, and how they experience the health care system in Thunder Bay, a northern Ontario city. As I will begin, the importance of place to participant's narratives concerning access to access health care was a central theme. This is followed by considering how gender and specifically, femininity, is constructed in relation to participants' experiences of chronic pain in health care settings and through their interactions with physicians. In particular, participants described how their bodies and especially, their body size became the focus of many medical encounters when trying to access diagnoses and treatment for their chronic pain. The chapter finishes by describing how women resist biomedicine and the health care system by advocating for themselves, undertaking their own research and seeking alternative approaches, such as heat therapy, stretching routines, and medicinal marijuana, to manage their chronic pain. Finally, participants explain how they value a holistic approach to their health, and share why that is important for them.

5.1 Place

For participants, the health care system in Thunder Bay is at the forefront of their experiences. As discussed in Chapter Two, in Ontario, the health care crisis deepened through the pandemic and problems with access have been widely publicized (Zimonjic 2023), with participants experiencing challenges firsthand. For example, participants were aware of long wait times, the need to have to travel for specialized care, and that there are not enough doctors or specialists to serve the population. As Hazel described, not being able to access a specialist caused challenges and frustrations for younger participants. She explained,

> I feel like, like a big thing in Thunder Bay, well we have so few specialists. We have so few specialists, especially that seem to understand anything to do with chronic pain in young people. And I just feel like they're all really old school, like outdated. I don't feel like we have a lot of young doctors here who are coming in with like new ideas. (Age 30, chronic low back pain and chronic shoulder pain)

Hazel believes that the doctors who are available to treat her are older and have an "outdated" approach to her treatment, which she positions in relation to her identity as a young woman with chronic pain. She contrasts her experiences in Thunder Bay with treatments she can access in Winnipeg, Manitoba, eight hours by car to the West. She described how she has traveled to Winnipeg every six months for the last 11 years to access radiofrequency neurotomy, a nerve blocking procedure. As her narrative reveals, her pain started when she was 15 years old, and as she explained, doctors would dismiss her because she was so young, treating her as if the pain was not concerning. Her lower back pain continued through high school until she was referred by her doctor to have cortisone injections, but she had to travel to Winnipeg because of her age as she could not access the injections while she was under 18 in Thunder Bay. The cortisone injections did not help, and actually caused further hip pain, so she was referred by the Winnipeg doctor for radiofrequency neurotomy with another specialist in Winnipeg. She describes,

> I got the referral to the other doctor in Winnipeg. And he does, well he does a multitude of things, but the thing that I was looking at is called a radio frequency neurotomy … […] Uhm, he explains it as he disrupts the signal of the nerve to the pain. (Age 30, chronic low back pain and chronic shoulder pain)

Although radiofrequency neurotomy is a common medical procedure for individuals with cervical and lumbar facet joint-related pain (Gungor and Candan 2020), it is not available in Thunder Bay so she must travel to Winnipeg for the procedure. As her narrative described, she must take extended time off from work to travel and pay out-of-pocket until she receives her travel grant from the Ontario government weeks later. She continued,

> Thunder Bay definitely needs more medical professionals and specialists, and needs to catch up to more research in chronic pain I would say for sure. Cause it's rough here, it sucks having to travel to like try and find a solution [...] I feel like chronic pain, even just not knowing what chronic pain resources are in Thunder Bay is like a big issue. Like we have a cardiac unit now, our Cancer Centre, like thankfully is getting bigger and our resources and stuff like that. I just wish that we could see the same when it comes to chronic pain and doctors that listen. (Age 30, chronic low back pain and chronic shoulder pain)

Hazel notes that there is a lack of resources and treatment options for chronic pain in Thunder Bay, saying she was only offered physiotherapy. She explains,

> like I love physio but like doing physio for years on end is not an answer. Like I've literally been to physios where they're like we're not helping anymore I don't know if you wanna keep coming, and I'm like yeah I don't know. (Age 30, chronic low back pain and chronic shoulder pain)

Through her own searching on Instagram, she found that the Thunder Bay Regional Health Sciences Centre offers a chronic pain clinic so she made a point to ask her doctor for a referral. This made her question what care for chronic pain is available in the city, and why she wasn't offered a referral to the pain clinic and instead had to ask for one. As this narrative illustrates, there are two overlapping issues. The first is a health care system that has limited treatment options for those with chronic pain which may be due to its size and location in a hinterland region of the province. The second issue, however, has to do with her intersecting age and gender, which produce interactions with her doctor where she feels overlooked, and has to seek out treatment options online instead of having them presented to her by the doctor, highlighting the unequal power relationship between them.

All of the participants described feeling frustrated with the long wait times for appointments and tests. Shay explains how waitlists are a barrier. She says,

> There are things that we actually don't have specialists for in Thunder Bay, or there's only one specialist and you're on a waitlist for years. So just the waitlist alone is a major

> barrier, because in all that time you spend waiting, you're getting worse, you're gaslighting yourself. Your mental health is going down, your physical health is going down. You're not getting the care that you need to start to get better. And by the time you get there, like the doctors… odds are, are so swamped and so busy that you're still gonna fall through their cracks because they're so, there's so many other patients.
> (Age 24, RRMS, migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

As described in Chapter Two, compared to other cities in the province, there are longer wait times for MRIs and CT scans. Moreover, the wait times participants experience are partly due to the lack of doctors and specialists in Thunder Bay. As participants described, not only do they fall through the cracks of the health care system, but their conditions worsen because they are not able to be seen by appropriate specialist care in time.

Several of the participants have chronic pain conditions with complex and specific symptoms that require specialists who understand women's pain symptoms relating to reproductive health for instance yet, none believed that the doctors they see in Thunder Bay understand their condition holistically. As Shahvisi (2019) suggests, the health care system reproduces gendered norms and biases, impacting how doctors treat and understand women's health conditions and pain, which I describe next.

5.2 Gendered Experiences in the Medical System

Participants' identities as women pose a significant barrier in the health care system. Several participants described that they don't feel that their pain is acknowledged during a medical encounter, and that they are not listened to by their doctors. Charlotte explains,

> I think being a woman has played a certain role in the dismissiveness with having pain cause I think, well most of the people I saw were men, my original doctor was a man, the specialist I saw was a man, occupational therapist, physiotherapists, massage therapists, were all male at the exception of a few. And immediately they have no way of relating to the experiences of a woman, automatically, let alone a woman who's living with pain. They don't understand that, and they aren't open to hearing about it. So, I think uhm, on top of being dismissed, there was also kind of that -well you're just a young woman, what do you know- about your pain, I'm a doctor, I'm a man, I went to school for a long time.

> So you know, and there's that power differential of do you speak up, do you not speak up. If there's anxiety, you don't really want to, you feel scared, you feel anxious. You kinda just go with whatever is going and roll with it because that's the kind of precedent being set. (Age 21, Occipital Neuralgia)

As she describes, her experiences highlight the patriarchal structure of the health care system. Most of the health care providers she saw were male, and because of the power that biomedicine wields, Charlotte does not feel that she can speak up about her experiences as a young woman. Similarly, other participants also discussed how women are treated in the medical system and broader society, where women are conditioned to think about women's pain as something to be dismissed and minimized. Paulina, who has lived with adenomyosis for 10 years, shares,

> My chronic pain condition being like one kind of like that effects the uterus and other organs but is like created by the uterus, if you will, but people with uteruses are not taken seriously with their pain. Like its very well documented at this point that its just not taken seriously, all medical studies are pretty much well done on men, right? […] they're not focused on women. So, its just I know that like, that was like a huge issue was like being able to be taken seriously. (Age 26, Adenomyosis)

She is aware that women's chronic pain is something that is not taken seriously in the health care system and acknowledges the lack of research done on women's pain. As Merone et al. (2021) and Barker (2005) argue, the medical system holds social power, and patriarchal values are reflected in the institution's structure. This results in an unconscious bias toward patients who are women, where their pain testimony and suffering is often deemed untrustworthy (Merone et al. 2021).

As mentioned, pain is a complex subject, and the medical system has difficulty reckoning with unexplained chronic pain, particularly for women (Hill and Harrell 2020). For example, Shay points out how patriarchal systems of power cause inequality in health care for women,

> Also everyone has just been conditioned to think that if a young woman comes to you and she's complaining about this pain, you can minimize it, because clearly she doesn't know

> what she's talking about and she's just whining, she's, she wants attention, she doesn't actually know what real pain is. She's like, it's all in her head, she's making it up, blah, blah, blah. Or that, that's just what we're supposed to deal with, so we just have to suck it up, and shut up and stop complaining. So patriarchy has put women into a different class of patients in the medical system, a class that is not seen as equal (Age 24, Relapsing and Remitting Multiple Sclerosis [MS], migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

Shay explains how women are socialized to minimize their pain because biomedicine is structured to see women's health concerns as unimportant or trivial compared to more acute medical conditions. Shay, who is 24 years old, is empowered to make sense of her experiences with chronic pain through a critical gender analysis in addition to her own research on pain.

As discussed in Chapter One, chronic pain is often connected with women's reproductive health, which has long been medicalized (Hoffmann and Tarzian 2001; McHugh and Chrisler 2015). For Paulina, who is in a same-sex relationship and living with adenomyosis, she wants laparoscopic surgery to relieve pain, yet her gynecologist remains focused on adenomyosis as a barrier to procreation. Medicalization occurs when women raise complex pain symptoms and their reproductive system becomes the focus of their health (McHugh and Chrisler 2015). For Paulina, she explains,

> The thing is like, I am kinda stuck with the care we have in town. I have like wanted to seek treatment elsewhere for adenomyosis and like I know that there is those options. But if like my gynos, my gynos are kinda like stubborn cause there is someone who does the surgery in her office, but she is like too stubborn to refer me out. Cause she's like if it was severe enough then my colleague would have scheduled your surgery, and it's like well no because she's focused on like [...] they're kinda focused on endometriosis as a barrier to procreation. And it's like I do want to have kids, but my current issue is that I'm in pain, I'm in chronic pain. Cause it's like if I take my birth control yeah, I'm in like less pain, less pain, it's still sometimes pretty severe pain, uhm, but then I have all these awful side effects. And then if I don't take it, the minute it's out of my system I'm curled up in a ball wanting to throw up from the pain, and then my wife is telling me why didn't you take your medication. (Age 26, Adenomyosis)

Although she wants to have children in the future, Paulina's experience of severe chronic pain is viewed as less important by her gynaecologist as her potential to have children. Paulina is aware of all her options, in part because she has researched herself what treatments might work, as well as she knows her own priorities, yet the gynaecologist still exerts power over her options for treatment and believes that because she is a young woman, it is better to wait than have surgery.

Doctors often take a paternalistic approach to care by categorizing, diagnosing, and finding solutions to health or pain concerns (Patterson 2021). Although biomedicine has led to many great advances in disease treatment, the structural power it holds as a hegemonic authority on health, plays a key role in the relationship between patient and doctor (Barker 2005). The way a patient describes their pain is important, but doctors rarely consider the narratives of patients (Patterson 2021). Yet, with the increase in readily available knowledge through the internet, individuals are able to access information more easily than before, causing individuals to research their own diagnoses (Patterson 2021). In this case, Paulina is the expert of her own body because she lives with adenomyosis. Moreover, she accesses online information and peer support from other women who share similar experiences. Yet in this medical encounter, the intersection of her gender and age has led to her being dismissed, ignored, and not taken seriously in relation to her own lived experience and embodied knowledge.

The intersection of age and gender came through participants narratives in significant ways, especially in their struggle to have their experiences of chronic pain believed. For several of the participants, pain started when they were in their teenage years, and most are now in their 20s and 30s. Shay explains how her experiences started in high school,

> So in high school, I- you know, started talking to my family doctor and various other doctors and they started doing tests and they would do blood tests all the time. And that was when all the dismissal started, like it was kind of right off the bat they would say, you're too young for anything to be wrong with you. Like you're young and healthy, so it's just nothing [...] so my age has played a huge part of it, especially starting this whole journey as a teenager and completely my gender because like if I was, if I was a guy my age and an athlete and like all these things, I would be taken seriously in different ways.

> (Age 24, Relapsing and Remitting Multiple Sclerosis [MS], migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

Doctors initially dismissed her symptoms because she was perceived as “young and healthy.” Shay recognizes that her identity as a young woman caused her to be dismissed, noting that she believes doctors would have taken her more seriously if she had been a man. Werner and Malterud’s (2003) found that women with chronic pain are questioned and judged by medical professionals as not being sick enough or as having an imaginary illness due to their appearance and age. These ageist and gendered assumptions create barriers so that young women are not believed, and therefore are delayed in getting a diagnosis and treatment (Werner and Malterud 2003). Hazel shared a similar experience,

> I feel like, like the biggest obstacle, the thing that always got me and I hated hearing and I’m only just starting to get to a point where I don’t hear it anymore, is that like you’re too young to be in pain. That was like the most frustrating part of it, because it's like you’re not too young to be in pain cause you can get injured and be in pain and nobody knows why. Uhm, so I would say that was a big obstacle [...] I think just typical being a woman, like people think you exaggerate your pain or something. (Age 30, chronic back and shoulder pain)

Similar to Shay, doctors dismissed Hazel’s pain saying she was too young. Being a young woman with complex chronic pain symptoms who is dismissed and not taken seriously is frustrating when trying to access a diagnosis and treatment.

5.3 Challenges of Diagnosis

Some participants saw the dismissal of their experiences and their inadequate care from doctors as the reason their chronic pain worsened or why they do not have a diagnosis. As mentioned in the Introduction, despite the barriers women may experience in the health care system, they seek medicalization of their experience in order to gain a diagnosis as the label helps them legitimize their chronic pain experiences (Barker 2005). Violet shares that she feels extremely frustrated that her chronic back and neck pain has never been diagnosed, doctors told her it would not be a long-term thing, yet eight years later she has the same issues.

> I don't really have any specific diagnosis in terms of like the chronic pain that I have […] I was told that it wasn't supposed to be long term, like doctors will be like, oh, 'you'll be fine,' like, 'it'll be okay'. But then like, it's been eight years now and I'm still having like the same issues. Even though I've done all the things that they've told me to do, so like, that's frustrating (Age 24, chronic neck and back pain, undiagnosed endometriosis)

Another participant, Paulina, was 12 years old when she first experienced minor symptoms of adenomyosis, and 16 years old when she first went to her doctor with symptoms of painful menstruation. She explains her experiences prior to being diagnosed,

> So those years I was just told like, it's probably, uhm, ulcers, it's probably anxiety, other things, whatever. Uhm, cause I've struggled with anxiety my whole life too, like kinda unrelated to the pain. So that's just uhm, an issue that I face as well. And then so they kinda blamed it on every single other thing, and since I had no other knowledge, because I'm like well, doctor knows best, I have no idea what this could be, he's telling me it could be an ulcer so I'm just gonna say it's probably an ulcer. Or it's probably just menstruation pain, and I'm just complaining about it too much. Like, so for those years I just did nothing, I just lived with it and just assumed it was like, I just was not able to handle life like other people were. (Age 26, Adenomyosis)

Paulina was given improper diagnoses for her adenomyosis, with the physician suggesting it was stomach ulcers and anxiety. She explains that she believes she was not diagnosed for years because this condition is experienced by women and people who have a uterus. As Jackson (2021) notes and was discussed in Chapter Two, women's specific conditions are under-researched and low priority in biomedical research. Biomedicine often lacks the language to explain and describe women's chronic illness conditions, which results in them being diagnosed with psychological conditions such as anxiety (Barker 2005; Swoboda 2008). Paulina could not reject these improper diagnoses because she was young and believed the doctor was the expert, which caused her to blame her body, and live with the pain until she was diagnosed at age 22. She explains how she went on social media to learn about her symptoms,

> I've kinda gone online in order to get the support and the understanding and the knowledge set, kinda like via Facebook groups, Instagram pages, kinda stuff like that in order to understand, in order to learn about my disorder because I'm not learning about it in doctor's offices. Because they don't probably know enough about them. (Age 26, Adenomyosis)

Paulina explains that she had figured out her own diagnosis at 22, after six years of going to doctors with symptoms, while she was watching a Buzzfeed video online about endometriosis. She felt like the symptoms the video explained matched with what she felt, so she told her doctor and asked to be sent to a gynecologist, which he was hesitant at first, but in the end, agreed. The female gynecologist performed a transvaginal ultrasound in order to diagnose her with adenomyosis. Her results were extremely justifying for her as her experiences were validated after six years of dismissal from her doctor. She explains how she felt when she was diagnosed.

> I definitely felt like, both like elated and depressed. Cause like now I have an answer for not all, but a good chunk of my symptoms. But the answer is also 'we have no cure' so it wasn't something like, oh you just have, you know like, somethings broken and we'll fix it. I was hoping it would just be something easy, but it wasn't […] the research *[on endometriosis and adenomyosis] i*s so thin, that its nice to have an answer but it sucks that the answer is 'we have no fix, keep living with this awfulness.' (Age 26, Adenomyosis)

Paulina then did a lot of her own research looking at treatment for adenomyosis because she was only given two options from her gynaecologist. The two options were surgery, which is invasive and would leave a lot of scar tissue, or go on birth control to minimize the pain. Paulina has had to become knowledgeable about her chronic pain condition first, to gain a diagnosis, and then second, to understand her treatment options. She was left feeling frustrated saying, "I'm an accountant, not a doctor." Being diagnosed with adenomyosis, and being medicalized (Barker 2005), gave her the label to be able to legitimize 6 years of unexplained symptoms, and helped her go online to find adenomyosis support groups, which will be discussed further later in the chapter.

In another case, Mia described her experiences of undiagnosed chronic pain and being unable to walk which resulted in numerous emergency room visits over 14 years. She shared,

> So it was basically just months of me dragging my butt over there [to physiotherapy], and I had a few breakdowns, and I'm sure they were like what's wrong with this girl. I was fine, five minutes ago I don't know why, I don't know why, why is this happening and why is no one talking to me. I had some people, uhm, when I was sent to doctors to see what this was, they said so what's everyone doing for you? And I said nothing. And they kinda thought I was exaggerating and one woman she even said- they've left you sick? And I said yes, I have been left sick, I don't know what's wrong with me. (Age 50, undiagnosed fibromyalgia)

Mia was sent by her primary care physician for MRI's, numerous tests and to specialists to figure out what was causing her symptoms, but she still has not received a formal diagnosis, although her doctor believes that she may have fibromyalgia. Her symptoms constantly change, which is characteristic of fibromyalgia (Barker 2005). She believes the medical system abandoned her and she has no trust in it. Through this difficult experience of trying to navigate the health care system, she has also developed depression, and for a period of time was agoraphobic where she was anxious to leave her house.

As explained in Chapter Four, participants' mental health is severely impacted by chronic pain. For Mia, she stopped going to medical appointments and instead of trying to figure out what is wrong, she has turned her focus on how she can manage the pain herself through alternative methods including using marijuana for her pain, and microdosing mushrooms to improve her mental health. As mentioned, the connection between mental health and physical pain was prominent for participants, as many had developed feelings of depression and/or anxiety as their physical pain got worse. The stress of having chronic pain, navigating the medical system, and navigating a new identity of someone who is sick can exacerbate pain symptoms, creating a cycle of pain (Babbel 2010).

Charlotte explained how after more than a year of experiencing chronic neck, shoulder and back pain, and getting nowhere with her older male doctor, she finally was able to find a new doctor who is a woman. Yet as she described, this doctor was also unable to help her.

> I made an appointment with her as soon as she became my new doctor and I explained the whole situation. I said most days I can't even move my neck that well, super painful. I get these shooting pains, I don't know how to describe it but it's like sticking a knife into the back of my head. And uhm, she initially seemed very concerned and she was like oh my god that sounds so awful someone should have been doing something for you- like we'll run all these tests. I think I got bloodwork done and that was probably it. I don't know what quote "all of these tests" were supposed to be. I got bloodwork done. I don't know what that was supposed to accomplish because obviously it didn't really show anything abnormal. (Age 21, Occipital Neuralgia)

Charlotte explained that it was case closed after her doctor was unable to detect anything specific through the tests. Although Charlotte continued to book appointments in an effort to try to find answers to her debilitating pain, her only recourse was a prescription for Naproxen, a pain reliever, and some massage and physiotherapy which did not bring relief. Similar to Mia above, she eventually just stopped going to her doctor. She says,

> So eventually I just kind of stopped going to talk to her about it because I felt that there wasn't really a use and I could just learn to live with it and that was how it was going to be. Uhm, because again nobody seemed to really care and they would just write it off or say that it was normal. (Age 21, Occipital Neuralgia)

Eventually however, after several years on the waitlist, Charlotte was contacted by St. Joes Care Group, a local pain management clinic, and invited to see a pain specialist. She saw a specialist who did a complete examination, CT scan, and was given the diagnosis of occipital neuralgia. As she explained,

> It was almost like a holy grail. His assistant reached out from St Joes and said you are on our referral list, we want to make an appointment with you, uhm, the intake will be 90 minutes to two hours, just prepare yourself. And I was like oh okay, this is like a serious appointment. So, uhm, I had hope and I went in and that was the first time that I ever felt acknowledged with the experiences that I had with my pain. And the whole intake process was very, almost validating, because it was the questions I actually wanted to be asked about my experiences. [...] he confirmed a diagnosis that I had, kind of what I had

> self diagnosed myself with at that point due to the research that I had done because of the doctors not helping me. (Age 21, Occipital Neuralgia)

This was a life changing moment for Charlotte, which as she goes on to say, “he has been the only medical professional who has given me any sense of validation or actually treated me properly.” Finding that diagnosis was important because prior to seeing that specialist, she had almost given up on seeking any type of biomedical care for pain, but it reaffirmed her symptoms as she began receiving trigger point injections that have relieved a lot of her pain.

Similarly, Leah had to wait months for an MRI, and then months again for answers while living with excruciating pain. She says,

> I think the most positive one was just like, like getting on board with Dr. X. I think that was like a game changer for me. [...] to have got my test, to have seen him, and had my surgery all in four weeks. It's like, it was huge because it was like, it's like oh, finally, maybe things will get better. Things will be better when I wake up, because somebody's playing with my spine. But like I can't live the way I am. (Age 37, chronic back pain, sciatica and numbness from herniated discs during pregnancy, adenomyosis)

She felt validation because the surgeon took her pain seriously, which brought her hope.

Other participants, however, did not have the same positive experiences with their chronic pain in the health care system in Thunder Bay. Shay explained that she did not receive enough information about her diagnosis of MS until she went to Toronto. She explains,

> They [the doctor's in Toronto] took a long time explaining MS to me, far more than any of the other doctors did. They explained the disease, they explained the diagnosis, they explained the various different treatment options out there. And you know, the one doctor is like, listen, I'm just giving you like these three really big choices between therapies, and I know that you're sitting there and you want me to tell you what I would tell you if you were my own daughter. So I'll tell you that I think you should do this. It's still your choice, but like, if you were my child, I would want you to take this course of action. And I really appreciated that because I was like, thank you for being that personal about it, uhm, you know, and then after they explained everything so thoroughly, they sat back and they're like, it's your turn. Like you have the stand. Like, go ahead and ask us all of your questions. Open up that laptop, ask us everything that you want to know. And it was like such a thorough, in depth conversation and I left feeling so heard and so seen and just taken care of for the first time ever. It was like for the last ten years of my life. [...] finally, like these doctors in Toronto caught me and I felt cared for, for the first time and

> it changed everything. (Age 24, Relapsing and Remitting Multiple Sclerosis (RRMS or just MS for the general term), migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

Although she has not had follow up in Toronto, she felt validated and informed through that experience. The new prescription they gave her changed her relationship to her pain and she was then able to start exercising again, improving her overall energy, happiness, and quality of life. As mentioned in the Introduction, a diagnosis is meaningful for women in that it legitimizes their experiences of pain and can be a life-changing experience for them (Barker 2005).

5.4 Lack of Trust in Medical Professionals

All the participants explained that the physicians they saw lacked empathy when discussing their chronic pain. As discussed, doctors did not offer treatment options for their physical pain beyond medications and referrals to allied health care professionals such as physio or massage therapy for pain management. Participants received care from the medical system, but they explained over and over that their concerns were not heard, or they were told that they must lose weight. Because participants struggled to receive timely diagnoses and did not feel heard by physicians, many seemed to have lost trust in the medical system.

These uncaring interactions with their doctors fits with research by Swoboda (2008), who found that physicians do not know how to treat chronic conditions and this leads to medical encounters whereby patients feel unheard (Swoboda 2008). Participants called the treatments of physio or pain killers as band-aid solutions because they only really offer temporary relief and do not provide long term solutions to their chronic pain. This is similar to findings from Westergården et al. (2021) who found that women with chronic widespread pain felt neglected by medical professionals who did not take their pain seriously, and dismissed their complex pain symptoms, leading women to feel isolated and alienated in their daily life.

Moreover, body size was integral to participant's narratives of their experiences of navigating health care with chronic pain. As discussed in Chapter Two, biomedicine reinforces the discourse in mainstream society that body size and in particular, thinness, equates to health (Taylor and Hoskin 2023), leading to weight stigma in health care and wider society (Puhl and Heuer 2009). As the participants narratives reveal, anti-fat bias and weight stigma were a significant barrier to their care and access to treatment.

5.5 Anti-fat Bias and Weight Stigma in the Medical Encounter

Participants described how gender and body size intersect to lead to stigmatizing experiences in the health care system including dismissal, misdiagnosis, and anti-fat bias. Charlotte, who is a full-time student with occipital neuralgia, raised her frustration with anti-fat bias when dealing with multiple medical professionals. She shared,

> My back hurts? Oh my god you're so fat so of course your back hurts. And I'm like yeah but my neck can't move, well… you could shed some pounds. And I'm like I really don't think that's gonna help [...] and then that also fuels more anxiety and like negative feelings about medical professionals and going to see doctors. Because I personally started making the assumption that, like another fear was… that I don't want to talk about my problems because they're immediately going to equate it to weight or something, like another type of factor. Do you get enough physical activity or exercise? Are you doing physical activity? Are you outside everyday? Are you doing yoga? Listen, I'm telling you literally I'm in excruciating pain and you're telling me to go for a jog. It doesn't make sense. (Age 21, Occipital Neuralgia)

Dismissal from doctors due to her weight is prominent in her experiences. The medicalization of weight reinforces anti-fat bias to the detriment of treating women's chronic pain. Medicalization occurs when fat bodies become medicalized as "obese" through standard measurements, which labels people with an illness based on solely body size (Friedman et al. 2019; McPhail et al. 2023). As Brady, Gingras, and LeBesco (2019) explain, anti-fat bias seeps into all aspects of medicine, and as Charlotte shared, doctors were quick to assume that their chronic pain was a result of their weight and body size. Similar to findings from Jiménez-Loaisa et al. (2020), who interviewed nine fat women to find their experiences of weight stigma in health care, participants were stigmatized by health care professionals as their symptoms were blamed on their weight, causing them to avoid medical encounters. As Charlotte's narrative explained, she is hesitant to make a doctor's appointment or see a specialist because of her experiences being dismissed and ignored as a result of her gender and larger body size.

Mia shared a similar experience to Charlotte. She explained,

> I feel abandoned by the medical system. I just, if you're not fat shamed, I know how they say 'oh your weight' and I'm pretty thin. Considering the Canadian thing, I'm considered obese right now, and I'm like I'm not that big but that's all my doctor cares about. He's just like you need to watch your sugar, I'm not diabetic. But he saw me and he's noticed I've put on some weight, cause I can't exercise, I can't do the amount of labour I used to. (Age 50, undiagnosed fibromyalgia)

Mia, who recently quit smoking, is trying to eat better, and is more focused on herself, feeling healthier now than when she was thinner. Yet, her doctor continues to focus on her weight and body size. This was a shared experience from participants of being dismissed by physicians because of their body size.

Participants discussed wanting biomedical interventions that focus on alleviating their chronic pain instead of interventions focused on their weight. Weight stigma leads to higher rates of anxiety when seeing doctors and navigating the health care system because the focus becomes on 'fixing' weight, while ignoring severe pain symptoms. Puhl and Heuer's (2009) review of fat stigma in health care found that weight stigma and shame from medical professionals has a drastic impact on mental health and health outcomes, which Brady et al. (2019) connect with the 'biochemistry of discrimination' that "describe[s] the physiological impact of individuals' everyday experiences of marginalization" (p 108), meaning that individuals experience greater ill health due to stigma and shame than they do from their actual higher weight. Finally, patients who experience fat stigma within the medical system are less likely to access care and seek preventative care such as screenings for breast, cervical and colorectal cancer due to negative attitudes from health providers and unsolicited advice to lose weight (Puhl and Heuer 2009).

For most of my participants, they have had multiple encounters with medical professionals where their visits were primarily focused on their weight as the cause of their chronic pain, by giving them advice on what to eat, reducing sugar intake, and exercising daily. Hazel describes her experience with her fertility doctor "He made a comment, he said oh you need to lose ten pounds to get your BMI down and that will help you conceive […] its so frustrating to hear like here's a quick fix that once I did it still didn't help which is like the best part right, okay did what you said. But it was difficult because […] like how do I lose ten pounds when my back is killing me so I can't do quick fixes to lose these pounds." Many participants described how their doctors routinely exhibited anti-fat bias and weight stigma through the medical encounter when they come in with serious symptoms, telling them to lose weight, and equating their pain to their weight even when they can not move or get up some days due to pain.

5.6 The Narrowness of Biomedicine and the Health Care System.

Participants described how their pain symptoms are fragmented within their experience of the health care system. They explained how they see multiple doctors and specialists who each explore parts of their condition. These narrow or isolated foci mean that participants are not viewed as a whole person, whose symptoms are interconnected. Shay shared how her symptoms were always changing, she had pain in her entire body that was difficult to explain but it would fluctuate, sometimes she would have migraines, or joint pain, or neck pain. Her symptoms constantly changed and she saw so many specialists who only focused on one aspect of her pain. She discusses her experiences seeing all of these specialists,

> And because it [the pain] was always so different and kind of complex and nuanced, doctors never really saw it as a whole picture. So they would look at one thing in particular, uhm, which was also the problem that I experienced being sent to so many different specialists because every specialist, understandably, looks at the one thing that they are specialized in. But that tunnel vision is so damaging for patients, especially young patients, when everyone is telling you that you're fine and they're invalidating you, because like the tunnel focus was missing so many things and people weren't thinking to look at me in a holistic model. And I kept telling everybody, I'm like, you might not think that symptom A and B are related to symptoms C through Z, but like I am one body therefore everything has to be related in one way or another. And you know what, even if they're not directly correlated, it's still my experience with pain and one symptom is going to exacerbate another symptom because, I feel like shit. So look at me from a holistic model, please for the love of God. But they never did. (Age 24, RRMS, migraines, allodynia, fibromyalgia, sciatica, and two bulging discs in lumbar spine)

The illness narrative that Shay tells is how her illness is unpredictable and frustrating to communicate. Patterson (2021) discusses the importance of moving toward an approach with more fluid communication among patient and doctor with ‘close listening’ techniques for the doctor to gain more nuanced understanding of the patient’s case. With this approach, the patient gains agency as they become the embodied expert and “it repositions the health care professional in respect to the patient’s life, rather than their illness. This affirms the patient’s individual identity […] this form of healing demands a different approach to care; one taught through narrative” (Patterson 2021:328). This approach would alleviate some of the tensions caused by the patriarchal nature of the health care system, as women are not being heard and their symptoms are easily dismissed because biomedicine does not consider women’s narratives to be credible knowledge sources (Gomes et al 2019; Merone et al. 2021; Barker 2005).

5.7 Taking Health into Her Own Hands

Participants developed ways to counter the fragmented care they received in the health care system by continuously advocating for their health, alongside figuring out their chronic pain themselves by doing research about their pain and finding ways to cope with the pain through alternative methods. Mia explains, “it’s just been non-diagnosis after non-diagnosis, I eventually just stopped going. And I’ve come up with my own ways to deal with pain through alternative methods.”

The fragmentations of care that participants experience in the health system causes them to develop strategies to manage their illness themselves, which corresponds to findings from Charmaz (1991), who notes that “ill people become innovators in handling their illnesses, inventors of their lives, and creators of ways of coping” (p 135). All of the participants described a process of becoming experts of their own illnesses through their everyday experiences including accessing care through the health care system. Similar to the findings of Campbell et al. (2022), my participants advocated for themselves and did their own research about their chronic pain because their experiences were dismissed by physicians, as I describe below.

5.7.1 Advocating for Themselves

The adverse experiences participants face in the health care system impact on how they receive care. For example, Leah explained how she had to advocate for herself in order to get diagnostic tests. She explains,

> And that's one thing too, like I’m pretty outspoken. I couldn't imagine someone in my shoes being super quiet and just relying on their physicians, or whoever they see, to kind of guide their health. Because I don't, if I wouldn’t have pushed and not accepted what was being said […] I would have just accepted what people were telling me through like the different specialists that they refer to me to first before Dr. X. So it was just like, yeah, it's like you're fighting tooth and nail for something that should just be a given. I shouldn't have to go to battle just to get an MRI. (Age 37, chronic back pain, sciatica and numbness from herniated discs during pregnancy, adenomyosis)

Leah explains how standing up for herself was not hard to do because she is outspoken, and also stresses how she can’t just rely on physicians to know what is best for her health.

For another participant, Hazel, she explained that her age has led her to advocate for herself more. She explains how when she was younger she would listen to her doctors and not question the care she was receiving. As she grew, she realized that she had to advocate for herself. She shared,

> I definitely was very much like passive and like okay whatever I'll tough it out like, yeah you're right, like I'm too young to be in pain or okay I guess it makes sense that they can't figure it out. I very much was like okay with being swept under the rug or toughing it out. Whereas now, I'm like nope this is unacceptable. I'm tired of this, I'm tired of, you know, I've come to accept that I'm never going to know or have a permanent solution. I think I'd be floored if there was ever a permanent solution. Uhm, but yeah, I'm definitely way more head strong now than when I was younger. And like I don't take just being told that it's this or nothing, or stuff like that. (Age 30, chronic low back pain and chronic shoulder pain)

Hazel knew the care she was receiving was unacceptable and it took time and negative experiences for her to gain the confidence to advocate for herself. Now, she advocates for herself in many ways. For example, she was told by a surgeon that they could not do cortisone injections in her shoulder and was instead prescribed pain medications, which she did not want to take. She resisted the prescription, and instead demanded radio frequency neurotomy. Once he agreed, the specialist wanted to use this treatment on both sides of her back; however, she knew that she only needed it on the one side, given that she had been getting this treatment on one side for the previous 11 years by a doctor in Winnipeg with successful results. She explained,

> When he said he was gonna do it on both sides I had to stand super strong on that and argue with him, and then get my doctor in Winnipeg to send a report just to prove, no, I don't need it on both sides. I know where my chronic pain is, I'm not stupid. And I've been doing this for years like don't tell me that this is how you're gonna do it when that's not what I want or need. (Age 30, chronic low back pain and chronic shoulder pain)

Hazel is confident in her experiences to insist that her doctor listen to her because she knows her pain best. Moreover, she demonstrates resiliency through this experience in holding strong to what she knows she needs. Some participants however find it hard to speak up for themselves because when they do they are shut down by their doctor's leading them to do their own research, and search for alternative methods to treat their pain.

5.7.2 Doing Their Own Research

All participants shared how they have done their own research over the course of their pain experiences because they did not receive enough or good information about their conditions from their health care providers. Mia, an older participant explains,

> I had to do my own “research” as I like to do, with my own quotations, because it's scary to do your own medical research. I shouldn’t have to look up spinal meningitis and uhm, regenerating encephalitis. I’m becoming a medical expert on chronic pain and I’m just an artist, right. (Age 50, undiagnosed fibromyalgia)

She had to become an expert, which she notes using scare quotes, of her own chronic pain.

This corresponds with Swoboda’s (2008) findings who says that when women experience a loss of control and autonomy in relation to their health, they seek to find control through alternative outlets, as I mentioned earlier in the chapter. The participants go online, read articles and books, watch videos, and talk to other people in online support groups and forums, to help them manage their chronic pain and in the process, they become lay experts because of their knowledge in tandem with their embodied experiences. Swoboda (2008) also found that women “forge an understanding of their illness based on experiential knowledge of their bodily symptoms combined with input from other individuals with contested illnesses” (p. 91). Charlotte explained,

> I spent years researching like uhm, acute intense neck pain, skull pain, all these different things and I'd read research articles and journals and you know, whatever I could find that vaguely resembled what I was going through. And one day I landed on what was labeled as occipital neuralgia and I spent like weeks reading about it. I read so much, I read every aspect of it. And I said this is it, like no one can tell me that this isn't exactly what I've been experiencing. Especially when up until that point I've been offered no

> other explanation and I've basically been told you know sometimes psychologically we make up pain, which again was something a man told me, and I was like oh… is that something ‘we’ do? [...] If you go see a professional and they're like dismissing you and they don't want to hear about your experience then yeah, where do you turn? The internet. And you try to figure it out yourself. Cause I never got any answers, I kept getting prescriptions, I kept getting told go to physio do these stretches, stay hydrated it will help the pain. (Age 21, Occipital Neuralgia)

Because she experienced multiple dismissals from health care providers and didn’t feel as validated by doctors who she trusted to find out what was wrong with her, she turned to the internet to figure out her pain for herself. In seeking alternative information, Barker (2005) explains that that women seek to gain back control over their diagnosis, treatment, and management.

Yet this experience of being dismissed and not entirely believed by physicians led participants to thinking about giving up seeking help. One participant, Mia, entirely stopped trying to find answers and interventions from the health care system. She completely stopped going to medical appointments and seeking help from her physicians.

Most participants explained feeling intimidated by having to undertake their own research because they are not medical professionals. They acknowledged that there is so much information online that can lead them to trying many treatments in a process of trial-and-error for different types of pain. Yet most participants dance back and forth between information provided by their health care team and what they discover from their own research. Paulina explains,

> It's like oh is Tylenol working- no, Aleve no, Advil no, and then, so now, kind of, my pain regime involves, you know I’ve got it down, not got it down to a science cause I know there’s still things I could probably add but like I have this really strong CBD cream that I’ll apply to my abdomen or my back, uhm, I’ve got heating pads which are really useful for my pain, and then like taking the birth control consistently has reduced my pain for the most part to a level where I’m able to function. And kind of like using these kind of tools now that I’ve kind of been able to figure out what the problem is, I have the diagnosis as adenomyosis, it’s allowed me to kinda be like okay this is the problem and these are the tools that I’ve, that the internet said will work so then using these tools have brought me back to a place where I am able to function at a level that I

> see is okay for me [...] Obviously, pain is not linear, I do still have bad days or days where I have flare ups or forget to take my meds and need to call in or whatever, but for the most part I definitely feel like I am on my way to like the focus that I had cause of the resources that I accessed but not because of the resources I accessed locally. (Age 26, Adenomyosis)

Paulina has gone online through Instagram pages and Facebook groups to find information and support from others with adenomyosis. She mentions that the online community is what has helped her find the tools and techniques to help her manage her pain and find support, as she hasn't found a lot of local support groups because, she suggests, Thunder Bay is small compared to larger cities who have specific adenomyosis support groups. For several participants, finding community with women who share similar conditions was something that helped validate their experiences as they feel less isolated with their symptoms, and build knowledge from other women's experiences.

5.7.3 Alternatives to the Health Care System

Participants explain how they use alternative strategies to manage their chronic pain experiences in ways that the medical system could never help. As mentioned, most participants weave in and out of the health care system because they continue to access treatments such as cortisone injections, trigger point injections, and radio frequency neurotomy. They also described seeking help from physiotherapists, chiropractors, and massage therapists; and some still seek to get answers about their pain. Yet they also seek out their own ways to make sense of their pain and use alternative solutions such as going to therapy, reading books about pain and women's health, using heat and ice to reduce pain, stretching, using creams and icy rubs, using marijuana, and finding support with their friends and family.

Leah explains that during her pregnancy, when her pain developed, she lost most of her mobility and could no longer walk. She shares that during that time, her family and friends became the biggest support for her in managing her pain and her mental health. Also, she described starting to see a mental health counselor again mid-way through her second pregnancy to help her to deal with the emotions she experienced due to her pain.

> I've been in counseling on and off since, like my late teens, and I believe in maintenance, like not consistently every day of your life. But, like you know, you have hurt and loss and grief from pain, but I think it's important to you know, process that properly. So it's not sitting within and eating at you. So that was a huge thing for me to walk through that, and to have that mirror and sound board to reflect and process to, you know, be able to move forward. (Age 37, chronic back pain, sciatica and numbness from herniated discs during pregnancy, adenomyosis)

Similarly, another participant, Mia turned to alternative methods of treatment and care after seeing multiple specialists and doctors without any clear answers about her pain or remedies that helped. She began using marijuana to relieve pain symptoms, which she explained helped immediately,

> I was in so much agony once the pain started. At first it was just a flu. I had pins and needles, I was numb, I couldn't walk right. But now there's this chronic ache that was in me, and my partner just couldn't handle watching me just lay there and he came home with drugs. He said I got you some marijuana, try some. And I was a smoker so it wasn't a question of smoking anything, so I don’t like being high. It's not anything that I ever want to be. And so I did and instantly felt better, I even jumped out of bed and got the remote control which I hadn’t done in years, right I was just this 80 year old trying to wobble around the house. And that was wonderful but I don’t like being high. And with mental health issues you don't want to mess with your anxiety and marijuana can be really bad if you don’t know what you're doing which I do not know what I’m doing. So, I’m glad now there's medical background on this stuff, so you can buy stuff now that doesn’t get you high. (Age 50, undiagnosed fibromyalgia)

Marijuana provided her with enough relief to do some of the things that her pain restricted her from doing, something she never felt from any medication or physical therapy prescribed to her by a doctor. According to Hoffmann and Tarzian (2001), a greater number of women than men use complementary and alternative approaches to health because of their lack of confidence in biomedical interventions.

Participants' pain is complex, and the women have developed their own pain management strategies that work for them using interventions from the medical system, and from their own research and experiences. As they see it, this provides them with a more comprehensive treatment than what has been offered to them in the medical system. This aligns with Swoboda's (2008) research findings that stress that in seeking of their own information, they become empowered to manage and take back control over their pain.

5.8 The Importance of Holistic Health Care for Women

The majority of women's experiences in the health care system have been negative, some participants even state that 100% of their experiences are negative and they have no positive experiences to share while others share one or two stories of positive experiences they have had. Whether it's finally finding a doctor or specialist who is empathetic and sees them holistically as a whole person, or when they go out of town and experience better care than what they have received in the health care system in Thunder Bay. Sarah explains a positive experience with her nurse practitioner John. She says,

> It took a long time to find a new family doctor, because when mine retired we didn't have any here, so it was really hard to find one. So when I eventually did that was really helpful, and the first one that I had was a nurse practitioner, and he was phenomenal like, I felt like we were getting somewhere. And then he went to an outreach program with the shelter house, and I got a new family doctor, and she is great, but she's not John, like John, surprisingly, but I think a lot of it, and he was very open about, uh, he was a very openly eccentric and gay, and like worldly man like he was just very open about how Lgbt+ he was, and I think that was really helpful, too, because he saw the health care system in a very different way than like a traditional doctor who may not see the barriers that people face, and that was really helpful. (Age 30, chronic sciatic nerve pain)

John acknowledged and understood the barriers that some people face in the health care system. He could also see the gaps in care because of his experiences as a gay man. Having a medical professional who may share aspects of identity with you or have an identity that does not follow the normative masculine or feminine expectations for physicians creates a different dynamic between patient and doctor. Sarah explained that she felt he understood her more, she felt heard by him, and he also provided better care for her than any other doctor. In physician-patient relationships, patients feel more connected to their physician when they have a shared standpoint and see similarities to their beliefs, values, and communication (Street et al. 2008). The relationship becomes strengthened as patients build trust with their physician and find it easier to navigate the health care system as they do not have to worry about being understood (Street et al. 2008).

5.9 Summary

Participant's narratives demonstrate the challenges posed by the health care system in Thunder Bay, particularly at the intersections of their chronic pain as this experienced in relation to place and their gender, age, body size, and ability. The chapter explored participants gendered experiences in health care, particularly how their social positionalities created challenges in being diagnosed and dismissed by medical professionals, causing them to lose trust in the health care system. The authority of biomedicine has caused participants pain narratives to be ignored as discourses surrounding women's bodies, health, and chronic pain cause women to be seen as untrustworthy in relation to their own embodied experiences. Participants experienced weight biases as doctors medicalize their body size over their chronic pain symptoms, which created gaps in proper treatments and finding a label for their pain. Participants' sense of self is disrupted by their experience of chronic pain, and their treatment in the health care system as they try to navigate their own grief and acceptance of their pain, alongside the dismissal that has defined their experiences. Participants weave in and out of the medical system, but they have all sought to medicalize their chronic pain, as they value the label of a diagnosis for understanding, treating, and legitimizing their pain experiences.

As participants have learned to accept their pain and have taken back some control in their autonomy and illness, they become empowered when they begin to self advocate for themselves. They do their own research and find alternative strategies to help manage their pain. Moreover, they want to be seen holistically by their doctor's and the health care system, which gives them agency over their experience.

Ch 6: Conclusion

Throughout this research, I have explored women's experiences with chronic pain in Thunder Bay, through an intersectional feminist narrative approach. Through interview data with eight women who self-identified as having chronic pain, I was able to explore their lived experiences in the health care system and the impact chronic pain has on their sense of identity. The main questions guiding this research were: How do women experience chronic pain, and what impact does chronic pain have on one's sense of identity? How do women draw on broader social and cultural discourses about the body and health to interpret their experiences of chronic pain? How are social differences such as race, social class, ethnicity, age, ability, and gender experienced in relation to chronic pain? This chapter explores the main arguments presented throughout the thesis with focus on the significance of biographical disruption, the intersections of participants experiences, and being medicalized. Limitations of the research will also be considered. This thesis adds to feminist, sociological and critical disability literature by utilizing an intersectional analysis to study the self in chronic pain through the concept of biographical disruption (Bury 1982; Charmaz 1995; Williams 2000) uncovering the intersections of women's experiences.

Participants' narratives highlight how they navigate femininity and ability alongside their education, work, parenting, relationships, mobility, and mental health. For all participants, their sense of identity has shifted following the onset of chronic pain, leading to a biographic disruption (Bury 1982; Charmaz 1995) as they are forced to navigate a new life with bodily physical limitations. Using intersectionality alongside biographic disruption allowed me to understand how their social positionalities impacted the pain experience. Participants' experiences were gendered as expectations of femininity fueled how they understood their chronic pain including the impacts to their physical bodies. Each participant faced their own interruption to the self, however there are shared experiences that take shape based on the social and environmental context. For example, the onset of chronic pain at a young age was a huge disruption for most participants as their identity did not match with what their body could do. Additionally, the identity of being a mother was disrupted as participants feared no longer being able to care for their children in ways expected of them. All participants have had to rethink their identity as women with chronic pain at the intersections of age, ability, and motherhood, as these points of identity shift their own knowledge about themselves and their health.

Participants' experiences were dependent upon their social positionalities as the social structures and accompanying ideologies surrounding gender, age, ability, body size, social class, and place are embedded with power. This plays out within the institution of medicine whereby participants experienced biases related to their identity, causing them to majority of their experiences in the health care system to be negative. This creates unique challenges for women when accessing health care, finding resources, and getting treated in the health care system. Participants experienced their body size being medicalized, but not their chronic pain symptoms. This caused them to seek out a medical label for their symptoms in order to legitimize their pain. Participants were empowered when they took their health and experience of chronic pain into their own hands, choosing to seek out their own resources and finding alternative approaches to managing their care. This gave them space to take back some of the power and autonomy that the health care system has not given them. As mentioned in Chapter Five, the intersections of gender, place, and body size were at the forefront of participant's experiences.

6.1 Outcomes of using an Intersectional Framework

Using intersectionality as a theoretical and heuristic device (Carbado et al. 2013; Romero 2023) within the narrative approach when studying women's chronic pain facilitated a deeper understanding of the complexity of pain through women's lived experiences. Very little research uses intersectionality as a framework to study chronic pain (Jackson 2021). This research took a unique approach with an intersectional narrative framework (Carbado et al. 2013; Collins & Bilge 2016; Romero 2023; Creswell and Poth 2016) As mentioned in the Introduction, Campbell (2023) employed intersectionality and biographical disruption together in his study of participants with HIV however, to date, no study has explored biographical disruption in relation to chronic pain using an intersectional approach.

In this thesis, the concept of biographical disruption remains salient in explaining the gendered realities of participants everyday experiences of chronic pain. Not surprisingly, chronic pain impacted their relationships, education and employment, and mobility and autonomy, while at the same time, participants were grappling with restructuring their sense of self within a new disabled body (Bury 1982; Charmaz 1995; Barker 2005). A feminist analysis of biographical disruption provides a greater depth of understanding about the structural constraints of biomedicine and femininity that women face in making sense of their new identity. This adds to the feminist literature as biographical disruption has rarely been theorized through an intersectional lens. Within an intersectional analysis, we learned the ways that the biographical disruptions that participants experience at the onset of their chronic pain are structured based on their gender, age, ability, and body size.

6.1.1 Place as an Intersection

Intersectionality is useful in studying chronic pain in Thunder Bay because the analysis can centre on the geographical constraints of a hinterland region as it is experienced by women. The health care system imposes health inequity on this group because of its northern location. Place, as Thunder Bay is socially constructed in relation to health care, is a prominent barrier for participants when they try to access suitable and appropriate care for their chronic pain. The intersection of place with participants experience of health care was similar for all women as their experiences highlighted long wait times, a lack of doctors and specialists, and a lack of treatment options available. Participants experiences were further gendered, as their interactions with doctors showed how their pain symptoms were dismissed and heightened due to the intersections of age and body size. Participants feel invisible and unheard in their interactions and when trying to access treatment, their pain was often considered a symptom of their gender or body size rather than a specifiable condition.

6.1.2 Body Size as an Intersection

Body size is often not considered as an intersection of identity within research (van Amsterdam 2013; Friedman et al. 2019). Farrell (2023) argues that gender and fatness not only connect, but they constitute each other as individuals are perceived by others through their body and gender. Within this research project, an intersectional analysis made visible the prominence of body size as a structural inequality that women face when accessing health care services. Participants experienced weight bias in their encounters with medical professionals, where their body size was medicalized, instead of their chronic pain symptoms. It is prominent for women with chronic pain, of varying body weights, to experience weight stigma in medical encounters with medical professionals (Mensinger and Olson 2019). Sedney et al. (2023) found that women with higher BMI report increased levels of weight bias and pain stigma compared to those with a lower BMI. As mentioned throughout the thesis, pain stigma is prominent for women where the biomedical system lacks the tools necessary to understand chronic pain and as a result, dismisses, ignores, and does not believe women's symptoms (Sedney et al. 2023). Then, when body size is added to that, women are further dismissed through weight-related interventions, as weight becomes medicalized through biomedical standards (Sedney et al. 2023; McPhail et al 2023). This directly relates to how participants in this study struggled to be taken seriously and get a diagnosis, especially when their body size was medicalized over their chronic pain. Weight stigma remains an under acknowledged area in pain research and the intersection between gender, body size, and pain is an area for further feminist research (Mensinger and Olson 2019).

6.2 Medicalization

Medicalization was a prominent theme throughout this thesis. Women's bodies become medicalized as natural bodily processes are treated as medical phenomena that medical professionals seek to treat (Barker 2005). As mentioned in the prior section, fat women are further medicalized through "obesity" discourses that enforce the idea that body size equates to health (McPhail et al. 2023). For my participants, they are conflicted about being medicalized by a diagnosis for their chronic pain. This tension of wanting a proper diagnosis to legitimize their experiences and wanting to resist biomedical discourses that have dismissed and minimized their symptoms (Barker 2005) was central to the participants narratives. It was important for my participants to be diagnosed because it gave them the label to become credible in their own lived experiences. As well, it is helpful to them in their own understanding of what their chronic pain experience means, allowing them to do their own research online and in forums to find resources and support with others who experience the same diagnosis. Being medicalized is a complicated process for my participants as many of them weave in and out of the medical system, hoping for a medical intervention that will help, while also contemplating giving up on seeking help in the system that lacks the tools to understand their pain.

6.3 Limitations

There are limitations to my study. First, as mentioned in Chapter 3, my sample was fairly homogenous racially, as the majority of my participants were white with one participant self identifying as Metis. Having a racially diverse sample would have added depth to our understanding of the chronic pain experience because as is, the study mainly reports on the intersections of place, gender, age, and body size. This created a gap in knowledge as we have not heard from racialized women's voices in the discussion of their experiences with chronic pain in Thunder Bay's health care system. Social and cultural positionalities have a significant impact on chronic pain and one's experiences in the health care system, especially in Thunder Bay where there is a large population of Indigenous people who face multiple intersecting inequalities when accessing health care (Lin et al. 2023). As a result, white women might experience better care than Indigenous women because of the intersection of race and gender, which further research could explore. Understanding the health care and chronic pain experiences of Black, Indigenous, and women of colour would have added to this research and in future, must be considered in NWO.

As well, the timeframe under which I conducted this research was limited because of my status as a Master's student. I was only able to conduct 8 in-depth interviews with participants, which is a small sample size. I recognize that in qualitative research there is some debate over how many interviews one should carry out. Some suggest sample sizes of 20+ individuals and emphasize theoretical saturation, which uses a "more is better" sampling approach (Rijnsoever

2017), wherein a feminist narrative methodological approach, sampling using a “less is more” philosophy is better for exploring in-depth the narratives (stories) of a group of people (Fraser and MacDougall 2017). Because I am in no way seeking generalizability and using a qualitative methodology, I chose to proceed with a sample size of 8, which led to a very rich set of narratives.

6.4 Future Research

To further understand the diversity of intersectional narratives of chronic pain, future studies are needed. Fist as I mentioned, future studies must consider racialized women’s chronic pain narratives, particularly the experiences of Indigenous women, Black women, and women of colour, and center their voices, as these narratives will offer insights that may differ from white women. There is also reason to explore women’s chronic pain further in the context of critical disability studies because many women end up on disability as a result of their chronic pain experiences. Lastly, future research should continue to explore the connection between intersectionality and biographical disruption as a feminist concept when understanding women’s chronic illness and pain experiences.

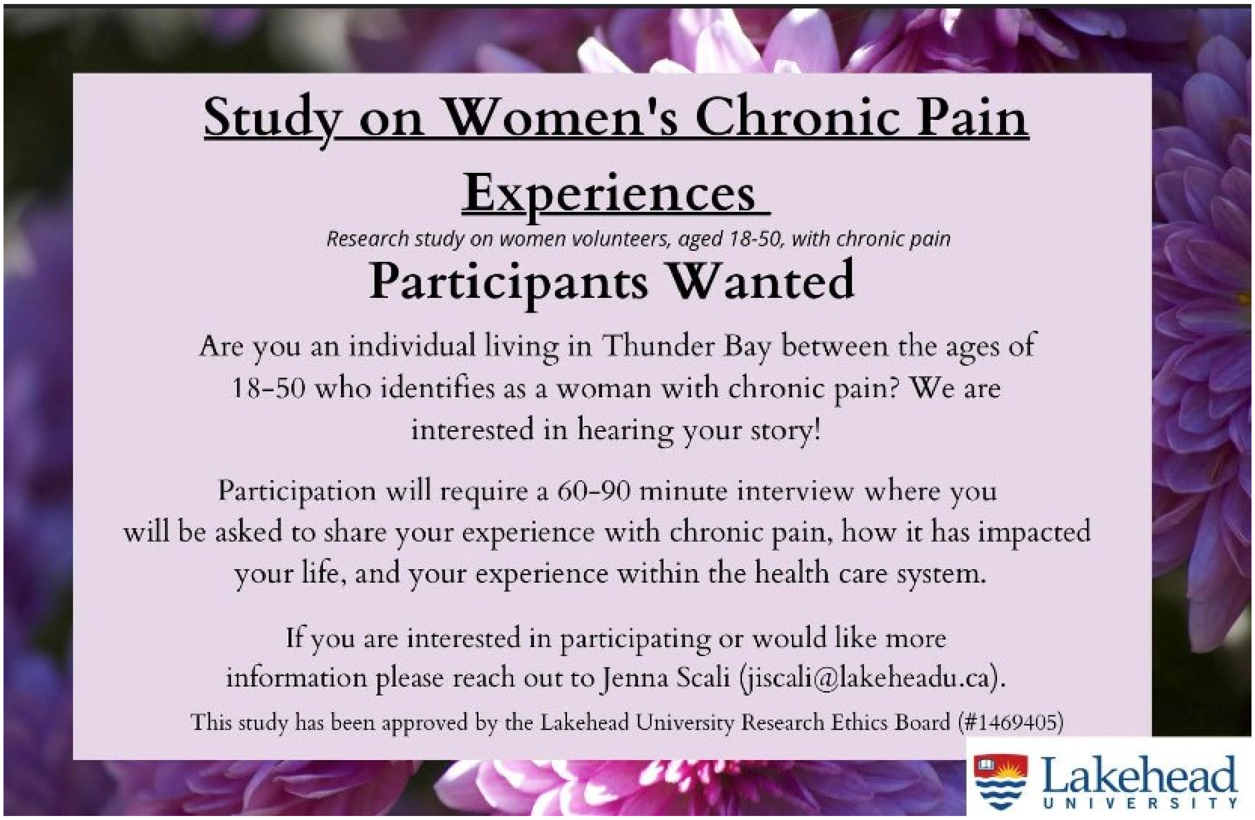
6.5 Conclusion

The findings presented adds to our understanding of the experiences of women’s chronic pain in the context of a feminist intersectional narrative study in Thunder Bay, NWO. There were significant impacts in accessing and navigating the health care system in Thunder Bay, with challenges of being diagnosed and finding interventions to help alleviate their pain, yet participants sought out medical labels to legitimize their pain. My thesis uncovers how women’s experiences in the health care system are informed and experienced their gender, ability, age, body size, and place. For participants, the health care system itself perpetuates ableist, ageist, and anti-fat biases.

Participants' sense of identity greatly shifted as the physical and emotional aspects of chronic pain impacted their everyday life and how they understood their past selves. Discourses about femininity and the normative body were present throughout participants' constructions of the self, which women both took up and resisted. The findings add to our understanding about the self using biographic disruption alongside intersectionality to illustrate experiences of women's chronic pain.

Appendixes

Appendix A: Recruitment Poster



Study on Women's Chronic Pain Experiences

Research study on women volunteers, aged 18-50, with chronic pain

Participants Wanted

Are you an individual living in Thunder Bay between the ages of 18-50 who identifies as a woman with chronic pain? We are interested in hearing your story!

Participation will require a 60-90 minute interview where you will be asked to share your experience with chronic pain, how it has impacted your life, and your experience within the health care system.

If you are interested in participating or would like more information please reach out to Jenna Scali (jiscali@lakeheadu.ca).

This study has been approved by the Lakehead University Research Ethics Board (#1469405)

Lakehead
UNIVERSITY

Appendix B: Interview Information Letter

Information Letter

A Feminist Analysis of Women's Chronic Pain Experiences in Northwestern Ontario

Dear Potential Participant,

My name is Jenna Scali, and I am a graduate student at Lakehead University in Thunder Bay, Ontario. I am currently working towards an MA degree in Sociology with a specialization in Women's Studies. My master's thesis project is about women's experiences with chronic pain and its impacts on women's lives and sense of identity. My interest in this topic comes from my own experiences as a woman who has chronic pain.

About the Study:

Throughout my university education, I have had a place to share my experiences with my professors and fellow classmates and use my story to inform my academic work. When I started studying women's health and chronic pain, I noticed a vast gap between the biomedical and social understanding of health. Our identities play a huge role in our access to health resources, how we respond to our health, and how we learn about health which is an important area that requires further research. Using my own experience to study women's chronic pain has allowed me to find empowerment in my work and provide women with a space to share their stories.

My research objectives are to:

- Empower women by listening to their voices
- To better understand the ways in which women experience chronic pain
- To create knowledge based in women's lived experiences
- To contribute to the scarce research and knowledge about the social impacts related to women's chronic pain

For this project, I am looking for participants who identify as women and who are between the ages of 18-50 who self-identify as having chronic pain (pain that persists longer than 3 months; examples can include but are not limited to conditions such as endometriosis, fibromyalgia, chronic pelvic pain, chronic joint pain) and must live in Thunder Bay. If you agree to participate in this research, I ask you to participate in a 60–90-minute interview in-person or on Zoom. Your comfort and safety are valued so you will be able to choose the environment which best suites your needs. Also, the interview will be scheduled at a time of your convenience where we will talk about your experiences with chronic pain and how it has impacted your life. The interview will be audio recorded digitally with your permission and later transcribed.

Ongoing Consent: Your participation is completely voluntary. You may refuse to participate or may discontinue your participation at any time before, during, or after the interview. You have the right to refuse to answer any question and we can take breaks at any point. After the interview, you may contact us to withdraw from the study up until the time that your transcript has been made anonymous and pooled with the rest of the transcripts.

Privacy and Confidentiality: All the information you provide during the interview will be strictly confidential, and no information that identifies you will be made public or published unless you indicate otherwise. To protect confidentiality, the interview transcripts will be anonymized by providing each participant with a pseudonym. In the dissemination of results, participants will be referred to by their pseudonyms, along with their gender and ethnicity.

Audio records and original transcripts of the interviews will be stored for five years on a password-protected Dropbox folder only accessible by myself and my supervisor. The paper records will be stored in a locked filing cabinet in my supervisor's office at Lakehead University. Following this study, digital data and paper records will be retained for long term preservation. Your data will not be used for any future research project.

Potential Risks and Benefits: There are no foreseeable risks related to your participation in this research. While I do not anticipate that the research will cause harm of any sort, I am mindful of the fact that some topics that we will discuss might cause you to feel upset or distressed. I am also mindful of the fact that there may be trauma behind your experiences. I have included a list of mental health and women's health resources for you to access in Thunder Bay should you require support following the interview. In addition, your willingness and bravery to share your stories will contribute to a better understanding of women's chronic pain in this region and contribute to broader knowledge of the social aspects within women's health.

The result of your interview will be used for the completion of my thesis as well as for potential academic publications and presentations. A copy of the thesis and other publications will be available for interested participants. After June 2023, you may call or email either myself or Dr. Parker to request a copy of the study results.

Attached you will find a consent form that is to be signed by you before we will start the interview. The interview is completely voluntary and confidential.
If you have any questions about this research, please contact me at (807) 632-7497 or jiscali@lakeheadu.ca; or my supervisor, Barbara Parker at (807) 343-8792 or Barbara.parker@lakeheadu.ca.

This research study has been reviewed and approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

Thank you for considering participating in this project.

Sincerely,

Jenna Scali

Contact Information Student Researcher:
Jenna Scali
MA Sociology candidate
Lakehead University
Phone: 807-632-7497
Email: jiscali@lakeheadu.ca

Contact Information Supervisor:
Dr. Barbara Parker
Associate Professor of Sociology
Lakehead University
Phone: 343-8792
Email: Barbara.parker@lakeheadu.ca

Appendix C: Consent Form

Interview Consent Form

Project Title: A Feminist Analysis of Women's Chronic Pain Experiences in Northwestern Ontario

Researchers: Jenna Scali (student researcher), Dr. Barbara Parker (supervisor)

STATEMENT OF CONSENT

My signature on this consent form means the following:

______I have read and understand the information contained in the Information Letter.

______I agree to participate in the project and have been told that I can change my mind and withdraw from the study at any time prior to the anonymization of the transcript. I also understand that I can withdraw from the interview at any time without penalty, and may choose not to answer specific questions or discuss certain subjects.

______The risks and benefits of the study have been explained to me.

______The data collected from this interview will be securely stored at Lakehead University for a period of five years.

______ I understand that the research findings will be made available to me upon request by email to the researchers after June 2023.

______I understand that I will remain anonymous in any publication or public presentation of the research findings.

______I have had a chance to ask any questions about the project.

Name of Participant (Please Print): ________________________

Signature: ____________________________ Date: ________________________

If you have any questions about this research, please contact Jenna Scali at (807) 632-7497 or jiscali@lakeheadu.ca; or Barbara Parker at (807) 343-8792 or Barbara.parker@lakeheadu.ca.

This research study has been reviewed and approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca

Sincerely,

Jenna Scali

Contact Information Student Researcher:
Jenna Scali
MA Sociology candidate
Lakehead University
Phone: 807-632-7497
Email: jiscali@lakeheadu.ca

Contact Information Supervisor:
Dr. Barbara Parker
Associate Professor of Sociology
Lakehead University
Phone: 343-8792
Email: Barbara.parker@lakeheadu.ca

Appendix D: Demographic Questionnaire

Demographic Questionnaire

Please take a moment to complete this short questionnaire. Your answers will remain confidential and will not be linked to your name or interview responses. The answers are intended to tell us about the overall diversity of our sample. You may choose to not answer any question.

1. **What is your gender? What are your preferred pronouns?**

2. **In what year were you born?**

3. **With what race/ethnicity do you identify?**

4. **What is your sexual orientation?**

5. **What is your medical condition/diagnosis?**

6. **How long have you lived with chronic pain?**

7. **Do you work? Full time, part time or casual?**

Appendix E: Interview Guide

Interview Guide

1) Tell me about your experience of chronic pain.

   Probes: how did your pain start? At what point did you decide to reach out for medical help?

2) Have you experienced any obstacles or barriers in the care you received within the health care system?

3) How has your experience in the health care system been positive?

4) How do you interpret your experiences of chronic pain in hindsight?

   Probes: were there any books, interviews, or podcasts that helped you make sense of your experience?

5) What aspects of your life have changed since the onset of pain?

   Probes: are there any impacts to your relationships… work… hobbies; impacts to how you feel about yourself; impacts to your emotions and feelings.

   How would you compare the person you were before pain with the person you are now?

Appendix F: Resource List

Women's Health, Mental Health, and Informative Resources

Mental Health

Crisis Response Line: Canadian Mental Health Association Phone # 807-346-8282 | District/Toll Free: 1-888-269-3100 or Kenora/Rainy River Region: **1-866-888-8988**

- Open 24/7, 7 days a week, 365 days a year and provide mental health services for anyone in need.
- **Crisis response mobile unit:** crisis response workers who are available from 12pm to 12am everyday within Thunder Bay who are able to go on site of a crisis and deescalate any immediate crises and provide support for individuals and families.

Thunder Bay Counselling: 544 Winnipeg Avenue, Thunder Bay ON**,** Phone # 807-684-1880

- Thunder Bay Counselling is a not-for-profit organization that provides counselling, psychotherapy, education and support services. They also offer addiction and mental health services, financial counselling, child and youth counselling, and multiple counselling programs.
- They offer free walk-in counselling every Wednesday from noon to 8:00pm on a first come first served basis. The walk-in counselling is at Thunder Bay counselling the 1st and 3rd Wednesday of the month and at the Children Centre Thunder Bay the 2nd and 4th Wednesday of the month. They also have free childcare during appointments.
- Website: https://www.tbaycounselling.com/
- Email: community@tbaycounselling.com

Dorset Pier Mental Health: 277 Park Avenue, Thunder Bay ON, Phone # 807-333-0896

- Dorset Pier Mental Health provides mental health services that provides tools for clients to empower themselves and cope with stress and trauma. They value creating a safe and comfortable space for individuals based in patient autonomy, growth, and development. They also offer animal therapy with their dog and bunny.
- Each of their therapist are specialized in specific areas such as trauma, anxiety disorders, 2SLGBTQ+ informed therapy, domestic violence, and Indigenous supports.
- They often offer funded programs with free counselling sessions and quick appointment turnarounds as they understand access to mental health services is extremely limited. Check out their website (https://www.dpmh.ca/) or Instagram (@dorset-pier.mental.health) for when they offer these programs.
- Email: support@dpmh.ca

Sexual Health and Women's Health

Umbrella Clinic: located within the Thunder Bay Medical Centre, 63 Algoma Street North, Suite 350. Phone # 807-698-7200

- The Umbrella Medical Clinic provides sexual health services and gender affirming health care to all individuals in an accessible, compassionate, and non-judgemental environment.
- Website: https://umbrellaclinic.com/
- Email: info@umbrellaclinic.com

Nor-West Community Health Centre: 525 Simpson Street, Thunder Bay ON, Phone # 807-622-8235

- Nor-West Community Health Centre aids in individual and local community needs by providing a range of health services through a social justice approach. They provide holistic, comprehensive, and integrated health care by improving access to services and reducing barriers in accessing health care.
- Website: https://www.norwestchc.org/locations/thunder-bay

Talk4Healing: Phone # 1-855-544-4325- call, text, or use their online chat option.

- Talk4Healing offers 24/7 culturally grounded help, support, and resources for Indigenous women, by Indigenous women across Ontario. They offer services in 14 Indigenous languages.
- They also have a crisis line: **Toll-free: 1-888-200-9997 Thunder Bay: 807-346-4357**
- Website: http://www.talk4healing.com/

Women's Centres

Ontario Native Women's Association: 684 City Road, Fort William First Nation, ON, Phone # 1-800-667-0816

- The Ontario Native Women's Association is a not-for-profit organization to empower and support all Indigenous women and their families through research, advocacy, policy development, and programs that focus on local, regional, and provincial needs.
- They offer culturally relevant. mental health services, programs ending violence against Indigenous women, community wellness programs, resources related to health, victim services, homelessness, and poverty, and more.
- They have a health clinic for Indigenous people called the Mindimooyenh Health Clinic focused on offering a holistic community member driven approach to health care. Located at 380 Ray Boulevard, Thunder Bay, ON, phone # 807-697-1753
- Website: https://www.onwa.ca/

Northwestern Ontario Women's Centre: 73 North Cumberland St, Thunder Bay ON, Phone # 807-345-7802

- The Northwestern Ontario Women's Centre is a non-profit community-based feminist organization that works with women to increase access to knowledge, skills, and resources in a safe environment.
- The centre offers resources and supports for a variety of issues such as poverty, family, child welfare and criminal law, immigration, sexual harassment, health care and more.
- Website: https://nwowomenscentre.org/ Email: ed@nwowc.org

Chronic Pain

St. Josephs Care Group

- St. Josephs offers a Chronic Pain Management Program that focuses on maintaining and improving physical, psychological, behavioural, recreational, spiritual, and vocational aspects of life.
- They offer a 6-week intensive, daily group program to focused on support and education. They also offer pain Assessment Collaborative Education Interprofessional Therapy for an individual approach to chronic pain support.
- Website: https://sjcg.net/services/mental-health_addictions/outpatient/pain.aspx

Appendix G: Description of Participants Chronic Pain Conditions

Chronic Back Pain

Chronic back pain is a pain that persists for longer than 12 weeks and can range from a dull pain, constant ache, to a sharp sudden pain (National Institute of Neurological Disorders and Stroke 2023). Back pain can include disc bulges or herniations throughout the spine. Discs act as “cushions between the vertebrae in your spine. They're composed of an outer layer of tough cartilage that surrounds softer cartilage in the center” (Mayo Clinic 2022a:np). Discs can deteriorate over time and create changes to the spine, causing the outer layer of the disc to bulge which may cause pain (Mayo Clinic 2022a). Disc bulges are not as severe as disc herniations. Disc herniations occur when the tough outer layer of cartilage cracks and inner cartilage protrudes out of the disc (Mayo Clinic 2022a). This can cause a lot of pain as it hits nerves in the spine. Lower back pain is most common among Canadians, as almost a quarter of those living with chronic pain have low back pain (Schopflocher et al. 2011).

Chronic Sciatica Nerve Pain

Sciatic nerve pain is “a type of nerve pain that radiates down the back into the hip and leg, usually because of a herniated disk. It often goes away in a few weeks, but can become chronic” (Medical News 2020:np). Chronic sciatica causes long term pain, and is most commonly caused from a herniated disk or spinal stenosis but can also be caused by inflammation, infection, spinal mass or cancer, and spinal misalignment (Medical News 2020). Symptoms include “electrical sensations along the side of one leg, pain that radiates from the lower back to the hip and down the leg, intense leg cramps, pain when walking or moving, numbness in the legs, hips, or lower back, and pain when sneezing or coughing” (Medical News 2020:np).

Occipital Neuralgia

Occipital neuralgia is a condition where “the occipital nerves, the nerves that run through the scalp, are injured or inflamed” (Pilitsis and Khazen 2023:np). Symptoms include migraine-like symptoms, headaches and throbbing, muscle tension, piercing and shooting pains in the back of the head, upper neck, or behind ears (Pilitsis and Khazen 2023). Any movement or touch can cause severe pain for the individual. It can be caused by pinched nerves, muscle tightness, or injury in the neck, and either a primary condition or secondary condition associated with an underlying disease (Pilitsis and Khazen 2023).

Fibromyalgia

Fibromyalgia is a disorder characterized by “widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues. Researchers believe that fibromyalgia amplifies painful sensations by affecting the way your brain and spinal cord process painful and non painful signals” (Mayo Clinic 2021:np). Symptoms often occur after physical trauma, surgery, infection or significant psychological stress, or occur gradually with no event triggering it (Mayo Clinic 2021). Symptoms include widespread pain, fatigue, and cognitive difficulties and often coexists with other conditions. Fibromyalgia can be treated with medications such as pain relievers, antidepressants, and anti-seizure drugs, and through therapies such as physical therapy, occupational therapy, and counseling (Mayo Clinic 2021). Other interventions that can reduce symptoms and anxieties include stress management, exercise, sleep hygiene, and maintaining a healthy lifestyle; others may adopt alternative medicines like acupuncture, massage therapy and yoga (Mayo Clinic 2021).

Multiple Sclerosis

Multiple sclerosis (MS) is a disease of the brain and spinal cord (central nervous system) where “the immune system attacks the protective sheath (myelin) that covers nerve fibers and causes communication problems between your brain and the rest of your body. Eventually, the disease can cause permanent damage or deterioration of the nerve fibers” (Mayo Clinic 2022b:np). Around 2.3 million people worldwide have MS (MS Society). Symptoms vary widely based on severity, and currently there is no cure but there are treatments to help manage symptoms, speed up recovery from attacks, and manage the course of the disease (Mayo Clinic 2022b). Common symptoms may include numbness or weakness in multiple limbs, tingling, electric shock sensations with neck movement, lack of coordination, partial or complete loss of vision usually in one eye, blurry vision, vertigo, fatigue, cognitive problems, and mood issues (Mayo Clinic 2022b). Around 85% of people with MS are diagnosed with relapsing remitting multiple sclerosis (RRMS) and occurs with relapses, where symptoms worsen, followed by recovery (MS Society). Currently, the causes of MS are unknown yet women are 2-3 times more likely to have RRMS, onset usually occurs around 20-40 years old, family history plays a role in genetic risk, and countries with temperate climates, such as Canada, have a higher risk (Mayo Clinic 2022b).

Endometriosis

Endometriosis is “a disease in which tissue similar to the lining of the uterus grows outside the uterus. It can cause severe pain in the pelvis” (World Health Organization 2023:np). Currently, the cause of endometriosis is unknown, yet it impacts around 10% of reproductive age women and girls globally (World Health Organization 2023). Symptoms may include pain during menstruation, during or after sex, and when urinating; other symptoms are chronic pelvic pain, heavy bleeding during periods, fertility issues, nausea, bloating, fatigue, depression and anxiety (World Health Organization 2023). Treatment varies based on the severity of the symptoms, but most commonly medications such as anti-inflammatory drugs, pain relievers and birth control are used to manage symptoms; surgery is sometimes used to remove endometriosis lesions, adhesions, and scar tissue or a hysterectomy to remove the uterus (World Health Organization 2023). Although endometriosis impacts 190 million people worldwide, women are often undiagnosed, as it takes on average 8.1 years to receive a diagnosis (Moradi et al. 2014).

Adenomyosis

Adenomyosis is a similar condition to endometriosis as it impacts reproductive organs. Endometriosis occurs when endometrial tissue grows outside of the uterus, while adenomyosis occurs when diffuse endometrial tissue grows into the walls of the uterus causing the uterus to enlarge and lead to heavy menstrual bleeding (Chernofsky 2022). Similar to endometriosis, the cause is unknown, but it impacts menstruation and fertility. Symptoms include enlarged uterus, feelings of abdominal bloating, fullness or heaviness, heavy bleeding during periods, pain during sex, pelvic pain and severe cramps during periods. Treatments are the same for endometriosis, and the only way to fully stop adenomyosis is to have a hysterectomy.

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