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The Socio-Political Shaping And Lived Consequences Of Involuntary Retirement For Women With MS

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree
in Health and Rehabilitation Sciences

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Abstract

Women with multiple sclerosis (MS) face a number of challenges negotiating and maintaining work, and are at risk for involuntary retirement and associated consequences. Few studies have positioned involuntary retirement and such consequences in socio-political contexts or examined their implications in women's lives. This study critically examines the socio-political production and lived consequences of involuntary retirement for women with MS within the contemporary context of Southwestern Ontario. Employing critical narrative inquiry, informed by critical life course theory and disability studies perspectives with an intersectional lens, narratives of work and retirement were co-constructed with five women with MS who self-identified as retired. Four main themes evolved from critical narrative analysis, including: negotiating the disconnect between retirement as imagined, and retirement as lived; the production of consequences in navigating ableist environments requiring certainty and the intersection of bodily and financial uncertainty; the failure of practices, systems and policies to understand the complex, intersectional reality of women with MS, and the navigation of identity tensions; and filling the gap. These themes reveal various dimensions of the socio-political shaping of involuntary retirement, generating insights regarding how stigma and marginalization shape if and how women navigate workplace accommodations; problematics related to the conceptualization of disability embedded in provincial and federal disability policies and benefit programs; and implications of the absence of an intersectional lens within policies. In relation to the lived consequences of involuntary retirement, these thematic findings are drawn upon to point to the utility of precarity as a lens to examine experiences of instability, unpredictability and uncertainty amongst women with MS. The discussion also highlights how existing social policies and systemic discrimination create the necessity of re-imagining idealized retirements, as well as how the lives of the participants became increasingly more precarious after involuntary retirement given the downloading of responsibilities to manage gaps in existing systems and structures. This thesis responds to a number of important gaps by critically and qualitatively exploring involuntary retirement for women with MS in Ontario, Canada to provide rich accounts of shaping forces and lived consequences produced.

Keywords

Employment, Work, Critical Narrative Inquiry, Disability Studies, Intersectionality, Critical Life Course Theory, Relapsing Remitting Multiple Sclerosis (RRMS), Gendered

Summary for Lay Audience

Canada has the highest prevalence of multiple sclerosis (MS) in the world. Women with MS experience difficulties managing and keeping employment which can lead them to retire involuntarily. There has been little research that has addressed what leads women with MS to retire involuntarily or the resulting consequences. This work is especially important given that women face higher rates of MS than men in Canada. This study looks critically at how social and political forces contribute to involuntary retirement and produce consequences for women with MS in Southwestern, Ontario. Five narratives, or storied accounts, were created together with women with MS who identified themselves as retired. Four main themes emerged including: negotiating the disconnect between retirement as imagined, and retirement as lived; the production of consequences in navigating ableist environments requiring certainty and the intersection of bodily and financial uncertainty; the failure of practices, systems and policies to understand the complex, intersectional reality of women with MS, and the navigation of identity tensions; and filling the gap. These themes demonstrate how social and political factors shape involuntary retirement and provide insight around how stigma and discrimination impact if and how women access necessary accommodations in the workplace; problems with how disability is thought about in provincial and federal policies and benefit programs; and the consequences if policies only focus on disability and ignore other aspects of individuals lives. Additionally, in relation to the consequences of involuntary retirement, precarity can be a useful lens to understand experiences of unmet needs and uncertainty in participant's lives over time. The discussion also points to how discrimination within existing policies and systems led participants to have to re-imagine what their retirement would be like, how that is different from what they imagined it would be, and how they are often left to find solutions to problems created by systems and structure that do not meet their needs. This thesis responds to a number of important gaps identified in the literature.

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Chapter 1

1 Introduction

Women with Multiple Sclerosis (MS) face numerous challenges in negotiating work, often leading to facing involuntary retirement and negotiating its implications. This thesis presents a critical narrative inquiry conducted with five women with MS that addresses the socio-political shaping of involuntary retirement for women with MS in Southwestern Ontario, Canada. Within this thesis, involuntary retirement refers to a permanent withdrawal from the labour force at a point in the life course that is prior to planned and desired transition (Hilt Pflieger, Meulengracht Flachs, & Koch-Henriksen, 2010a; McDonald & Donahue, 2011). The study also critically examines the lived consequences of involuntary retirement, and seeks to unpack how involuntary retirement and its consequences are shaped through ageist, ableist, and sexist practices, systems and policies.

Involuntary retirement for women with MS is important to explore within the context of Canada given that Canada has the highest prevalence of MS in the world (MS Society of Canada, 2020). Involuntary retirement is also important to explore with women given that particular types of MS like Relapsing-Remitting Multiple Sclerosis (RRMS) are three (MS Society of Canada, 2020) to four (Johns Hopkins Medicine, 2020) times more likely to occur in women. Women also experience MS at a crucial point in their work careers and family lives (Brown, 2018; Chen et al., 2019; Dyck & Jongbloed, 2000; Ernstsson et al., 2016; Howard, Trevick, & Younger, 2016; Hilt Pflieger, Meulengracht Flachs, & Koch-Henriksen, 2010; Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008; LaRocca & Hall, 1990; Messmer Uccelli, Specchia, Battaglia, & Miller, 2009; Roessler & Rumrill Jr., 2003), face higher rates of unemployment and poverty over their life course than men with MS (Jongbloed, 1998; Novak, Campbell, & Northcott, 2010), and often leave the workforce a number of years before the 'standard' age of retirement (Jongbloed, 1998). Lower lifetime earnings, pensions, and benefit systems can position women with MS negatively as they transition out of work and enter retirement; raising a number of questions around how to plan, prepare, and survive in retirement.

Individuals living with a chronic illness have a much higher rate of involuntary retirement than the general population (Denton, Plenderleith, & Chowhan, 2013a), and much of the limited research to date on involuntary retirement for people with disabilities has largely focused on understanding predictive factors linked to biomedical and demographic factors. More specifically, research has shown that MS is associated with high rates of early retirement (Sterz, Ellenberger, Meißner, Friede, & Flachenecker, 2016). Despite this, there is a dearth of empirical studies specifically focused on involuntary retirement for individuals with MS, and an absence of focused attention around Canadian women's experiences of involuntary retirement with MS.

Guided by disabilities studies perspectives, this thesis aimed to extend beyond approaches that focus on biomedical factors associated with MS as primary causes of involuntary retirement to interrogate ways that contemporary socio-political structures, systems and practices fail to meet the complex needs of women with MS within work, contributing to involuntary retirement and its lived consequences. Given that individuals occupy multiple social identities such as age, gender, race, or class simultaneously (Crenshaw 1989: 1991; Mirza, 2013) and knowing that these identities do not occur in isolation within individual lives (Mirza, 2013), an intersectional lens was also applied to this thesis in order to attend to how women with MS experience marginalization on multiple fronts. Furthering the critical nature of this work, the application of a critical lens to the study of the life course was used to explore the implications of embedded conceptualizations of a 'normative' life course trajectory within workplace and governmental systems and structures on ways women with MS are able to think about and plan for their lives and retirement over time.

1.1 Research Objectives

The purposes of this critical narrative study, conducted in the context of a mid-sized city in Southwestern Ontario, Canada, were to:

- 1) reveal the lived consequences of involuntary retirement for women with MS who had to leave work before they had planned, wanted or were ready to and who self-identify as retired;

and

2) critically examine how involuntary retirement and its consequences are shaped within and through the current socio-political context and how existing practices, systems and policies marginalize these women.

1.2 Conceptualizing MS

1.2.1 Terminology and Definitions

Within this thesis I am conceptualizing MS as a chronic illness, and use the term disability to refer to oppressive consequences that arise from the interactions between a person with chronic illness and environmental features. Given the differential ways that authors use the terms, I highlight how I am using and conceptualizing these terms throughout this thesis, and why this is an important clarification to make in the context of MS. I then provide a brief overview of the characteristics of MS as a chronic illness.

1.2.2 MS as a Chronic Illness and the Experience of Disability

For the purposes of this thesis, in agreement with the MS Society of Canada (2019) and existing literature (Stone, Crooks, & Owen, 2014), MS is being conceptualized as a chronic illness. Although challenging to define, a chronic illness can be broadly defined as having gradual or sudden onsets, may be incapacitating or not, may result in episodic/fluctuating or constant symptoms, may or may not impact the lifespan of an individual, and is often diagnosed through a lengthy process (Stone et al., 2014). Some examples of common chronic illnesses include multiple sclerosis, diabetes, osteoarthritis, and chronic fatigue syndrome (Government of Canada, 2019). Being clear about how I am conceptualizing MS as a chronic illness is important because “most of the [...] characteristics relevant to the experience of chronic illness are also relevant to the experience of disability, and sometimes the terms chronic illness and disability are used interchangeably” (Stone et al., 2014, p. 5). However, based on theoretical frameworks this thesis draws upon, the two terms mean very different things, and this is an important distinction that needs to be clarified.

The term chronic illness refers to the cognitive and/or bodily experience of illness and the cognitive and/or bodily differences produced by the chronic illness (Stone et al., 2014). In contrast, disability is viewed as “the experience of social oppression and its disabling outcomes in order to signal that disability is relational, something produced as a consequence of the interaction between the individual and the environment” (Stone et al., 2014, p. 5). This definition of disability highlights the relational nature of disability. Therefore, an interaction between an individual with cognitive or bodily differences produced by chronic illness, and the physical, social, and political environment must occur in order for disability to be produced. It is important to draw attention to the fact that the “mind/body differences produced by chronic illnesses and the ways in which they change over time [which may result] [...] in experiences of disablement and disabling outcomes” (Stone et al., 2014, p. 5), are different, and “should not be confused with the chronic illness itself” (Stone et al., 2014, p. 5). More clearly, “while chronic illness may have disabling consequences (e.g., the physical environment may not be set up to allow the individual to have easy access or perform valued activities, or the social environment may promote discriminatory attitudes) these consequences should not be confused with the chronic illness itself” (Stone et al., 2014, p. 5). These points highlight not only the distinction and relationship between chronic illness and disability, but draws attention to how “the often episodic and fluctuating nature of the chronic illness experience can lead to a wide variety of challenges that those with stable impairments do not generally face” (Stone et al., 2014, p. 14), and individuals living without chronic illness may not fully understand.

The distinction between chronic illness and disability is important in relation to this topic for a number of reasons. First, distinguishing between illness and disability based on the social model, separates the bodily differences produced by chronic illness from the experience of disability, while still valuing the body as part of the experience. This then allowed me to question how changed and uncertain bodies produced by MS interact with oppressive systems and structures and the ensuing consequences. Second, clarifying this distinction highlights how experiences of disability in the lives of women with bodily differences produced by MS occur through interactions with contexts that promote ageist, ableist, and sexist discriminatory attitudes that privilege able-bodied individuals on the

assumption that having a bodily difference is inferior to having a ‘normal’ functioning body. Finally, it separates this thesis from existing literature that understands ‘disability’ as medicalized or individualized (Oliver, 1990) and, underpinned with biomedical framing, assumes that symptomology or bodily limitations are the primary factors shaping work outcomes.

1.2.3 Characteristics of MS as a Chronic Illness

MS is a chronic neurological illness characterized by inflammation and damage to the myelin covering of the nerves in the central nervous system (CNS), which interrupts the transmission of nerve impulses through nerve fibres throughout the body (MS Society of Canada, 2020). An estimated 1 in 385 Canadians are diagnosed with MS (MS Society of Canada, 2020b). MS can occur at any age, but it is generally diagnosed between the ages of 20 and 45 (Vijayasingham & Mairami, 2018). As previously mentioned, there are gender differences in the prevalence of MS, with women three (MS Society of Canada, 2020) to four (Johns Hopkins Medicine, 2020) times more likely than men to experience particular form of the illness, specifically RRMS. Symptoms of MS may include weakness and fatigue, mobility and dexterity limitations, difficulty sleeping, decreased quality of life (QOL), vision problems, bladder problems, emotional distress and anxiety, cognitive impairment or changes, memory issues, and sensory changes (Benito-Leon, Morales, Rivera-Navarro, & Mitchell, 2003; Crooks, Stone, & Owen, 2009; Kikuchi et al., 2011; MS Society of Canada, 2020; Phillips & Stuifbergen, 2006; Putnam & Tang, 2006; Townsend & Fox, 2011; Messmer Uccelli, Specchia, Battaglia, & Miller, 2009; Vijayasingham & Mairami, 2018).

Living with MS can be quite unpredictable, and symptoms may be highly variable not only between individuals, but within the same individual at different times, making the illness highly complex (Beatty & Joffe, 2006; Putnam & Tang, 2006). For certain individuals, “the disease progresses quickly, leading to disabling symptoms that do not improve over time” (Beatty & Joffe, 2006, p. 188) while other individuals may “live with illness symptoms that develop and subside in fits and starts, creating disruptive episodes” (Beatty & Joffe, 2006, p. 188) at various times over their life course. The unpredictable and variable nature of symptoms can present challenges to negotiating various aspects of

daily life. For example, in relation to employment and work, previous research suggests challenges can be encountered in acquiring paid work (Crooks et al., 2009); re-evaluating and negotiating roles in the workplace after onset (Crooks et al., 2009); deciding whether to ‘pass’ as able-bodied due to fear of employment loss or discrimination (Stone et al., 2014); negotiating and receiving appropriate workplace accommodation (Stone, Crooks, & Owen, 2013); and planning for retirement (National Multiple Sclerosis Society, 2017).

The symptoms produced and the progression differs based on the type of MS with which an individual is diagnosed. According to Lublin and Colleagues (2014), there are both relapsing (previously referred to as relapsing-remitting) and progressive phenotypes of MS. These are determined by both clinical and imaging criteria (Lublin et al., 2014). Within these phenotypes exist four clinical courses of MS: Clinically isolated syndrome (CIS) (relapsing), relapsing-remitting (RR) (relapsing), secondary progressive (SP) (progressive), primary progressive (PP) (progressive) (Lublin et al., 2014).

Relapsing diseases (CIS and RR) are characterized clinically by “relapses, acute or subacute episodes of new or increasing neurologic dysfunction followed by full or partial recovery, in the absence of fever or infection and/or [by imaging by the] occurrence of contrast-enhancing T1 hyperintense or new or unequivocally enlarging T2 hyperintense lesions” (Lublin et al., 2014, p. 283). These are also further differentiated by whether they are active or not.

Progressive diseases (SP and PP) are characterized clinically by “steadily increasing objectively documented neurologic dysfunction/disability without unequivocal recovery (fluctuations and phases of stability may occur)” (Lublin et al., 2014, p. 283). These are further differentiated whether they are active with progression, active but without progression, not active but with progression, and not active and without progression (stable disease) (Lublin et al., 2014).

Various guidelines for the naming of MS disease courses exist and are maintained today. For example, RR (as defined by Lublin et al., 2014) is also often referred to Relapsing-Remitting Multiple Sclerosis (RRMS) (National Multiple Sclerosis Society, 2020). All participants indicated they were diagnosed in this way (RRMS); therefore, this

terminology will be maintained throughout their narratives and terminology will remain intact as it has been stated or used in any referenced sources.

1.3 Significance of this Research

Statistics over the past few decades have shown that women in the Canadian general population experience lower rates of labour force participation, somewhat lower rates of unemployment (Statistics Canada, 2020), and lower average ages of retirement than men (Statistics Canada, 2020b). This highlights that gender matters in relation to work and retirement, and reinforces the necessity of taking into account gender when exploring the work and involuntary retirement experiences of women with MS.

Compared to the general population, people with MS experience higher rates of unemployment (Busche et al., 2011; Honan, Brown, & Batchelor, 2015; Simmons, Tribe, & McDonald, 2010; Honarmand, Akbar, Kou, & Feinstein, 2011; Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008; Kornblith, LaRocca, & Baum, 1986; Messmer Uccelli, Specchia, Battaglia, & Miller, 2009; Pack et al., 2014; Pompeii et al., 2005; Strober, Chiaravalloti, Moore, & DeLuca, 2014; van der Hiele et al., 2015), and there are observed differences in employment and labour force participation rates (Conference Board of Canada, 2018; Dorstyn, Roberts, Murphy, & Haub, 2019; Garcia-Dominguez et al., 2019). When making comparisons amongst people with MS, existing literature also suggests that gender differences in employment rates may exist (Conference Board of Canada, 2018), highlighting the need to consider how chronic illness and gender may intersect to shape labour force outcomes.

Labour force participation, employment, and unemployment rates give some indication of the state of work engagement for people with MS, however, they offer little explanation for how or why these trends exist nor attend to factors that may shape workforce exit in MS including and beyond gender. Involuntary retirement can be a useful lens for probing challenges to maintenance of sustainable employment, specifically in relation to MS, because individuals with MS who leave the workforce often permanently disengage (Roberts, 2008). Qualitative exploration of involuntary retirement can contribute to an

expanded understanding of how various factors intersect in contributing to workforce exit.

To date, there is a dearth of evidence on involuntary retirement people with disabilities (Denton, Plenderleith, & Chowhan, 2010a:2010b:2013a:2013b). The limited body of research on involuntary retirement for people with disabilities that exists, although not specifically focused on gender, has highlighted to the need to explore this topic in relation to gender due to the distinct implications for women (Denton et al., 2010a). Currently, there is an absence of focused of attention on involuntary retirement for people with MS, and, therefore, exploring the involuntary retirement stories of women with MS is timely and responds to an articulated need in the knowledge base.

A small body of literature has problematized unemployment in MS as gendered, and highlights some of the consequences, particularly financial consequences, that exist at the intersection of gender and MS. For example, women with MS experience unemployment and poverty at increased rates than men with MS (Jongbloed, 1998; Dyck & Jongbloed, 2000). A challenging financial situation may be further complicated depending on the relationship status of a woman with MS. Moreover, research shows that a diagnosis of MS carries a risk of relationship cessation (Hilt Pflieger, Meulengracht Flachs, & Koch-Henriksen, 2010b) and points to an increased risk of divorce when a woman becomes chronically ill (Glantz et al., 2009; Karraker & Latham, 2015; Kirchhoff, Yi, Wright, Warner, & Smith, 2012). Results from a prospective cohort study based in the USA that included 108 MS patients as part of a larger sample indicated that serious illness occurs for a spouse in a heterosexual relationship, women tend to remain in a relationship while men have a greater likelihood of leaving (Glantz et al., 2009). Beyond finances and relationship breakdown, other gendered consequences of MS have received little attention despite the recognition that the timing of MS combined with an unpredictable illness trajectory complicates the ability of individuals to plan for or predict their future (Working Mother Research Institute, 2015). As such, further research on the experiences of women with MS in relation to involuntary retirement can serve to expand understanding of its gendered implications within the contemporary socio-political context.

Finally, existing research that explores the reasons why people with MS ultimately leave work has largely been biomedically based and primarily focused on symptoms. This positions workforce exit as an individual issue and ignores larger contextual factors that may be at play. Critical social theories points to the importance of attending to socio-political forces that shape disability and its consequences, pointing to the need to shift beyond such an individualized approach.

1.4 Locating this Study

In order to locate this study, this section addresses keys aspects of the socio-political context for women with MS in the context of Ontario, specifically addressing relevant federal and provincial disability and retirement programs, systems, and policies.

Providing an understanding of this context is necessary because what it is to be a working or retired woman with MS varies depending on where an individual lives, the type of MS, and the socio-political context that exists. According to Mikkonen and Raphael (2010) living conditions are “strongly determined by decisions that governments make in a range of different public policy domains” (p. 7). For example, “governments at the ... provincial/territorial, and federal levels create policies, laws, and regulations that influence how much income Canadians receive through employment, family benefits, or social assistance, ... and even what happens when Canadians lose their jobs during economic downturns” (Mikkonen & Raphael, 2010, p. 7-8).

Neoliberalism has been a major factor shaping contemporary policy in a Canadian context since the 1980s. Neoliberalism is an ideology that promotes individuals as responsible and self-sufficient, ideally without need for public or social interventions in their life (Gazso & McDaniel, 2010). Neoliberalism or neo-liberal forms of governing are distinguished by an erosion of state support, inclusive of reduction in social welfare and protections for individuals through austerity measures (Asquith, 2009; Pack, Hand, Laliberte Rudman, & Huot, 2019; Rose 1999). At the same time this state retreat is occurring, there is also an intensification towards enacting life as an activated citizen who takes up individual responsibility to, for example, be prepared for the future, limit harm through prevention, save for retirement, plan for unemployment, accrue resources, manage health, and align with the economic imperatives of the state and market (Asquith,

2009; Pack, Hand, Laliberte Rudman, & Huot, 2019; Petersen & Lupton, 1997; Rose 1999). Choice and freedom are two principles that are emphasized in neoliberal thought, with governing technologies aimed at producing rational, active citizens who take up responsibility for their individual futures and bodies through risk management and prudential choice (Rose, 1999). The premise of neoliberalism is that the state should not be responsible for ensuring the wellbeing of citizens, and that citizens need to be activated and be responsible for themselves. The concepts of individual responsibility and activation also assume that there is an even playing field for everyone (Harvey, 2005).

Within this study, understanding the composition and organization of existing systems and structures will shed some light on the challenges women with MS may experience as they navigate existing disability and retirement-based practices, systems and policies within a socio-political context increasingly shaped through neoliberal rationality. Critically examining how these programs, systems and policies shape the involuntary transition out of work and into retirement for women with MS and the consequences that are produced as they interact within these systems and structures, will help in advancing scholarship around this topic from a critical perspective. Given this, relevant benefit programs and policies that women need to negotiate as they make decisions about and experience involuntary retirement within the study context of Ontario, Canada, are outlined below. Finally, I will locate who I am as a researcher, how I came to this topic and why I care about it while being explicit about the critical lens I am taking up in this work.

1.4.1 Locating the Study in the Contemporary National and Provincial Policy Context Pertaining to Retirement and Disability

There are a number of channels an individual can take to access disability or retirement programs as a person residing in Southwestern Ontario. Their course through and eligibility for these systems are often based on work history. There are also federal and provincial based supports which differ based on benefits provided. In the next sections, existing federal and provincial policies and systems relevant to contextualize retirement and disability for women with MS are described. Given the critical nature of this inquiry, these systems and policies have been analyzed for how they may not meet the needs or accommodate the lived realities of women with MS.

1.4.1.1 Federal

The Canada Pension Plan (CPP), in the event of retirement, disability or death, provides contributors and their families with partial replacement of earnings (Government of Canada, 2020a:2020b). The CPP is a federal framework that includes CPP Disability and CPP Retirement which are both wage-earning dependent benefits. Old Age Security, which is also federally distributed but separate from the umbrella of CPP, is wage earning-independent.

1.4.1.1.1 CPP Disability

The wage-dependent CPP disability provides disability benefits, including the disability pension and post-retirement disability benefit, to individuals who have made sufficient CPP contributions and who are disabled and are unable to work at any job on a regular basis (Government of Canada, 2020c) due to “severe and prolonged disability” (Torjman, 2002, p. 2). CPP disability benefits provide coverage for Canadian workers and guarantees coverage for disability until recovery, retirement, or death (Torjman, 2002). As of 2020, the basic monthly amount for CPP disability was \$505.79 plus additional monies based on contributions to CPP during the individual’s working career (Government of Canada, 2020d). The maximum monthly amount was \$1,387.66 and the average monthly pension amount was \$1010.26 (Government of Canada, 2020d).

The structure and eligibility for CPP disability fails to recognize the realities of many individuals who live with episodic illnesses such as MS (Longfield & Bennett, 2003; Standing Committee on Human Resources Development and the Status of Persons with Disabilities, 2001). Requirements for CPP disability state that a contributor must have a severe and prolonged disability inhibiting their ability to attend work on a regular basis, be under the age of 65, and have worked four of the last six years, or three of the last six years if they have been contributors to CPP for the last 25 years (Government of Canada, 2020e). As one example of a misfit with the lives of those with episodic illnesses, the four-out-of-six rule actually introduces a type of systematic discrimination against individuals with chronic illnesses like MS, with its characteristic relapses and remissions. Over the course of these illnesses, periods of wellness may become shorter and periods of

illness longer (Longfield & Bennett, 2003, p. 51). What this criteria highlights is that many individuals with intermittent chronic illnesses may not meet contributory criteria as the “cyclical and unpredictable nature of [chronic illness] [...] can impede the establishment of a long-term and stable employment history” (The Standing Senate Committee on Social Affairs, Science and Technology, 2006, p. 174). The relapsing and remitting nature of certain types of MS may also make it more difficult to assess how bodily differences produced by chronic illness can complicate the work experience for individuals who may not be ‘ill’ continuously, but instead tend to cycle between periods of illness and wellness (The Standing Senate Committee on Social Affairs, Science and Technology, 2006). The way that CPP disability frames disability as a static condition is an example of how policy frameworks do not ‘fit’ the reality of many persons with MS who may need support at particular times and not at others; or may require different supports or accommodations as circumstances change, exacerbations occur, or bodily differences are produced (Stone et al., 2014).

Gender inequality also exists within the benefit itself. CPP disability is an earnings-dependent benefit, and it is well documented in the literature that differences in earning levels exist between men and women (Doe & Kimpson, 1999; Torjman 2002). Proof of gender disparity was evident in the earnings-related portion of CPP disability even 20 years ago. In 2000, the average monthly CPP disability benefit was \$737.21 for men and \$625.15 for women, with the gender difference deriving from the earnings-related portion of the benefit and reflecting the reduced contributions of women over the life course (Torjman, 2002). Unfortunately, more recent figures broken down by gender were unable to be located.

1.4.1.1.2 CPP Retirement

CPP Retirement is a taxable, monthly benefit that was designed to provide a partial income for Canadians who have made valid contributions to CPP when they retire (Government of Canada, 2020b). CPP reforms in 2012 made it financially lucrative for individuals to remain in the work force longer and draw retirement benefits at or after age 65, while simultaneously increasing financial penalties for individuals who access retirement pensions at earlier ages (Leonard, 2011; Parliament of Canada, 2009;

Government of Canada, 2018). As of 2019, for each month after age 65 a contributor delays receiving payments, the CPP retirement pension would increase by 0.7% per month although there is no financial benefit to delaying pension past the age of 70 (Government of Canada, 2018). Similarly, and implemented in 2016, a contributor's pension will be reduced by 0.6% for each month it is received prior to age 65 (Government of Canada, 2018). Financially, these numbers mean that if an individual delays drawing their CPP retirement pension until age 70, they will receive 42% more than if they had taken it at 65. However, if they draw their CPP retirement pension at age 60, they will receive 36% less on a monthly basis than if they had waited until they were 65 (Government of Canada, 2018).

Additionally, with the removal of the work cessation test in 2012, individuals who were able to continue working while receiving CPP retirement benefits, could increase retirement income through the post-retirement benefit (PRB) (Leonard, 2011; Parliament of Canada, 2009; Government of Canada, 2018). This lifetime benefit allowed individuals' between the ages of 60 and 70 who continue contributing to CPP while simultaneously drawing CPP retirement pension, to increase their retirement income by building on existing CPP benefits, even if they receive maximum amounts (Government of Canada, 2018). These changes made delaying retirement financially beneficial for CPP contributors who were able to delay retiring and continue making a contribution in the workforce, however, they also marginalize and penalize individuals who are unable to prolong employment or who are forced to retire involuntarily prior to age 65.

CPP Retirement is discriminatory in the sense that people are being rewarded for the fact that they are able to continue working without recognizing that not everyone has the capacity and the resources to do so. Individuals are being positively rewarded for continuing to work without consideration of the reasons why some people may not be able to work. CPP Retirement does not take into consideration that there are people who are unable to continue working even if they want to, and it does not modify itself to deal with those circumstances or people on an individual basis. This is not an argument that people who are able to work until the age of 70 should not receive the benefits they do, instead, merely that people who are unable, but want to work, should not be penalized.

For example, if someone is 60 and financially well off and they make the decision to leave work, receiving a deduction in their CPP retirement may not have the same impact that it does for an individual who starts drawing CPP retirement at age 60 because they have a chronic illness and are unable to maintain work. CPP Retirement should be looking at those two people differently, but the system is not designed to distinguish between them. Currently, there is no way to deal with or differentiate between individuals who *have* to draw an early CPP retirement pension versus the person who is *choosing* to take early CPP retirement. There is also a lack of recognition that things are not always choices for everyone or that everyone has the same degree of choice.

While many individuals living with chronic illness are forced to leave the workforce before ‘typical’ retirement age codified as 65 in the CPP benefit system, if they leave prior to 65 due to chronic illness, they are penalized for taking retirement pension early (i.e. age 60). Individuals under the age of 60 could attempt to qualify for CPP disability, but that process requires a lot of individual navigation and the negotiation of another layer of income supports at the provincial level many may not be familiar with. However, these individuals will face inequality as they reach eligibility for CPP retirement benefits, because their benefits will be based on outdated and disrupted earnings which will result in the receipt of significantly lowered pension amounts given that “the amount of ... CPP retirement pension is based on how much you have contributed and how long you have been making contributions to the CPP at the time you become eligible” (Government of Canada, 2020f, ¶ 1).

New as of 2019 was the addition of the Disability Exclusion and Disability Drop In provision. When calculating base CPP benefits “periods during which individuals are disabled in accordance with the CPP legislation are not included in their contributory period. This ensures that individuals who are not able to pursue any substantially gainful work are not penalized” (Government of Canada, 2018b, p. 11). Individuals who became disabled in 2019 or later “will have a credit dropped-in to the months they are disabled. The value of the credit is based on the individual’s earnings in the 6 years before becoming disabled” (Government of Canada, 2020g, n.p.). Although a positive step forward in addressing the implications of chronic illness in relation to sustaining work

involvement, basing the value of the credit on the six years prior to becoming ‘disabled’ marginalizes individuals with intermittent work histories and those who may have become ‘disabled’ prior to reaching prime earning years.

CPP retirement is also gendered. In 2010, CPP retirement recipient rates show that only 86% of senior women receive CPP retirement benefits compared to 95% of senior men (Li, 2012). Furthermore,

for men, 92.1% of them receive CPP retirement benefits and 8.7% of them collect a CPP survivor benefit ... The proportion of women receiving retirement benefits is 75.4%, which is 16.7% less than that of men. This suggests that numerous members of the current generation of elderly women did not participate in the paid work force long enough to build up retirement benefits in their own right (Li, 2012, p. 33-34).

However, senior women have been shown to receive survivor benefits at four times the rate of men (35.7%) which suggests that women are likely to outlive their spouses to collect survivor benefits which may help to narrow the overall gender gap in existing recipient rates (Li, 2012).

1.4.1.1.3 Old Age Security (OAS)

OAS is the wage earning-independent portion of federal government benefits for individuals who do not have a work history or may have a work history that does not meet the eligibility requirements of CPP Retirement. OAS is now the largest piece in Canada’s national social security system, designed to provide finances that support a minimum quality of life for older Canadians (Li, 2012). OAS was originally created with the intention of reducing poverty in seniors, and grew to include the Guaranteed Income Supplement (GIS) in 1967 as an additional, temporary measure to achieve this goal (Human Resources and Development Canada, n.d.); however, the GIS was never removed. These measures were created to provide a guaranteed minimum income for those with the lowest income levels. The creation of OAS allowed senior women, who had previously not been entitled to benefits or whose labour force participation had not

been sufficient to claim earning-dependent pensions, to draw benefits alongside their male counterparts (Li, 2012). OAS shaped the opportunity for women to draw secure benefits independent of their spouse or work and social history (Street & Connidis, 2001).

When individuals receive OAS, they may also qualify for additional supplements through the GIS and the Guaranteed Annual Income System (GAINS). The GIS is a monthly non-taxable benefit to OAS recipients who qualify as low income in Canada, with a maximum annual income under a specific cut-off (Government of Canada, 2020h). Despite being received in conjunction with the federally distributed GIS, the GAINS is actually a provincial (Ontario) monthly payment system that ensures a guaranteed minimum income for OAS and GIS recipients if income from all sources is below the level guaranteed by the province (Government of Ontario, 2020). These benefits are available as additional supports for individuals in the lowest income brackets. As of 2010, recipient rates of OAS for women and men were 98.1% and 98.7% respectively. In addition, reinforcing the importance of the OAS pension system for senior women, considerably more women (37.9%) than men (28.2%) receive GIS (Li, 2012).

Similar to CPP, OAS also offers pension deferral options that make delaying the receipt of OAS financially lucrative. As of July 2013, individuals can defer their OAS pension for up to 60 months or five years with a financial benefit of 0.6% increase per month up to a maximum of 36% at age 70 (Government of Canada, 2020i). This creates an opportunity for individuals who are able to continue working and who earn more than the maximum annual income allowed by OAS, to delay drawing their OAS pension until they have a lower income in order to keep more of their pension amount (Government of Canada, 2020i). Similar to CPP, OAS offers financial incentives for individuals who are able to delay drawing OAS, and marginalizes individuals who are unable to hold off on drawing OAS pension. OAS has been successful in bringing poverty rates down (Human Resources and Development Canada, n.d.) and for equitably creating opportunities for women to receive benefits independent of spouse and work tenure, however, it has been modified in ways that support those who can extend work, but has not been

modified in ways for those who face challenges in maintaining work due to chronic illness.

1.4.1.2 Provincial

A number of systems also exist at the provincial level to provide services in the form of disability income and medication support. In Ontario these include: the Ontario Disability Support Program (ODSP), the Trillium Drug Benefit (Trillium), and the Ontario Drug Benefit (ODB).

1.4.1.2.1 Ontario Disability Support Program (ODSP)

For individuals without a work history or with a work history that precludes them from receiving CPP Disability, ODSP is a provincial framework that provides disability benefits to eligible individuals. In 1997, the Government of Ontario passed the Ontario Disability Support Program Act “to provide a separate income and employment support program for eligible persons with ‘disabilities’, recognizing their unique needs” (Government of Ontario, 2018, ¶ 3). ODSP is a benefit program not tied to employment history that provides income supports and additional benefits for individuals with ‘disabilities’ who are unable to work due to disability. On top of income support, ODSP also provides drug and dental coverage, hearing and vision, and other extended health benefits that are not available to recipients of CPP disability (Government of Ontario, 2018b), and individuals are eligible to receive ODSP until they transition to age-related supports at age 65. As of October 2020, there were 299,451 individuals and 44,422 couples receiving ODSP supports (Government of Ontario, 2020).

The definition of disability for ODSP states that an individual must “have a substantial mental or physical impairment that is continuous or recurrent, and is expected to last one year or more and your impairment directly results in a substantial restriction in your ability to work, care for yourself, or take part in community life and your impairment, its duration and restrictions have been verified by an approved health care professional” (Government of Ontario, 2018c, n.p.). The definition of disability used by ODSP has been widely critiqued in the literature. Smith-Carrier and Colleagues (2020) through the lens of mental illness, critique the ODSP definition of disability as narrow and highlight

how individuals with mental illness fall both within and outside the bounds of it eligibility criteria making them particularly vulnerable to poverty and associated insecurities. They also highlight how as ODSP “fails to recognize the fluidity and mutability of various impairments, many are rendered outside the program’s remit [and how a] ... narrow definition of disability, focused on continuous or recurrent impairment, rules out those with difficult to diagnose conditions and episodic impairments” (Smith-Carrier et al., 2020, p. 23). Wintermute (1999) argued that the narrow definition of disability in ODSP excludes many individuals living with disabilities and may leave them with no option besides Ontario Works (OW), a social assistance program that offers no disability related supports and services and a significant reduction in monthly amounts. In relation to biomedicalizing the chronic illness the experience, Carrier-Smith and Colleagues (2020) highlighted the limitations of using biomedical markers of difference to establish disability and how this is the dominant approach of current income support programs. Finally, the biologically driven, dichotomous markers that constitute disability regularly found within current policy fail to capture diverse experiences and structural considerations or factors that may shape or perpetuate experiences of disability (Oliver, 1990). Despite these critiques, at present, the definition has been maintained.

I would argue that the ODSP definition of disability is a slight improvement to the definition of disability used by CPP Disability for the way it acknowledges the recurrent nature of chronic illnesses like MS. However, the time parameter may exclude the lived realities of many living with episodic illnesses, and by nature, the definition biomedicalizes the chronic illness experience in the way it positions the restricted ability to work, care for themselves, or take part in community life as an inevitable consequence of chronic illness.

Another aspect of ODSP provides eligible individuals who “have a substantial physical or mental disability that is expected to last a year or more, and makes it hard for you to find or keep a job” (Government of Ontario, 2018d, ¶ 1) with access to employment supports. However, despite offering these supports, ODSP fails to acknowledge the lived reality of many individuals living with episodic chronic illness that may require, or experience, frequent and unexpected transitions in and out of the workforce, and lack clear guidance

around how individuals could negotiate these processes within an ODSP context (Smith Fowler, 2011).

1.4.1.2.2 Trillium Drug Program (Trillium)

For individuals under 65 years of age, the Trillium drug program (Trillium) is a provincial program in Ontario that helps individuals pay for high prescription-drug costs. In order to be eligible for Trillium, individuals must live in Ontario, have a valid Ontario health card number, and must not qualify for the Ontario Drug Benefit Program through Ontario Works (Government of Ontario, 2020c). They must also not have an insurance plan that covers 100% of drug costs, and spend about 4% or more of after-tax household income on prescription-drug costs (Government of Ontario, 2020c).

1.4.1.2.3 Ontario Drug Benefit (ODB)

Upon reaching 65, individuals become eligible for prescription drug coverage through the Ontario Drug Benefit (ODB) program. This program “requires seniors to pay deductibles and co-payments based on their income and other factors. Under the ODB, seniors are paying an average of \$240 a year out of pocket for their medications” (Government of Canada, 2020e, n.p.).

Having an income based drug benefit system creates at least somewhat of a financial buffer for individuals when they turn 65, however, the ODB has received a number of critiques around coverage options and non-approved drugs. The ODB does have restrictions on specific types and brands of medications it covers. Karam (2013) investigated perspectives of primary care physicians on the ODB and found that physicians expressed concerns “about the potential negative side effects of ... replacement drugs for their patients [and] while it was recognized that generic drugs are less costly, this saving needs to be balanced with the costs associated with the impact the replacement drug may have on patient outcomes” (p. 7).

The ODB program also does not cover the costs of non-approved drugs or those being investigated in a clinical trial (Government of Ontario, 2020d). This can be problematic for individuals with episodic chronic illnesses like MS, where medications are often

costly and generic options unavailable or not fully approved as part of drug trials (Government of Ontario, 2020d). It also raises questions about whether necessary medications that have been helpful prior to age 65 would still be available, and whether they would have to switch from what they currently use when they enroll in ODB.

1.4.2 Location of the Researcher

Before moving forward in this thesis, it is important to understand how this study came to be and why I selected this topic. Using a critical approach in this thesis was new for me, and was a challenging process. I have always had a critical voice inside me, and I have always been driven to help others; so I came to this project wanting to show how I thought people were being marginalized in order to make even some kind of difference in the lives of people who were experiencing disability. Unfortunately, I lacked the confidence to voice these concerns, knowledge around how to question the way things ‘have always been’, and the tools to make some kind of meaningful difference on my own, even if just for my participants.

My mother was injured when I was eight and it changed our lives. She sustained spinal nerve trauma after a surgical error to fix a herniated disc and has been living with chronic pain and a number of complications ever since. Being young at the time, I did not understand fully what the loss of employment meant, how it changed our lives, and what a reliance on social assistance meant for my mother’s and our family’s future. Knowing the challenges she experienced physically, socially, and financially, I always had questions about what her future would look like and what her experiences of disability would mean for her down the road. I knew she struggled with getting the things she needed, and often had to make difficult decisions out of necessity because there was just never enough or the right things to meet the needs she had. In my Master’s work, I chose to focus on the experience of aging with disability and factors that impacted people’s experiences. I was fascinated at how the experiences could be so different and how different factors seemed to impact the experiences people had very differently. I knew I wanted to deepen my understanding of how their experiences were shaped and shed light on the challenges many face. Continuing on my PhD journey was a way to do so, but the

path forward and the project was unclear. I never imagined that it would bring me on this critical journey.

I never had any experience in the MS community until my step mom was diagnosed with MS, and even then, my involvement was limited given that they lived at a distance. It was never my intention to focus on MS in this thesis. At the time, I was struggling with how to make an impact, and learn about the things I wanted to. It was then I became increasingly aware of how MS, given its unpredictable illness trajectory, could highlight the challenges experienced as people negotiate work and retirement with an often unpredictable chronic illness. I also learned about some of the consequences people face which in my experience, are largely unsupported and individualized.

From my experiences, I believe that people living with chronic illness are marginalized in a number of ways and I believe there are a number of assumptions and ways of thinking about disability, gender, and aging that exist socially, discursively, and politically that marginalize individuals. Applying a critical lens to this thesis allowed me to question the marginalization of my participants and problematize the involuntary transition out of work into retirement in order to understand the way larger social systems have influenced the lives of this group (Carpenter & Suto, 2008).

1.5 Chapter Overview

In **chapter two**, I present a review of the broader context of employment and retirement statistics in Canada and Ontario for the general population, highlighting the need to consider gender in relation to involuntary retirement for women with MS. In the second section, I explore data around labour force participation and unemployment rates for individuals with MS and compare those to the general population to show the challenges of maintaining sustainable employment for people with MS. I then turn to how involuntary retirement can be a useful lens to understand the employment challenges faced by people with MS. In the third section, I explore gender and MS and argue for research that investigates how gender and chronic illness intersect to produce implications for employment and involuntary retirement. In this section, I also highlight existing gaps in this knowledge base. Finally, in the fourth section, I discuss how the

persistence of biomedical framing around reasons why people with MS leave work, despite longstanding critique in the literature, has limited research contributions. I then argue the need for critical Canadian based, intersectional, qualitative research to reveal the lived consequences of involuntary retirement specifically for women with MS and to unearth how those consequences and such retirement is shaped within and through the current socio-political context in Southwestern Ontario, Canada.

In **chapter three**, I outline the theoretical perspectives underpinning this research. As I critically examine the involuntary transition out of work and into retirement for women with MS, and how such retirement and its consequences are socially and politically shaped, it was necessary to draw on a range of critical theoretical perspectives to explore this topic most fully. Within the chapter I outline how disability studies perspectives that take up an intersectional lens, and a critical life course perspective were used to inform my data collection, analysis and interpretation.

In **chapter four**, I present the research methodology and methods used for the study. I begin by outlining narrative inquiry and critical narrative inquiry and explore my specific ontological, epistemological, and methodological assumptions. Next, in the methods section, the overall design of the study, how participants were accessed, details regarding the collection and analysis of data, and quality criteria related to the study are addressed.

In **chapter five**, I present the participant's narratives around their involuntary transition out of work and into retirement. Five narratives are presented by participants with the pseudonyms Judy, Billie, Amanda, Noreen, and Carissa in order to create a space for the stories of women with MS to be holistically shared in the ways they wanted to tell them. In subsequent chapters, I analyze within and across individual narratives.

In **chapter six**, I present and interpret the results of this study. Four overarching themes are presented. These include: 1) 'Negotiating the Disconnect between Retirement as Imagined, and Retirement as Lived'; 2) 'The Production of Consequences in Navigating Ableist Environments Requiring Certainty and the Intersection of Bodily and Financial Uncertainty,' 3) 'The Failure of Practices, Systems and Policies to Understand the

Complex, Intersectional Reality of Women with MS, and the Navigation of Identity Tensions’; and 4) ‘Filling the Gap’.

In **chapter seven**, I present the discussion of findings and conclusions of this research. The discussion addresses the four main themes drawing on my theoretical lens, and raising considerations regarding the socio-political shaping of involuntary retirement and the lived consequences of involuntary retirement. More specifically: the stigma of disability and workplace accommodations; problematics in Canadian disability policy; the importance of addressing intersectionality in practices, systems, and policies; the socio-political production of multi-faced precarity, the need to retreat from an imagined, idealized retirement; and ‘filling the gap’ due to systemic failures. Finally, I highlight the contributions of this research to the area of involuntary retirement for women with MS, the boundaries and strengths of this thesis, the implications of this work, and re-visit reflexivity.

Chapter 2

2 Literature Review

Although research to date suggests that women with Multiple Sclerosis (MS) face numerous challenges in negotiating and maintaining sustainable employment and are at risk of involuntary retirement, defined as the early and/or forced withdrawal from the paid labour force and transition into retirement at a point in the life course that is earlier than planned or desired by an individual (Hilt Pflieger, Meulengracht Flachs, & Koch-Henriksen, 2010a; McDonald & Donahue, 2011), few studies have situated such involuntary retirement intersectionally in socio-political conditions or examined its implications in women's lives. This review begins with a brief overview of the broader context of employment and retirement statistics in Canada and Ontario for the general population, aiming to show the need to consider gender when addressing involuntary retirement for women with MS. In the second section, I attend to labor force participation and unemployment data to show that persons with MS face particular challenges in maintaining sustainable employment, having lower labour force participation and higher unemployment than the general population. However, I also argue that there is a need to further focus on involuntary retirement to enhance understanding of the challenges faced by persons with MS. In the third section, I consider MS and gender, arguing for the need to look at how chronic illness and gender intersect in ways that have implications for employment and involuntary retirement. Highlighting gaps in understandings addressed through this research, I point to the paucity of Canadian based qualitative research informed by an intersectionality lens that is specifically focused on the involuntary transition out of work and into retirement for women with MS within the current socio-political context. Finally, in the fourth section, I highlight the pervasiveness of biomedical framing in research attempting to advance understanding of factors that lead individuals with MS to leave work. Moreover, I demonstrate that despite calls for more critical understandings and intersectional approaches to understand the employment and retirement experiences of persons with MS, recent contributions have been limited. I also discuss the consequences if this framing continues to dominate.

2.1 The Context of Employment Participation, Unemployment, and Retirement in Canada and Ontario for the General Population

Given the centrality of work within contemporary society, work is framed as a right that should be equitably available to Canadian citizens; this is supported by federal and provincial legislation within Canada including The Canadian Charter of Rights and Freedoms (Government of Canada, 2020j) and the Ontario Human Rights Code (Ontario Human Rights Commission, n.d.). Indeed, access to and engagement in sustainable employment, that is, employment that can be maintained over time with the possibility of advancement (Kellard, Walker, Ashworth, Howard, & Liu, 2001), is associated not only with obtaining financial resources necessary for survival, but also with other potential health, social and economic benefits (Kirsh et al., 2009), such as the promotion of health, social integration, and providing a sense of identity. Although it is acknowledged that work can be associated with negative outcomes, it is also clear that lack of sustainable employment is associated with health risks, financial challenges, and social isolation (Raphael, 2006). The employment and retirement experiences of women with MS in Canada are situated within a broader context of Canadian trends in labour force participation, unemployment, and retirement. As detailed below, gender differences exist in the general population, and thus gender matters when considering labour force participation, unemployment, and retirement timing,

To understand the distinct challenges that women with MS face in maintaining sustainable employment, we must first appreciate the broader Canadian and Ontario context of employment and retirement. Two common measures used to depict this employment context pertain to labour force participation and unemployment rates. Labour force participation “measures the total labour force (comprised of those who are employed and unemployed, combined) relative to the size of the working-age population. In other words, it is the share of the working-age population that is working or looking for work” (Statistics Canada, 2015, ¶ 1). While unemployment describes the “number of persons who, during the reference week, were without work, had looked for work in the past four weeks, and were available for work” (Statistics Canada, 2020, n.p.). Retirement

is typically measured by Statistics Canada as persons aged 50 or over who has not worked in the preceding 12 months, was not working at the time of the survey, and self-identified as retired (Carrière & Galarneau, 2011).

It is important to note that the context of employment is not static. Over the past ten years, at both a federal and provincial (Ontario) level, labour force participation and unemployment rates have fluctuated for the general population. Over the past 10 years (2009-2019), Canadian labour force participation rates for the general population aged 15 years and over have varied between 65.4% and 67.1% (Statistics Canada, 2020); and in Ontario, labour force participation rates have varied between 64.5% and 67.0% (Statistics Canada, 2020). Similarly, with unemployment, Canadian rates for have varied between 5.7% and 8.3% (Statistics Canada, 2020); and in Ontario, unemployment rates have varied between 5.6% and 9.1% (Statistics Canada, 2020). Further examining these statistics, it is clear that differences exist in the labour force participation and unemployment rates for men and women in the general population. Overall, women, as a collective, have lower labour force participation rates than men, despite increases over the past few decades (Statistics Canada, 2020). For example, considering Canadians aged 15 and over, labour force participation rates over the last 10 years (2009-2019) for men have varied between 69.6% and 71.9%, while those for women varied between 61.2% and 62.4% (Statistics Canada, 2020). Similarly, for men in Ontario, labour force participation rates have varied between 68.7% and 71.5%; and 60.5% and 62.8% for women (Statistics Canada, 2020). Differences in unemployment have also been observed between men and women in the general population, with women as a collective tending to have lower unemployment rates. For example, for Canadian men aged 15 and over, unemployment rates over the last 10 years (2009-2019) have varied between 6.0% and 9.5%. While the unemployment rates for women in the same category have varied between 5.3% and 7.2% (Statistics Canada, 2020). Similarly, for men in Ontario, unemployment rates have varied between 5.6% and 10.5%; and 5.4% and 8.0% for women (Statistics Canada, 2020). These differences provide important context to understand the uniquely gendered challenges that women with MS face in establishing and maintaining sustainable employment.

Given the focus of this study on involuntary retirement, it is also important to provide some context around retirement ages for Canadians and highlight how those also differ between men and women in the general population. Based on data from Statistics Canada (2020b), the average age of retirement over the last 10 years (2009-2019) for all retirees ranged from 62.0 to 64.3; men ranged from 62.2 to 65.2; and women ranged from 61.5 to 63.3 (Statistics Canada, 2020b). These statistics highlight that women appear to retire earlier than men.

In summary, as a whole, over the past few decades, it appears that Canadian women in the general population have lower rates of labour force participation, slightly lower rates of unemployment, and lower average retirement ages than men, reinforcing the importance of considering gender when exploring the employment and involuntary retirement experiences for women with MS.

2.2 Multiple Sclerosis, Work, and Involuntary Retirement

In this section, I highlight the differences in labour force participation between people with MS and the general population and draw attention to how chronic illness is associated with lower rates of participation and higher unemployment rates. I also flag important gender differences in labour force participation for men and women with MS, and underline the need to consider the interplay of gender and chronic illness in shaping the ability to maintain sustainable employment. I then provide a new lens for understanding the distinct employment issues faced by Canadians with MS and describe how existing research on involuntary retirement from the broader disability knowledge base provides a useful starting point to understand the complex nature of employment and retirement for women with MS.

Research has shown that people diagnosed with MS struggle to maintain sustainable employment and that the magnitude of this struggle is significantly greater for people with MS than the general population. Internationally, a number of studies have drawn comparisons between employment rates for individuals with MS and the general population. Employment rates differ from labour force participation rates in that

employment rate statistics include only those who are currently employed at a particular point in time, whereas labour force participation rates include both those employed and those looking for work. A small number of these studies also attend to gender differences. For example, Bøe Lunde and Colleagues (2014) reported Norwegian employment rate comparisons between individuals with MS and the general population and found that across various age group comparisons, employment rates for people with MS were consistently lower. For example, for individuals aged 55-66 years, only 33.3% of men and 32.4% of women with MS were employed, compared to 75% of men and 68.8% of women from the general population (Bøe Lunde et al., 2014). These differences point to the need to explore the interplay of gender and chronic illness in shaping labour force outcomes for people with MS.

The finding that individuals with MS have lower employment rates when compared to the general population has been reported in several international studies. For example, Garcia-Dominguez and Colleagues (2019) conducted a Spanish multicenter, non-interventional, cross-sectional study of 199 clinically stable individuals with Relapsing Remitting Multiple Sclerosis (RRMS) and Primary Progressive Multiple Sclerosis (PPMS) to investigate the economic impact of MS. They found an employment rate of 47.3% (Garcia-Dominguez et al., 2019) in a sample made up of 60.8% women, although they did not report specific rates by gender. Also in Spain, Oreja-Guevara and Colleagues (2017) as part of a larger cross-sectional retrospective study across 16 countries, investigated resource consumption, work capacity, health-related quality of life (HRQoL) and symptom prevalence for individuals with MS. They reported an employment rate of 45% in their sample of 462 people with MS. Although also not specifically broken down by gender, women made up 67% of their sample. These findings appear lower than the labour force participation rate of the general population in Spain; for example, CEIC Data (2020) reports a labour force participation rate of 58.740% as of January 2020 for the population of Spain. Finally, from Australia, Dorstyn and Colleagues (2019) conducted a meta-analytic review of 33 cross-sectional studies carried out primarily in the Northern Hemisphere in regard to employment in individuals with MS. They reported that employment participation in MS ranged from 12% to 74% with an average of 44% across

all studies (Dorstyn, Roberts, Murphy, & Haub, 2019). This review did not report employment rates specific to gender.

Being cognizant of the fact that stark differences exist between countries in terms of resources, and socio-political, cultural and health care contexts, similar trends have also been observed in the limited body of Canadian literature. From a sample of 96 patients with MS from two studies in Calgary and Nova Scotia, Busche and Colleagues (2003) found that at baseline, 50.1% of the 96 participants (all with MS) were employed. Two and a half years later, only 40.6% of participants were employed – highlighting a drastic 22% loss of employment in a relatively short period of time (Busche, Fisk, Murray, & Metz, 2003). The authors assert that their results support existing evidence of low employment rates among individuals with MS; compared to the regional Alberta employment rate of 68.6% during the same timeframe, the rates for people with MS were significantly lower (Busche et al., 2003). Statistics by gender were not provided. In a 2014 report titled ‘MS in the Workplace: Making the Case for Enhancing Employment and Income Supports’, The Conference Board of Canada (2018) applied the international findings by Bøe Lunde and Colleagues (2014) to the Canadian context. They estimated that the 2017 labour force participation rates among people with MS as 42.7 percent for women and 35.7 percent for men (Conference Board of Canada, 2018). Compared to the 2017 Canadian labour force participation rate provided for the general population of 65.8% for all individuals and 70.2% for men and 61.5 for women (Statistics Canada, 2020), estimates for people with MS appear drastically lower and highlight existing differences in relation to gender and employment in MS.

What is clear from this literature, both internationally and within Canada, is that obvious differences exist in employment rates and labour force participation between people with MS and the general population, and these rates speak to the role of chronic illness in shaping employment. These studies also suggest that gender differences may exist in relation to employment rates for people with MS; and raise questions about how the interplay between chronic illness and gender may shape labour force outcomes for people with MS, and the distinct challenges that may be produced.

In addition to lower employment rates for people with MS, what the literature has also shown is that compared to the general population, people with MS face higher rates of unemployment, both internationally and within Canada. Rates of unemployment for people with MS from the USA (Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008; Kornblith, LaRocca, & Baum, 1986; Pack et al., 2014; Pompeii et al., 2005; Strober, Chiaravalloti, Moore, & DeLuca, 2014), Australia (Honan, Brown, & Batchelor, 2015; Simmons, Tribe, & McDonald, 2010), Italy (Messmer Uccelli, Specchia, Battaglia, & Miller, 2009), and the Netherlands (van der Hiele et al., 2015) range from 40% and 80%. A review of literature conducted by an Italian team exploring work-related problems in MS, and the variables or determinants associated with work difficulty, estimated an average unemployment rate of 60% across studies (Schiavolin et al., 2013).

Canadian studies exploring unemployment in people with MS, although scarce, have shown similar results. For example, a Toronto, Ontario, based study by Honarmand, Akbar, Kou, and Feinstein (2011) examining demographic, neurological, neuropsychological and personality factors associated with unemployment, found an unemployment rate of 61.3% in their sample of 106 MS patients. As previously discussed above, Canadian work by Busche and Colleagues (2003) also confirmed the low employment rate and high unemployment rate among people with MS.

The rates of employment and unemployment for individuals with MS provide only a partial picture of work engagement in MS; they cannot tell how or why these trends exist. However, when placed in the broader context of pre-illness work and education histories of people with MS in the labour force, they raise concerns about their marginalization from the labour force. Existing research has shown that many individuals with MS have work histories and engagement in full-time education at or before diagnosis, and express a strong desire to work (O'Connor et al., 2005; Sweetland, Howse, & Playford, 2012), therefore, is it unlikely that their absence from the workforce post-diagnosis can be explained by a lack a willingness alone and additional unknown structures or social factors may be at play. When examined through a critical disability lens, the trends in employment and unemployment for individuals with MS are not understood as being a natural, or inevitable outcome of having MS, but rather are a product of culture and

systems that are designed for well, able-bodied workers. To better understand this phenomenon and generate a more comprehensive picture of labour force participation and challenges for people with MS, an exploration of all the factors or circumstances that influence, or shape workforce exit in MS inclusive of and beyond gender, must be undertaken.

A first step to understanding the landscape of sustainable employment for people with MS is adopting the lens of involuntary retirement. Involuntary retirement is a less common but important lens for examining sustainable employment, particularly in regard to MS, because people with MS who disengage from the workforce often times do not return (Roberts, 2008), and their lived realities are often excluded from other measures or counts in the broader picture of labour force participation in MS. For example, persons who become discouraged from looking for work and those who retired are not captured in many measures of labour force participation and unemployment (International Labour Organization, 2016), only attending to these statistics leads to an incomplete picture of the implications of MS for work engagement.

Research has shown that people with MS leave the workforce early, before the age of eligibility for public retirement pension (Dyck & Jongbloed, 2000; Sterz, Ellenberger, Meißner, Friede, & Flachenecker, 2016); earlier than the general population (Organisation for Economic Co-operation and Development (OECD), 2020). For example, Landenfelt and Colleagues (2016) found nearly four out of 10 patients with MS in Sweden were on full-time disability pension within a decade of diagnosis, at a mean age of 43 years, which was greater than 20 years prior to the country's pensionable age, discussed in the study as the official retirement age. Similarly, also within the decade after diagnosis, they reported that nearly eight out of 10 patients in their study were partially or fully absent from the labour force (Landenfelt et al., 2016). These findings are echoed in another recent retrospective study in Finland where the median time between MS diagnosis and retirement was 8.3 years before 1995, and 11.1 years after 1995 (Heinonen et al., 2020). Another study of 13,186 people with MS across Austria, Belgium, Germany, Italy, Netherlands, Spain, Sweden, Switzerland, and UK found that the proportion of patients recruited for their study, self-defined through mail

questionnaire as being in early retirement due to multiple sclerosis, ranged from 33% to 45% across the nine countries, with an average of 35% of participants in early retirement due to MS (Kobelt et al., 2006). The number of women included in the various country samples ranged between 63.8% and 74.5% (Kobelt et al., 2006).

The literature demonstrates also that when compared to the general population, people with MS have been shown to retire earlier. For example, García-Domínguez and Colleagues (2019) reported a mean retirement age of 43.6 years for Spanish individuals with MS in their study which appears to occur significantly earlier than the effective age of retirement, defined as “the average effective age at which older workers withdraw from the labour force” (OECD, n.d., ¶ 1), of 62.1 years for men and 61.3 years for women in the general population. Similarly, Phillips and Stuijbergen (2006) reported that men and women with MS in their study were found to exit the workforce via retirement at a younger age than the current US national average. Unfortunately, no specific Canadian statistics comparing typical retirement ages for people with MS could be located. Although not directly tied to retirement, statistics indicate lower rates of employment amongst individuals with disability aged 55 and above, and when examining gender in relation to employment rates, men with no or mild disability were found to have higher employment rates than women across almost every age group; with gender disparity most pronounced in the 55 to 64 year age range (Morris, Fawcett, Brisebois, & Hughes, 2018).

Applying a critical lens to this literature reveals the problematic nature of these trends - people with MS are discontinuing work early and stark differences exist in relation to retirement trends for the general population. Unfortunately, there is not an established literature base around MS to understand why these differences exist and how such retirement is experienced differently by people with MS; how individuals with MS negotiate the transition out of work and into retirement; what shapes that transition; and what retirement looks like. Given these important gaps, there is a clear need for more focused, intensive study of the factors that shape the involuntary transition out of work and into retirement for people with MS to question and understand these differences.

2.2.1 Involuntary Retirement and Disability

Although not directly related to MS, a small body of scholarship exists that does explore involuntary retirement more broadly for people with disabilities in general, including research from the UK and Canada. For example, in a small UK-based qualitative study of four men and seven women with disabilities, Bradley and Colleagues (2004) using semi-structured interviews conducted by three researchers who had all experienced involuntary job loss, investigated the experience of involuntary retirement and redundancy as a result of disability (Bradley et al., 2004). Their results illustrated that participants felt pressure to leave work as a result of disability; many experienced bias in seeking work after being forced to retire; reduced incomes impacted their lives, lifestyle and family; physical and mental health also suffered; and they faced difficulty adjusting to job loss (Bradley et al., 2004).

A Canadian study by Schellenberg and Silver (2004) analyzed the Canadian 2002 General Social Survey (GSS) to explore the concordance between the retirement preferences and actual experiences of recent retirees, where those who involuntarily retired were referred to as low congruence retirees (Schellenberg & Silver, 2004). Although not specifically measuring disability, their results showed that 27% of retirees retired involuntarily; 43% of these low-congruence retirees indicated poor health as a reason for retirement; 37% rated their health as fair or poor at time of retirement; and nearly half of them expressed that they would have stayed in the workforce if their health had been better (Schellenberg & Silver, 2004). Financially, most of these retirees expressed they felt they were in a weak financial situation and only 34% felt retirement was financially feasible, positioning them negatively financially after retirement (Schellenberg & Silver, 2004). Due to the combination of financial insecurity and poor reported health, these low congruence retirees were found to be less satisfied with their lives (Schellenberg & Silver, 2004).

The bulk of Canadian research around involuntary retirement for people with disabilities has been led by Dr. Margaret Denton, who has conducted a series of analyses using data from a large national data set called the 2006 Canadian Participation and Activity

Limitations Survey (PALS). This body of work has illuminated some important patterns in involuntary retirement.

Denton and Colleagues (2010a, 2010b, 2013b) analysis of data from the PALS study examined involuntary retirement amongst Canadians aged 15 to 74 with disabilities, with foci on age of onset as a predictor (2010b), characteristics associated with involuntary retirement (2010a), and economic consequences (2013b). Another analysis (Denton, Plenderleith, & Chowhan, 2013a) examined involuntary retirement amongst Canadians aged 45-74, with a focus on how choice and control play a role in the decision to retire. These analyses indicated a high rate of involuntary retirement amongst persons with disabilities, with 38% (Denton, Plenderleith, & Chowhan, 2013b) and 39% (Denton, Plenderleith, & Chowhan, 2010b) of the samples of people with disabilities retiring involuntarily between 2001 and 2006. A multivariate logistic analysis that controlled for socio-demographic, socio-economic, geographical and health status variables, indicated that persons who acquired a disability between ages 55 to 64 had the highest risk of involuntary retirement (Denton et al., 2010b). More specifically, adults who acquired a disability after age 54 were five times more likely to indicate involuntary retirement than adults who had onset of disability prior to age 35 (Denton et al., 2010b). Other results identified particular socio-economic and socio-demographic characteristics of individuals who involuntarily retired: being aged 55 or less, having less than a high school level education, renting their home, residing in Quebec, and having a fairly low income (Denton, Plenderleith, & Chowhan, 2010a). The prospect of retiring involuntarily was greater for individuals with poor health at retirement, those with an age of onset after 55, increased severity of disability, and comorbid disability (Denton et al., 2010a). In fact, worsening health and disability were overwhelmingly identified as the principle factor influencing the involuntary retirement of people with disabilities (Denton et al., 2010b: 2013a); accounting for between 41% and 90% of departures respectively (Denton et al., 2013a: 2010a). They also found that people with disabilities were seven (Denton et al., 2010b) and eight (Denton et al., 2013a) times more likely to retire involuntarily than people who did not have to retire because of their illness (Denton et al., 2013a). These individuals were also found to be further disadvantaged financially after retirement, and be the recipients of social assistance or disability benefits (Denton et al., 2010a).

No significant association was found between gender and involuntary retirement (Denton et al., 2010a: 2010b: 2013a: 2013b), concluding that “involuntary retirement occurs when people with disabilities are no longer able to work rather than due to differences in socioeconomic characteristic” (Denton et al., 2013, p.170). In a subsequent analysis of the same data set, Denton and Colleagues (2013b) highlighted the adverse economic consequences of involuntary retirement for persons with disabilities, but did not differentiate such consequences by gender. For example, this analysis, which also controlled for socio-demographic, socio-economic and geographical factors, found that persons with disabilities who retired involuntary had greater risk of being under the low income cut-off point, and were more likely to be receiving disability benefits as opposed to other forms of retirement income (Denton et al., 2013b). On the basis of these analysis, their team highlighted the need for research to focus on why the risk of involuntary retirement is associated with the age of onset of disability, supporting the need to extend beyond biomedical understandings to consider sociopolitical forces (Denton et al., 2013b). For example, they proposed that research address employer practices related to accommodations and retirement incentives, older workers willingness to sustain work involvement, union practices, and attitudes towards age and disability within workplaces and broader society (Denton et al., 2013a). In addition, Denton and Colleagues (2013b) highlighted the need for further research on the economic consequences of involuntary retirement for persons with disabilities that extends beyond showing an association in order to address lived consequences and how these are socio-politically shaped. Although Denton and Colleagues did not specifically focus on gender, and did not find a significant difference in voluntary or involuntary retirement based on gender, they emphasized there was still a need to look at this topic in relation to gender due to the varying implications for women (2010a). For example, they discussed how more research should “be directed towards the impact of the interactions between family roles and work on the retirement decision, gender differences in factors leading to retirement and the consequences of involuntary retirement for women with disabilities” (Denton et al., 2010a, p. 8). These analyses support the association of disability and involuntary retirement, as well as concerning economic implications associated with involuntary retirement. Further, they point to the need for further research to investigate

the implications of involuntary retirement for women with disabilities, and how intersectional factors can impact or shape involuntary retirement and the consequences produced.

The present work aims to address these gaps by examining the interplay of gender and MS in shaping involuntary retirement. More recently, within a commentary paper drawing on Denton's work, Brown forwarded the need for more focused study on 'disability retirement', a concept used to refer to earlier than expected work cessation because of a chronic health issue that presents increased challenges and is likely to be associated with poor adjustment to retirement. In addition, Brown (2018) highlighted a number of key gaps in knowledge surrounding involuntary retirement for people with disabilities including qualitative explorations of the experience of disability retirement and adjustment to disability retirement. The present study aims to explore and expand upon these gaps.

To date, there remains little focused research on involuntary retirement for people with disabilities. While the existing studies discussed above provide some insight around specific demographic, socio-economic or disease related characteristics associated with involuntary retirement, factors that may influence perceptions of involuntary retirement, and existing knowledge gaps around involuntary retirement for people with disabilities in general, what remains unknown is how these findings translate to individuals with MS. These studies identify critical gaps in our understanding of involuntary retirement more generally, draw attention to the scarcity of Canadian based, qualitative research on involuntary retirement around specific types of disabilities, and articulate the need for exploring the role of gender in shaping involuntary retirement and its consequences for women with disabilities. These gaps solidify the importance of further, more intensive study around involuntary retirement for people with disabilities in general, and those with MS more specifically.

In summary, there is ample evidence signalling the need to explore how chronic illness and gender may intersect to shape, produce differences in, or further complicate the process of maintaining sustainable employment for people living with MS. Involuntary

retirement is a useful lens for examining sustainable employment in MS and allows for the exploration of factors or experiences that contribute to higher rates of unemployment and earlier retirement ages as compared to general population. Narrowly focusing on statistical measures of workforce participation and unemployment limits our understanding of what happens next in the lives of people with MS when they leave work involuntarily, and neglects that involuntary retirement is a reality for many people with MS. What we do not have is a clear sense of what retirement looks like in people with MS; how people with MS navigate the transition out of work and into retirement; the full extent of the consequences produced as people with MS involuntarily retire; how those consequences are shaped; and how gender plays a role in shaping involuntary retirement. Critical Canadian-based, qualitative approaches are needed to reveal the lived consequences and lived realities of involuntary retirement in MS and enhance our understanding, beyond statistical measures, around how chronic illness and gender intersect in the lives of women with MS who involuntarily retire. While the research examined in this section has provided some information about the impact of gender, it is not strong, and research to date has suggested that men and women with MS have different experiences. In the next section, I make the argument for focusing on women with MS and involuntary retirement.

2.3 Women, MS, and Work

Employment in MS has been problematized as gendered within a very small body of literature that demonstrates how the employment experiences of women with MS differ from those of men with MS; illustrating the challenges that arise at the intersection of gender and MS. In this section, I outline what is known about the gendered dimensions of MS and employment and draw attention to the gaps in the current knowledge base. In so doing, I argue that careful work is needed to better understand the landscape of employment and unemployment for women with MS and the consequences that arise when women involuntarily retire.

Several authors have problematized the struggle to maintain sustainable employment as gendered, and have called for research that attends to how gender shapes labour force participation and unemployment in MS (Raggi et al., 2016; Upton & Taylor, 2015).

Literature outside of Canada has demonstrated that women with MS face unemployment at higher rates than men with MS (Grytten et al., 2017; Julian et al., 2008; LaRocca, Kalb, & Scheinberg, 1985; Solari & Radice, 2001). For example, Solari and Radice (2001) found higher rates of unemployment for women with MS than men in Milan Italy; women made up 64% of their sample and of those, 45.4% were unemployed compared to only 32.9% for men (Solari & Radice, 2001). Similarly in the US, Julian and Colleague's (2008) secondary analysis of a large patient registry data set in the US found that among patients with MS in their study, women were significantly more likely to be unemployed than men, representing 72.3% of the unemployed sample. This trend was also present in a recent Norwegian study using logistic regression analysis by Grytten and Colleagues (2017) who found that women with MS had an almost a four-fold increased risk of unemployment (Grytten et al., 2017).

A small body of international and Canadian research has been conducted specifically focusing on the distinct employment and unemployment experiences of women with MS. Rumrill Jr. and Colleagues (2016) examined the employment experiences of US women with MS in an effort to identify high-priority employment concerns from the perspective of women with MS. The women were presented with a list of 38 employment concerns addressing issues such as health insurance, information around disability benefit programs, discrimination present in hiring and retention practices, legislation, the quality of rehabilitation and employment services, assistive technology access, return to work supports, and future planning (Rumrill Jr. et al., 2016). Participants were asked to indicate whether they felt the concern to be important, and their satisfaction around how they felt the concern was being addressed in their communities; each employment concern was then assigned an importance and a satisfaction rating by participants (Rumrill Jr. et al., 2016). Their study identified a number of weakness in US employment policies that make it difficult for women to gain or maintain employment. Two major themes in employment weaknesses existed around health insurance coverage and disability benefits; and understanding legal rights, disclosure of disability status, and requesting and implementing necessary workplace accommodations (Rumrill Jr. et al., 2016). The findings demonstrated that women with MS in the study faced and had to negotiate a number of systematic barriers to employment and that their experiences are

gendered; leading the authors to advocate for improved services and policies that support women with MS to enter, re-enter and remain the workforce and ameliorate these weaknesses (Rumrill Jr. et al., 2016).

A small body of Canadian research conducted between 1991 and 2000 also suggests that women with MS have higher rates of unemployment and face gendered barriers to continued employment. For example, Edgley and Colleagues (1991) found that 58% of men and 70% of women with MS were unemployed. While 78% of participants indicating their reason for work cessation was related to symptoms of MS, women (26%) were more likely than men to cite reasons unrelated to MS as their primary reason for unemployment including marriage and children (Edgley, Sullivan, & Dehoux, 1991). These findings demonstrate that despite being an important consideration, factors beyond symptoms – like gendered responsibilities of care - can play a role in shaping the transition out of work for women with MS. While this work illustrates the distinct employment experiences of women with MS, the work is dated, impeding the ability to draw comparisons within the current socio-political context. Further exploration and understanding around the multitude of factors that may play a role in shaping workforce exit for women with MS in the current Canadian socio-cultural context is needed.

In the 1990s, Lyn Jongbloed conducted a two phase mixed methods study and presented the results across two papers. The first phase, an ethnographic study exploring the lives of 54 women with MS, reported findings pertaining to financial challenges, employment experiences, housing situation, personal relationships, and illness management (Jongbloed, 1998). The second, quantitative phase, used a questionnaire with 812 women with MS to explore factors that played a role in maintaining or leaving employment (Jongbloed, 1996). Ethnographic findings illustrated the constrained finances of women with MS; participants relied on a multitude of income support programs (i.e., Canada Pension Plan (CPP), long-term disability, social assistance) and experienced a number of challenges related to accessing benefits, benefits insufficiency, program constraints and administration or negotiation fatigue (Jongbloed, 1998). In particular, women struggled with the limited definition of disability used by CPP and the bureaucratic bi-annual re-application requirements to secure and maintain long-term disability benefits that

required them to prove themselves incapable of working at any job. Women commented that these processes contributed to their sense of marginalization; particularly the intrusive process of determining financial need of applicants and the difficulty they faced securing medical documentation for the 'invisible' aspects of their disability (Jongbloed, 1998). This work highlighted a number of important consequences that arose from existing regulations of long-term disability programs including: the inability to change careers because they would not qualify for long term disability insurance for their pre-existing condition; hesitancy to return to work after establishing disability benefits due to additional support for costly medication; and having flexibility to leave employment or work part time if spouse had a high income (Jongbloed, 1998). In relation to gendered implications, Jongbloed (1998) argued that existing programs, which based benefits on employment earnings, function to marginalize women "who may have worked part-time because of fatigue and other symptoms associated with MS, combined part-time work with domestic responsibilities, or taken time off work to raise a family" (p. 196).

In Phase 2, Jongbloed (1996) found a number of socio-demographic and disease related differences between employed and unemployed women with MS in British Columbia (BC) (Jongbloed, 1996). Specifically, a number of statistically significant findings showing that employed women were found to be younger and younger at diagnosis, have higher levels of education, and higher gross income (Jongbloed, 1996). Unemployed women with MS were more likely to use mobility aids, report their MS as visible, and occupy clerical/sales, health and teaching jobs based on questionnaire responses (Jongbloed, 1996). No statistically significant findings were reported between the employed and unemployed women with MS in relation to marital status, household composition, city of residence size, employment status and home ownership, and place of employment (Jongbloed, 1996). The results suggest that a number of factors inside and outside the workplace enabled women with MS to maintain employment including: having an understanding employer; access to and ability to use sick time as needed; flexible or reduced and modified hours/days; having understanding family members, help with childcare and household tasks; and reduced social activity to conserve energy (Jongbloed, 1996). Symptoms were identified as main reasons for leaving employment, but "17% of these women would like to have reduced their hours of work, but were

unable to negotiate this condition” (Jongbloed, 1996, p. 218). Findings from both Phase 1 and Phase 2 paint a partial picture of unemployed women with MS in relation to a number of financial, demographic, disease, workplace and personal factors. These findings illustrate that accessing and negotiating income support is cumbersome and involves a number of administrative challenges that women with MS must navigate. Furthermore, once benefits are accessed, they are often inadequate and without a spouse, the financial challenge was even greater. The inadequacy of benefits may also disadvantage women by not accounting for unpaid care work. For example, Jongbloed (1998) found that basing benefits on employment earnings actually marginalizes women “who may have worked part-time because of fatigue and other symptoms associated with MS, combined part-time work with domestic responsibilities, or taken time off work to raise a family” (p. 196). Jongbloed (1998) raised awareness around how the employment needs of women with MS differ from those of men because they have the additional responsibility of running a home and caring for children; and how the decision to remain in or leave paid employment often requires negotiation of the complex interactions of a number of factors in addition to those of men. Importantly, this work hints at how factors beyond symptoms (age, gender roles as a parent, marital status, income, etc.) may be shaping or further complicating the decision to leave or remain in employment for women with MS. They also highlight how women with MS face additional challenges at the intersection of chronic illness and gender, supporting the need for further exploration of these factors and women’s experiences in more depth intersectionally.

Dyck (1995) noted that “although the patterns of ... disadvantage [for women with disabilities] are well documented, there has been relatively little analysis of the specific social practices and experiences of such women as they live with and manage the consequences of unemployment” (p. 307). To address this gap, Dyck (1995) explored the daily lives of women with MS in BC and revealed the complex interactions of space, physical impairment, and gender in how the women experience place. Women in this study experienced shrinking social and geographical worlds and had to adapt or restructure their homes, neighbourhoods, social relationships, and domestic tasks (Dyck, 1995). Women's residential and household changes were mediated by their marital and socio-economic status, and the strategies the women used to reconstruct their lives were

socio-politically shaped by discourse, policy structures, social relations and norms (Dyck, 1995). What was evident from these findings is the layered complexity women with MS face as they negotiate their life with MS in multiple physical, social and work environments. The findings also highlight how despite commonalities across illness experiences, they also show gendered dimensions of the illness experience in MS (Dyck, 1995). For example, the women spoke about resisting having to re-order, delegate or renegotiate tasks or aspects related to physical space and domestic work (Dyck, 1995). Because of power relationships between men and women there are existing structures that place specific gendered expectations on women, such as additional home and caring responsibilities discussed as the 'second shift' (Hochschild & Machung, 2012) or 'double duty' of women. If those expectations were not placed on women in these circumstances, they would have more choices, but within this study and on top of their illness, the women had to negotiate those expectations that men with MS would not, and that reduced their options. Their findings also highlight how the multiple social identities occupied by women with MS intersect and overlap to produce experiences distinct not only from men with MS, but other women with MS (Dyck, 1995). Although not explicitly labelled as using an intersectional approach, this study took an important step in advancing understanding around how these social identities converge and intersect in the lives of women with MS.

Finally, Dyck and Jongbloed (2000) focused on issues of disclosure and identity for 31 gainfully employed women with MS aged 25 to 49 years in order to illuminate, theoretically, the intersections of occupational performance and the social and institutional dimensions of environment. Findings "indicate that although severity of symptoms affect employment status, non-medical factors, including modification of work conditions and understanding employers, and a supportive home environment with the possibility of delegating household tasks, can enhance women's ability to work" (Dyck & Jongbloed, 2000, p. 337). For example, having a spouse with a higher income supported women with MS in the study to reduce their work commitments or leave work altogether, than women who were single or whose spouses had smaller incomes (Dyck & Jongbloed, 2000). Further, participants identified experiencing tension around work status and how a large contributor to this tension was concern around their social identity as either able or

disabled (Dyck & Jongbloed, 2000). Their analysis also revealed the role of workplace organization and culture in shaping the decision to disclose their diagnosis and how that act of disclosure impacted the women's identity as able-bodied (Dyck & Jongbloed, 2000). The participants also expressed fear that they would face discrimination or stigma related to disability after sharing their MS diagnosis; discrimination that may have limited their employment advancement or jeopardize their eligibility for disability benefits (Dyck & Jongbloed, 2000). Further, the norms and expectations of a particular workplace culture impacted how the women managed their symptoms or revealed their diagnosis of MS (Dyck & Jongbloed, 2000). Finally, when the participants were unsure of the consequences their disclosure may bring, some developed concealment strategies to avoid disclosing, and spoke of the difficulties of having to negotiate the physical environment, specific workplace expectations and the careful advance planning needed in order to appear able-bodied (Dyck & Jongbloed, 2000). This work highlights a number of factors beyond symptoms that can support the maintenance of employment for women with MS and speaks to some of the challenges and tensions that women with MS face as they negotiate paid work and MS, despite being relatively limited to issues of disclosure and identity. This study also points to gendered dimensions; showing the importance of gender in the organization of the labour market and highlighting the experience of disability as gendered, shaped through the particular ways in which the labour market and disability benefits are organized based on gender (Dyck & Jongbloed, 2000). For example, the authors discussed the varying capacities of women with MS in the study to negotiate flexible work options and how not all women have enough power or resources to be able to re-negotiate options or implement the changes they really need, ultimately impeding their ability to maintain work. They also spoke about women's place in the labour force and their experiences of double jeopardy which leads to various forms of vulnerability. For example,

women in traditional female occupations such as clerical and sales jobs ... which are commonly non-unionized and paid by the hour, are in double jeopardy as they have little option in restructuring their work environment in a way that enables their continued employment. They are also vulnerable to poverty, particularly if

they are sole-earners in households, are divorced, and/or have gaps in earnings through child-rearing responsibilities (Dyck & Jongbloed, 2000, p. 344).

Less clear from these results are the long-term implications of the challenges women with MS experienced and how they unfold to create circumstances where women with MS leave the workforce early and involuntarily. Further exploration of gendered and socio-political factors and how they shape the transition out of work is needed.

While the evidence is limited, some literature has looked at the specific consequences of unemployment for women with MS produced at the intersection of MS and gender. Consequences discussed are largely financial in nature, and highlight how the combination of gender and MS actually produces distinct challenges that compounds the marginalization they face. Women with MS experience poverty and unemployment at higher rates than men (Jongbloed, 1998; Dyck & Jongbloed, 2000). Already disproportionately excluded from the workforce, the timing of MS may further complicate or exacerbate an already difficult or limited financial situation for women. A diagnosis of MS is typically received between 20 and 49 (MS Society of Canada, 2020) which is most often during an individual's most active and productive years including peak schooling, mid-career employment, and child rearing years, having significant impacts on these life events (Brown, 2018; Dyck & Jongbloed, 2000; Ernstsson et al., 2016; Howard, Trevick, & Younger, 2016; Hilt Pflieger, Meulengracht Flachs, & Koch-Henriksen, 2010a; Julian et al., 2008; LaRocca & Hall, 1990; Messmer Uccelli et al., 2009; Roessler & Rumrill Jr., 2003), given that women often experience work discontinuities with multiple exits and entries in and out of the workforce (Julian et al., 2008; Simmons & Betchild, 2001) both due to illness exacerbation and childbearing or caring responsibilities (Julian et al., 2008). Further compounding the financial hardship of having intermittent work histories and negotiating multiple entries and exits from the workforce, is the fact that women with MS typically withdraw from the labour force approximately 20 years before the 'standard' age of retirement; signaling the permanent loss of employment income during what would be peak training and employment years, and creating a situation where, due to lower total earnings over their work tenure, they

face the additional risk of reduced pensions and benefits (Dyck & Jongbloed, 2000; Jongbloed, 1998).

In summary, unemployment for people with MS has been problematized as gendered and there have been calls for further exploration of the gender differences in employment and unemployment for people with MS. Despite an articulated need, “for all that is known about the factors associated with labour force participation among people with MS in general, the specific employment experiences and concerns of women with MS are not well understood” (Rumrill Jr. et al., 2016, p. 2). While a small Canadian body of literature exists that highlights the distinct employment experiences of women with MS, it fails to provide us an understanding of the experiences of women with MS within the current socio-political context. Although some literature exists that explores the distinct consequences women with MS face, there has been a primary focus on financial consequences leading to an incomplete picture of the complexity of negotiating life and unemployment in MS for women, the range of consequences produced, and how those consequences are shaped. Although hints are provided that point towards the need for an intersectional approach to this topic, current evidence fails to explicitly explore the full scope of the problem intersectionally with a genuine appreciation of how factors intersect with gender may also influence the consequences produced and how those ultimately lead women with MS to leave work. Further exploration around the involuntary transition out of work and into retirement as it is experienced by women with MS is necessary to provide some understanding around if, how, or in what ways gender compounds involuntary retirement.

2.4 Women, Multiple Sclerosis, and Involuntary Retirement

In this section I highlight how a lack of focused attention on involuntary retirement for women with MS has created a gap in our understanding of the gender experience of involuntary retirement; including what happens during this important transition and how it is negotiated; the range of consequences that are produced; and how involuntary retirement and associated consequences are shaped. To date, research that investigates why people with MS struggle to maintain sustainable employment, and ultimately leave

work, has been primarily biomedically focused on symptoms which positions exit from the workforce as an individual issue and ignores larger contextual factors that may play a role. Despite a long-standing critique in the literature calling for an expanded understanding of shaping forces beyond symptomology, research is lacking to support the development of a coherent knowledge base around this topic. In this section I also question the consequences if this type of biomedical framing continues to dominate research focus and what may be obscured if we fail to critically explore involuntary retirement for women with MS.

Given that the struggle to maintain sustainable employment and experiences of unemployment in MS can be experienced differently by gender, it is logical to assume that involuntary retirement in MS may also be experienced differently by women. Given the lack of an established knowledge base around involuntary retirement in MS, at best, we know that “women’s retirement experiences are very different from men’s because of the gendering of work and family life ... [and how] more research should be directed towards ... gender differences in factors leading to retirement and the consequences of involuntary retirement for women with disabilities” (Denton et al., 2010a, p. 8).

Literature to date has largely focused on biomedical factors leading to workforce exit and ultimately involuntary retirement. This theme is evident in both Canadian and international literature where this biomedical framing of the problem is predominant. For example, Vijayasingham and Mairami (2018) identified how “a core theme in MS employment research is the strong influence of disease status and progress on employment participation” (p. 16). Indeed, several previously discussed studies have also identified a particular focus on physical and cognitive functioning as shaping loss of employment and workforce participation (Dyck & Jongbloed, 2000; Edgley, Sullivan, & Dehoux, 1991; Jongbloed, 1996; Julian et al., 2008; Kornblith, LaRocca, & Baum, 1986; LaRocca, Kalb, Scheinberg, & Kendall, 1985; Morales-Gonzales, Benito-Leon, Rivera-Navarro, Mitchell, & GEDMA Study Group, 2004; O’Connor, Cano, Torrenta, Thompson, & Playford, 2005; Smith & Arnett, 2005).

Despite the dominant biomedical framing, there is a longstanding critique in the literature that there is a need look beyond symptomatology to understand what shapes workforce exit (Dyck & Jongbloed, 2000; Rumrill Jr. et al., 2016). In particular, researchers have argued that looking solely at symptoms biomedically characterizes unemployment in MS, and neglects broader, societal and structural complexity of employment issues in MS (Johnson, Yorkston, Klasner, Kuehn, & Amtmann, 2004). For example, Dyck and Jongbloed (2000) urged the need to consider “other, contextual factors that might shape decisions to remain in employment, or that act as barriers or facilitators of employment” (p. 339). Despite calls for a paradigm shift from biomedical to critical understandings, a focus on symptoms has continued to dominate the literature (Amankwah et al., 2017; Vijayasingham & Mairami, 2018). This is problematic because if the dominant focus remains on symptomatology, involuntary retirement remains a problem framed in research as that of individuals, and not a broader social problem with policy implications and larger consequences. What gets obscured in biomedical framings are intersections of social markers like gender, age, race, and class in relation to socio-political or contextual features that shape people’s lived experiences of MS, employment, and retirement.

2.5 Conclusion

Existing research has shown that women with MS face various challenges in navigating and maintaining sustainable employment and have been found to be at risk of involuntary retirement. Despite this, few studies have situated such involuntary retirement intersectionally in socio-political conditions or examined its implications in women’s lives. Involuntary retirement has received a lack of focused attention within MS in general and for women with MS specifically, which has limited our understanding around gendered experiences of involuntary retirement; what happens during this difficult transition; the range of consequences produced; and how involuntary retirement and associated consequences are socially and politically shaped. Existing gaps reveal a desperate need for critical Canadian-based, intersectional, qualitative research to explore the socio-political shaping of ‘choices’ around work and retirement for women with MS to begin to fill some of these gaps, and broaden our understanding of the transition out of work and into involuntary retirement for women with MS. Given that retirement is a

social process, it can provide a “useful framework for understanding the ways in which women’s experiences are shaped” (Denton et al., 2010a, p. 53) by gender and socio-political factors. Therefore, this thesis seeks to reveal the lived consequences of involuntary retirement specifically for women with MS, and to unearth how those consequences and involuntary retirement are shaped within and through the current socio-political context in Southwestern Ontario, Canada.

Chapter 3

3 Theoretical Perspectives

This study brings together disability studies perspectives with an intersectionality lens and critical life course theory in order to most adequately explore the full scope of this topic and inform subsequent analysis. The purpose of this study was to reveal the lived consequences of involuntary retirement for women with Multiple Sclerosis (MS) who had to leave work before they had planned or were ready to, and critically interrogate how such retirement and its consequences are shaped by larger social and political practices, systems and policies that marginalize these women. A disability studies perspective was selected to reveal how participants' experiences of involuntary retirement are socially-politically shaped and to unearth the lived consequences that are produced as participants interact with oppressive systems and structures. Disability studies is increasingly taking up an intersectional lens to study chronic illness and disability. Adding an intersectionality lens uncovers some of the multiple social identities or categories, such as age, disability, gender, class, or race, that exist in the lives of these women, and how they impact interactions and outcomes in the world. Therefore, it became necessary to consider the interplay or intersection of all social identities in order to understand the ways their experience of moving out of work and into retirement was shaped. Finally, applying a critical lens to the study of the life course was necessary to enrich the disability studies perspective by unpacking the ways in which constructions of the normative life course, and related work and retirement practices, systems, and policies, are shaped within the current socio-political context. It was also necessary in order to attend to how such constructions relate to how the women described their work and retirement transitions, and how those transitions occurred within the women's life courses over time.

3.1 Disability Studies Perspectives

As this study focuses primarily on the work and retirement stories of women with MS, a disability studies perspective was selected for its critical interrogation of disability and

human difference, and for its ability challenge the way disability is constructed in society. A number of programs, fields and disciplines have taken up the study of disability as a concept over the years, and the meaning of disability has continued to evolve and be understood in new ways (Haegele & Heard, 2016). Within the study of disability, a number of models exist that attempt to explain the meaning of disability as a concept and articulate the experiences of those who live it.

The medical model considers disability to be the result of a body or bodily functions that are impaired due to injury or illness (Forhan, 2009). This early, and continued, perspective views disability as an individualistic experience, something intrinsic to an individual, a medicalized problem that requires fixing, and the result of deficits in the body (Haegele & Heard, 2016; Mallett & Runswick-Cole, 2014; Oliver, 1990; Shakespeare & Watson, 2001) that are independent of an individual's physical or social environment (Brittain, 2004). Critiques of the medical model relate to the negative perceptions of disability embedded within the perspective (Haegele & Heard, 2016), and how "at the heart of the medical model [...] is an ableist view that depicts people with disabilities as deficient and inherently inferior to nondisabled people" (Berger, 2013, p. 27). Finally, other limitations center around how within the model, "the root cause of any disadvantages experienced [...] can [...] only be rectified by treatment or cure" (Crow, 1996, p. 208) which may not be realizable for a growing number of individuals living with long-term chronic illness. Despite its limitations, the medical model has continued to be a dominant conceptualization of disability in a number of medical and scientific fields, and still exists amongst perspectives that have built upon its ideas (Wendell, 1996).

With the emergence of the disability rights movement of the 1970s, activists and scholars like the Union of the Physically Impaired Against Segregations (UPIAS) and Michael Oliver, sought to critique the medical model and explicate a new perspective of disability that encourages thinking about disability in a new way. UPIAS (1976) fought to shed light on the fact that individuals are not disabled by their impairment, and instead disabled by societal barriers. The social model evolved in response to criticisms of the medical model and attempts to clearly distinguish between disability and impairment. Impairment is seen as a physiological, non-standard variation of the body, such as a

missing or malfunctioning limb (Forhan, 2009; Goering, 2015; Goodley, 2001; Oliver, 1996), whereas disability is described as something socially constructed, and “imposed on top of impairments by society” (Haegele & Hodge, 2016, p. 194). Within the social model, the importance of “making and emphasizing [...] [the] distinction [between impairment and disability] is to show how much and sometimes all of what is disabling for individuals who have impaired bodies has to do with physical and/or social arrangements and institutional norms that are themselves alterable” (Goering, 2015, p. 135). Disability became about marginalization, disadvantage, and restriction that is constructed by a society with existing physical and social environments that do not allow full or meaningful participation for people with impaired bodies and minds (Goering, 2015; Goodley, 2001; Oliver, 1990; Shakespeare & Watson, 2001; Shakespeare, 2006). Berger (2013) clarifies “how it is not an individual’s impairment or adjustment but the socially imposed barriers [...] that construct disability as a subordinate social status and devalued life experience” (p. 27) making disability an artifact of society rather than a product of or inherent to the body (Owens, 2015).

The social model has had a substantial influence in advancing the study of disability. The model provides clear direction for necessary social change, and has been liberating for individuals experiencing disability to be free from the oppression and constraints as a biomedical construct (Crow, 1996). However, even though the social model has contributed significantly to the body of work conceptualizing disability, criticisms are growing (Shakespeare, 2006). Although the social model has “succeeded in shifting debates about disability from biomedically dominated agendas to discourses about politics and citizenship” (Hughes & Patterson, 1997, p. 325), in its attempts to do so, some have problematized how it fails “to appreciate that impairment itself is an experience that begs for illumination” (Berger, 2013, p. 28). More specifically, “the social model in its purest form leaves the body out of the picture altogether” (Berger, 2013, p. 28). Other critics have raised questions surrounding how the social model handles chronic illness (Goering, 2015) and how the distinction made between disability and impairment unfairly separate the experience of the body and the physical, psychological and emotional suffering attached to particular bodily differences in the presence of chronic illness, from the disabling effects these differences may have in the

social world with which the individual engages (Morris, 1991). Crow (1996) further explains how at times, bodily experiences of pain or chronic illness may limit participation and engagement in ways that are so significant, that restrictions encountered in the outside world actually become irrelevant; and that these bodily experiences will persist even if disabling barriers are removed. In response to these criticisms, Oliver (2013) explained how even 30 years ago he made no “claim that the social model was an all-encompassing framework within which everything that happens to disabled people could be understood or explained. Subsequently, however, the social model took on a life of its own and it became the big idea” (p. 1024) which has highlighted an important issue, the fact that only models exist, no theories.

The study of disability has continued to evolve in recent years and disability studies emerged as a field of study that seeks to advance knowledge and scholarship on disability beyond the social model, and further encourage thinking about disability in new ways (Ware, 2003). Disability studies is an interdisciplinary approach to scholarship that challenges how disability is constructed in society and “offers a distinct critical perspective on the mechanisms society has used to exclude disabled people and [...] how these can be challenged” (Cameron & Moore, 2014, p. 37). Disability studies perspectives recognize

that disability is a key aspect of human experience, and that disability has important political, social, and economic implications for society as a whole, including both disabled and nondisabled people. Through research, artistic production, teaching and activism, disability studies seeks to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to advocate for social change (Society for Disability Studies, n.d.).

Disability studies perspectives view disability as a socio-political construction (Baglieri, Valle, Connor, & Gallagher, 2010; Ferguson & Nusbaum, 2012; Stone, Crooks, & Owen, 2014) meaning that the complex, intersecting lives of individuals occur within larger socially, politically constructed systems that interact to shape how an individual

negotiates and experiences the world. Within disability studies perspectives, disability is defined as “the experience of social oppression and its disabling outcomes in order to signal that disability is relational, something produced as a consequence of the interaction between individual and the environment” (Stone et al., 2014, p. 5). What this means and another way disability studies advances thinking beyond the social model, is that in order for disability to be produced, an interaction between an individual with cognitive or bodily differences produced by chronic illness, and the physical or social world must occur. It is the interaction and the relational aspect of disability within disability studies that positions the individual in the production of disability, and not as merely an individual that disability is imposed upon.

Disability studies perspectives have a number of “core themes and beliefs” (Ferguson & Nusbaum, 2012, p. 70) that seek to advance knowledge and scholarship beyond the social model to allow for the critical examination of human difference (Connor, 2011) and disability in the lives of individuals. First, “the study of disability must be social” (Ferguson & Nusbaum, 2012, p. 72). Disability studies perspectives draw on concepts of the social model of disability to encourage new ways of thinking about disability (Ware, 2003) and question bodily differences. Despite criticisms of the social model, disability studies perspectives see it as an important key contributor in that it highlights the importance of studying disability from a “social, cultural and historical context” (Ferguson & Nusbaum, 2012, p. 73) while extending beyond it by simultaneously acknowledging the relevancy of the personal experience (Ferguson & Nusbaum, 2012). Disability studies perspectives help advance thinking beyond the social model in how it considers the cognitive or bodily experience associated with chronic illness, and the bodily differences produced by chronic illness as part of the chronic illness experience (Stone et al., 2014) where the social model leaves the body out. It also recognizes the disabling outcomes or consequences that may be associated with the experience of chronic illness. For example, how “the physical environment may not be set up to allow the individual to have easy access or perform valued activities, or the social environment may promote discriminatory attitudes” (Stone et al., 2014, p. 5); while simultaneously understanding that the disabling outcomes or consequences an individual with chronic illness may experience are only produced through an interaction with the social or

physical environment, and are not related to the chronic illness itself (Stone et al., 2014). Finally, selecting disability studies perspectives was important because of their ability to support a relationship between chronic illness and disability while still clearly distinguishing between the two.

Employing disability studies perspectives was necessary given that MS is a chronic illness that has the potential to produce bodily differences through exacerbation or symptom fluctuation. As previously discussed in Chapter one, these symptoms may include neurological degeneration, significant pain, fatigue, mobility and dexterity limitations, weakness, emotional stress, lack of movement, numbness, and vision loss (Benito-Leon, Morales, Rivera-Navarro, & Mitchell, 2003; Crooks, Stone, & Owen, 2009; Kikuchi et al., 2011; MS Society of Canada, 2020; Phillips, & Stuijbergen, 2006; Putnam & Tang, 2006; Townsend & Fox, 2011; Messmer Uccelli, Specchia, Battaglia, & Miller, 2009). These bodily differences deviate from able-bodied individuals and ableist perceptions of what is considered a ‘normal’ functioning body (Stone et al., 2014), and in selecting a theoretical perspective to inform this thesis, it needed to recognize the cognitive or bodily experience associated with chronic illness as part of the experience, the potential for disabling outcomes or consequences, the relational nature of disability in the lives of individuals, and have an ability to support critical interrogation of disability in the lives of individuals; which will be discussed in further detail.

Second, “the study of disability must be foundational” (Ferguson & Nusbaum, 2012, p. 73). Scholars within disability studies believe that their approach to examining disability and human difference is “fundamental to deepening our understanding of how that status is experienced in society” (Ferguson & Nusbaum, 2012, p. 73). Studying disability through a disability studies lens, lends itself to understanding not only how the status or power associated with disability is experienced in society, but also that other categories of human difference exist that shape how an individual interacts in the world (Ferguson & Nusbaum, 2012). There are a group of scholars within disability studies that see disability studies as moving towards and acknowledging an intersectionality lens, making this another way disability studies extends scholarship beyond the social model. They believe that the study of disability is at the foundation of understanding how other

socially constructed identities such as gender, class, race, and age interact in the lives of individuals and position them socially within power relations (Crenshaw, 1989; Ferguson & Nusbaum, 2012) to create simultaneous opportunities for privilege and oppression (Crenshaw, 1989). What this means is that that disability cannot be studied in isolation from other social identities (Goethals, De Schauwer, & Van Hove, 2015) in order to fully understand the complexity of human difference.

Intersectionality is an immense body of scholarship and in no way do I assert that I am engaging broadly with the entire field of intersectionality, merely that I am engaging with how that lens has been taken up within disability studies and the need for it given the nature of this thesis. In very basic terms, intersectionality is a collection of perspectives and an approach to scholarship that emerged out of the work of feminist critical race scholar, law professor, and activist Kimberlé Crenshaw in the late-80s and early-90s (Crenshaw, 1989: 1991). Crenshaw's (1989) work on employment discrimination and judicial process introduced the term intersectionality as a way to draw attention to the ways that particular industrial plants, on the basis of gender and race, excluded black women from holding jobs. Crenshaw (1989) described how these women were being discriminated against not simply as black people, or women, but as black women, because they were facing not just gender or race discrimination, but both at the same time. She focused on how black women's distinct experiences of gender and race discrimination were suppressed underneath the gender experiences of white women and race experiences of black men (Crenshaw, 1989). Through applying an intersectional lens to the study of how race and gender interact in these women's lives, her work demonstrates how multiple forms of discrimination are intersecting in the lives of these women in ways that are difficult to understand or anticipate, and to show that discrimination can occur along multiple axes at the same time (Crenshaw, 1989).

Intersectionality is based on the idea that individuals simultaneously occupy multiple social identities, for example, disability, age, race, gender, class, and sexual orientation (Crenshaw, 1989: 1991). These social identities intersect or overlap with one another to produce varying experiences of marginalization. Applying an intersectionality lens "draws [...] attention to the ways in which identities, as subject positions, are not

reducible to just one or two or three or even more dimensions layered onto each other in an additive or hierarchical way” (Mirza, 2013, p. 6). Instead, they intersect, interact, and converge to “produce economic, social and political inequality in women’s real lived lives” (Mirza, 2013, p. 6). Existing systems of oppression (e.g. racism, sexism, ableism) situated within hierarchies of privilege and power, shape and construct the multiple identities and social locations individuals occupy (Carastathis, 2014) and “we all have our own unique histories and experiences that determine our social location. However, depending on who we are, we can experience greater or lesser degrees of privilege and exclusion” (Simpson, 2009, p. 8). Intersectionality seeks to “understand what is created and experienced at the intersection of two or more axes of oppression” (Hankivsky et al., 2010, p. 3) and emerged as a way to draw attention to how these systems of oppression intersect or overlap to produce distinct and unique experiences of marginalization for individuals who are facing multiple forms of discrimination (Crenshaw, 2016).

Within disability studies there are a number of scholars using an intersectional lens. Some scholars feel it is an important contribution, given the aim to critically interrogate disability and human difference, to reveal how individuals see themselves as “same and different” (Devlieger, Rusch, & Pfeiffer, 2003, p. 9) and to question how constructions of “what is different as well as what is normal” (Ferguson & Nusbaum, 2012, p. 74) are experienced and perpetuated in individual lives. Audre Lorde (2009), a self-described “black, lesbian, feminist, socialist, poet, mother of two including one boy and a member of an interracial couple” (p. 219) who in later years dealt with vision loss and cancer, describes how consistently throughout her life she found herself “as part of some group [...] the majority defines [...] as deviant, difficult, inferior or just plain “wrong”” (p. 219). She lived her life trying to be the strongest person she could in order to effect change, but recognized that in order to live life most fully and be successful in her mission, no “one aspect of [...] [herself] can possibly profit from the oppression of any other part of [...] [her] identity” (Lorde, 2009, p. 219). What she is trying to convey through her work is that, within the lives of individuals, “there [can be] no such thing as a single-issue struggle because we do not live single-issue lives” (Lorde, 2007, p. 138). In later writings she elaborates on her earlier thoughts by explaining how she

cannot afford the luxury of fighting one form of oppression only. I cannot afford to believe that freedom from intolerance is the right of only one particular group. And I cannot afford to choose between the fronts upon which I must battle these forces of discrimination, wherever they appear to destroy me (Lorde, 2009, p. 220).

On a different note, yet still consistent with disability studies transformational approach to conceptualizing disability, Lorde (2007) discusses how

if there is one thing we can learn from the 60s, it is how infinitely complex any move for liberation must be. For we must move against not only those forces which dehumanize us from the outside, but also against those oppressive values which we have been forced to take into ourselves (p. 135).

Her observations align with the social aspect of disability studies to reveal how disabling consequences may be produced when an individual interacts with a social environment that promotes ableist attitudes, or any other form of discrimination that exist as taken-for-granted ways of thinking about, and structuring the world. Eli Clare (2015), a disabled, trans, white, genderqueer activist and poet writes of the need for “nondisabled progressive activists to add disability to their political agenda. And at the same time for disability activists to abandon their single-issue politics and strategies” (p. xxi), but describes a reality where “not many disability or nondisabled progressive groups engage in multi-issue thinking and organizing that deeply embeds disability politics into an agenda that includes race, class, gender, and sexuality” (Clare, 2015, p. xxii). His desire to encourage thinking beyond single-issue politics is to create opportunities for individuals to “talk honestly and wrenchingly about all the multi-layered systems of injustice that target some of us and privilege others for who we are” (Clare, 2003, n.p.). Finally, Ferguson (2003) cautions scholars “not [to] ignore or diminish the intersectional complexities that exist within the disability community” (p. 138), however, despite being an important step in advancing scholarship on disability, “disability studies itself has been critiqued for neglecting these crosscutting points of inequality that further diversify and fragment the disability community” (Berger, 2013, p. 34). Saxe (2017) credits how

“disabilities studies scholars have already taken a great step forward in integrating the theory of intersectionality, [but] progress is still required” (p. 153).

For the purposes of this thesis, I am focusing on women whose identities cross “the boundaries of traditionally constructed groups” (Dill, 2002, p. 5). On the basis of disability, age, employment, and gender alone, recognizing that other social identities may be present in their lives, these women “reflect multiple subordinate locations” (McCall, 2005, p. 1780), and research has often failed to capture the complexity of lived experiences for such groups at these “neglected points of intersection” (McCall, 2005, p. 1780). What this means is that the intersection of multiple factors in the lives of these women cannot be captured fully by looking at the gender, age, employment, or disability dimensions of their experiences separately or discretely (Hankivsky et al., 2010). Taking up an intersectionality lens within disability studies demonstrates how oppression can only be fully understood by considering all the categories or social identities an individual can occupy (Crenshaw, 1989:1991; Hankivsky et al., 2010; McCall, 2005).

Third, Ferguson and Nusbaum (2012) discuss how “the study of disability must be interdisciplinary” (p. 74) and efforts “to understand the experience and concepts behind that status must cut across traditional academic disciplines” (p. 74). As previously discussed, the way intersectionality is taken up within disability studies creates a need to engage additional perspectives and bring them into the discussion surrounding disability in order to reveal the complexity that exists within these women’s lives and experiences. This is eloquently illustrated by Eli Clare (2003) when he talks about

the multi-layered systems of injustice that target some of us and privilege others for who we are [...] [...] The layers are so tangled: gender folds into disability, disability wraps around class, class strains against race, race snarls into sexuality, sexuality hangs onto gender, all of it finally piling into our bodies (n.p.).

It would be inappropriate and presumptuous to assume that any one discipline could lend itself to explain all the intersections or address the complexity that make up these women’s experiences of chronic illness or disability. Disability studies interrogates human difference and as such, can benefit from the contributions of other fields including

gender or race studies, that have historically also sought to challenge the structuring of or thinking around concepts and how those constructs shape individual lives. In relation to this thesis, through the application of an intersectional lens to the study of disability, it allows me to consider all the various social locations the participants occupy and look at how they overlap and intersect amongst various systems of oppression and socio-political forces to complicate women's lives and produce distinct experiences of privilege or oppression as they involuntarily retire.

Fourth, "the study of disability must be participatory" (Ferguson & Nusbaum, 2012, p. 74) such that it is essential that individuals experiencing disability be centrally involved in the research process (Ferguson & Nusbaum, 2012). This commitment exists for a number of reasons. First, individuals who experience chronic illness or disability are often underrepresented in universities, colleges, and research institutions (Ferguson & Nusbaum, 2012) which creates issues surrounding not only what research gets conducted, but also whose voice is informing that research and asking the questions (Ferguson, Ferguson, & Taylor, 1992). Research has shown that involving "members of the [disability] community in the research process [...] is thought to lead to more valid and insightful data and yield more beneficial outcomes for those involved" (Southby, 2017, p. 128). Second, there is also the assumption that an able-bodied individual cannot fully articulate the experience of disability, providing further support for research that is participatory in nature. Jenny Morris (1993) speaks about how

disabled people – men and women – have little opportunity to portray our own experiences [...]. [...] Our experience is isolated [...] [which] means that it is difficult for non-disabled [...] [people] to incorporate our reality into their research, their theories, unless it is in terms of the way the non-disabled world sees us (p. 59).

By not ensuring research is participatory, people experiencing chronic illness or disability are further marginalized and disempowered through research. Disability studies draws attention to the need to move away "from doing research on people to doing research with people" (French & Swain, 2004, p. 1) and how "involving disabled people in

participatory research might thus give them a chance to share their voices and experiences of disability issues [and open] [...] the door to further research” (Alenaizi, 2018, n.p.). For this thesis, doing lived experience research enables a space for the women to tell their stories in the ways they wanted to tell them, and for them to exist in their entirety. This study also uses a tailor made approach to data collection and analysis approach to forefront participation, with the addition of an additional phase for consultation and co-construction, allowing for discussion and refinement of the narrative and giving the participants and myself the opportunity to complete the process together.

At its core, disability studies is critical and uses language that transforms, changes, and empowers. Finally, “the study of disability must be values-based” (Ferguson & Nusbaum, 2012, p. 74) meaning that disability studies challenges how disability is constructed in society and scholarship within this perspective is inherently critical. Ableism can be defined as “a form of discrimination based on the perception that being able-bodied is the normal human condition and is superior to being disabled” (Hehir, 2005, p. 10). Ableism is a major discursive construction and system of oppression that disability studies pays attention to, and given how I am drawing on an intersectionality lens within disability studies, it is also relevant to how ableism intersects with other systems of oppression such as ageism, sexism, and racism in the lives of the participants in my study. Disability studies seeks to critique “the widespread belief that having an able body and mind determines whether one is a quality human being” (Siebers, 2008, p. 84) and draw attention to how “ableism is so taken for granted that it remains unconscious and invisible to most people, even though it constitutes an overarching regime that structures the lives of people with disabilities” (Berger, 2013, p. 15). Therefore, a goal of disability studies perspectives is to unearth, deconstruct and reveal ableism as a dominant ideology (Berger, 2013) that shapes the way people experiencing chronic illness or disability are viewed and the way they view themselves, as well as how their lives unfold.

Specific to this thesis, disability studies helps to advance scholarship in how it considers the cognitive or bodily experience associated with MS, and the bodily differences produced by MS as part of the chronic illness experience, while acknowledging that the disabling outcomes or consequences that may be associated with the experience of

chronic illness are only produced through an interaction with their social or physical environment (Stone et al., 2014). The very notion that disability studies perspectives views disability as a socio-political construction (Baglieri et al., 2010; Ferguson & Nusbaum, 2012; Stone et al., 2014) with the goal of re-imagining disability in new ways (Ware, 2003), speaks to the inherently critical nature of the approach and the values embedded within its key assumptions. This emphasis on values-based research allows for critical analysis (Ferguson & Nusbaum, 2012) of the work and retirement stories for women living with chronic illness and how they experience disability as they move out of work and into retirement involuntarily. It also allows for the questioning of how living with chronic illness is shaped and experienced, how disability is produced, and how the current practices, systems and policies support or marginalize the research participants.

3.2 Critical Life Course Perspective

A critical life course perspective was selected to explore how the women's work and retirement stories occurred and were situated throughout the life course as a social and political construction. Applying a critical lens to the study of the life course allows me to question the notion of a standardized life course, given the often unpredictable nature of living with a chronic illness like MS; how the women's choices and actions have been shaped within social structure, relationships, and historical context; the impact these illness and contextual factors have had as they moved into retirement; intersecting oppressions throughout the life course; how their lives may impact and are impacted by others; how policy frameworks are capturing their lived realities and meeting their needs given changing conceptualizations of the life course; the impact having to retire involuntarily has on their possibilities and options; and to examine challenges within a particular place, time and socio-political context. Drawing on this perspective will inform the analysis of how participants' position and connect their experiences of moving out of work and into retirement involuntarily with MS in relation to the rest of their lives, as well as broader discursive and policy constructions of 'normative' lives.

As with the study of disability, the study of the life course spans a number of disciplines, programs, and fields, and has been applied to the study of various topics (Hutchison, 2010). Research on the life course emerged in the 1960s and was popularized by the work

of Glen Elder Jr. (1974). Many scholars have since worked to build a knowledge base around the life course as a concept. Within a life course perspective, “the ‘lifecourse’ is conceptualized as a sequence of age-linked transitions that are embedded in social institutions and history” (Bengston, Elder Jr., & Putney, 2005, p. 10) that raise awareness of the “importance of historical conditions and change for understanding individual development and family life (Bengston et al., 2005, p. 10). At the center of a life course perspective is the concept of institutional structuring, meaning that individual lives consist of and are structured by, a number of socially constructed institutional contexts (Mortimer & Shanahan, 2003). These institutional contexts, for example, family, government, school, work, and retirement, define normative pathways for transitions, trajectories and social roles (Bengston et al., 2005; Mortimer & Shanahan, 2003). Therefore, “a key aspect of the life course is thus, the age-structured movement into, through, and out of social institutions, and the age-structured configuration of roles an individual takes on” (Mortimer & Shanahan, 2003, p. 530).

The life course perspective is a framework that draws attention to how individual lives are located within, and influenced by social, political, and historical contexts and personal biography (Elder, Johnson, & Crosnoe, 2003). A life course perspective is made up of five principals that will be drawn upon to help analyze the work and involuntary retirement stories of the women in this study. These principals include: linked lives; historical time and place; transitions and their timing; human agency; and life-span development (Bengston et al. 2005). First, the principal of linked lives

emphasizes the interconnectedness of lives particularly as linked across the generations. Lives are embedded in relationships with people and are influenced by them. They are linked over time in relation to changing times, places, and social institutions (Bengston et al. 2005, p. 10-11).

For example, the entry of a stay at home mother into the workforce may help to bring in additional income to offset her family’s financial difficulties, but this may also upset established routines and roles within the home. Within this principal “lives are lived interdependently, and social and historical influences are expressed through this network

of shared relationships” (Elder Jr., 1998, p. 4). In this study, the linked lives of participants will be explored in how their transition out of work and into retirement and the consequences they face are shaped within the existing socio-political context. Linked lives will also be explored in relation to how the women navigate their illness amongst the other social roles they occupy as mothers, daughters, spouses, grandparents, and other relationship connections in their lives. Finally, the linked lives of participants will also be explored in relation to how their lives impact and are impacted upon by others.

Second, is the principal of historical time and place. This principle looks at “the importance of social and historical context in shaping individual lives” (Bengston et al. 2005, p. 11) and how “historical events and conditions create the opportunities and constraints that circumscribe choices and behaviours and can change the direction of lives” (Bengston et al. 2005, p 11). Elder (1974) discussed in detail the profound impact a major historical event like the Great Depression had on children, as a cohort, who grew up during it and how it shaped their development, choices, and opportunities throughout their lives. This thesis will explore the lives of the participants within a particular socio-political context of Ontario, Canada and a particular time in history in an effort to raise insights about the current socio-political context these women live in and how their lived realities are socially-politically shaped.

The third principal discusses the importance of transitions and their timing and how “the developmental impact of a succession of life transitions or events is contingent on when they occur in a person’s life” (Elder Jr., 1998, p. 3). When “events or exposures [...] occur at a particular or more vulnerable period of early life [they] may have long-lasting effects on how a person or body develops” (Wethington, 2005, p. 117). For example, research by Elder Jr. (1998) found that individuals who marry earlier tended to experience a culmination of life disadvantages ranging from socioeconomic challenges to education withdrawal compared to individuals who married later in life. This principal will be helpful in exploring if and how leaving work early and involuntarily impacts the options the participants have available to them as they transition out of work and into retirement.

The fourth principal relates to human agency and states that “individuals construct their own life course through the choices and actions they make within the opportunities and constraints of history and social circumstance” (Elder Jr., 1998, p. 4). This means that individuals are “active agents in the construction of their lives [and] [...] they can make choices with the opportunities and constraints provided by family background, stage in the life course, structural arrangements, and historical conditions” (Bengston et al., 2005, p. 12). This principal will allow me to investigate how participants are able to make choices, navigate, and construct their life course within the opportunities and limitations of existing systems and structures.

The fifth principal is life-span development, and this principal focuses on the idea that “ageing and human development are life-long processes, and the relationships, events, and behaviours of earlier stages have consequences for later life relationships, statuses, and wellbeing. For example, research on positive nurturing by parents correlates with higher self-esteem in adulthood (Roberts & Bengston, 1996). In this study, the impact of having to leave work and retire involuntary can be explored over the long term and provides a lens to investigate the long term implications of involuntary retirement for women with MS, the consequences produced, and how those are shaped.

During analysis of the women’s stories, these concepts will sensitize me to how relationships and connections have shaped and influenced their movement out of work and into retirement; the timing and significance of important events personally, socially and historically; how their movement out of work and into retirement has occurred and been shaped in relation to the rest of their life; choice and decision making; and how all these have aspects have intersected throughout their life course of growing older with MS. Despite its usefulness for understanding human development by taking into account the ways individuals grow and change throughout their lives, and how social, historical, and cultural conditions influence individual development over time, a group of scholars have aimed to critique the notion of a ‘normative’ life course construction, and apply a critical lens to the study of the life course.

The Fordist life course is a social construction that emerged out of the 1960s, an industrialized period of vast economic growth, expansion of the welfare state, and low unemployment rates in the 'Western' world (Kohli, 2007; Mortimer & Shanahan, 2003). During this period in history, the majority of the male population in the 'West' enjoyed a "normal work biography" of continuous full time employment, and long job tenure" (Kohli, 2007, p. 258) until pensioned retirement. At the same time, women could be mostly be found "gravitating around a male breadwinner with various forms of limited engagement in paid work or none at all" (Kohli, 2007, p. 258) residing in a "normal family biography" set in motion by early and almost universal marriage and childbearing" (Kohli, 2007, p. 258). This construction of the life course shaped normative standards for the ability to attain, timing, and sequence of important life events such education, acquiring a job, the ability to support oneself, marriage, child rearing, employment, and retirement (Holme, 2013; Mayer, 2004; Mortimer & Shanahan, 2003; Quadagno, 2004) as well as perceived normative social roles for individuals.

Critical scholars have argued that the Fordist construction of the life course has benefitted certain individuals and marginalized others. First, it has been critiqued for being gendered in ways that disadvantage women, as their realities do not 'fit' the 'ideal' life course constructed by policy (Kohli, 2007; Morris 1996; McDowell, 1991). For example, Morris (1996) discussed how the Fordist social regime is built upon gender asymmetry in ways that disadvantage women. McDowell (1991) also wrote about how the entry of women into the labour force during this period was unequal to men, and how often the jobs for women were concentrated at the bottom of the occupational hierarchy in 'female' jobs where caring and servicing were poorly rewarded. Similarly, in terms of wage earning, "women's work in the household and in care did not enjoy the same economic and social valuation as paid work in the labor market" (Kohli, 2007, p. 262), and also during this time, the "life courses of housewives were dependent on their husbands not only in monetary terms but also in the social criteria of full individuality and public participation" (Kohli, 2007, p. 262).

Second, in addition to being gendered (Kohli, 2007), the Fordist life course has also been critiqued for being ableist as many individuals living with chronic illness may be

marginalized by the normative standards reinforced by this construction of the life course. For example, Grenier, Griffin, and McGrath (2020) discuss how “disability is often positioned conceptually and/or practically ... outside the standard view of the life course” (p. 22) and how it “challenge[s] the dominant view” (p. 21), as many people living with disability are forced to permanently withdraw from the labour force before reaching eligibility for retirement based government pensions (Denton, Plenderleith, & Chowhan, 2010a). Social policy during this time and it continues to today, determine eligibility for services and supports such as retirement, and outlines at what time these life events should occur. Because of this, many women and individuals living with chronic illness have found themselves ineligible or deemed ‘off-time’. What this means is that “to be outside the norm is to become different and probably socially categorised” (Holme, 2013, p. 47). According to Hockey and James (1993) participation in paid employment is an essential part of an individual’s social identity, and those who are excluded or unable to engage in paid work are therefore marginalised in a number of ways. It comes down to how, “in a work society, where paid employment remains key to social inclusion, children, youth, the elderly and disabled people are marginalised” (Irwin, 2001, p. 19). It is also important to keep in mind how “the relative success of claims to a family wage for men in many Western societies is inseparable from the economic vulnerability of women, the widespread poverty of women and children in lone parent households, and the poverty of many women [and those living with chronic illness] in later life” (Irwin, 2001, p. 19).

As time has gone on, changing social trends including an increased presence of women in the paid labour force, delayed workforce entry, diversity of family types, increasing instances of precarious employment, and population aging (Cooke & McWhirter, 2011; MacEwen, 2012; McDonald & Donahue, 2011; Moulaert & Biggs, 2012); have been drawn upon by critical life course scholars to show who is privileged and marginalized through the idealized construction of the life course that continues to be embedded in social policy. Critical scholars argue whether normative conceptualizations of the life course, at any point, have ever adequately captured the reality of many individuals including women and those living with chronic illness. In fact, Priestley (2001) argues how “it is the image of [a] non-disabled white, heterosexual, male adult that has been

central to the idealised life course constructions” (Priestley, 2001, p. 246) and therefore, “it is, thus, men who constitute the norm that women, [those with chronic illness and the aging] are expected to strive to imitate” (Krekula & Vickerstaff, 2020, p. 35). What has become clear, is that “as the life course [of individuals] has become more complex, the assumption of a unified model [is becoming] [...] less and less appropriate” (Kohli, 2007, p. 261).

Other criticisms exist for how social policy has failed to acknowledge changing social trends, and how “social and political structures are designed to attend to the needs of singular identities, which omit the experiences of multiple identities” (Buettgen, Hardie, Wicklund, Jean-François, & Alimi, 2018, p.17). Failing to consider that individuals live intersectional lives, also fails to acknowledge the fact that they may navigate discrimination on multiple levels, and the life course will continue to reflect the reality of even fewer. Through the development of social policies based on the Fordist ‘normative’ construction of the life course as well as ableist, ageist and sexist notions, the picture of an idealised adulthood is illustrated, and ways to police its boundaries clearly established (Priestley, 2001). Policy is therefore a series of “scripts [that] reflect the generic behavioural patterns of individuals, with which a policy or program fit is sought” (McDaniel & Bernard, 2011, S5). Unfortunately, what this means is that these policy frameworks are not able to meet the needs of a large number of people, and particularly those who are somehow marginalized from being able to meet normative expectations of a Fordist life course, even if they wanted to, including women, individuals with chronic illness, and the aged. In these terms, “normative concepts of age appropriateness (or generational location) have been employed as the yardstick by which to measure [...] people’s human rights” (Priestley, 2001, p. 247) leaving many individuals marginalized. For individuals who experience marginalization based on these frameworks, deviating the established social schedule is seen as not socially desirable. Their deviation highlights the fact that they “have not previously been able to live fully according to a socially established schedule, and therefore have lived their life outside biographical normality” (Holme, 2001, p. 47). In these instances, individuals whose experiences reside at the perimeter of the productive domain and their need for dependence or welfare, becomes problematic (Hockey & James, 1993).

Critical life course scholars have articulated a need “to reclaim and redefine this concept of an ordinary life, and the normality in life course progression” (Priestley, 2001, p. 247). Engaging an intersectional disability studies perspective and a critical life course approach can make a significant contribution towards “problematizing the ‘normal’ life course, and in revealing the social framework that defines its boundaries” (Priestley, 2001, p. 247) as in need of change. The critical, participatory nature of disability studies perspectives lend themselves nicely to a life course perspective to facilitate a means to create space for individuals who have been marginalized and often left out of these discussions previously (Priestley, 2001, p. 247).

Specifically related to this work, questioning the structures that construct these employment and relationship dynamics as normative, reveals how the realities of aging women living and working with chronic illnesses have been shaped and how they have been marginalized. For example, women not only face gender discrimination as women attempting to gain employment outside the home in an economy that values the contributions of male workers, but as women with a chronic illness who experience ableism in their social and physical work environments where they are not the ideal type of worker; they are neither male nor able-bodied. As they approach retirement, they are often aging workers who may have experienced intermittent work histories associated with exacerbation of symptoms associated with MS (Denton et al., 2010a; Simmons & Betchild, 2001). Research demonstrates that because a diagnosis of MS is typically received mid-career, individuals with MS have been linked to high rates of unemployment as many struggle to continue working (Sweetland, Howse, & Playford, 2012). More specifically, women with MS often have to leave the workforce in their 40s (Jongbloed, 1998), which can present a number of challenges related to long-term planning and preparation for typical retirement-related issues (Sheets, 2005). By this standard alone, women with MS are set up to not meet the demands of the standardized life course constructed by policy, and thus become marginalized by institutionalized norms. This becomes a circumstance where policy creates particular life course opportunities for some people and not for others, and when realities do not match social norms (Grenier, 2012), individuals occupying particular intersecting social categories tend to become disadvantaged.

Finally, applying a critical lens to the study of the life course informs analysis of how multiple forms of discrimination overlap throughout their lives to create distinct burdens for the women in this study, how the women may experience marginalization on multiple levels as women with MS who are retired, and how existing systems and structures understand or accommodate the multiple social identities in the participant's lives. I will also be able to see how participant stories have been shaped by family, social, political or historical factors, how choices are made and framed, the significance of timing and transitions, and how the values and experiences they connect to these transitions are shaped. Approaching the study of the life course critically also highlights the need to consider alternative or varying life course trajectories. Although constructions of the life course are influenced and shaped by institutionalized norms, it is important to reiterate that not everyone moves through their life course the same way (Närvänen, 2004). In conclusion, research is needed that investigates the experience of chronic illness in relation to employment, given the central place of paid work in the lives of individuals, and the unique ways chronic illness can impact work experience (Stone et al., 2014) for women with MS. Drawing on disability studies perspectives with an intersectional lens and critical life course theory, allows me to reveal the lived consequences of involuntary retirement and how those consequences and such retirement are socio-politically shaped through ageist, ableist, and sexist practices, systems and policies within the current socio-political context.

Chapter 4

4 Methodology and Methods

Within this chapter, the study methodology and methods will be presented. This chapter will present an overview of narrative inquiry and critical narrative inquiry and explore specific ontological, epistemological, and methodological assumptions. Next, in the methods section, the overall design of the study, how participants were accessed, details regarding the collection and analysis of data, and quality criteria related to the study will be addressed.

4.1 Critical Narrative Inquiry

Narrative inquiry can mean many different things and spans a variety of disciplines, topics, analytic approaches, and researchers. However, what holds work together within the label of narrative inquiry is the focus on story or stories (Chase, 2005; Daiute & Lightfoot, 2004; Riessman, 2008). Stories can be as simple and unstructured as dinner table discussions or naturally occurring conversation, or they may be purposefully elicited through formal techniques for research purposes or told in professional settings (Riessman, 2008). Within the context of research, story can be broadly defined as anything from a short segment of an interview to the telling of an entire life story. Narrative is grounded on the assumption that individuals share their subjective experiences through stories (McAdams, Josselson, & Lieblich, 2001)

Narrative inquiry is “a way of understanding experience. It is a collaboration between the researcher and participants, over time, in a place or series of places, and in social interaction with milieus” (Clandinin & Connelly, 2000, p. 20). In a general sense, “narrative inquiry is stories lived and told” (Clandinin & Connelly, 2000, p. 20). The stories shared may be contextualized for a particular individual as the listener, for a specific situation or environment, or for a particular time in the individuals’ lives (Clandinin & Connelly, 2000), however recognizing the fluid and contextual nature of stories is an important aspect of narrative research (Chambers, 2005).

However, narrative is about more than just telling stories or sharing experience, it is about conveying and negotiating identity and the self, re-telling and re-shaping experiences so as to portray different kinds of identities (Riessman, 2008). Individuals tell stories to make sense of their lives and who they are. Individuals “construct identities through storytelling” (Riessman, 2008, p. 8). When people tell a story, it is not an unmediated report of what happened in their life, it is a story that is being told at a particular moment in time, within a particular context, with the purpose of conveying something about themselves in a particular way (Clandinin & Connelly, 2000). The way a story is told is a way for individuals to convey aspects of who they are as a person and what their life has been like. Stories are selective. They are pieced together to share specific events and portray a certain perspective in order to convey a particular sense of who they are and what has occurred in their life (Riessman, 2008). They provide a means “for individuals to make sense of the past. And stories must always be considered in context” (Riessman, 2008, p. 8). It is not just a story about their life, it is *their* story of who they are, how their life came to be the way it is, and how they make sense of it.

As a researcher, within the context of narrative analysis, it is important to try and figure out how individuals are portraying themselves, how they are portraying their lives, how are they making sense of their lives, how things have come to be the way they are, and how their lives are situated within the contextual factors being explored. For the purpose of this study, exploring the narratives of participants will allow me to investigate how they come to understand the lived consequences of involuntary retirement for women with Multiple Sclerosis (MS), and these narratives of involuntary retirement and its consequences will be analyzed in relation to ableist, ageist and sexist practices and systems within the current Canadian/Ontarian socio-political context.

As a method, narrative provides a mechanism and space for individuals to tell their stories and talk about significant moments of their lives on their own terms and gives researchers an opportunity to listen (Creswell, 2007; Josselson & Lieblich, 1993). Individuals’ storying of their lives, or of particular events or processes in their lives, forms the basis of narrative research (Creswell, 2007). In this study, narratives of how

these women came to be retired and how life is experienced and negotiated in retirement will be elicited.

Critical narrative inquiry, like narrative inquiry, is a methodology for investigating people's experience, identity, and how they make sense of their lives through story, with the addition of a theoretically informed critical lens for analysis. Using a critical approach to narrative inquiry allows researchers to problematize and question "taken-for-granted aspects of reality and social practices that are viewed as producing, sustaining or reproducing social dominion or privilege of one group over another and as leading to situations of injustice, marginalization, exclusion and inequity" (Laliberte Rudman, 2013, p. 174). A critical approach also recognizes that people's stories are not independent of context, which shapes how stories can be and are told. Doing critical narrative inquiry will allow me to look within and across individual narratives for the stories of how these women came to be retired and what life is like after retirement and bring to light the ways that involuntary retirement for women with MS is shaped within aspects of contemporary socio-political contexts.

4.1.1 Ontology

As a critical theorist, ontologically I am taking a historically realist position, which means that when I read a story, I see that people's realities are constructed over time and they are influenced by a multitude of factors, some of which they are aware of and some of which they are not aware of (Guba & Lincoln, 1994). People take for granted particular aspects of their reality and may or may not question the situations in which our/their lives are lived. People may not question them, because these take-for-granted aspects of reality are often thought to be just 'the way things are' (Ravenek & Laliberte Rudman, 2013). For example, certain social realities, such as retirement, have become crystallized over time to have a particular meaning in our society. That meaning is taken for granted, and lives are planned around that meaning, but in reality, it is not experienced as a social construction; it is experienced it as part of our reality.

People cannot tell their story outside of the discourses in which they live, and when trying to make sense their own life, they draw on the discourses around them (Gubrium &

Holstein, 2009). Individuals negotiate a multitude of discourses in their daily life, and using narrative inquiry provides a means to study how these competing discourses shape possibilities and opportunities (Laliberte Rudman, 2015) for individuals, within the context of the broader current socio-political climate. “Storytelling is a complex process that responds to multiple layers of resources and varied forms of narrative influences, contest, struggle, and control” (Gubrium & Holstein, 2009, p. 183) Additionally, while narrative work is central to sharing stories, understanding the meaning of the story within a particular context, how circumstances shape that story is critical (Gubrium & Holstein, 2009). This often requires not only looking within a situation but across situations for the ways in which factors, including the past, present, and future, may shape accounts (Gubrium & Holstein, 2009).

4.1.2 Epistemology

Epistemologically, critical theory is transactional and subjectivist, meaning that knowledge is co-created in the relationship between researcher and participant who are joined in the interaction. Because knowledge is co-constructed between the researcher and the participant, the truth cannot exist outside of their relationship (Guba & Lincoln, 1994). Findings are also value-mediated, because the values of the investigator inevitably influence inquiry, and what can be known is intertwined in the interaction between a particular individual and a particular investigator (Guba & Lincoln, 1994). As a researcher, I have an impact on the story and the person being interviewed has an impact on the story. The participant’s voice is not unmediated, as it is told at one time, within a particular context, to a particular person, for a particular purpose. I recognize that my values will influence our interaction and the interpretation that will take place when constructing the narrative. The story will be influenced not only through the interaction between interviewer and interviewee but by the contextual factors that exist as part of our reality (Lieblich, Tuval-Mashiach, & Zilber, 1998).

4.1.3 Methodology

In terms of methodology, critical theory is dialogic and dialectical where “the transactional nature of inquiry requires a dialogue between the investigator and the

subjects of the inquiry; that dialogue must be dialectical in nature to transform ignorance and misapprehensions into more informed consciousness” (Guba & Lincoln, 1994, p. 110). The goal here is the reconstruction of previously held constructions through dialogue (Guba & Lincoln, 1994). Interpretations are changed, shaped, or modified through the interaction process and dialogue between researcher and participant. For narrative purposes, the interaction between researcher and participant is shaped and modified through the interaction process. As the story is co-constructed within the interactions, the dialogic power of narrative is evident.

4.2 Inclusion and exclusion criteria

Inclusion criteria for this study were women with MS, who self-identified as having left work earlier than they had planned, wanted or were ready to, and who considered themselves ‘retired’. I was willing to include women with probable MS in the sample due to the difficulty of obtaining a formal MS diagnosis, however, no individuals with probable MS were recruited for this study. Individuals were required to have spent a period of their adult life working in the formal labour force. In order to qualify for CPP disability, individuals must have worked four of the last six years, or three of the last six years if they have been contributors to CPP for the last 25 years (Government of Canada, 2020e). This policy parameter of six years in the paid labour force was selected as a criterion to include participants based on their employment contributions during adult years. An age parameter was not selected due to the unpredictable nature of MS and the uncertainty surrounding the process of leaving work with MS. What was more important was that these women were growing older with chronic illness. Participants needed to be English speaking and have the cognitive ability to take part in a multi-stage process of telling and reflecting on their narrative.

Exclusion criteria for this study included individuals with any congenital, cognitive, developmental, or psychiatric disabilities. Although I recognize that neurologic lesions and cognitive issues are a part of the MS disease process, I did not exclude participants based on this fact alone. The exclusion criterion was set such that, if during my interactions with the participant it became evident a participant was having difficulty with informed consent, recounting a history, or sequencing a story, the process was to continue

the interview, thank the person for their contribution, and exclude the data. Fortunately, I did not encounter this situation.

4.3 Sampling

In narrative research, answering the research questions depends on information-rich cases and data-rich participants (Creswell, 2007; Wengraf, 2001). Therefore, this study employed purposeful sampling to access participants. Participants were recruited based on the inclusion criteria outlined above in order to ensure high quality, rich data that could adequately provide meaningful contributions towards answering the research questions (Patton, 1990; Wengraf, 2001). Purposeful sampling was employed in order to target the portion of the MS population that the literature has demonstrated may face additional challenges, those being women with MS who self-identify as having left work earlier than they had planned or wanted to and who consider themselves to be ‘retired’.

4.4 Participant Recruitment

The recruitment process began after ethical approval (Appendix 1) was received from the University of Western Ontario’s Research Ethics Board (REB) and the Clinical Research Impact Committee (CRIC) through Lawson Health Research Institute. Recruitment took place at two MS clinics located in London, Ontario. At these settings, a gatekeeper approach was employed. A gatekeeper was identified at participating organizations to help make eligible participants aware of and inform them about the study. Once a potential participant was identified, the gatekeeper distributed study materials (either in person or electronically) to potential participants and interested individuals were free to contact me. The gatekeepers had access to study information and were able to answer a limited number of questions. The materials they provided to potential participants outlined the inclusion criteria for the study so potential participants could assess her own eligibility. Patients visiting the clinic could also view the study information via the recruitment posters that were posted in the clinic waiting room, patient exam rooms, and handed out to individuals expressing interest. These individuals could choose freely to contact the study investigators. If patients showed interest, to avoid any undue influence of the gatekeepers collecting consent, I was responsible for the consent process. The

gatekeepers were not informed of who agreed to be in the study. Recruitment information was also be posted in the free local newspaper ‘The Londoner’ and on social media, and listservs. Finally, snowball sampling was used as an additional means of recruitment.

Recruitment tools for this study included: a letter of information and consent form (Appendix 2); a recruitment flyer posted in and distributed through MS Clinics, by participants (snowball sampling), and by the research team; recruitment postcards were handed out by the gatekeepers, research team, and participants (snowball sampling) to potential participants listing basic inclusion criteria and researcher contact information; a newspaper recruitment ad; a recruitment letter of invitation email, social media/listserv recruitment ad and letter of invitation mailing template so study materials could be sent or posted electronically. Ultimately, all five participants were recruited through one MS clinic.

4.5 Data Collection

There are a number of varying approaches that can be used to conduct and structure interviews in narrative inquiry (Clandinin & Connelly, 2000; Wengraf, 2001). For the purpose of this thesis, five narratives were elicited using an adaptation of the Biographic-Narrative-Interpretive Method (BNIM) described by Wengraf (2001). Five to eight narratives were selected as an appropriate range based on the number of participants in published empirical critical narrative studies, however, the exact number was determined through continued consultation and reflexivity between myself and my research supervisors. This method of narrative interviewing included multiple stages between the interviewer and interviewee and provided opportunities to create an in-depth understanding of the lives of the individuals through stories. Wengraf (2001) suggests three stages, each with specific tasks, method, and purpose; however, for this thesis, a fourth stage was added to foster a more collaborative approach to narrative inquiry. After our initial phone contact and prior to my first meeting with participants, they were mailed or emailed a copy of the letter of information and given time to review and make a decision on participation. If they were interested in moving forward with the project we scheduled the first stage. I was responsible for conducting all data collection stages with participants.

It is important to note that during the data collection phase of this thesis, I went on maternity leave for a year. Therefore, some participants have a larger gap between their data collection stages. Recognizing the significance of this time in the lives of the participants who were affected by the maternity leave gap, I provided a summary of our previous discussions and allowed the participant the opportunity to provide updates regarding what had been happening in her life and share details relevant to the topic of the thesis. I also used process consent to ensure the participant's ongoing willingness to participate in the research project. A detailed outline of the timing of study interviews can be found in Table 1.

Table 1. Participant Meeting Dates

	Stage 1 and 2	Stage 3	Stage 4
Participant 1 - Judy	October 19, 2016	December 13, 2016	July 25, 2018
Participant 2 - Wilma	November 29, 2016	August 13, 2018	March 7, 2019
Participant 3 - Amanda	November 30, 2016	April 11, 2018	August 14, 2018
Participant 4 - Noreen	September 11, 2018	November 6, 2018	February 12, 2019
Participant 5 - Carissa	April 5, 2018	August 10, 2018	February 1, 2019

4.5.1 Data Collection Stage One

At the start of the initial visit, the letter of information and consent form were discussed in detail with participants and any additional questions answered, after which a demographic questionnaire (Appendix 3) was completed to gather some basic demographic information about the participants. Some of these demographics included: age, marital status, children, current living arrangement, years since onset, age at diagnosis, symptoms, treatments/medication, work status, date of 'retirement', employment history, finances, and pension information (public and private). The demographic characteristics of participants are presented in Table 2.

Table 2. Participant Demographics

Characteristic	Judy	Billie	Amanda	Noreen	Carissa
Age					
Age at Diagnosis	41	25	40	44	34
Age at Retirement	42	47	58	53	52
Relationship Status					
Married			X	X	
Common Law					X
Divorced	X				
Widowed		X			
Children					
None		X		X	X
One	X				
Two			X		
Education (Highest Grade Level Completed)					
High School			X		
Some College or University		X			
College Degree or Diploma	X				X
Graduate Degree				X	
Financial Status					
More Than Enough		X		X	
Enough			X		X
Just Barely Enough					
Not Enough	X				
Current Income Source(s)	ODSP	CPP Disability, Life Insurance, Family Inheritance	CPP Disability, Hospital Pensions	Teacher's Pension	Savings, Optional Purchased Long Term Disability Insurance

For the adapted BNIM approach, the first stage consisted of me asking a single carefully selected question “designed to elicit the full narrative” (Wengraf, 2001, p. 119) without interruption, changing the question, directing, or prompting from the interviewer (Wengraf, 2001). For this project, two narrative elicitation prompts were used in order to not only gather the story about how these women came to be retired and the process, but to also hear stories about the lived consequences of involuntary retirement and what life

has been like after leaving work. However, it is important to note that the second prompt and data collection related to that prompt only took place after this first stage of data collection had been completed in full for the first prompt. It was at that time the process was completed again for the second prompt. The narrative elicitation prompts were: 1) Tell me your story about how you came to be retired; and 2) Tell me about what your life is like in retirement. For each prompt, after the prompt was given, the only intervention from myself was non-directional prompts to encourage and support the flow of the story (Wengraf, 2001). I used open facilitative prompts, and was cautious not to engage the participant topically. Next, a break of at least 15 minutes was taken so that I could review notes made and prepare questions for the second stage. The second stage occurred as an extension of the first stage, as all participants were willing and able to continue participation. I had been willing to do this second stage separately if required.

4.5.2 Data Collection Stage Two

During the second stage the participant was asked for ‘more story’ about the topics discussed in the first narration. The content of the questions was based solely on the elicitation from the open facilitative prompts, and I only asked them about what they spoke about in the first stage. I was careful to follow the order in which topics were raised and ask questions using the words and language used by the interviewee in order to elicit more about topics already raised (Wengraf, 2001). My goal at the time was not to unearth new information, but to clarify shared information and timeline. During this stage I was able to ask questions, but directionality was highly restricted, and while the interviewee was responding, I made notes about topics discussed requiring further follow-up questioning (Wengraf, 2001). After these two stages were completed, in private and undisturbed, I completed self-debriefing using field notes, audio tapes, and debriefing notes (Wengraf, 2001).

For the first participant, after engaging in self-reflexivity, peer debriefing took place with my research supervisors at each stage of the interviewing process. Following the first participant, I continued to engage in self-reflexivity and used peer debriefing with my research supervisors as needed.

4.5.3 Data Collection Stage Three

The third stage was completed as a separate interview after preliminary analysis of the materials from stages one and two had occurred (Wengraf, 2001). The purpose of this stage was to, on the basis of preliminary analysis and in relation to the research purpose and theoretical perspectives, develop and ask questions I was not permitted to ask in previous stage and allow for directionality in the flow of interview (Wengraf, 2001). It was an opportunity for me to ask additional questions of interest that emerged out of what was shared (or not shared) in the previous stages (Dennhardt, 2006; Wengraf, 2001). Drawing on the theoretical frameworks informing this study, a critical examination of the story shared in previous stages and contributions from the other women helped to guide these questions. The interview guide was individualized for each participant and was created after reviewing contributions from the first two stages, but the parameters of the questions were always tied back to the research questions of how the woman came to be retired and her life in retirement. For example, tell me about making the decisions to leave work, or tell me about the process of applying for disability half-time.

4.5.4 Data Collection Stage Four

For the purposes of this study, a fourth stage was employed where the re-written narrative was presented and discussed with participants in a collaborative approach to ensure adequate representation and collaboration between interviewee and interviewer (Dennhardt, 2006) and to encourage reflexivity about the process. Prior to this stage, participants received the constructed narrative (see analysis) and were given time to reflect on it. This fourth stage created an opportunity to collaboratively have a discussion about the constructed narrative and gain comments, feedback, or suggestions for editing. After this process was completed and the narrative was mutually agreed upon and amended, the narratives and transcripts were then analyzed within and across individuals in the analysis phase.

4.6 Data Analysis

Analysis in qualitative research is an evolving process and is determined by the nature and form of the data, along with the purpose of the research (Denzin & Lincoln, 2003)

and theoretical underpinnings used. There is no formally accepted method for data analysis in critical narrative inquiry, with standard rules of how to analyze your data. Instead, it is common to develop tailor made analyses informed by a number of approaches. More generally, “narrative analysis refers to a family of methods for interpreting texts that have in common a storied form” (Riessman, 2008). For the purposes of this study, narratives were analyzed within the larger socio-political context in which retirement is occurring, because individual narratives are bounded within broader cultural, social, and historical discourses (Hardin, 2001).

Narrative data can be “analysed along myriad dimensions, such as contents; structure; style of speech; affective characteristics; motives, attitudes, and beliefs of the narrator; or his or her cognitive level” (Lieblich et al., 1998). The approach to narrative analysis in this study drew upon a number of approaches, including the work of Lieblich and colleagues (1998), Wengraf (2001), Hardin (2001), Gubrium and Holstein (2009), and Dossa (2009). The analysis for this project took place in four stages: Data analysis (D.A.) Stage one included creating a timeline or chronology (Wengraf, 2001); D.A. Stage two continued building the narratives; D.A. Stage three included collaborative co-construction; and D.A. Stage four was the application of a critical lens within and across the narratives.

Lieblich and colleagues (1998) propose two continuums on which to situate narrative reading, interpreting, and analysis. Locating this project on their analytic continuums allowed me to formulate a tailored analysis process for the tasks being completed in each stage. Stages one through three, when I was building and constructing the narratives, were located on the holistic end of the holistic versus categorical continuum. This means that “the life story of a person is taken as a whole, and sections of the text are interpreted in the context of other parts of the narrative” (Lieblich et al., 1998, p. 12). For D.A. stages one to three, analyses were also located on the content end of the content vs. form continuum. The focus of analysis was on the content of what was being said within the narrative, and exploring the meaning associated with the narrative or section of narrative (Lieblich et al., 1998). A holistic-content reading, “takes into consideration the entire story and focuses on its content” (Lieblich et al., 1998, p. 15).

For D.A. stage four, both ends of the holistic vs. categorical continuum were drawn upon in that I still analyzed the data within the context of the entire narrative, but I also looked for particular pieces across and within the narratives. The focus on the content vs. form continuum for stage four remained on content as well. Specific analysis procedures related to these four data analysis stages are explored in greater detail below.

4.6.1 Data Analysis Stage One – Creating a Timeline or Chronology

Following Wengraf's (2001) approach, building a narrative is an analytic process and by constructing a timeline and chronology you are actually engaging in analysis. The purpose of this stage was to create a temporal frame with significant events ordered chronologically. Each meeting with participants was audio recorded and transcribed verbatim by me in order to add an additional layer of immersion with the data. Using the transcripts, re-listening to audio files, reviewing field notes, and drawing from the key words, phrases, topics and ordering from the first two data collection stages, these methods were helpful in the identification and ordering of important moments in the lives of participants specific to their leaving work and retirement, which were used to prepare for D.C. stage three. This process also served useful in highlighting areas where clarification or follow up was required.

In creating a timeline or chronology, after reviewing the transcripts, re-listening to audio files, and reviewing field notes, I started by organizing important moments in the lives of participants specific to their leaving work and retirement in chronological order in a word document. Any supporting information or details about specific employment or life events provided in the interviews were then organized under each heading. In a separate document, in preparation for data collection stage 3 and to help visualize their stories in their entirety, I kept track of any questions that arose as I was creating their timeline, places where further clarification or refinement was required, and any questions related to the sequencing of events. I also noted areas where more story was required or interesting places where further critical exploration could be helpful. In addition to the list of prepared questions, the visual timeline was a helpful tool during our discussion to help broaden my understanding of these events and make sense of the emerging story.

4.6.2 Data Analysis Stage Two – Building the Narrative

Building on the timeline and after completing D.C. stage three with the interviewee, the building of the narrative continued out of preliminary analyses. Preparing the temporal frame was the first step in writing the narrative. Next, I immersed myself in the data through reading and re-reading the transcripts, field notes, and journals in a holistic manner for content (Lieblich et al., 1998). Being self-reflexive and engaging with my supervisory team also aided this process. Writing was done while constantly interacting with the data and questioning the taken-for granted ageist, ableist and sexist assumptions and lived consequences explored in this study both within and across narratives. This questioning was documented in my reflexive notes and analytic memos. Research supervisors reviewed and provided feedback on all completed narratives.

4.6.3 Data Analysis Stage Three – Collaborative Co-Construction

Prior to this stage, the participants were provided with, and given time to review, the constructed narrative. Providing the interviewee with the constructed narrative created an opportunity to share the story and engage in further dialogue. This meeting was not to factually check that the information was accurate, rather it was an opportunity to give back the narrative, give the participant time to reflect on it, and then have a final discussion together to finish co-constructing the story. Through this discussion, participants were able to provide feedback and to propose changes and edits they felt necessary, and I had the opportunity to consider and incorporate their feedback into the story. It was through further dialogue that the women were able to re-examine their experiences and their stories related to leaving work and what life is like post-retirement. This stage in itself was a way to critically reflect on the information shared and discuss the content within the constructed narrative. No participants requested modifications to their completed narratives, only a couple clarifications on dates or timing were provided. At the end of this stage, I left with a mutually agreed upon narrative and offered participants a copy of their own final revised narrative if they wanted one. However, after this stage was completed, participants were no longer involved in any further data collection or analysis tasks.

4.6.4 Data Analysis Stage Four – Critical Lens Application Within and Across Narratives

An additional layer was applied to this analysis process to continue the critical nature of this inquiry. At this stage, a shift in the kind of analysis completed took place. I shifted away from building each woman's narrative to a different kind of analysis, continuing to layer on a critical perspective. This stage continued to critically look within individual narratives and began to look across narratives, so the latter portion did not begin until at least two women had completed the process. Looking across narratives was helpful in purposefully selecting women for future recruitment and data collection and helped to explore how people told their stories and the socio-political kinds of issues they drew on in shaping their lives. I also looked at how participants placed their stories in relation to contextual factors, and how those factors were brought into the narratives and set boundaries for how stories were told. By applying this critical lens and looking across and within narratives, it allowed me to reveal the lived consequences of involuntary retirement for women aging with MS and how involuntary retirement and its consequences are shaped within and through ableist, ageist and sexist practices and systems within the current socio-political context.

This stage was very important in the analysis process, because the stories individuals tell reveal a social world, and the analysis considers the various narrative environments and contextual layers an individual life is occurring within (Gubrium & Holstein, 2009). Dossa (2009) describes how “to grasp the meaning of the storied content and the multiple ways in which it is expressed, we must pay attention to the larger socio-political contexts that suggest the complex ways in which individuals are connected to the world” (p. 25). Riessman (2008) discusses “a good narrative analysis prompts readers to think beyond the surface of a text” (p. 13). Individual narratives are bounded within broader cultural, social, and historical discourses (Hardin, 2001). Complex and intersecting discourses exist about what it means to have a chronic illness, what it means to be an aging person, what it means to be a woman, and what it means to be retired. This stage was further broken down into four phases.

4.6.4.1 Phase 1 – Open Reading

Phase one included reading and re-reading all the transcripts and narratives, re-listening to audio recordings, reviewing notes, and memoing. This stage was an intensive process of immersing myself in narrative and transcripts. During this stage I documented broad, overall reflections, initial thoughts or impressions, notes, similarities or differences between narratives and transcripts in my analytic memos. This stage was important in order to keep interpretations open in early analysis. Also during this stage I worked to re-write the theoretical chapter of this thesis which was an additional re-familiarizing process in itself.

4.6.4.2 Phase 2 - Reading Informed by Theoretical Lenses and Theoretically Informed Research Questions

In this stage I again read and re-read each narrative and transcripts but this time while drawing on my theoretically informed research questions. I read the transcripts and narratives with a critical lens and paid particular attention to parts of the women's stories that my theoretical lenses sensitized me to. For example: I was sensitized to instances of ageism, ableism and sexism (internal and external) and where these may be factors in the story, the impact of social policy, how social policy impacts timing and decision making, the kinds of opportunities available, when opportunities were lost, transitions, being on or off-time in the life course, social repercussions, the social roles or identities the women experience, how multiple intersections and social identities create opportunities for oppression and/or privilege, how the combination of identities exposes different types of marginalization or discrimination, instances of gender inequality, how women's gendered experiences impact the stories they tell, and thinking about disability and human difference. This stage provided an opportunity for me to critically reflect on instances of ageism, ableism, and sexism in the women's stories, and the consequences associated with how they negotiate the transition out of work and into retirement, and the physical, social and political environments they encounter. This phase was done to ensure rigorous reading of the text informed by theory, and to help interrogate the women's stories beyond the surface of the text. This stage included a considerable amount of analytic memoing and theoretical reflection.

4.6.4.3 Phase 3 - Line-By-Line Coding Informed by Theoretical lenses

In this phase I used line by line and inductive coding to capture pieces of story not fully explained through my theoretical lenses. This line-by-line coding process was completed using Quirkos 2.0 and was done to continue explicating themes, augment the development of patterns or codes, and assist in drafting findings. It was also an approach to ensure nothing was missed in the data. By the end of this stage I had prepared a summary document to present to my research supervisors and advisory committee summarizing findings with rich descriptive quotes inserted. The summary document was a comprehensive summary that illustrated and described the prominent themes from the women's stories.

4.6.4.4 Phase 4 - Consultation with Research Supervisors and Advisory Committee

Each iteration of the summary document was reviewed and approved by all research supervisors and advisory committee members. All members of the research team provided feedback about the plausibility of my interpretation, the application of a critical lens, and the quotes I drew on to explicate the themes.

4.7 Quality Criteria and Ethical Considerations

Quality considerations that are responsive and flexible to the nature of qualitative research can be challenging to employ (Ravenek & Laliberte Rudman, 2013). For the purposes of this study I selected three criteria to ensure the quality of this process. These bridging criteria put forward by Ravenek and Laliberte Rudman (2013) included: Social Value and Significance of Research; Thoroughness of Data Collection and Interpretation; and Transparency and Reflexivity of the authors. Each is discussed individually below. As well, an additional criterion, ethics, (Smythe & Murray, 2000) was selected, because it is often difficult to separate quality from ethics.

4.7.1 Social Value and Significance of Research

A detailed literature review of the knowledge base on involuntary retirement for women with MS, and the existing social-political context was completed to highlight this topic as an emerging area of research worthy of further study, and to demonstrate the value of exploring the transition out of work and into retirement for women with MS. Applying a critical lens allowed me to look within and across narratives for how possibilities or opportunities were shaped for some and not others in order to better understand how their retirement was socio-politically shaped and the consequences associated with involuntary retirement for women with MS.

4.7.2 Thoroughness of Data Collection and Interpretation

An intensive structure using an adapted version of the BNIM method of data collection was used to ensure data-rich interviews were conducted. Multiple stages with each participant and the opportunity for collaboration and consultation through dialogue, helped ensure the thoroughness of data collection and analysis. Participants were also given a chance to review, comment on and edit their personal narrative.

4.7.3 Transparency and Reflexivity

Transparency was achieved through being explicit about how this topic was approached, by clearly articulating my theoretical perspectives, documenting decisions made along the way in field notes and journals, and clearly sharing my location as a researcher. Reflexivity took place individually and as a team continuously. During the collection and analysis process, debriefing took place with my supervisors on a regular basis and as required. All study materials were shared among the research team. This allowed for reflection on how the relationship between researcher and participant evolved, how power imbalances were managed, and allowed for exploration of the co-construction experience from multiple lenses (Finlay, 2002). My research supervisors also read all transcripts, provided feedback, and gave approval on all completed narratives. Additionally, my reflexive journal and detailed field notes documented all aspects of study progression and personal thoughts on progress, further questions, challenges and difficulties.

Throughout the project I also engaged in co-reflexivity through the addition of the fourth stage of data collection and third stage of analysis, where myself and interviewee, through dialogue, communicated and collaborated about the constructed narrative. The nature of collaborating together and adding this stage of engagement with participants promoted the opportunity to reflect together. At the end of the fourth stage, I left with a mutually agreed upon narrative that would move forward as the unit of analysis.

4.7.4 Ethics

Incorporating ethics into your study, beyond ethics board approval, is part of a good study, because it is very difficult to separate ethics and quality. Some of the ethical considerations in narrative inquiry described by Smythe and Murray (2000) will be explored below. Ethics was addressed in this study by obtaining free and informed consent from participants and making sure participant were fully informed and able to withdraw consent at any time. This was supported by the act of providing the letter of information and time to review it before having participants commit to the study. Process consent was also used to ensure ongoing support for continued research participation. Taking additional measures to maintain privacy and confidentiality included the use of pseudonyms and alphanumeric codes, using password protected data files, and locked file cabinets for documents. Participants were also provided with contact information for local support organizations and counselling services should support and debriefing be necessary. Finally, providing participants with the constructed narrative was an additional method to promote respect for narrative ownership and ensure the ethical treatment of the work and participants.

4.8 Conclusion

Critical narrative inquiry provided a means and opportunity for the participants of this study to tell their stories of how they came to be retired and what their life is like in retirement. Next, the co-constructed narratives of the five participants, Judy, Billie, Amanda, Noreen and Carissa, will be presented.

Chapter 5

5 Participant Narratives

In this chapter, I present the narratives of five women, Judy, Billie, Amanda, Noreen, and Carissa, with Multiple Sclerosis (MS) from Southwestern Ontario, Canada. The participants were asked to share their stories of how they came to be retired and what their life is like in retirement. Pseudonyms have been used for all participants and direct quotations from participant transcripts have been integrated into the narratives in italics.

5.1 Judy's Story

Judy began her story telling me that *it really wasn't her intention to retire*. She was essentially forced out of work by employers who made her *feel she wasn't understood, considered, or cared about as an employee*. They *phased her out by not giving her hours* after sharing the potential of an MS diagnosis. Early in her career, Judy was the target of numerous instances of abuse and sexism as a female worker in a heavily *male-dominated profession*. These sexist attitudes and behaviours followed her as she moved through different careers and were compounded in later years by her experience of disability after the emergence of her MS related symptoms and subsequent diagnosis. *Feeling defeated* is an expression Judy used to describe multiple, varying situations throughout her story, however, being *a grateful person, knowing yourself, going inside yourself, wanting more of a purpose*, and doing *what you got to do* helped her to find new *meaning* and realize *she can still help people* even after leaving the workforce.

Judy was born in the mid-1960s and grew up in Ontario. She mentioned that her parents died a number of years ago, but she did not elaborate on any further family information besides the fact that *after her parents died it really, the family really blew apart. I live way out here, and they live all over Canada. As far as family goes, nobody lives close to me and I'm not very close to my family, emotionally close to my family*. The only other mention of immediate family was of her brother who passed in 1998 and her daughter who was a constant thread throughout her entire story.

Most of the stories Judy shared focused around her work life and being a mother. As a worker, she described herself as someone who had always *challenged her mind, challenged herself with new information and she had always been interested in medical and legal jobs*, which set the stage for many of her future career decisions. She also described herself as someone who *always enjoyed learning, enjoyed learning new things and she always thought learning was important for neuroplasticity. The first job she shared about was that of being a medical transcriptionist, for which she went to college and worked at for a couple years until she was just past the age of 23. After working for a couple years in this field she wondered to herself, do I really want to be sitting behind a desk for the rest of my life?*

Her entire life, Judy had *been physically fit and active*. After leaving the medical transcription field, she *started training, doing ride alongs, doing the jogging prepping and push-ups*, in order to get herself *physically fit before she took the tests* to become a police officer. At the time of her application, *1500 individuals applied to become police officers and she was one of the select few*. Judy described that being hired under those circumstances *made us feel like we were the cream of the crop*. The officers told them that they were *hand-picked* for the job and she should *be proud, so she was*. She completed *Police College* in the early 1990s. Despite feeling very proud to be hired under such selective circumstances, Judy soon learned that the year she was hired *was the golden year for employment equity. Visual [sic] minorities were just being hired in as part of employment equity and were ushered in as long as they passed the criteria*. She *was one of them*. She described the police force as a *good ol' boys network* that was being forced to *embrace this new turn and make themselves look like they were forward thinkers; but they didn't believe it at their core*.

Over the next several years, throughout her six year career in policing, Judy was the subject of a number of heinous and disrespectful instances of harassment at the hands of her fellow officers; both peers and those in leadership positions. From the beginning, Judy always had *a very strong sense of right and wrong*. She expressed that she believes that it was these values that *got her into trouble* and that even to this day *gets her into trouble*. Three incidents relatively early on in her policing career had a significant impact

on her as a woman and a police officer, and were the starting point of her long-term struggle with post-traumatic stress disorder (PTSD). These early career experiences of marginalization and violence based on gender shaped her entire policing trajectory and contributed to the ultimate demise of her much adored policing career.

The first incident occurred when Judy was around 26 years old and was the first responding officer to a 10-45 *sudden death* call for an *elderly gentleman living in a rooming home*. As per protocol, she *waited for the duty inspector* to show up *and* worked to ensure *all* important information was *documented*. There were large amounts of *cash, change, bills, and uncashed veteran's cheques* laying around the entire apartment when a fellow officer arrived on scene and asked Judy, *do you want to take some of this money?* Feeling extremely *uncomfortable* she *laughed it off* and told him *yeah right*. She then described how the officer turned away and pretended to look around as he was speaking to her, but in a particular way that she knew with almost certainty that he was putting money into his pockets. She felt helpless because she could not be 100% certain exactly what the fellow officer was doing. Judy felt as though she should *have handled it completely different*. However, with it being her first time as the first responding officer, a new female hire, and the recent attention and suspected unfavorable attitudes surrounding the inclusion of *visible minorities* on the force, she recalls that her *brain* was *swimming* at the time. Unable to prove anything, nothing further ever came of the situation.

Shortly after the first incident and still in the winter, Judy found herself in a second situation where her *strong sense of right and wrong* was challenged. A man, in her opinion, was unlawfully arrested by a fellow officer at a scene they were responding to. As she transported him, Judy let the man know that *when they get back into the station* he had *every right to ask the other officer who arrested him* on what grounds he was being arrested. Judy's actions to help an individual she felt was being unlawfully targeted, started a negative reputation for her once her fellow officer spread the *rumour that she was not a team player*. *From there, everything went to hell*. *Officers stopped talking to her, they stopped backing her up at calls and things*, on a number of occasions, *got very dicey*. The harassment continued *on and on and on* to the point where even her *sergeant*

tried *his best to get her to quit* telling her to either *go along and shut the hell up or get out*, and *the radio room would give her all the shitty calls*. Completely overwhelmed and feeling *powerless*, Judy went home one day and couldn't *come back*.

She ended up taking *10 months off* when finally, *the two Sergeants that hired her* came to speak with her about *what was going on*. Judy was a *nervous wreck* but was finally able to share everything that had been happening. Her suspicions related to the *10-45* and the officer *stealing*, being ostracized by her peers and leadership because of rumours manufactured about her, and ridicule by her Sergeant. Finally, after some time, Judy returned to work knowing *it wouldn't be the same*, so she requested assignment to a *different station* in the area. After approving her stationing to the new location, more difficulties followed her. In the meantime, Judy married a fellow police officer in the early 1990s, although very little was shared about their life together throughout these challenging times.

The new work location introduced her to a partner who would ultimately subject her to near constant on-duty sexual harassment, even *in front of civilians*. He would say *sexually derogatory, demeaning, devaluing and humiliating* things that undercut her position as his partner and a respected officer in the community. These inappropriate comments included things like, *do you see that tiny tits or hey deep throat* to name a few. She tried to *change beats*, but the switch only lasted until her regular Sergeant returned from holidays and reversed the change. *Everything was horrible*. Judy struggled with *trying to hold on to her job* but at the same time, knew that she physically, mentally and emotionally could not *go through this abuse again*. She wrestled with *where her place* was in *policing*, the place *for honesty and truly helping people*. After *parade* one morning, her inspector let her know the partner who had been sexually harassing her had some things he would like to apologize for, and with that came bursting in all regretful. When Judy started reciting the instances of sexual harassment and abuse, the inspector immediately sent her to *downtown central* to formally charge the officer under the *Police Services Act* for *sexual harassment*.

While waiting for the trial to commence, Judy, now almost 30 years old, became pregnant with her daughter and was pregnant during the actual trial, which lasted *10 days*. Ultimately, the officer *was found guilty and* received *three days without pay* as his sentence. Their rationale was that *if he had touched her, the penalty would have been more severe, but he didn't touch or lay hands on her*. The officer *appealed that decision and won his appeal*. He was reimbursed for those *three days* of lost wages. *The injustice was so overwhelming*, and Judy found herself thankful to be a mother through the very difficult time following the appeal decision. Not only was it incomprehensible that such a minor punishment was given for such marginalizing actions, but that the punishment was ultimately rescinded made the systemic sexism engrained in their policies and processes so apparent.

Although the first trial did not produce the results she was hoping for, she *made case law*. It set a *precedent, a benchmark*, and *for everything she went through*, finally she was able to protect *other police officers* from enduring the same kind of treatment. It made her incredibly proud to create these new standards and protections for female police officers. Ultimately, when the trial finished, she *was supposed to go back to work* but would have no choice in *where she would be put*. She *was feeling too vulnerable and weak*, and after *six months of maternity leave* she just *wasn't ready*, so she *didn't come back*. She returned her *uniform* and that marked the end of her policing career in her early 30s. Judy *was a good cop*. She received commendations from *the chief for helping people*. Policing made her *feel good, feel useful*. Being a police officer and leaving policing behind as her career *left a lot of scars and open wounds for many years*. She ended up having to *give up her career because of the oppressive and abusive treatment* she was subjected to and has since struggled to make sense of this loss her entire life.

Soon after leaving the force, Judy began a job as a health inspector in her early 30s. However, some two years later, she was in a horrific car accident that left her in critical condition. Over the next three years she endured *15 surgeries between her ankle, knee and bowel*. She required the use of a *wheelchair*, and the rehabilitation process was long and difficult. She was unable to work during this time.

In the background while all these employment and accident challenges were taking place, Judy's marriage was breaking down. Her husband was a police officer whom she described as a *cruel man*. Judy shared that she felt her daughter was never *emotionally safe* with him and that she had to *protect* her from him. She recalls *looking up from* her wheelchair after the accident *and thinking, I'm a sitting duck to his mood swings, to his anger, his throwing things, and how he treats our daughter. I'm a sitting duck to all this. Money and image* were very important to him, and in fact, he married Judy in efforts to *offset his child support and alimony payments* for his previous marriage and *three daughters*. When Judy was 38 they decided to separate. The divorce and custody process was a *very bitter and nasty battle that went on for years*. Judy lived with the fear, knowing he was still a police officer, and worried about the people *he had in his pocket* and what they could do. Her ex-husband was determined to get the money she received as part of a settlement for her car accident, however, the Judge decided she did not have to give him the money. Being the manipulative person he was, he used *other ways* to get money from her. It ended up costing her \$54,000 to be free from him, money that could have served her recovery or their daughter much better. The process was incredibly challenging for Judy, because she was still dealing with recovery from the accident, feeling emotionally and physically vulnerable, managing being a single parent, and having to deal with an *ex-husband who hated her*. In the end, aside from *child support* for their daughter, *there was no help financially from him*. Their divorced was finalized when Judy was 39.

After the court proceedings, Judy was looking to move on in her life with a fresh start. Her lawyer from the car accident suggested, given her policing background, she *do some investigation work*. He offered to connect her with a retired officer who was working in the investigation field already. She was hired and began working in large Ontario city as a private investigator when she was 40. Her work included investigating *sexual assaults, thefts from corporations, and WSIB investigations*. In her reflection, given her negative experiences in the male-dominated policing profession, Judy felt that entering a field that was primarily made up of retired police officers would bring about many of the same issues. However, this remained a struggle for her because she had *all the training already* and she was a single parent looking to provide for herself and her child. The necessity of

needing a job to support herself and her daughter made this job her best option, despite her many reservations. Unfortunately, despite her best intentions, she experienced a number of similar harassment challenges. The man she was working for would force her to meet him outside of work in order to get her paycheque. He would request they meet at coffee shops and these 'social' meetings became a real issue for Judy. Not only was it inappropriate that he attempted to exercise control over her in holding her pay *hostage*, but the nature of their interactions were unprofessional. Regardless if his goal was to exercise control or domination over her because she was a woman in a traditionally patriarchal role, or engage in a questionable work social relationship that positioned her in an unsafe situation, this never should have occurred. Finally fed up with the treatment, Judy approached her boss for assistance in dealing with the co-worker and to inform him about the co-workers actions. Her boss was less than supportive. His response was that she *needed to lighten up* and that he would talk to the co-worker *later* because they had plans to go *golfing together* later that day. Another very clear example of the good ol' boy's mentality she experienced previously. After their discussion, she received no more hours to work.

Later that fall, Judy took on another private investigator position in a new city. Her workload was much the same as the last place. She would often spend her days sitting *on a house* and *watching for activity* in someone who was under investigation. When you *sit on a house* you have to be discreet, she explained. You can't have *the car running* or the *AC on* because you need to *be discreet*. While working for this company, Judy woke up one morning after *sleeping on her stomach* and had *pain in her upper and lower back, numbness and hypersensitivity in her leg, and pins and needles*. Her first thought was that she had *pinched a nerve* and vowed to never sleep on her stomach again. She *suffered for three months* and went to a *chiropractor* and *massage therapist* without success. *The pain was to the point where she couldn't handle it anymore*. Finally she went to her family doctor hoping for some answers, but the doctor wrote off the symptoms to a pinched nerve as well and *didn't do anything for her*. As a last resort she went to the regional hospital, but they were also unable to give her any answers, so they continued *running tests* to get to the bottom of the issue. Oddly enough, while sitting in the waiting room and chatting with a fellow patient, Judy and the patient got on the topic of MS and how

the individual suspected her symptoms were MS based. Judy *laughed her off* and felt the claims were absurd. That was the start of her MS symptoms, although she was unaware at the time. These symptoms began to emerge when Judy was 43 years old.

One day in the summer of that year, Judy started having significant difficulty on a particular case where she was required to *sit on a house* from 6:45 am until 5:00 pm. In order to complete the assignment successfully, she was unable to have the *car running* or leave the scene. She struggled with the heat of sitting in the car all day. She started to feel as if her body was unable to *regulate temperature* anymore and she was *overheating*. She was also running to the *bathroom all the time*. She had to *sit for three days at this place*. It was *unbearable* for her. At this point they were *doing all the testing* and it was *pretty clear that MS was the issue, but the doctors had to rule everything else out before the final diagnosis*.

Judy decided to approach her employer and let them know about the suspected diagnosis of MS and what was happening in terms of her medical state. She *told her supervisor that everything was pointing towards MS, but he really couldn't care less*. On a number of occasions she made the effort to dialogue with her employer, but he was resistant and *unsupportive*. His attitude was that she needed to *lighten up, stop playing the sick card*, and maybe she wasn't *cut out for this work*. He was not *understanding* at all and made her feel like *if you can't do your job, it's not our problem*. All he was interested in knowing was *bottom line, did you catch him? Did you get the money shot? Did you catch him doing anything?* His response to her suspected MS was *just to give Judy less and less and less hours*. He was hoping she *just wouldn't want to come to work and wouldn't give her any hours to do investigations anymore*. They were cautious, however, to reiterate the fact that they had *not done anything to encourage her not to be at work*. Judy continued to try and maintain her employment, but her boss would *avoid even meeting*. She telephoned and emailed asking for an opportunity to *get together and talk* but again *he ignored her*. Eventually the work *just dried up and nobody talked to her again*. No one called her to *say we don't need you anymore, they just didn't say anything. They just stopped giving her hours and nothing more was said*. She believed this was done in the

hopes of having *her go away quietly*. The end of summer 2008 was when they stopped giving her hours.

There was a *lack of understanding and un-willingness to understand* what was happening to her medically or to support her as an employee with suspected MS. She felt *defeated*. *They were holding all the cards of whether she could make money or put food on the table* for her family, or *pay her mortgage*. She shared that she knew she needed *energy to fight*, but at that point she was being *pushed out* she was *vulnerable*, and it was hard to *fight a battle you know in the end you are going to lose anyways*. By the time her 43rd birthday came around she was *in bed, not able to see or hear with high pitched whistling* in her ears.

At the same time her symptoms were emerging and worsening, her daughter Nora, who was around 14 at the time, contracted Lyme disease and became very ill. Nora's journey to diagnosis was very challenging and Judy, while dealing with her own issues and trying to protect her daughter from *the reality of things, had to fight for her to get treated*. Similar to Judy's experience, with Lyme disease they had to *rule everything else out first*. Judy had to balance being an *advocate* for Nora and *carrying the burden* of her own troubles all by herself. *The weight of responsibility* Judy described in *protecting* Nora and *advocating* for her is one of the things that helped Judy through that very difficult time and has always been a source of strength for her.

For the first time in her life, Judy was living in unfamiliar territory. She had a house to pay for, a child to support, bills to cover and very little money left from her settlement after a costly divorce. She now found herself suddenly without an income and in a precarious state of health with an unknown future. She was unable to work and provide for her family, she had *no financial support* from her ex-husband or emotional support from family, and she wondered *where the hell am I going to go now? What's going to happen? Thank god she owned her own car*. She described the *immobilizing fear* associated with this *very scary* time in her life. She ended up having to *remortgage* her house just to *make ends meet* and shared about the desperation associated with these

changes. Her future was uncertain, and she was left completely alone trying to figure out how to *get ahead*. Even reflecting now, she doesn't know *how the hell she did it*.

It wasn't long after Nora became ill and her symptoms really exacerbated that Judy was formally diagnosed with RRMS. The process of learning she may have MS and receiving the formal diagnosis was *devastating* for Judy. She felt defeated and struggled to come to terms with what was happening. Judy had devoted her whole life to being *physically fit and active*. She was continuously *learning* and engaging her mind. She had *read about relapsing remitting MS (RRMS)* and knew *medically* what MS meant, but when she received the actual confirmation of an MS diagnosis, she felt *completely, totally emotionally, physically, mentally, psychologically, and financially defeated*. Judy became *suicidal* but knew she *couldn't do anything* about it *because she had to be here for her daughter*. This angered her at the time, because she felt her *choice* in dealing with the situation had been *taken away*. That loss of control was hard for Judy because she hadn't *smoked, didn't drink* and was *proactive about her health* her entire life. She couldn't understand why her body was *defying* her after she had lived her whole life making positive choices in an attempt to avoid something like this. Judy described that another difficulty with RRMS was the *unpredictability* and how it was *hard not to feel sorry for yourself*. You would *just get yourself together* and *another bout* began. Judy found it very hard not knowing *what the rest of her life was going to be like*. She was finding it hard just managing her symptoms, *let alone working*, trying to be a *good mom*, managing a *mortgage, advocating* for her daughter, and keeping everything together. *When she was in the thick of it* she didn't know *when it was going to pass*. She didn't know *when it was going to get better*. She *hopscoched* through a *grieving process* of who she *knew herself to be before MS*, where at times things were *really crappy* and then were *pretty good* but in the back of her mind always knew they could *revert back to being bad*. Judy found herself in a *hellish kind of limbo* and struggled remembering how she was able to *make it through*. If not for *the love of her daughter* she probably wouldn't have. Judy also struggled with being understood by people during this time. She felt that people could *appreciate* what she was going through, but they didn't *understand unless* they had been in a similar position. Judy and Nora didn't have any close family so all they had was each other. Judy found that she *internalized a lot, shopped at night* so she could avoid people,

and *wasn't* really *a part of anything* while this was going on. She struggled again during this period with her PTSD in addition to all the new challenges of living with an unpredictable chronic illness. She had to be *emotionally smart* and *educate* herself in order to come back from the dark place she was in and it took a lot of time and effort.

After her diagnosis around the age of 43, things finally started to turn around for Judy. With the support of the MS Society she was able to get some assistance setting up her application for Ontario Disability Support Program (ODSP) and a *nurse came out to the house* with a *social worker* to support her in completing all necessary forms. They also offered emotional support and counseling for her. Judy described that she really *needed to be hand held* during *that time* and that she *needed help* because things were *really bad*. She was still struggling financially, and bills continued to pile up, but ODSP would at least provide a steady source of income to count on, even if it wasn't enough. Once she was able to start regaining some stability, she started to think about her life and *analyze* where things were going and what she was *left with*. She knew she was a *good mom*, a *quality person*, a *good friend*, and she knew she still had *value* and *worth* to *contribute* to the world. She felt that she still needed a *purpose* to get up in the morning. It was difficult for her *to do and provide for* herself *for so many years* to then lose her *identity* as a worker. To go from being *a working capable part of society* where she felt like she *fit*, and having that *stop* or be *taken away*, *both in her case*, created an *identity crisis* for her. Her life felt like a *tangled mess* of *what now* and *who am I* questions.

By the time she was 46, Judy was ready to try and tackle some of these difficult questions and make a change by deciding to return to school. She received funding through the Second Careers program and returned to school for Medical Office Secretary and Administration. Completing the program gave her *hope* that she could still *contribute* in a meaningful way, but unfortunately after graduation Judy was unable to find work in the field.

For the next couple years, Judy continued to struggle. Emotionally she continued to struggle with the uncertainty of her MS, the defiance of her body, and the precarious nature of her current *work* and financial situation. She continued to try and maintain a

level of emotional stability for herself and her daughter, but these new challenges were compounded by a lifelong struggle with PTSD and depression. Financially, although ODSP provided a consistent source of income, it wasn't enough. She described her anger and resentment over having to show up *hat in hand looking for any additional financial assistance from ODSP* and how *that attacks your pride* when you already feel very low. This was especially difficult when the ODSP workers are *callous* as a coping mechanism and aren't *understanding* in the way you need them to be when you are *really struggling*. Being the *problem solver* that she was, Judy also spoke about her desire for ODSP to create working incentives for people receiving ODSP; like *paying a portion of their validation tag* or contributing to the cost of *getting taxes done each year*. Judy had always been a contributing member of the work force and suddenly being unable to work on ODSP added to the *identity crisis* she was already dealing with because of her MS. She wasn't *making ends meet*, but being an *honest person*, she struggled because she knew the only way to receive additional income was to get a *legitimate job* which meant ODSP would then *hack* away the amount of money she already received. She would be *left with very little and very little incentive to go to work the next day, fighting symptoms all the way*. She felt the system was broken. It keeps people who are accustomed to contributing in a meaningful way and trying to find purpose in their life, out of work for fear that they will lose what little financial support they already receive. She didn't feel like the system was working for her. Judy shared a lot about drawing on her own resources to cope with the stress and struggles she faced. She talked about her *love for her daughter, looking inwards, having a positive attitude, self-knowledge, and a sense of gratitude* as being the resources that she drew on through the difficult times. She never felt the system worked for her or supported the complex needs and challenges she was facing.

Eventually, even with *re-mortgaging her house* she was barely getting by and had acquired a significant amount of *debt*. Out of *financial necessity*, despite being on ODSP, she began cleaning houses *under the table*. The *financial burden* was *very great*, and she *had to clean a little bit when she had the energy* in order to *make ends meet* because, ultimately, they had to *eat* and have a *roof over their head*, it was *as simple as that*. Judy described her struggle with being an *honest person* with a *strong sense of right and*

wrong, who was *transparent* and *follows rules*, however, at that point in her life she was breaking rules and doing something she felt was dishonest. It was never a choice of hers to do that, she very much framed the decision to clean *under the table* as a decision of necessity and something she was *forced* to do because the systems in place were not supporting her or meeting her needs. She was just not able to make it on what she was receiving. During this time, her daughter Nora also moved away to College and Judy became an empty nester at the age of 47.

Despite the additional income from her *under the table* work, Judy was still forced to sell her *house*. Nora had already left for school, so the decision was easier. She was able to *get out of debt with the proceeds of the house* and moved to her current location when she was 49. Her new rental was more manageable financially, because she no longer had to worry about additional costs such as *hydro, heat, or taxes*, and physically more appropriate given that *grass cutting* and *snow shoveling* were taken care of. This was a huge relief for her especially given the uncertainty regarding her future abilities.

After getting settled into her new place Judy once again attempted to find legitimate gainful employment through an employment agency. She was hired as an employment specialist and asked to complete a PowerPoint presentation not even a month after her hiring. In her opinion, the *timeframe wasn't fair*, and she *couldn't do it*, so she *resigned the job and left feeling like a failure*. There was a deadline that needed to *be met and wasn't negotiable*. They asked if there was something to accommodate her *MS*, but she *felt she wasn't good enough for the job* and just decided to move on, placing the responsibility for her departure on herself and her own limitations. After this disappointment, she continued with the *under the table* work.

The *under the table* cleaning work she started eventually transitioned over a 3 year period into her working as a *personal health advocate* for a small group of seniors in her community. Judy has a strong background in the *medical* and secretarial fields, and she *joined policing to help people*. It seemed a natural transition for her when the opportunity presented itself for her to use her skills that way. Her roles in the past have included: taking seniors to *doctor's appointments*, *taking notes* to share with family members,

documenting information about *appetite* and general health, driving and *grocery shopping*. She enjoys building relationships with the clients and helping them find new ways to enjoy their golden years most successfully. She continues to work under the table cleaning and as a personal health advocate presently, but the hours and commitment she is able to give depends on her current health status. She helps one lady in particular with her *shopping* and getting around outside of the *house*. Having Judy to assist with some more challenging tasks allows the client to *save energy* and spend time with her husband. This makes them both happy because he feels he may not have *much time left to go*. For Judy it was *kind of nice because* the job solves *two problems* for her. First, the *extra money is nice*, and it was certainly *needed*, but secondly, she feels like she is *giving back*, and it feels *good*. The *biggest payoff* is being able to *give back* and having a meaningful *reason to get up every day*, which is something Judy has struggled with since the onset of her MS symptoms and having to leave work.

Judy considered herself 'retired' after her last private investigation job where they stopped giving her hours after the emergence of her MS related symptoms. She considers herself retired despite still continuing to work *under the table* and attempting to re-train in later years as an older woman with MS. Life as a retired person is not what Judy anticipated it would be, and it really wasn't even her *intention to retire*. Having to leave the workforce before she had planned or was ready to, while being a woman living with MS, has had a significant impact on her life and retirement. When discussing her retirement, Judy shared about a number of losses she experienced, choices she was forced to make out of necessity, how this necessity influenced her decision making, and finally, things she had to do that she never imagined she would. The most notable act of necessity being the *under the table* work she continues to engage in. Multiple times Judy stressed that having to continue working under the table is something that has been difficult for her to come to terms with. However, she frames her actions related to this decision as sheer *necessity*. In reality, she is a member of this underground working economy because she is unable to live on what she receives as a disabled person who is retired. After losing her job and not being supported by her employers, Judy ended up losing her *home* in order to settle the *debts* she accrued and was unable to pay. She used to take Nora every *Christmas* to go *see a live production*, but she doesn't *have the money* to do

that anymore. That was an especially *sad* loss for her. She is no longer able to afford to *eat as well as she normally would*, and she certainly cannot afford going *out to eat*. These are some of the decisions she had to make and assets she had to give up in order to survive. Judy also never imagined she would have to *take in a roommate*. Originally, she had the extra bedroom in the apartment for when Nora would come home from college, but with expenses again piling up, she was forced to seek out the additional *400 dollars* a month in rent to help cover costs. Thankfully she was able to find a suitable roommate, but this was *not what she anticipated of her retirement*. Judy has had to drastically *re-imagine* what her retirement will be like. Even ten years ago she thought she would have a *decent retirement*, because she had *paid into retirement* since she first began working on the police force at the age of 25. *Unfortunately, that did not end up being a career spanning decades* and retirement, in general, came much earlier than she expected.

Many times in her story Judy spoke of having to *adapt to change* and referenced the *never-ending change* she felt was present in her life and retirement. Changes in her body she never imagined she would be dealing with at her age, changes in her career, changes financially and having to *re-imagine* what she *thought retirement would be*. Consistent with her *love of learning* she has also had to continue learning in retirement. She has had to learn what helped her manage her MS symptoms and what exacerbated them because *with MS it is a constant challenge learning what your limits are*. For example, she knew that even if she was able to afford it, *vacationing south* was out of the question because of her difficulty in *regulating body temperature*. She has had to learn how to minimize the amount and frequency of *inflammatory responses* in her body. Limiting her intake of caffeine to *one coffee in the morning*, and reducing her intake of *sweets* has been helpful in doing so. Her life became about consistently trying to *balance herself* to successfully manage her *limitations* while still *indulging* occasionally in the things that bring her joy and *reduce her stress*. She has worked to get to a place of happiness and positivity. There was a long period where she was *very negative, bitter and angry*, especially given the uncertainty she was facing. Recognizing that her *prime resources* like time, money and energy come in *very limited quantities* she has worked to achieve *balance*, be grateful she is not *worse off*, learn what she *can't do* and to *be OK with it*.

Regardless of the physical, emotional, social and financial challenges Judy faces, she remains grateful. She knows that the only way to continue moving forward in a positive way is to *turn things around* and *start being positive*. *Knowing* herself and *turning inward* has helped her to know *what* needed to *change*. She finds that being *emotionally intelligent* and her *rational thinking* nature has helped her through the PTSD she experiences from policing and will continue to help her though whatever may come in the future.

Overall, Judy has come to a good place in her life. *I look at myself and think I'm doing pretty well, I really do*. She is *thankful* for what she is still *able to do* and continues to work finding *balance* in knowing her limitations. She continues to focus on being the best mother she can to Nora and *finds value* helping those in her community. Being able to still *help people* makes her feel like she is *not totally inept*, and she is *thankful* being able to do so. Judy's retirement is not what she imagined it to be, and there were a number of instances in her retirement where necessity influenced her decisions and assets had to be given up in order to survive. She also experienced a number of losses of important, meaningful things in her life in order to *get by*. She has worked very hard to move beyond feeling defeated, as she used to so frequently in many of life's situations, although the memories do still cause pain for her. She focuses now on being a good person and continuing to be the best mother to Nora.

5.2 Billie's Story

Billie began her story by telling me that she has *never handled stress well*, and around the time she was given her *walking papers*, there was a lot of stress going on in her life causing her MS to be *very active*. She was *missing* a lot of *work* and was no longer able to do her job so they *couldn't keep her*. She *took early retirement* when she was in her mid to late 30s and since then has been fortunate not to have any exacerbations. She credits her *strong faith in the Lord* for many of the blessings in her life and tries to stay positive in her health and mindset. Billie has a strong support network made up of family and friends who are always there when she needs *something*. Unfortunately she has experienced the loss of three family members recently which has left her struggling with depression, but she knows she will be able to pull herself out of it when she feels ready.

Billie has a *fighting spirit*, and she works hard not to *give in to the disease* or her recent *depression*. She strives to follow her motto in every aspect of life to *let go and let God*, but it is not always easy.

Billie was born in 1956 and grew up in Southwestern Ontario. Around the time she was 18, Billie left *high school* to start working, only to return and finish *high school* about a year later. After finishing high school, Billie moved into the apartment *building* she still currently resides in although her tenure in the building has not been continuous, moving in and out of the building a number of times during her adult years. She initially moved out of her parent's home because she and her mother *just never saw eye to eye on a lot of stuff*. She worked a number of odd jobs in and around her hometown making *blower hair dryers*, caring for *the elderly*, and seasonal work *doing rhubarb and plants*, after which Billie went to University in her early 20s. After finishing *two years* of University, Billie began her job at a manufacturing company.

Shortly after beginning her job at the manufacturing company as a *manual labourer*, Billie was diagnosed with RRMS. She described how at the time she was *kind of walking around drunk*, *getting numbness in her extremities*, and her *eyesight was kind of seeing double*. Given that she was exhibiting a number of *symptoms of MS*, her doctor sent her for an *MRI* and *made the final determination* she had MS when *they saw the damage in the myelin sheath on the MRI in her early to mid-20s*. It was at this time that Billie took part in her *first drug study*, a *shot* called Interferon, and she continued on that drug until around 2013 or 2014. *When Billie was first diagnosed she had to leave work* for a time and *had a bit of a pity party* for herself. *At first*, she found herself *kind of weepy* and wondering, *why me? Here she was just a young lady and she was going to be disabled now for the rest of her life*. She was only in her *early 20s* and it was difficult for Billie not to think about and wonder *what her life was going to be like? Would she be able to survive?* Thankfully, those feelings *didn't stay very long*. As time went on and she thought about *it more*, Billie came to the realization that you're not disabled unless you make yourself disabled, and *it's all about your frame of mind*. It took her some time to come to terms with the fact that she had *been diagnosed with something*, but she was

finally able to *realize that it was not a thing that was going to kill her*. She decided to follow her own motto to *let go and let God*.

Initially when Billie was hired at the manufacturing company she was *a manual labourer*. After some time and prior to her car accident, *they promoted her because she had more education than anybody else*, giving her *an office job and then eventually, a quality control position*. She *got a little bit better pay* with the new responsibility, although *manufacturing still didn't pay excessive amounts of money*. With the increase in responsibility came more *stress*. As she moved into the new position where she was *walking around checking stuff to make sure it was done properly*, her *stress level went up*, and she believes *that contributed to the fact that her MS came on more and more while working*.

Throughout her time at the manufacturing company, Billie had a number of *exacerbations* related to her MS, repeatedly and consistently *missing a lot of work*. Despite this, she was able to hold her job at the company for *13 years* until she was ultimately *given her walking papers*. Billie hypothesized that many of the exacerbations and the appearance of symptoms were brought on by two main factors, stress and conflict over her lifestyle at the time. Billie *could never handle stress too well*. She reflected on the fact that she would often *make things a lot more stressful than what they needed to be* as well. After her diagnosis, Billie experienced a lot of *stress in her life*.

Around the time Billie was 30 she purchased her first car. It was a *1982 model*, and she took out a *three year loan* through the local *credit union* to pay for it. During the time she held the loan, Billie started a relationship with a man she referred to as *the French Man*. She was *living with him* and throughout the relationship they both were doing *a lot of drinking and carrying on*. He was *a drunk* and would *drink a case a day of beer*. Being the *only one working*, Billie was *supplying the money for the beer* and kept buying both of them *booze*. She described how during that time in her life she was *being foolish* with her actions and decision making. She was moving further and further *away from her faith*, which had been a huge part of her family life growing up, having been *baptized when she was 12*, and she *started drinking and acting like a fool*. This was a great source of stress

and conflict for Billie, and she talked about how during that time in her life she *was always in turmoil*. Billie *knew that drinking all the time was not a good thing* for either of them *to be doing*. She *didn't come from that kind of a background*, so she *knew* what she was doing *was wrong* and felt conflicted; causing herself *a lot of stress because she didn't have the guts to walk out of it*. Billie's relationship with the *French Man* also put strain on her relationship with her parents as they *didn't like him from the beginning*, and certainly did not *approve of her living with the guy*.

Eventually she *got her car all paid off by the end of the three year loan*, and shortly after doing so she and *the French Man* were in a terrible *car accident*. Billie does not believe *the MS had anything to do with the accident*, instead it was because of her *own stupidity*. *The French Man came out of it practically unscathed*, but Billie was badly injured. She *shattered her hip* and injured the *left side of her body*. She recovered with a lot of *therapy* and required the use of *a cane* for quite some time. Both of her parents were *right by her side after the accident* and were *really there for her*. After some recovery time Billie returned to work, but the *car she had worked so hard for was no more*.

After the accident Billie continued her relationship with *the French Man*, still *conflicted* and struggling with what was *right and wrong*. Even after such a traumatic accident he continued *to drink*. While Billie was at work she *got the call that he and his buddy had been killed in another car accident*, adding *another element of stress* to her life. Billie shared how she had *mixed emotions* over his death because she *felt like he caused his own demise*, but she was also *kind of relieved* to be able to move on with her life.

Overwhelmed with everything going on, Billie *decided she couldn't live by herself anymore*, so she *decided to move back to the home she grew up in with her brother* while her parents were *living out of town*. She continued to drive despite admitting the fact *that she was never a very good driver*. Billie *had a lot of minor accidents* before and after her big accident, *which may have had something to do with her MS and the fact that she would stress frequently about things like bad weather when driving*; creating even more *stress* for herself when she already did not *handle stress well*.

With everything going on in her life, Billie started having *exacerbations* and her symptoms became very difficult to manage. She started *missing a lot of work*, sometimes *six months at a time because her MS would start acting up, and just kept coming back; sometimes more fervent than others*. Although she could not remember for certain if she had received wages during her absences, Billie believes there was a possibility that she received some short term disability, however, she mostly just recalls being off work for extended periods. She continued taking the *interferon* she was prescribed when she was first diagnosed and would see her doctors at the *MS Clinic* as exacerbations took place. She explained how it felt like *the more stressful the job and life was, the more the MS and her symptoms would show up*. Billie *would have trouble walking* and described how she *walked like a drunk man*. She was seeing *double all the time* which impacted her *ability to do fine work*, and the *numbness in her hands* certainly did not make things easier. There was even a time *when she had to be put into the hospital*. Billie explained how that *when you have stuff like that, you can't work* and talked about how her MS *culminated to where she just couldn't do her job properly* anymore. Being the *type of person who likes to do a job well*, this was difficult for Billie to come to terms with. She *did the best she could, but it just wasn't good enough for the company*.

Billie speculated that due to her *symptoms* and ongoing *work absences*, given that the company was well aware of her MS diagnosis from previous time missed, *they probably thought well, she can't do her job anymore properly* and that is why they gave her her *walking papers*. She explained how as a company *they are going to take note of* situations like hers and likely couldn't *afford to keep her on if she was not going to be there a lot of the time*. Billie did not ask for accommodations in order to extend her time working.

Given that this occurred so many years ago and Billie currently has some memory issues due to serious falls, she did not remember all the specifics of how she was *let go*, but she believes *they either gave her a letter or pulled her into the office*. She also shared a number of theories and feelings related to why she was given her *walking papers*. One was that *they were looking down the road and weren't thinking the company would exist too much longer*, and given *the fact that she wasn't able to do the precision work of her job anymore or do her job well*, they could not *keep her*. Another was related to her

absences and how *they probably just got rid of her for that reason alone, because what's the point of keeping someone who is not going to be there for 6 months of the year.* These were her thoughts because *they never had any fault with her work previously.*

In our discussions she appeared to rationalize the company's actions to *let her go*, describing how she does not *blame them*. She got *MS* and what were *they supposed to do? It's not their fault she got MS* and it was *not her fault she got MS* she explained, *but* she repeatedly emphasized how *you can't be in the workforce and do your job when you're not there all the time*. At that point in her life she tried not to *really stress out about losing her job because she knew it was not her fault and not their fault*. She believes *they were just doing what they felt was best for their company* and she does not *hold anything against them*.

Billie added how *probably now they wouldn't be able to get away with something like that but back then, they did*. She talked about how now *they would be charged with discrimination* but *back then it was easy for them to let her go, because she didn't have any kind of protection at work*. Billie described the company as small, *low rental or low income* so workers *didn't have a lot of protection* and she never made any mention of asking for accommodations or discussing her options with Human Resources. She described how the company *did not have a union and they were afraid of getting a union because if they got a union, a few things would have to be straightened out as things weren't quite up to snuff*. *They just gave her her walking papers* and she figured she *really couldn't say too much because her MS was pretty active at that time*. She talked about how she didn't feel like she could advocate her case and *say to them well, keep me because my MS is going to go away, because she knew it wasn't going to be doing that*. Billie figured she *might as well just forget about her job and take early retirement* in her mid to late 30s *because she did not like stress or confrontation of any kind*.

Billie *applied for [Ontario Disability Support Plan] ODSP disability* and *it was a process that took quite a bit of time*. *They kept asking questions over and over again which got on her nerves, but she knew it had to be done*. The whole process *took about a year, but eventually she got approved and has been on disability ever since*. After receiving

disability she thought, wow. Finally. Relief. Billie had difficulty remembering what source of income she received in the year it took for her disability to be approved, but she recalls it being a struggle. With disability, Billie was thankful she did not *have to worry about* making ends meet. *It wasn't a lot, but it was enough to live.* In her mid-30s, Billie left her parent's home and *moved back in* to the apartment building she lived in prior to the car accident because it was geared to income, and since being approved for disability, she *could manage it* financially. Disability allowed her to *have a fairly decent place to live and the ability to look after* herself. She was also connected with supports that could provide *help if she needed.* Financially, before going on disability, Billie often *got behind in the rent* and felt as though she was *always behind the eight ball.* She *borrowed a lot of money from her dad* and *didn't like having to borrow money* even though he never asked her to *pay it back.* She was grateful for that because she knew she *never could have paid it back.* Finally she would be able to *pay things up* because being behind constantly and borrowing was *the worst stress* of all she explained. Billie also felt *kind of relieved that she didn't have to go to work every day* and she was grateful to have the comfort of knowing that *if she was having an exacerbation, she didn't have to try and go to work,* although she *would miss her friends.* Unfortunately, none of her work friendships continued after she left the workplace. Although Billie initially started receiving ODSP, she switched over to Canada Pension Plan (CPP) disability *not that long* after.

Billie was *quite young when she went on disability* and after leaving work, continued to manage her MS with the support of her family and doctors. She eventually met and married her husband when she was around 40 years old. He was *totally blind,* and Billie described him as her *rock.* She talked about how he *grounded* her during stressful times, and they *were constantly together.* After marrying, she moved out of her building into his apartment also in town. Unfortunately after around 10 years of marriage, he *passed away* from *diabetes complications* and failing to thrive after he *fell and broke his hip.* When Billie was married she spoke about how they *were both on disability* and *had both cheques.* She explained how they *were really affluent at that time, but when he passed* she was forced to *adjust to only her own CPP disability cheque, and manage things differently.* Financially speaking *it was better* for her *when it was both of them.* After his

passing Billie again applied to move back into her apartment building and has remained there ever since.

In terms of life now in retirement, Billie feels that she has *done very well and enjoys her life now*. She has *not gotten to the point where she can't do things for herself like her personal care and cooking, but she does notice that it is harder to walk and do stuff*. She has been *noticing numbness, particularly in her hands, a lot more now* as well. Billie believes she has *done really well up to this point in her life and attributes that to the pills and also the fact that she has a strong belief in the lord*. The lord has been a major thread throughout many of the stories she shared and something she very passionate and emotional about. Despite being *baptized when she was 12* and growing up in the Baptist church, when she started *drinking and acting like a fool she went away from the faith*. However, after moving back to her parent's house upon her retirement, a *Jehovah's Witness group* came trying to *convert* her. She went back to church to find the answers she was looking for and has *been there ever since, faithful as the day is long*. Billie reads *the bible all the time and studies the scriptures every day*. She is proud of the fact that she is *no dummy when it comes to the bible* and passionately believes that when *you realize how strong your faith can be and who you believe in, things really change for the better for you*.

Billie is fortunate to have a *good support system around her* and she goes to the local *meeting* hosted by the MS society *once a month usually*. They also hold *bible study in the common room* of her apartment building, and since she *voluntarily gave up her license and car* in recent years, there is a *lady in her building that drives her to church*. She is thankful to have *lots of friends in her building that she can count on for help*. For example, *if she fell and could not get up, all she has to do is call and they will come right down to help her up*. Probably most important to her is her *cat who is good company for her*. Billie's *father, brother, and sister* also live only a couple streets *over* and she has a wonderful *relationship* with her dad. Billie has been able to use her power scooter to *go over to play games and get home without too much trouble* since the *occupational therapist* has helped her become more *confident in the chair*. She does *not feel held back in any way*. Billie has also remained close to husband's family even after his death,

visiting them twice a year. They have always been very good to her and accepted her with open arms.

Being surrounded by people who she can *count on* and who support her is *worth its weight in gold* Billie explained. She talked about how *someday she will have to forfeit her independence*, but *right now she can still manage* which she attributes to her *fighting spirit*. She believes it *is good* that she has a *fighting spirit because she does not want to give in to the disease*. Billie talked about how *sometimes she wishes she could do this or that*, but most of the time she tries not to *focus on what she can't do* and *focuses on what she can do* and reminds herself that she is *better off than a lot of people*. She is able to *make her own bed, have a shower, and make her own meals*, although she admits she *bakes a lot more than she should because once she starts she will eat the whole damn thing*. Billie shared how she has been fortunate to be given or loaned all the equipment supports she requires. A *walker from her aunt*, a wheelchair from someone who *passed away in the building*, a *raised toilet seat from her husband*, and a *power chair loaned from the MS society*.

She feels her *mental health is good* and is looking forward to a *diet and exercise* program her church will be starting in the New Year *because she would like to get some weight off*. She feels her *extra weight is hindering* her mobility and that she is not getting around *as good as she could*.

Health wise, Billie is fortunate to *only take two pills a day, one for MS and the other for arthritis*. She has not *had any exacerbations since she retired* and will tell you she believes that *God has had something to do with that*. Billie *can't attribute all the positive blessings in her life to only the pills*, and *believes that God directs the doctors to help her*. Within the last five years Billie switched from an *Interferon* injection that she had been on since her diagnosis to a *pill called Aubagio*, because she kept getting *infections at the injection site*. The new pill has been working well for her. *Other than walking with a limp and having to use a walker*, Billie talked about how she does not *feel like she is disabled sometimes*. It is only *when she uses her walker or other devices* that she becomes more

aware of her *limitations*, although she is *better off than some people* and is *thankful to the Lord for small mercies*.

Financially, Billie feels she has *got more than enough* money although she does not have retirement savings. *If she gets in a stressful situation especially with money*, her *dad will help her out*. *He will give her a little bit here and there*, but she tries not to ask her *Dad for money* because *he's 86 and doesn't need a 60 year old daughter asking him for money*. She expressed that she does feel the need to *manage her money a little better* and realizes that if she did, she would *have enough money to do all the stuff she needs to*. At the end of the first interview Billie planned to continue doing *the best she could to just go with the limitations*, think positively and not to *stress about* things beyond her control while enjoying life with her cat and her *faith*.

During our second meeting, which occurred 20 months after the first meeting, there were a number of updates Billie had to share with me and some things in her life were very different. First, there was a visible difference in her demeanor, and she thought she may be *depressed*. She went on to share that in the time between our meetings she had experienced a tremendous amount of loss in her family with the *death of her mother, father and sister*. *Three members of her family gone now*. Billie shared that she has been coping *not too bad* but that she does *get kind of weepy sometimes*. She tries not to let herself *dwell on sad stuff* because she understands that *death is a part of living*, but she is grateful that her *mom and dad accepted Christ* before they passed so she *believes they are in heaven*.

The sadness of losing her family members appears to have affected other areas of her life as well. Billie talked about *how her whole demeanor has gotten a little weepier*, and she often feels sorry for herself these days. However, she tries to *push those thoughts away* because she *knows it's not healthy to do that*. *Whether* what she is feeling is *depression or what*, she explained how she has been using *food as a weapon against herself*. Eating has been a real struggle for her because she will stuff her *face full of junk* when she *knows it is bad for her*. Yet another difficult confliction in her life although it appears to be one of the few things she has control over lately. Eating is an outlet for her to say *hey, I can*

do what I want so don't bother me. However, when she starts gaining weight and finds it harder to move around, she feels like a fool. Even in relation to her faith things have changed. Billie used to read her bible every day but even that has slipped. She doesn't do it every day like she did before and has had to do catch up reading which is not what you are supposed to do she explained. She recognizes that her behaviour is so not like her and wonders why that's been happening.

Another loss in her life since our first meeting has been the monthly MS Society meetings she *enjoyed* taking part in. Billie revealed that she is no longer able to attend those meetings because *they don't have anyone who can take her*. She explained how the meetings are *later at night* in another city, and *they can't seem to get people to drive her at that time* given the distance of the *small town* she lives in. She *enjoyed* the meetings and misses being able to go because she *always had a good time and had built up a comradery with the other members*. She reflected on how this is *part of her life just gone now*, but at the same time, she does not want to *impose on anyone* else to give her a ride; especially since there are only *two people* in her town with MS.

In the past, Billie had a number of falls at home and *two falls at church*. The *church has high stairs to go up and thankfully both times she didn't hurt anything*. However, she has *not been able to be as active in the church as she used to be* because of her falls and the fact that she finds it *harder* with having *gotten more tired*. There are currently no accommodations in place to assist individuals with mobility issues despite *a lot of the elderly and disabled members of the congregation now being unable to attend*. Billie shared that they had *asked about the possibility of a lift like the other old church in town, but there was not enough room in the stairway to make a big turn they found*. She explained how the church is currently *in the process of building another church which is going to be all one level without a lot of stairs*, however, they *have yet to raise the funds to do it*. Having raised only *\$60,000 towards the \$100,000 total so far*, the new church still remains a fairly distant hope for the congregation, with the purchase of the land to build the church on still pending. The church's solution is to have *somebody walk behind Billie in case she falls, but she is uncomfortable with that because she worries if she falls, she will hurt someone else and does not want to have that on her conscience*. In the

meantime, the congregation will need to continue to manage the old building without adequate supports in place.

Since we last met, financially things have changed for Billie as well. She talked about how she is *better off than she has ever been in her entire life money wise*, and has *no complaints*. With the passing of her father she will *get money from his estate* and she plans to *tithe part of that to the church, and set up investments with the help of an investment place* for her future. Billie *tithes a lot to her church, and she tries to help people out whenever they need it*. In fact, she *probably gives away too much money* she believes. Billie also started receiving *the survivor's benefit* after the death of her husband, *an extra \$514 a month* so, if anything, she is *just rolling in money it seems now*.

Nowadays, Billie tries *not to get bored* but admits she watches *too much TV* because *there's not much else that she can do*. She still visits friends and neighbours, but her mood, mobility and energy has been more of a challenge. She notices that she has *gotten a little more depressed* lately and *things bother her*. She *knows they shouldn't bother her because half the time it's her own actions that have caused things to happen*, but on a positive note, *as long as she knows it's because of her, then she knows she can turn it around*. Billie realizes that we never *know how long we are going to be here on this earth, that's up to God*. She continues to try and *to do the best she can while here on earth* and use that to guide *how she lives her life*. Even though it is difficult not to let herself feel *depressed* given everything that has happened lately in her life, Billie always circles back to thankfulness that she has not been *hit as bad with MS as other people*. Billie has *done very well* with her MS and now sees that *all her worrying was for not because she believes strongly that the Lord looks out for his own and that's what He's done in her life*. *A lot of people she knows that have MS are in wheelchairs* and she doesn't *know why, but believes that only through the grace of God is she able to the things she can*. Billie *attributes all the positives in her life to the Lord, and knows she is going to be well looked after*. *Other than MS, she is not really debilitated in any way*. Billie continues to work on getting herself *back on track* and knows *it's just going to take some time*.

Overall, Billie's story is one of stress, inner conflict, and learning to embrace her faith. Throughout her work and retirement life there are many stories that Billie shared where she had to negotiate stressful situations when what she knew to be right did not align with her actions. These situations caused a lot of turmoil in her life, but she has always been able to turn to her *faith*, and have things work out. Billie's *life has gotten a lot better from when she was working because she was carrying on, drinking, and doing foolish things*, but now she has *gotten the Lord and some brains*. She believes the *upturn in her life* is due to her *faith in the Lord* and how He guides her life and treatment, blessing her without any serious MS related issues or exacerbations in retirement. Currently her MS *seems to be steady*, but she knows that could change *in the future* and *prays that won't happen*. Financially, she has *more than enough money to work with* if she does not *spend too much, too often*. Given the recent loss of three family members Billie continues to struggle quite a bit mentally and emotionally which has led to poor eating habits and weight gain, however, she is positive when the time is right, and she really wants to change, she will pull herself out of this difficult time. Billie appears to be realistic that there may come a time when she has to *give up her independence*, but she is *not at that point* yet and has good people around her to help with whatever needs she may have. Billie has a wonderful support system in place and is enjoying her retirement participating in church, visiting with friends, brother and in-laws family, taking care of her cat, and trying to lose weight.

5.3 Amanda's Story

Amanda began her story by telling me that she finally decided *to retire* because she was *exhausted when she came home from work and she felt her legs weren't working as well as they used to*. She *did not plan to retire until she was 60* but she *had a hint of what could be coming down the road* and wanted to *get out* while she *could still enjoy some mobility*. Despite *humming and hawing* about retiring for quite some time, her actual decision to retire was hard to come to. When she did retire she was 58 years old and had reached *full pension* at the *hospital* where she worked. Throughout her story, Amanda expressed that she experienced a lot of *guilt* over her retirement. Part of this guilt was over having to retire for her own personal health reasons. Very much used to putting

others first, she struggled to come to terms with the new limitations she was facing and the reality of no longer having an identity as a worker, making a meaningful contribution to society. The other part of her guilt came from her family situation. Amanda has a daughter still living at home who takes care of a lot of the household tasks that she is no longer able to do, and Amanda is dealing with how her changing needs may affect her daughter's ability to leave the home and live her own life as she sees her decline. Guilt was also attached to the fact that her husband was working a difficult, physically demanding job with a precarious health situation himself. He had *no pension* to draw from and *little retirement savings*, making the reality of him being able to retire unlikely. She also had to consider what her retirement would mean for their shared financial situation and factor in the uncertainty of both their health situations. Amanda was also very resistant to the thought of having to consider herself *disabled* and not letting a disability status *define who she was*, but she understood there was some degree of *uncertainty* surrounding her future health status for which she may need to plan. Amanda's story demonstrates how complex the decision making process of leaving work and entering retirement with MS can be and how there are often a number of factors that need to be weighed and considered.

Amanda was born in the late-1950s and grew up in Ontario. She lives with her *husband* and has *two daughters*, both of whom are now young adults and only one still remains living in the home. She has two grandchildren and *family* is a very *important* priority in her life. Her aging parents also live relatively close by and she has always had a close relationship with them and continues to *be there for them* to support their independent living.

Amanda started working at the local hospital *when she was 17*. Over her *41 year* career at the hospital, Amanda held a number of roles within the organization. She first *started working at the hospital on a casual basis* after a babysitting job for another employee led her to her new role at the hospital. Her casual position in admitting turned into a full time position rather quickly after the retirement of another staff. *A few years in* she moved into *OR scheduling*, a position she held for approximately *25 years* up until she retired.

Amanda was formally diagnosed with RRMS when she was *around 40* years old. Looking back, she believes her symptoms were present *in her early 30s* now that she *knows what some of her symptoms are*. She remembers regularly walking with her daughters and her mother at a local provincial park and *by the time they would finish walking, both of her legs would be tingling*. This *would happen all the time if she went for any length of walk*. This was her first memory of feeling symptoms related to her MS, although she didn't know it at the time. Around the same time she visited her doctor for *numbness in her legs* but *never mentioned the tingling because, why would she?* When Amanda was around 39 her family was *away at a cottage* and while picking up *stuff off the floor the kids had dropped*, she *whacked her head on the corner of an open window*. Upon returning to work Amanda started to have *dizzy spells* and *vertigo*. While working *one day it came on like a tornado, her head went down*, and her colleagues *put her on a stretcher* and took her to the ER for a *CT head scan* although the *CT head scan* did not show anything of concern. Although she knew the *whack on the head wasn't the cause of her MS*, she always felt *this occurrence was sort of the beginning of it*, the really noticeable start of the disease progression. Soon after her visit to the ER she started noticing *numbness* in her body and specifically, *a numb patch on her leg that didn't go away*. It persisted for quite some time, so Amanda finally went to doctors and said, *I got hit in the head with this window, it cracked my skull, now I have this patch on my leg of numbness*. The doctor didn't believe the bump to the head had anything to do with the *numbness*, but she decided to investigate further and *send her for an MRI*. Working in the hospital she was able to get an appointment rather quickly and *had an appointment with the neurologist the day he got the results in*. *The neurologist at the time was not known for his bedside manner*, and when Amanda walked into his office *he said, well the MRI results show that you have MS. Like, BAM! Do you have any questions?* he asked. Amanda *didn't really know anything about MS except that it's a scary word*. The *first question out of her mouth was am I going to end up in a wheelchair?* Because that is *what she associated MS with, you're going to be in a wheelchair*. The doctor replied *well, I don't know*. Amanda started thinking about all the *little things* that had been manifesting health wise over the years. The *vertigo, numbness, dizziness, leg dragging*, they were all *part of MS*, but she had *never associated them to MS at the time*. Receiving her diagnosis

was difficult for her because she didn't have any information. Not only was the doctor unsupportive and tactless, Amanda had no idea what this diagnosis meant for her life and family. *All she knew about MS was that she saw people in wheelchairs very disabled.*

She returned back to her office after the appointment and *said to her colleague, apparently I have MS. She stayed at her desk and worked for the rest of the day, still not understanding what was going on.* The diagnosis was difficult for many people in Amanda's life because it really came out of nowhere. *Everyone around her was so upset.* When she first told her mother, she *wouldn't even talk to her because she was so upset.* With the little bit of information her mother had, she experienced the same fears of significant *disability and wheelchairs* that Amanda did. It weighed on her mother *that her daughter would be possibly disabled and not functioning knowing she had two kids to raise.* This left Amanda to *break the news to her father.* Amanda's husband *really didn't get it at first.* She had to *really throw it in his face* and say things like, *I could end up in a wheelchair. You could end up looking after me.* It was very much a shock for him.

It took a while to get into the MS clinic and it was a while before she was able to really sit down to talk to anyone about MS and her diagnosis. While waiting to have her questions answered, she *made a point of educating herself about MS.* She *read tons of stuff about it, some good and some bad.* Google can be a very scary thing, she described. Eventually she *just decided, right then and there, that it wasn't going to get the best of her.* She shared that *it's not in her nature to let things get her down. We will deal with it and move on* she said. Amanda used the phrase *does not define me* multiple times throughout her story. It was very important that her life be about more than the MS. She had worked hard not to *say when things were bothering her so people would not know from day to day that she is living with MS, because it is not foremost in her life.* She made a conscious effort to *not make it foremost in her life.* After that, she *started attributing everything to her MS. If she had a cold, got sick, or something would feel funny, she would blame the MS because she knew nothing about it.*

About a year after her diagnosis *things started to progress* to a point where some form of medical intervention was needed, and she looked forward to her MS clinic appointment.

One incident in particular *scared the wits out of* her where she lost the use of her hands after a night of drinking with girlfriends and vowed to never drink again because of the MS. She finally got an appointment at the MS clinic and *got into a clinical trial for Avonex*. After starting on that, *everything calmed down* and she wasn't having *symptoms*. She was part of the *Avonex* study for quite some time until *it ended*. After the study *ended*, Amanda was left with a *\$250 per month* expense for the medication not covered by her *drug plan*. She *couldn't afford* the *out of pocket* cost of the medication and unfortunately, had to *quit taking it* despite the benefits it provided her. It was an unfortunate decision that had to be made because she had young children and a family to support and knew of no other options to assist with the cost. After she stopped taking the medication, there was a long period of time *that symptoms were surfacing* that *led her to realize that she needed to be back on some kind of drug*, but she knew they would not be able to afford it. Around the time Amanda was 54, her neurologist *got her into* another *drug study* that was *very new on the market*. It was important for Amanda to clarify that this was a new neurologist she was assigned to, and unlike the neurologist who initially diagnosed her, he was incredibly supportive, and always had time to sit and talk with his patients. She did not want her experience with the first neurologist to be confused with the care she has received from her present neurologist. At the time of the initial interview Amanda had been on this new drug, called BG12 (later known as Tecfidera), for about four years and believed she had another year or two left as part of the study where drug costs would be covered for her.

While part of the clinical trial, Amanda was recruited to do an *interview for the drug company about the drugs, their effect, and how well they worked for her*. When the *study* portion of the trial ended and the drug was *coming out on the market*, she was again *hooked up* with a local news crew for an *interview*. Amanda talked about *how a lot of people who didn't know she had MS found out that way*, and she hadn't even considered that this private knowledge would come out prior to doing *the interview*. She described it *like she had just come out of the closet*. Extended family and work colleagues who saw her on the news were now aware of something she had tried very hard to protect, and she hadn't considered the way she *was putting herself out there* when she agreed to participate.

Over the next three to five years prior to her retirement, Amanda noticed her symptoms progress, but still not to the point where it significantly affected her work. She noticed she had *more numbness in her fingertips, dexterity became more of an issue*, using a pen became more difficult, she experienced *fatigue* to the point where she would find herself *nodding off at her desk with her hands on the keyboard*, *weakness in her left leg with walking*, and *balance* became an issue. She *knew personally that* some of these things were starting to *affect her work a little bit, but only she knew that*, no one at work did. The fact that her job at the hospital was an administration one with little need to carry out very physical tasks was conducive to helping Amanda stay in her role, despite her changing abilities. She didn't need to *lift 60 lbs*, and the amount of walking she would do on a typical day likely wouldn't cause her knee to go *wonky* or leave her *leg dragging*.

At this point, she had *never had a formal relapse* but still knew that it was a possibility and that things *could get worse*. Because of this, Amanda started to contemplate retirement. Around this time, in addition to her progressing symptoms, there were other incidents that put the idea of retiring on Amanda's radar. While on an annual girl's trip to Grand Bend when Amanda was around 55, she *came down the stairs* and her *leg literally gave out* and she *fell on the floor*. Noticing that this *happened sometimes when she was just walking normally* made her think more about retiring while she could *enjoy mobility still*. Around the time Amanda was 56, her daughter and her husband went to Mexico and she *took a week off work to babysit the kids*. *As exhausting as that was, she thought, I could totally do this. I could totally not work*. Family was extremely important to Amanda, so having that time and enjoying her family made her think retirement could be a reality sooner than later. Finally, the summer before her actual retirement, Amanda went on a girl's trip to PEI and *found herself really struggling* to keep up *with all the things they were doing*. She was having to *take a lot of breaks* and her legs were not working properly, which *just reiterated to her that the disease was progressing whether she liked it or not*.

Throughout the diagnosis and post-diagnosis period, Amanda continued to work as normal. Despite the fact that she was noticing changes to her abilities, the changes and limitations were taking place in the background of her work life where she was selective

with whom she shared her diagnosis, and despite having some exposure after the TV interview, her work colleagues and direct supervisors were relatively unaware of her situation. She was *never forthcoming with her employers*, except in a few rare situations, *because*, in her eyes, *it wasn't an issue* in terms of her job performance. She *wasn't off sick a lot* and she did not ask for any accommodation. Over the years, she had *very good relationships with certain managers* and she *would be upfront with them* about having MS. She decided to share with them because she *was unsure of what* may happen in the *future* and wanted to be *honest and fair and put it all on the table*. *Close friends knew* but she *never talked about it*, so it *wasn't something she advertised at work*. At many points throughout her story, Amanda was very clear when she talked about how she never wanted MS to be *something that defined who she was* and never wanted *to use it as an excuse*. She used the term *play the MS card* frequently throughout our discussions emphasizing it was something she never felt comfortable doing. She would joke with her friends, *can you get me a coffee I have MS*, and they would all laugh because everyone knew that's *not who she was*. Amanda has always been resistant to *ask for help* and worked hard to maintain the impression that she *can do it herself*. She has shied away from asking for help and not letting people know the extent of her limitations, because getting to the point of having to rely on another person is *scary*. She was also afraid it would make people *pity her* and she made it very clear that she doesn't *do the pity party*.

As Amanda moved closer to retirement, her work environment was changing. Having done the same job for the last 25 years, she had seen a number of managers and coordinators *come and go*. For the last portion of her working years, Amanda *wasn't really crazy about her manager* or the work environment. She *was not happy about the political bullshit that was going on* and she was starting to *find the job overwhelming*. She had *done the job for 25 years*, so it *shouldn't have been overwhelming*, but she felt *a lot of demands were being put on her that she didn't feel were her responsibility*. The newest coordinator was *constantly making changes to things and not telling Amanda*. *In some sense, she was losing control of what she had always had control of, and she didn't like that*. She struggled with *losing the control* and she *found it hard to be able to keep up with what she was doing every day*. Amanda *did not respect* what the *new manager or coordinator* were doing and at the same time, *felt very disrespected because they didn't*

value her. Amanda believed they didn't value her as an employee that had been doing the job and knew it like the back of her hand. She had always loved her job, but it started to become more of a chore than a job. She enjoyed the work itself and she enjoyed the people, but it started to feel like work for her and she wasn't enjoying it anymore.

Combining everything together, feeling unhappy in the job, disrespected as an employee, wanting more time with family, and the progression of her symptoms, compounded by the uncertainty of how her health was going to be she thought, just get out. Don't deal with the bullshit anymore.

Despite being unhappy in her job and knowing all the reasons she should retire, she still felt incredibly conflicted about the idea of leaving work. She talked about the head game of do I stay, or do I go? Do I stick around until this thing gets out of control, or do I do it now on my own terms? Amanda had worked at the hospital since she was 17. This was all she knew. She talked about how working had always been a huge part of who she was as a person. She was never a stay at home mom. She had four months off for maternity leave and wasn't home even that long. The house, the home, and the family, where it was a priority in Amanda's life, it wasn't where she saw her contribution to society. Working had always been what she did, and it was all she knew how to do. She described how she was having a very hard time wrapping her head around the whole not working thing, even though she knew physically it was the best choice. After 41 years, it was hard to think about flipping the switch on that part of your identity. Had the MS not been a deciding factor, she would still be working.

Financially she was concerned about what it would mean for her family. Her pension was at full benefits and her husband was currently working full time; however, his health state was somewhat precarious, and she wasn't sure how long he would be able to do the physically demanding job he held. After many lengthy discussions with her husband, he was very clear that she would be coming up \$500 short financially if she were to retire. Losing this amount of money would make a significant difference for their family. It became a possibility that she may have to return to work casually after retirement to make up the \$500 difference. She sought out the person in charge of hiring in the department, and they made an agreement that a casual position would be available for

Amanda when she was ready to return. The financial aspect of retirement was difficult for Amanda to accept because she felt like she was *going into the unknown*. She described it that you have *worked your entire life* and you are used to having *a pay cheque go into your account every two weeks*. The pension would go into her account once a month and things would need to be rebalanced. Would that mean they had to *eat bacon and eggs*, like when she was young and it was tight at the end of the month, she wondered? The uncertainty about the future was difficult to accept and added to *the head game* of whether to *stay or go*.

She had been *humming and hawing* the decision to retire seriously for *probably about three years* but had a number of things to consider in making the decision. She knew she would likely have to continue working at least *casually* to make up the \$500 deficit monthly, although she had *never had a relapse* she knew her symptoms were progressing and she wanted to *enjoy mobility while she still could*, she no longer felt supported or *valued* by her employer, and she was looking forward to having time with her parents, children, and grandchildren. She knew she wanted to retire *on her own terms* and not because she was limited physically, that would *have just ticked her off*. Amanda wanted to be retired in time for *fall* because *fall* was her *favorite time of year*. One day she just *marched over to Human Resources (HR), filled out the paperwork, didn't even tell anyone, and said it's done*.

Amanda formally retired from the hospital at the end of the summer 2016 with full pension. In sharing about her life after retirement, I will discuss what Amanda shared in her first meeting and then separately discuss the changes that had taken place in the time between our meetings. Her *very new retirement* at the time we first met had already been *a whirlwind*. Almost exactly to the *day* Amanda *retired*, her *dad ended up in the hospital for a week or two with sepsis*, and her *mom was at the house by herself*. Being 86 and 87 *it started to become obvious that they needed a lot more help* than they previously had. Shortly after his hospitalization, her parents decided to move into an apartment from the house they had lived in for *63 years*. *They put the house up for sale*, and both her and her sister were responsible for the massive *downsizing* and move for her aging parents. Only a week before we first met in November 2016 had things finally started to settle down.

The majority of the stories Amanda shared about her life after retirement were about the struggle and guilt she felt related to being a retired person. First, Amanda struggled with losing her identity as a worker. She had been working *since* she was 17 and all of a sudden she didn't have anything she had to *do in a day*. Her days had been full since she retired with little *down time*, but she wasn't making a tangible contribution. Amanda also struggled with a lot of guilt related to that fact that her *husband couldn't retire yet*. Her husband did a *very physical job*, had *congestive heart failure*, and his *knees were shot*. He had *no pension* to draw from and *he starting saving for retirement* quite late. She talked about how she would love for him to be able to retire but she knew it wasn't a reality at that time. This was hard for her because she has *never been the kind of person who does things for herself*. She described it that, as a woman, you *are a daughter, a wife, a mother*, and *somewhere in there you kind of get lost* yourself. You make your life about the people you care about. She felt *that this retirement was all about her*, her limitations and her future needs. Finally, Amanda felt she had *to be accountable for her days* when her husband came home. Here he was out working this *physically demanding job* that he hated, and she felt she had to prove that she *accomplished something* throughout the day. That she was not just *sitting around watching TV and eating bonbons all day*. Her husband would *come home* from work and *not meaning anything by it*, ask Amanda *what she did today?* She felt like she had to *have a list of things* she accomplished ready when he came in the door, and it weighed heavily on her. She finally explained to him that she was *resentful* of him asking, because she felt like she had to justify her days.

Other stories Amanda shared about her life in retirement were related to trying to navigate her *new retirement*. *At the time of the first interview, financially they were* managing fine. In fact, Amanda shared how she had *never had this much money in her bank account*. Neither of them *made huge amounts of money* and at times it felt like they *were going pay cheque to pay cheque*. In the last few months since retiring, thankfully they hadn't dipped into *the red zone*. What changed for Amanda was her ability to save money. They are *not saving any money right now*. Amanda was a planner who *had six accounts* all with different purposes to save and preserve money. She talked about how she would again like to *have some play money* to be able to continue to do the things that are important to them, things like their semi-annual trip to *Las Vegas, girl's weekends*,

and family cottage rentals. Traveling with family and friends was an important part of Amanda's life that they were, for the most part, always able to enjoy. However, navigating her new financial situation, she was still unsure of how much they would be able to continue.

Amanda felt uneasy about the possibility of *living on one income in retirement* when the reality of her husband's precarious health and employment situation presented itself.

When her pension first started, the pension company sent a letter informing Amanda that they had *under-calculated* the *pension* amount and she would be receiving an extra \$600. Her husband started discussing the possibility of *living on one income* due to the extra money, however, after receiving the payment it only ended up being an additional \$300. What happened was that with the extra support she received, *bumped her into a new tax bracket* and the money was deducted. Money Amanda could have used for health-related expenses. The idea of *living on one income* was a *curveball* for Amanda. She described how didn't *sign up for that* and likely *would have stayed working if her husband was* considering leaving work. He had *no pension to draw from* and his Registered Retirement Savings Plan (*RRSP*) might allow them to *get by for a year* but after that he would only be 58 and not eligible for federal *old age pensions*. A big *part in* her thinking she may need to return *to work on a casual basis* was to *pick up a little bit of the slack* and *take the pressure off*. Even though she was already bringing in her *pension* income, Amanda struggled to feel like she was *contributing* and believed she needed to *work to contribute*.

Realizing that returning to work might become a necessity for her family, it was also a concern for Amanda. Although prior to her retirement the coordinator promised a casual position for Amanda, the job they *would likely want to train her in* was physically and mentally demanding. People in that particular role are *pretty much on their feet all day long* having to track, process, and manage all the nurses, doctors and patients moving through the clinic. Being on her feet all day long was just not something Amanda could do. On a regular day, any amount of physical activity outside of normal levels would leave her *useless by the end of the day* and her *leg dragging*. Amanda feared that she would not be able to do the job where she would be needed, and she had reservations about sharing her limitations with them. As she reiterated many times throughout the

sessions, Amanda never wanted the MS to *define who* she was. She *never used the MS as a reason or an excuse*, but she felt she might be forced to *play the MS card* if she was to return to work. She could tell them she was available for the work, but worried how they may react if she was unable to do the job they really needed someone to fill. She knew she might have to *play the card* in this situation, which left her uncomfortable at the thought of having to divulge information that was deeply personal to her while having to deal with their reactions to it. Amanda worried her limitations could be a factor in the hospital wanting to re-hire her after retirement, and felt that perhaps *they would want to hire someone who could give them no limitations. Why would they hire her when they could only put her into two jobs when they could hire another one and put her into four jobs?*

The discussions related to her husband wanting to retire and the possibility of having to live on one income forced Amanda to *drop her expectations of retirement and their future*. Amanda *expected that* when she retired they would *get a really nice one floor condo, open concept, hardwood floors, granite countertops, with a bar in the kitchen*. She has had to *scale that back* because she knows husband *wants to or will need to retire at the age of 60, reducing their income significantly*. She described how the reality is that they would *probably have to move into an apartment* based on both *financial and physical* reasons. The reality was that her husband would not be able to *work past 60*, and she tried to be realistic about the fact that they would *have to get out* of their current home. *Physically neither one* would be able to *keep up with it after their daughter moves out*. Amanda struggled trying to manage her limitations and has had to *learn to space things out* in order to complete them. There were so many things she wanted to accomplish now that she finally had the time, but she *can only do one thing at a time* because it *will wipe her out*. One day she may *clean the closet* and *that is all* she is up to doing. *The next day* it may be the windows. Amanda had to realize she *can't go through the whole house and clean it like she used to when she was working on a Saturday*. She groups tasks into *pockets* and if she knows she has something *big is going on*, she will *pick and choose what's important*. Doing too much will *do her in* for the *rest of the day*. There have been many times she had *overdone it*. She *started off feeling fine but after a*

while her leg would be dragging, her arm wouldn't be working, her fingers had gone numb, and the cumulative effect of her symptoms slap her in the face.

Amanda also talked about the uncertainty about the future. When they were both working full time with health insurance, there was still a time where they could not afford the out of pocket portion of her MS medications. When she retired, they had the option to extend her hospital benefits within *60 days of retirement* but with a *cost of \$2000 a year* and a reduced income, extending the coverage was not a feasible option. With that possibility out of reach, it became very clear that they would never be able to secure health insurance for future needs. A new insurance company *would find out* Amanda had MS, her husband *had congestive heart failure* and likely *no insurance company would take* them. While Amanda remained part of the MS study her medications are provided free of charge, but having been in a similar situation before, she feared what would happen when the trial ended. *Going forward*, Amanda discussed how both her and her husband *would need to reach 60 or 65 when old age would take over*, but she was still uncertain whether her MS medications would even be covered at that point.

Amanda spoke about how she *sort of explored* disability supports, *but quickly dismissed* the idea *because she didn't think she was disabled*. The difference between retiring or receiving disability supports and what it would mean for her future financial and health needs, wasn't something Amanda *took into consideration*, and she realized that she kind of *leapt into* retirement. Even at the time her husband *would ask* her *questions* and she wouldn't *know*. He would *say why don't you have the answer?* Amanda described that she *just didn't find out* a lot of information and didn't really know where to look for it or have anyone to help her. She did mention that *disability* may be something she *has* to explore *because of the drugs* in the future.

Amanda continued to find ways to do the things that are meaningful to her and to effectively managing her changing limitations, while not letting the MS define who she was as a person. At the end of the first interview, she remained unsure of what the future held and was concerned that she may need to make changes she was not entirely comfortable with in order to adapt.

After our second meeting there were a number of updates Amanda had to share with me and things were very different. Amanda had experienced her first relapse in the *20 some odd years* since she was *diagnosed*. At the beginning of February 2017 Amanda was *set to watch her grandchildren* while her kids went to *Punta Cana*. Just before they were set to leave, she *started to feel like things just weren't right*. Her *legs just weren't functioning the way she thought they should be functioning* and inside she just knew things were off. Up until that point things had been *continuing as they were*. She had *no indication that things were starting to slide*, and everything had been *status quo*. Amanda contacted *the study clinic nurse*, as she was still enrolled in the *Tecfidera study at the time*, and got in for an appointment right away. They found she was in *full blown relapse*. Her husband ended up *having to take a week off work to help her watch the grandchildren*, because she couldn't *get around* at all. She ended up on *an insane amount of prednisone, taking 25 pills every morning*. The relapse *lasted about a week and a half until the prednisone kicked in* and she started to feel like *a million bucks*. The relapse may have been over, but the effects of the relapse would be widely felt in many areas of their lives.

The relapse *was hard*. It was especially for Amanda's *husband*, because throughout her entire journey with MS, she had *always maintained an I can do it attitude*. Even when she was first diagnosed she *rarely talked about MS and the effects*, so *seeing her on a daily basis all of a sudden not be able to do things, was a bit of an eye opener for him*. While her husband was at work, *he wouldn't always see if she did too much gardening and had to stumble back to the house and sit down for a while*. The relapse made everyone realize that *this is what could really happen, and this is the way things could be in the future*. Amanda *lost complete confidence in her body and what it would do on a day to day basis*. Losing *faith in her abilities* made the decision not to return to work on a casual basis after retirement much easier. While in the midst of the relapse, Amanda finally received a call from the hospital coordinator about the casual position she had been promised, *after months of harassing her*. Amanda had sent *numerous emails, put in a resume with her daughter, contacted HR*, and even after speaking with them *continued harassing with emails*. No one would contact her or return her calls. HR told her that *she could not be hired for a position that wasn't posted*, so this angered Amanda even more that even the information she was being given didn't seem to add up. Amanda started to feel quite

bitter and felt that nobody was really working that hard to get her to come back. Finally when the call came asking Amanda to call to discuss a position, Amanda's decision was already made. Having never faced a relapse before she just decided no. It wasn't worth it to her anymore and she didn't know when or if a relapse like this could happen again. Before retirement Amanda struggled with her identity as a worker and her contribution to society through working, but after the relapse she was just done with the whole thing. Once she got past the whole 'I can't go back to work thing', she just stopped thinking about it. Since Amanda never spoke with the coordinator she didn't even know for sure they had a job for her at that point, but she assumes they did. Amanda attributed the difficulty she experienced to the fact that she didn't believe they were going to bring her back in a capacity that had anything to do with her old job and foresaw problems knowing Amanda may not play the game they wanted her to play. Not having to return to work was a relief for Amanda and a big weight off her shoulders. She was finally able to release some of the guilt she had been carrying about making the decision to retire. Knowing that she would possibly have to go back and learn something brand new did scare Amanda. She hadn't had to learn anything different like that in so many years and wondered if she had the mental and physical capacity to handle it? She was left questioning her capabilities as an older, retired worker re-entering the workforce.

The relapse really changed things and put them into perspective for Amanda. Amanda was so glad that she retired when she did, and she could finally feel confident about her decision. All those questions like *what if this progresses, were forefront in her mind* and she felt strongly that she didn't want to retire when her legs didn't work anymore. A number of times she expressed that she was glad she did go when she did because of the progression she had seen since the relapse and how she is a little more limited than she was. She didn't bounce back 100%. Before the relapse people close to Amanda knew she had MS, but it wasn't always obvious because she didn't talk about it. She wouldn't share when she had a bad day or that she couldn't feel her fingertips, so after the relapse brought forward the reality of MS in their lives, people took notice. Everyone became a little more aware of it and aware that it had progressed.

About six months after her relapse, Amanda's husband went off work on Employment Insurance (EI) Sickness Benefits because of *his knees*. *He just got to a point where he thought, I can't do this anymore*. He received 13 or 14 weeks of benefits, but they both knew he would not be returning to work after they ended. This was the one-income situation Amanda had been hoping to avoid. However, at the same time his EI benefits were ending, Amanda was accepted for Canada Pension Plan (CPP) Disability benefits. Amanda had previously struggled and decided not to apply for disability benefits in retirement, although she was aware the impact of not having some kind of disability supports in place as her needs and limitations changed could have. *All along her mantra had been I'm not disabled*, but it got to the point where she *started to feel a little bit more disabled*. So a combination of needing to fill the income void of her husband not working, knowing that she wasn't returning to work, friend and family encouragement, and finally starting to accept the severity of her changing limitations changed Amanda's mind to apply. Amanda's first installment of CPP disability was perfectly timed to fill the gap of lost wages from her husband retiring. Amanda called it *a blessing she got accepted for the CPP Disability*, otherwise she wasn't sure *what they would have done*. *The combination of Amanda's CPP Disability and her hospital pension enabled them to continue living pretty much the same way they always did* and released Amanda from the guilt she had felt about *picking up the slack*.

Amanda talked about how the entire process of navigating her way through retirement and all the different services and supports was *overwhelming* for her. After the drug study ended abruptly, *the drug company had agreed they would supply people in the study with medications for another four years*. However, when Amanda arrived at her next clinic appointment the *research nurse* told her circumstances had changed and now they were *going to look at each case individually and assess*. Amanda received a call through the drug company *nurse case worker* that she had been accepted. Amanda wondered what she would have done had she not been accepted, because she would never have been able to cover the *\$2500 a month* cost without income or insurance. This meant that her pills would now be *delivered to her free of charge* and she would deal directly with *the drug company* now. *The drug company also gave her an application for Trillium benefits* to which she was also accepted. Amanda didn't have much knowledge of Trillium prior to

them initiating her application. However, based on her family income, there was a \$3000 deductible that would need to be paid for *Trillium*, which was a huge financial burden on Amanda's family. Then out of nowhere, the drug company informed her that they had covered the initial \$3000 deductible. Amanda was stunned, incredibly grateful, and not totally sure how this decision was made or how this assistance came about. She was not sure if the drug company would pick the cost up next year because there was no, and has been no, past or future communication about the decision or process. Amanda shared how this was not her first interaction with getting support from drug companies. Back when she was beginning the *Avonex* study she was going to have to pay out of pocket for drug costs prior to enrolment in the study. She mentioned to the neurologist at the time that the cost was really expensive, and she didn't think she could afford it. With that, he turned to a kind of petty change jar and wrote her a cheque for \$1200. Just like that. Apparently, the drug companies do this sometime, they give money. She didn't know the specific politics around the assistance but there is sometimes money there to help people who can't afford it, although it is not widely advertised. Unfortunately, that same support was not available when the study ended, and she was having to cover \$250 a month out of pocket. The drug company ended up being a very unlikely source of support for Amanda that lessened some major financial concerns in her retirement. While the process wasn't entirely clear to Amanda, the drug company took the lead on getting her set up with *Trillium* and helping her manoeuvre that benefit system, which was something Amanda likely would not have done herself given her struggle to even consider herself disabled. They stepped up as a source of support even when she didn't know she needed or was entitled to any.

What came out of all this was that Amanda found that through networking with people and exploring the whole disability pension options, there are a lot of things out there that people don't know about. Amanda drew on a lot of resources and she still didn't know everything. She talked about how the average person doesn't know about drug company assistance, or the ins and outs of these pensions, or disability tax credits available, and how it takes a lot of effort to negotiate the waters. Government sites are so confusing, and even her husband struggled in assisting with her disability application. Amanda described it as a mud pit to try and work your way through with so many hidden things in

there. There seemed to be a lot of professionals that people encounter who could educate people about these services, but not a single person with all the information who acts as a *navigator.* People need a *navigator* to educate and help sift through all *the layers that the average person doesn't know are there.* They need an advocate *sitting in an office that they can go to and say, OK I need to retire, help me plan this out, where do I need to go, how do I make this financially feasible. And I'm not talking about investments and banking, I'm talking about managing life with a disability.* This is an obvious gap that needs to be filled in order to support individuals better. The policies and systems are not user-friendly to people living with chronic illnesses and seem to create a certain amount of anxiety over the complexity of the process. People need to know *what kind of help is out there for them.* Amanda described the process as *a little bit overwhelming,* but at other times she described the complexity of navigating the systems and taxes. Consistent with her nature to minimize difficulty and challenges, she appeared to do the same with how workable it was moving within these systems.

Something her *mother pointed out* to her, that has been very difficult for Amanda to deal with, is the fact that her *youngest daughter,* who is 28, *still lives at home* and is a *huge help.* Amanda spoke about how her daughter just *gets her and knows when she's hit a point and can't do anymore.* She will be right there to *pick up the slack and does it without making comments or discussion.* Her daughter has been wanting to move out for quite some time and start her own life. Amanda's mother *pointed out* that Amanda needed to *encourage her to move out because the more she sees Amanda decline, the harder it will be for her to leave.* Amanda was very emotional sharing how that *is not something she wants for her daughter.* It is a struggle, because Amanda is *not sure how she could handle things around here without her daughter here, but at the same time doesn't want her daughter to feel that she has to stay because of her.* This *discussion happened only recently,* and it is something *that's really front and centre right now for Amanda.* It is not something she has been able to discuss with her daughter or even her husband yet, *because she doesn't know how accepting of the discussion her daughter would be. True to how she is, Amanda has probably tried to not seem too dependent and not let her do as much as she's been doing. Cover it up. I don't need you. I'm fine.* Amanda didn't know how to proceed. She didn't *want her to feel like she was kicking her*

out but wants to encourage her to live her own life and follow her own path in life. Amanda continues to try and find the right way to work through this very emotional decision that has larger implications for everyone involved.

Overall, Amanda's story is one of change with the relapse really at the center of making her realize what is most important to her. Her journey to retirement was difficult, and even after retirement, she struggled to find her place as a retired person and be comfortable with the idea of being retired. She had to make compromises and *scale back* her expectations of what her retirement would be like given her *changing limitations, financial* and family *situations*. She experienced losses, like having to give up her *Pilates*, and on her weekly park walk and coffee with friends, Amanda will *join for coffee* but not the *walk* because she *knows* she *would hold them back*. After the relapse, so many of the things Amanda previously felt guilt over or struggled with, didn't seem to matter anymore. She is learning to come to terms with her limitations and has been more open to accepting help from others. She was *offered* and *accepted gardening* help from a *friend* this year for the first time, which was a big deal. She now realizes that retirement was the *best decision* for her, and she is thankful she got to *go on* her *own terms*. Amanda has become a lot *more aware* that physically things have changed, and she has tried to *not push as hard* whereas before she *wouldn't admit* she couldn't do things and *would push harder*. She has *seen what happened* and now she doesn't *quite push as hard*. She may have *lost confidence in her body*, but she is *so glad* she retired when she did and is still *able to enjoy* mobility. She worked hard to move on from the guilt of retiring for her own health needs, and she continues to tackle new challenges as a caregiving support to her aging parents while she navigates her relatively *new retirement* and focus on things that bring meaning to her life.

5.4 Noreen's Story

Noreen began her story telling me that when she *first got sick*, it *didn't really affect* her *that much*, but *very quickly* from that point on it *started to affect* everything. Noreen needed and wanted to *quit* her *teaching job* of almost 30 years for years before she was finally able to do so. She was unable to quit previously because of the *financial* impact losing her income would have on her family, and the *lack of awareness* by her husband of

what her job entailed. Over the years as Noreen's illness progressed and the demands of the job became too much, even with adjustments and accommodations she began to feel incompetent and really stupid all the time. She had loved teaching because she is a very creative person, but it got to the point where she was no longer doing the job she wanted to and was barely getting by. Noreen felt frustrated. Losing the ability to do the job she loved was just one of many losses Noreen endured throughout her teaching career. She also dealt with a tumultuous fertility journey and a very emotionally and financially devastating disability insurance application process. Ultimately, retirement benefit policy changes accelerated her timeline for retirement and helped her convince her husband that she needed to retire. Life in retirement has provided Noreen with the flexibility and leeway to create routines that promote her well-being and help manage her MS on a daily basis. She continues to strive for balance between her desire to do too much and the need to be realistic about her limitations. Noreen enjoys being a lady of leisure and taking care of her three dogs.

Noreen was born in 1963 and grew up in Southwestern Ontario. She attended Teacher's College in the Toronto area and began teaching around the age of 24. She spent two years teaching in the Toronto region before moving back to her hometown where she has worked and resided ever since. She currently lives in her hometown with her husband who works full time and owns his own business.

Almost immediately after she began teaching, Noreen started to develop issues with fatigue, her short term memory, and simple adding. Initially she just figured it was new teacher stuff given that it was not uncommon to still be working on a weeknight until 9:00 pm. She would walk across the classroom and forget where she was going or what she needed, and would regularly have to keep repeating numbers to herself until she had the problem figured out otherwise she would forget. She was formally diagnosed with chronic fatigue syndrome, but reflecting back, there is some uncertainty in her mind whether it was the MS or in fact chronic fatigue since chronic fatigue produces symptoms very similar to MS. Now having a confirmed diagnosis of RRMS, Noreen questioned whether she may have had it a long time ago as she remembered talking to her Grandma

years previously about needing to lay down after having a bath and other little things that at the time, didn't mean anything.

In her late 30s, Noreen moved to a new *multi-level school without air-conditioning* in her hometown where she would spend the next ten years teaching. Around the same time, she started *looking into having a baby on her own*. Upon investigation the doctors informed her that *there were going to be problems with fertility, and her chances would be a lot better if she started in the fertility program straight off*. While investigating her fertility options, Noreen met and became engaged to her husband. They *married in 2004 and after a few months of being married, went to the fertility clinic to start the process of having a baby.*

While going through her *three year fertility journey*, Noreen experienced a number of medical, employment and personal challenges. First, around the time Noreen was 42 she found herself overwhelmed by *the combination of the fertility drugs, at six times the normal dose, and her current classroom which she described as the class from hell*. She was *crying 24 hours a day and unable to deal with all that crap going through her system, describing that time in her life as absolute hell*. She *went home at Christmas break and informed her husband that she was not going back*. Overwhelmed and emotional, Noreen *didn't even give a shit* if they fired her, and when January came to go back, she knew she *couldn't do it*. What made it possible for her to take time off was, at that time, the policy on *sick days* was different. Up until around the time Noreen first began having issues with her MS in late 2006, although not yet diagnosed as MS, teacher's used to be able to roll over their sick days from year to year. Teachers often have a surplus *built up*, so when Noreen needed time off she was able to use some of the *couple hundred sick days* she had *built up* without having to apply for formalized disability supports. Taking time off work was a concern for both Noreen and her husband financially, however, the fact that she was able to use her accumulated *sick days* that paid her *90 percent of her regular day salary*, made the financial impact significantly less than if she had needed to apply for workplace or governmental disability supports.

As September of the same year approached, Noreen was feeling ready to return to school. While she was off, she and her husband had discussed the possibility of *doing a three over four*; a program where teachers could take three years pay but are given it over four years so they would still receive an income while taking a year off. It became a *joke* in their house that her husband *promised* her a *three over four just to get her to go back to work*. Noreen returned to work that September and for a very short time things went back to normal until she received her *last pregnancy test from the fertility clinic, and it was negative*. She felt like she *couldn't even grieve* the end of that journey because her *sister's due date was that same day, and her nephew was born and died the same day*. She felt like she could not *even be sad because it would make her look like an idiot*. Noreen decided she could not let this be the way she ended her fertility efforts and booked *surgery for fertility in December, planning to go ahead with treatments again in the spring of 2007*.

The second significant event during her fertility journey occurred about a month after returning to work when Noreen had her *first MS attack*. She *woke up* one morning and *went blind in one eye*. Her *left eye went black momentarily* and when her vision *came back, there was a vertical black line* that remained. Despite this, Noreen went to work where she later called the *optometrist*. The *optometrist* did some investigation to ensure the blindness *was not caused by a torn retina*, which it was not, and started the process to try and get her in to see an *ophthalmologist* right away. The first *ophthalmologist* administered a colour test, typically associated with the diagnosis of MS, which Noreen passed, and she was ultimately *misdiagnosed with flaky eyelids*. Disappointed with the diagnosis, her optometrist sent her to another *ophthalmologist* immediately. The second *ophthalmologist* sent in a request for an MRI because again Noreen passed the red cap test despite his suspicions that she may have MS. *Not related to the blindness*, Noreen *happened to be at her family doctor's* and mentioned *what had gone on* and he also *put in for an MRI* in the hopes that it would *get her in* quicker. It took *a few weeks* to get in, but Noreen got the MRI and kept *waiting, waiting, waiting, and waiting* for the results. She *kept calling the doctor's office* asking if they had *the results*, which *they did but they were lying to her* and withholding the results. A couple months later as she was *about to go on Christmas break*, she couldn't take *not knowing the results* any longer. She knew

she couldn't go on *Christmas holidays* with her *very active imagination still thinking* she had *an aneurysm*. It just so *happened* that her *mom and dad* were going to the doctors just before Christmas and Noreen asked them to tell the doctor that *he* needed to *call her today*. He finally returned her calls and told her she *could possibly have MS* explaining that they *were trying to wait till they got her an appointment before they told her*. Taking the news in Noreen said, *you know what, I'm OK with this. I can deal with it because I know what it is. The end. I'm not upset. This is not a big deal. I don't have an aneurysm or a brain tumour, we're good.*

After the initial attack, *for months and months* her vision was *blurry*. *Fatigue* also became an issue a few months later. Her symptoms came on *very quickly* and started to affect her ability to work and teach while she waited for an appointment. Noreen got into the MS Clinic in that *January or February* where they confirmed that the MRI report said *probable MS*. Being the type of person who would *want to know right now*, they scheduled Noreen for a *spinal tap* for the same day which also came *back probable* and left her with a terrible *spinal headache*. The irony of the situation was that Noreen had been *in fertility for three years* and *hadn't had any alcohol, caffeine*, she took *stinky vitamins*, did *Chinese Acupuncture, you name it* in order to be successful. Now the *neurologist* was telling her *the best thing to do* for her spinal headache is *have caffeine*, she could even *go get the pills*. Noreen had the *coffee and thought whatever, there goes three years. Fuck!* The *neurologist* also sent Noreen for *another MRI* even though it had only been a short time since her last. Unfortunately when she went, the techs *were supposed to give her contrast* in order to see any new *active lesions*, but *they didn't*, which made the results *useless upon follow up* for the doctor. At that point, discussions *about meds* took place despite her *probable* diagnosis. *For a couple of years no one actually said you have MS* to Noreen. She would *joke* about it with her friend who also has MS and finally, after mentioning it to the doctor *he just looked at Noreen and goes, you have MS* and that was the confirmation she was looking for.

Also in early 2007 and unrelated to her MS, Noreen was *kicked out of the fertility program* which was a devastating end to her fertility journey. She described how in late 2006 and early 2007, *life sucked* for her. There was a tremendous amount of sadness and

loss with the *death of her grandmother, her sister's baby, the negative pregnancy test, being kicked her out of the fertility program, and being told she had MS*. After deciding to move forward with the *surgery for fertility* that previous *December*, she had been hopeful for positive fertility results, but ultimately her fertility was unsuccessful for a number of reasons, *some of which she blames the school board for*. Teachers *have three days a year for doctor's appointments*, although there is some debate whether that is *three doctor's appointment about the same item or three per item*. At one point the board *started checking and calling Noreen* inquiring whether her time off was related to *the same thing* she had previously taken time off for and *what was she doing?* She *took the inquiry as harassment* and she felt *harassed because of what she was doing* and made to feel like she *couldn't take time off*. In turn, after having her *surgery for fertility and endometriosis*, she *waited between the surgery in December to do her fertility treatment on March Break* and she believes that *in waiting that time, everything grew back*.

After being *kicked out of the fertility program* Noreen continued working but began finding it very difficult. She was *highly heat sensitive* with a *classroom on the second floor, west side of an un-air-conditioned building*. *If her internal body temperature changed even half a degree centigrade, that was enough for all her symptoms to come out, and she would get totally exhausted*. The *fatigue really got to her* and she had *reached the point of sitting down to teach, which doesn't really work well with eight year olds* and is *not a very good classroom management tool*. She also began struggling with *cognitive fatigue, which means thinking takes three times as much effort*. Noreen and her husband discussed *trying to find a transfer to a building that was air-conditioned, and on one floor to at least give her a fighting chance*, but unfortunately she remained at her current school struggling, wishing she could *quit*.

Finally, around the time Noreen was 46, her *year off came up*, and it could not have come at a better time. Noreen was *exhausted and she ended up having a relapse while off*. She ended up *on the couch for about four or five months with terrible fatigue*. She was *sleeping all the time* and went through *months of sheer exhaustion*. While Noreen was off there was a *posting for a job at a school that had not only air conditioning, but was all primary* which is what she had experience teaching. Normally if she had *applied for a*

position in the middle of the year, you actually moved at that time and in the state she was in, she could not visualize packing up a classroom because it takes months. However, given the fact that she was off it was a lot easier to contemplate taking on a new role. The job was not a classroom job. Instead it was half librarian, half preparation time which meant she went into other people's classrooms in 40 minute chunks, and her subjects were limited. Being in 40 minutes and out she hoped would help with her managing her symptoms because normally when you're in the classroom there are 4000 other things that you are responsible for, and this role could be positive for her. She wouldn't have normally applied for a prep job because that would have meant teaching any grade, and depending on the schedule, she could have been stuck with all new stuff which would not have been beneficial for her at that time. However, she met and was hired by an amazing principal who unfortunately changed schools before Noreen returned from her year off, so they never got to work together. Aside from hiring Noreen, he didn't know her from a hill of beans but did know she was sick. The principal put preparations in place prior to Noreen's arrival so the new principal could support her. Right off the bat she said you cannot do gym with the Kindergarteners because she knew that meant Noreen would have to participate with them and how the heat would affect her. She was four steps ahead of Noreen in that respect, so Noreen thought that she obviously knew somebody with MS to offer support so well. Instead she started teaching science to the Kindergarteners. The new role and school was like her dream job until it got to Christmas. Four months after starting the new position Noreen thought to herself, I can't do this anymore. She realized after the New Year that this job too was getting exhausting.

Early that New Year Noreen started to look into accommodations. She had a meeting with her representative from her union and board who unfortunately was not supportive and despite her job description, Noreen felt like she was not a person who really wanted to organize your gradual return, she wanted you back to work. She informed Noreen that they could do her accommodations for one year, but the nature of the beast was that it's not guaranteed for beyond that because schools, subjects, and classes change, and every year it will be different. The lady's suggestion was for Noreen to do disability half-time instead. Noreen had looked into that while she was still at the old school years ago and struggling so badly. She remembered checking on the computer their pension plan site to

see if it could work financially, but that *wasn't going to happen because it was way early*. Also, at the time she was told *there was no such thing*, but this lady assured her *there was now*. Noreen felt the lady was pushing for disability over accommodations *because she couldn't be bothered, and it would have been too much work to do accommodations*. The lady had even made comments about how Noreen could *only get accommodated for certain things* after *cognitive testing* revealed she *needed longer to work on things*. She provided the example of *report cards*, and how Noreen could not *really get accommodated on that because she would still have to write report cards and they still had to go home* on time. Noreen understood that certainly, given the dynamic nature of teaching year to year that accommodations may be *difficult to come up with or accommodations that are even possible*, however, she also genuinely felt that the lady was *very happy not to even think about them*. Noreen believed other factors played into this push for disability as well. She explained how *if you're on disability they don't need to pay you and how the person who is in for you would likely be a young supply teacher with less experience costing the board less money*. The experience was less than supportive in other ways as well. Noreen felt she *had to keep having meetings to prove she was still incapable* to the woman. At one point, *the insurance company* was inquiring whether she *had any proof or evaluations that said Noreen was not doing her job*, obviously not information Noreen *would willingly share with someone evaluating her*. Noreen talked about how if she was *not able to live up to her own high standards*, she made *sure others were not around when she was having extra difficulty and made sure to work twice as hard*. Things *may have taken her three times as long, but she would get them done*. Noreen felt a lot of the time the woman *had no idea what the job was*.

Starting that May, Noreen applied for *disability half-time* because although she was *coping*, she was still *wiped and exhausted*. Noreen described the process of applying for *disability half time as three years of horror* where you had to *stand on your head, twirl around three times, say the magic words, and then they would turn you down*. During the *approval process* Noreen actively had *people following her*. They followed her, took *pictures*, took *videos*, and collected information about what she did each day. They would actually *park down the side street or around the corner* and were very *obvious* in the beginning so she would know they were there. It got to the point where she *didn't see*

them half the time but was still quite aware of their presence. The application process took a year and a half of fighting then ultimately they turned her down. Noreen had the support of a world renowned neurologist and the claim was still unsuccessful. Through the policies the teachers paid extra for, it provided them access to an appeals expert who works in the same insurance company as the person who turns you down. Since the claim was denied, the appeals person had access to the documents and reports on which the denial was based. She was able to share the comments and the files with Noreen and her husband, and walked them through what she needed to write in her appeals letter to refute their assertions. The information in the case file was overwhelming and some of the phrasing Noreen described sarcastically as absolutely fabulous. Subconsciously, Noreen wondered if the fact that she drove a hard top expensive convertible made the investigators question how this person could want disability when she is not sick. They reported that they didn't see why she couldn't do her job when she was able to drive, go shopping, and have a social life. She talked about having to explain that for her, driving is done sitting down, and the multi-tasking involved in driving, if she happens to forget where she's going and have to take the long way around the block, it's not a safety concern. Where the multi-tasking required in a classroom is very different. Her shopping was not for leisure. It was her dragging herself to the store after being out of something for three or four weeks or for her meds. Shoppers Drug Mart was not a very exciting shopping option for her. She was photographed 'having a social life' while talking to two people in a parking lot who happened to be her mom and sister; socializing about her grandmother who was in the process of dying and how Noreen was only able to visit her once.

Throughout the application process they followed her constantly taking pictures and video. Noreen talked about the difficulty of knowing they were watching her, and challenges associated with the invisible nature of her disability. She described how you don't want to look too healthy, because they are going to assume that you are healthy and tell you that you have to work. So if she was having a little bit of pain or she was tired, she had to make sure it was visible that she had pain or was tired. For example, coming out of the store she would make sure she was not energetic to get home. She walked slowly and in an exhausted way to the car. Noreen shared how with MS your

brain runs everything in your body, so when signals get screwed up, limitations are not always physical or visible. Noreen struggled a lot with problem solving, executive functioning, cognitive fatigue, and breaking down information, all things that are not always obvious. She talked about how people don't see her laying on the bed for 20 minutes after she has a shower, or that if she doesn't use the handicap parking at a particular place, by the time she gets to the front door she's done before she has even gone in. She has heard rude comments about her usage of handicap parking and how it is supposed to be for physical disabilities, because she doesn't look sick. Which has in turn made her try to use it less often even though sometimes she needs to.

Finally they finished the letter, sent it to appeal, and it was approved in two days. Noreen was relieved but the approval created some new issues to deal with. Since the board had been paying Noreen in the meantime, disability had to do back pay for her and she in turn had to pay back the board thousands of dollars. Of course those two numbers were not the same, so she and her husband had to come up with tens of thousands of dollars and write a cheque to her employer. After that nightmare, that year and a half was already gone off of your disability. At the time her plan had a timeframe of three years before they re-evaluate the disability situation, so just getting the approval and appeal taken care of had already put her halfway through the term. She only had a relaxing life for about six months before she had to apply again. When the time came, Noreen said we're not doing this process again. We will put the disability application in, they will deny us and I'm not appealing it, I can't. She and her husband had already decided that if they had to live on half time salary and starve, they didn't care. Her husband was working full time at their business, but losing any part of her income still would have affected them significantly. Disability was making her sicker because of her constant awareness that someone was watching and following her. Even though her first appeal was ultimately successful, she didn't want to be constantly aware of her disability, she wanted to actually live her life. She joked how after making the decision not to appeal the second time she was able to rush out of the house and be in a hurry. How she could then actually do things and it would be her and her body that determined when she had done enough or when she could not do something. Her decisions were no longer made because she was worried about

what someone was going to think incorrectly about her. It was not going to be healthy for her if she had continued down that path.

Noreen started working strictly *half time* without any disability around the time she was 50. She continued to *use the sick days she hadn't used up in waiting for her disability, but she was getting worse by the day.* Thankfully with the planned changes to the sick day policy unclear, their plan to build *short term disability into sick days* and only pay 60 percent of regular wage was never implemented by the board. This *worked in* Noreen's benefit because that meant she could remain employed and use her remaining *sick days* at a pay rate of *90 percent of her regular salary.* Financially, the confusion surrounding the implementation of a lower percentage sick day policy *worked out for* Noreen in helping to extend her work tenure and avoid having to apply for full disability. She explained how after all, *you still need your money. Walking up and down the halls* was getting more difficult *and she was adding to her accommodation list* all the time. She was very fortunate that she *had another fabulous, fabulous principal* due to school changes. Her last excellent principal had *let him know her issues* and that he *may have to do a lot of scheduling around* for her. He knew she could not *do temperature changes* and no *outside yard duty.* Noreen let him know she could do *social studies and science and all the things* she was used to doing, but she *certainly* could not *teach anything new because dissecting information from a big government document down to a teaching unit and then breaking that into lessons* was beyond what she was capable of anymore. She explained how principals have *discretionary time* to fill voids in timing and *he was really trying to* give Noreen *as many minutes as he had available* while meeting her needs. *The following year* their plan was to *work with the chunks so that she wasn't teaching three or four hours in a day.* Instead she would *do a chunk and then have some time off, so she had time to sit.* Technically she was *still working, but* she was able to have *more independent time because she had different responsibilities.* She would go *from classroom to desk, from classroom to desk to do different things.* That *worked really well* for a while, but *it was still quite difficult.* Everything was extra difficult because Noreen was *exhausted.* *There were so many things she wanted to do and occasionally she could do things or get creative ideas (because she is a very creative person and the reason why teaching is her dream job), but she didn't have the energy.* Her *halftime* was always in the afternoon so

she would *get up at 11:00, be in the car by 11:30, and still be late*. In the back of her mind she was also *consciously thinking that anything she didn't do, somebody else had to pick up*. Noreen had a hard time thinking that *somebody else* was having to do *more because she was doing less and couldn't get rid of that guilt*. She doesn't think her staff *thought bad of her for it, but she was conscious of it, and felt bad about it*. Noreen would think to herself, *please let me quit early, please let me quit early*. She would even *put the numbers in the benefit calculator and every year you go early it's a bigger percentage they dock you in your pension plan. It really is exponential the sooner you go*. Her *husband wasn't really happy* when that option presented itself.

Looking back now, Noreen doesn't think *he realized how bad it was for her because he's not a teacher*, and a lot of people have misconceptions about teaching just *because they went to school*. Noreen was really struggling with the *multi-tasking and processing was tricky because she was no longer able to take things in quick enough*. *Executive functioning* became a huge issue *which was why she couldn't break down tasks or information, and why she couldn't multi-task*. *Short-term memory, oral comprehension, and all of those things made up significant parts of her job*. *Those tasks were continually getting more difficult*, but they were not happening in an environment where her *husband would ever see*, so there was some hesitation from him when she discussed needing to leave work. Noreen believes her husband had a *lack of awareness of what her job entailed*. He didn't have any idea *how much multi-tasking was involved, and how being physically drained and cognitively fatigued in addition to having deficits was the reality she was facing daily*. She doesn't *blame him for not knowing* and believes *there were just an awful lot of facets being affected that he would not have seen*.

Everything that was happening started to make Noreen *feel really stupid* and *she thought there was no way she could get any stupider*. She was always the person who had *the brains*. She didn't *play sports, she wasn't the popular girl*, so it was devastating that the MS was taking her *brains away from her*. *In the meantime, while Noreen was in her early 50s, negotiations for benefit contracts with the province were going on for teachers. They encourage teachers to start going to information sessions five or six years ahead of time so with her need and hope to retire early, Noreen had been to them to learn about the*

different benefits options once you're retired. At the time, Noreen's drugs were costing \$4000 a month, the 85% majority covered by her benefits, and the new gold plan being offered to retired teachers only had an annual limit of \$2000. That amount would only get Noreen through the first two weeks of January. The new benefit plans being offered in retirement weren't good. She knew insurance companies didn't want old people because they have a lot of drugs, but they really don't want sick people. Luckily, Noreen's board had the option where a retiree could stay with their pre-retirement plan through your board and just pay 100% of the premiums. So for Noreen the premiums would be basically \$1000 a month, a hefty amount but clearly still worth it and the best option for her needs. They were getting organized to implement these changes and why this was important was because they had a timeline. They were doing negotiations over 2015/2016 were planning to roll in a small group at a time, so once your board was in that roll over then you were a part of the new program. It became clear that Noreen had to retire then, prior to her board's roll over or she would have no benefits, and she needed benefits. These changes were part of what pushed the timing of her retirement. Noreen was losing her capability to teach, and she needed to retire but the timeline of those changes was what helped her convince her husband that she needed to leave and that she had to be gone before they implemented those new plans.

Noreen signed the paperwork and formally retired in December 2016 mainly because the government messed with her benefits. Once she did, she was out of there. Knowing that she felt so incompetent, she wanted out and it was not difficult for her. She talked about how some people get out and miss it so much, but she was past that point because of being sick. Noreen explained how she wasn't retiring from a job that she loved, she was retiring from a job she wanted to love and did, but she could no longer do it to the best of her ability, so she felt different. It wasn't as hard for Noreen to adjust to retirement as it is for others. She was not dreading quitting because she needed to quit. In fact, there were so many times she wanted to quit years before she was able to.

In retirement, Noreen sleeps a lot and needs a lot of sleep. It took her about a year and a half to just get into a groove, and learn what she could and could not do. She explained how even in retirement you're still sick, so you deal with it and learn you can't do

everything you want which is the frustrating part. Noreen arranges and plans her schedule very carefully and tries not to be out of the house every single day, because it's very easy to do too much and she will pay. She can basically do anything she wants, just not when she wants.

Noreen is able to *work around her* physical fatigue more easily now because she has the *flexibility to start and stop* tasks if she realizes they are not *a good idea* for her. However, she *still* finds it *frustrating* that her abilities are not *consistent*. Noreen believes she has *definitely got rid of the incompetency thing* and she doesn't feel *the cognitive stuff* is *affecting* her as significantly *day to day, because she's not doing too many things at once*. She described how in retirement she doesn't always *notice many of her limitations because she's not up against objective things*. She doesn't *have to be at her job at a certain time or have things done at a certain time. There are a lot fewer times where her life is working against an objective point, time or task now.*

Noreen is still able to do things that are meaningful to her. She and her husband love to *travel* and have selected *vacations* with her *disease and limitations* in mind. They *go on cruise ships that are meant for old people* where *the excursions have accessibility descriptions* that help them *choose carefully* what they do so it does not *wreck her vacation*. She and her husband still enjoy going out *quite a bit* for *dinner* and the theatre, and *as long as they don't do two things in the same weekend* Noreen will have *recovery time* that she would not have had while working. Noreen continues to see her long time *counsellor about every month and a half to check in and have a chat* although it is no longer covered through her *Employee Assistance Program*, a benefit she lost upon retirement. She helps Noreen with *coping strategies* and *checks to see how her MS is doing*.

In terms of the future, Noreen does have some concerns. She worries about *when her husband gets frustrated with her*. For example, he will say *oh, that bush just looks bad it needs to be cut and you're not going to go do it [IN A SNARKY VOICE]*. She worries what will happen to that *frustration because she is only going to get worse over time, and*

doesn't want to see herself *in a position where she could not defend herself verbally against crap like that.*

Physically, Noreen admits she has some denial about her MS. She often jokes how she's *not going to have 'that' MS* and how *there's the one she has, and the one everybody else has.* She attributes some of that denial to her tendency to *deal with problems when they are a problem, and the MS is not a major problem right now.* Sometimes she has a *reality check* that brings concerns about the future to the surface. *When they went to the neurologist recently they told her that her recent clumsiness was related to new lesions, and the best medication so far had stopped working.* That was disappointing for her and she talked about how *that kind of thing kind of makes you go, oh wow* and think a little about what may come.

Financially, since retiring with *benefits* and being *responsible for 100% of the premiums,* Noreen now *pays \$1000 a month and takes a dock in her pension pay because she went early.* She didn't retire *a lot early, only a year and a half, but it's enough that they still take a chunk* from her. Noreen talked about how she doesn't *bring in a lot of money anymore,* and how *unless you're married to some guy that has a really good job, you're screwed basically.* Reflecting back on some of the financial challenges they have had to deal with pre and post retirement, she does not *know what some single people do* in similar situations. For example, *coming up with chunks of cash quickly* to repay the board, and making the decision *not to bother with the disability process a second time and just live on half time pay.* Those are good options to have *but when it came down to it, they didn't really want to have to suck it up* and be without that income. Noreen feels fortunate they had *that option as part of their conversations.* *If you're by yourself, you don't always have that option.* That may not be an option for people *if they are used to making a professional wage with bills to pay and housing based on the wage they made.* *Unless people have very supportive families with a large bank account, it is not an easy situation.*

After Noreen's experience with the insurance company she will not consider applying for any other forms of disability supports. She feels it's a pittance amount, she currently still

has her *benefits*, she has *somebody else bringing money in*, and her past *experience* with disability insurance made her feel *sicker* having to prove to *people* that she was *worth it* and *not cured*. Noreen was very clear that she would *rather just have her good days and enjoy them*.

In terms of medication, as Noreen *was part of a study*, the drug company still gives her the *pills* that she takes for *cognitive fatigue*. They cost about *\$600 bucks a month* and *they give them to her for free* because the study wasn't big enough and *didn't get approval to use it for cognitive fatigue*. However, the *actual modifying drug* she takes for her MS she gets directly from the *company's pharmacy* because pharmacies like *Shopper's Drug Mart* do not let you run a tab, especially when it's *\$2500*. They also *deliver to her door* which saves her a trip and call every *three weeks* to arrange payments and *delivery*. The drug company provides a helpful method for getting medication because they will wait to charge Noreen's *credit card* until she has got *her money back* from the insurance company, *which would be a lot of money* to put out otherwise.

In summary, *retirement lets* Noreen have the *routines* she needs and *leeway* to make decisions that benefit her well-being. *Retirement is fabulous* and her life is now *just so much more relaxed* with *flexibility to work around* what she needs to do. *There are very few things* that she is *required to do* where she is *powerless* to outside demands. Noreen continues to try to *know things ahead* and *plan as best as she can*. There are times when she still has to *deal with things* she doesn't have control over, *but for the majority of her life*, *retirement gives her flexibility* which *helps her deal with her MS proactively*. Financially, things are *stable* for her family, but she is becoming more open to the potential of exploring some other financial options to help offset growing costs. Noreen does not *think she actually dealt with either one*, the MS and the *fertility issues*, *as fully as she should have*, and feels like she *didn't have time to do both at the same time*. She is still dealing with her feelings of loss and *frustration* in *retirement* related to both the fertility and the MS. Noreen *still cannot go to A & W* because *they have Mama and Papa burgers*, despite the fact that they raise money for MS. She sends her husband instead but continually works towards *letting go* of those difficult feelings. Her frustration with the MS comes from trying to find balance in wanting to do more while recognizing her

limitations. She has to be realistic about what she is feasibly able to do without continually putting it all off for another better day that may never come. It *is a tricky balance*. Noreen has *hobbies but has not done any of them yet*, and uses the visits with her *counsellor* to help her cope and work through her feelings. She often has to remind herself to *stop feeling* bad about the things she *didn't* get done in the day and to focus on having *a nice life*. For the most part Noreen *is a lady of leisure to the enth degree* and enjoys her life with her dogs and her husband. She tries not to worry about the future and manages her *limitations* while continuing to do the things that bring her joy.

5.5 Carissa's Story

Carissa began her story by telling me that she had *been a nurse for 30 years*. Although it *wasn't* her *choice to retire* two years ago, she has *accepted it*, and now knows that leaving work *was in her best interest* in order to have *any kind of retirement*. Throughout her story, Carissa spoke a lot about not wanting to *draw attention to herself, be a baby, or play that card*, referring to her MS. Throughout the years she *put up with* limitations, and *struggled through* to continue *pulling* her *weight* at work. Her goal was to always appear *normal*, so she drew on her own resources to prolong working, and did not seek accommodation given the negative culture in her workplace towards illness. Ultimately, Carissa had to retire at the age of 52 because she *was exhausted* and *felt terrible* all the time. Despite dealing with some family issues related to her spouse's alcoholism, Carissa has been enjoying retirement. She didn't really *have a picture* for what she thought *retirement* would be, but *so far she is liking what she has*. She has a *lovely home* with her dogs, she can still do the things that are meaningful to her, and as long as she can *walk and wipe her own bum, that's quality of life* for her. She continues to learn about her body and managing her MS to live the best life she can. Financially, she has some changes taking places recently that have produced some stress, but ultimately she *will always eat and have a place to live*, so she tries not to *sweat the small stuff*. When she was diagnosed with RRMS, Carissa made the conscious choice not to *wallow* in what may happen in the *future*. Throughout her story she presented herself as realistic about what may happen *down the road*, but chooses to focus on her life *right now*.

Carissa was born in the early-1960s and grew up in Ontario. She lives with her *common-law* spouse and *two dogs*. Her *mother* and *sister* also live relatively close by and she has a close relationship with both of them. Carissa graduated from the nursing program at Mohawk College in the mid-1980s and worked as a nurse for 30 years until she retired in June 2016.

After graduating, Carissa spent four years nursing *in ortho* before moving over to *ICU* in the early-1990s. Also in the early-1990s, Carissa developed *neuritis* in her eyes *a couple times*. After the *second time*, she *ended up going to an optometrist who also happened to be a good friend*. He suggested that she see an *ophthalmologist*, but the neuritis went away so she *ignored it for another year*. During a visit to the family doctor, Carissa explained the situation about the neuritis, and the family doctor *made an appointment* for her to see the *ophthalmologist*. Upon seeing the *ophthalmologist*, he suggested that Carissa see a *neurologist*, because *neuritis can be an indication of MS* even though she had not *had any other symptoms*. *Hesitant to investigate further, again*, Carissa *let that go*. In the meantime, Carissa married her first husband in the mid-1990s. Finally *feeling ready*, and knowing she *better go do what they told her to*, at her next doctor's appointment she asked for the referral. Through working at the hospital, Carissa was able to investigate *who was the best neurologist and who she should see regarding the situation*, and was able to provide her family doctor with this information for the referral. It *took about six months to be able to see the neurologist*, and *within five minutes, he told Carissa she had MS*. She had *classic symptoms of MS* including the *neuritis*, and the *electrical impulse down her back into her groin* when she would put her *chin to her chest*. An *MRI* was scheduled to serve as *definite confirmation*. Only being in her *early 30's* at the time she received her diagnosis, Carissa described it as *a shock*. She struggled to *believe she had it, but at the same time believed the doctor because he knew what he was talking about*. The diagnosis was especially difficult to reconcile for her, because *she was feeling fine at the time*. On a number of occasions Carissa described herself as *very much a person who believes there is no point in worrying about something until there is something to worry about*. She felt she was realistic about the fact that she *had MS, but it wasn't bothering her at the time, so there wasn't anything to worry about*, and she would *worry when it started to get worse or became a problem*.

Her family on the other hand, struggled immensely with the diagnosis, and her parents *were more upset* than she was. At the time of her diagnosis in the late-1990s, *the social worker* had given her *papers regarding all the stuff and research, should she choose to look into the disease and what it entailed*. At the time, Carissa *didn't want any part of it*. She felt that *there was no point in knowing too much*, but her *parents on the other hand*, wanted to *know more*. They attended *information sessions offered at the local university where they saw a lot of disabled people in wheelchairs and walkers with real bad problems*. They were *quite upset about it*. Carissa tried to explain to them that her decision not to attend the *information sessions* was because those images were not her *right now*. *Whether it could be her in the future* was a different story, but for now, she consciously made the decision not to *wallow in the information*, and felt that they shouldn't either.

Moving forward, Carissa continued on *with her normal, knowing in the back of her head* that she had *this* chronic illness. Around the time Carissa was 36, her first husband *had an affair and left*, ending their marriage. At the time of her diagnosis he hadn't been *overly worried*, and she really hadn't leaned on him to be *supportive*, because *there was really no need to be*. She had been living without any symptoms, complications or relapses from the MS for years, but the affair still happened. When she asked him if it was *because she had MS*, *he said yes*, but Carissa felt that *he probably would have had the affair regardless*. The MS was obviously something that *bothered him* even though *he didn't ever express that*. On that other hand, when Carissa told the doctor about her marriage breakdown, *the DR wasn't really surprised, because there is a large percentage of spouses who will leave after a diagnosis*.

Carissa began working full time as a nurse immediately after leaving college. Throughout her nursing career, she worked full time until she moved to the country with her first husband prior to her diagnosis. After moving, working part time made sense with the hour drive to and from work, and this decision was reinforced after her MS diagnosis. For a number of years after she continued working without *having any further trouble* health wise. Given her first *husband had left*, Carissa was aware that it *would have been beneficial for her to work full time, but in now knowing she had MS, realized it was*

probably in her best interest to stay part time. Around the time her divorce was finalized in her mid-late 30s, Carissa began a relationship with a man she met working at the hospital. They eventually moved in together and have been in a *common-law* relationship ever since.

Just before Christmas in her late-30s, Carissa was in the process of transitioning out of her current role in *critical care*, to a new position in *dialysis* where she was due to begin *orientation in January*. One morning, Carissa had *gotten up to have her morning coffee, and noticed the right side of her body had gone numb*. Her first *thought* was that she had *had a stroke*, and she became *short of breath and worked up* rather quickly. However, after taking some time to calm herself, she *thought, oh yeah, this isn't a stroke, this must be the MS*. She *had never had any kind of MS related exacerbations* before, so a *stroke* was the first logical place her mind went. When she *realized* it in fact was an *MS attack*, *there was a little bit of fear, but there were a lot of questions about what to do next*. Since her MS had been relatively stable in the *years* since her diagnosis, she had never been back to the MS clinic, and she *had no idea what you were supposed to do when a relapse happens*. First, she *called work* and let them know *that she wouldn't be in, and then she called the MS clinic to see what you do about this sort of thing*. Unfortunately, Carissa was not able to get into the clinic for quite some time which was very *frustrating* for her, and left her wishing she could have got *in to see anybody more quickly*. When she was finally able to get an appointment, *they didn't treat her, because they categorized the relapse as not serious* given that it was only *half of her upper torso, right arm, and chest*. Their instructions were to *go home, rest, and if it gets worse, call and we will decide what to do*. Carissa felt lost, *confused*, and without any tangible, *helpful* information. She knew in general that *everyone's MS is different*, and due to that fact, it was difficult for them to *really tell her how she was going to feel, what would work, or what could happen*. However, that was very difficult for Carissa come to terms with, and she found herself struggling to be okay with the limitations of the information.

Knowing it was in her best interest to stay off work, Carissa made the difficult decision to call to her new *nurse manager* and explain that the reason she would *not be coming for orientation* was because she was having an *exacerbation of her MS*. Upon hearing the

news, the new *nurse manager* replied *well, you can sit in a classroom, can't you?* To which Carissa replied, *well, yeah, but I can't really write right now.* Certainly not the response Carissa was anticipating, but at the same time, she *didn't want to argue about it* because she was starting a new job and already feeling stress over the logistics of that. She described how at the time, she really *didn't know any better*, and without clear instructions from the doctor telling her *what* she should or shouldn't *do*, she felt the only choice was to go to orientation. *Sitting in a classroom* didn't *sound stressful* or difficult to Carissa, so she said yes. Despite knowing it was not the right decision, Carissa started her *orientation five mornings a week from 7:00 am until 3:00 pm with an hour drive each way.* Carissa talked about the incredible pressure she felt to continue with the orientation and not let the nurse manager down. *This was what she signed up for, and to all of a sudden say no, I can't do it, puts them in a bad situation,* she felt. Carissa rationalized the decision to continue orientation and the inappropriate comments made by her nurse manager as a *case of live and learn*, and a *learning process* for both.

During the orientation, there were a number of times Carissa expressed to her bosses that she needed to *have a day off*, which *they gave to her.* She would use those days *just to be home and sleep, only to go back the next day.* She used *little* strategies like that when she felt she just *couldn't get up* the next day. Eventually the *stress* and *fatigue* caught up with Carissa, and the *numbness* started *going down her leg.* She ended up having to return to the MS clinic because she *couldn't drive* or use her leg very well. Again, their *advice* was *to stay at home, get your sleep, eat well, and exercise.* They discussed possible *trials* available to help manage her symptoms, however, *at that point, she had already been diagnosed for quite some time, and her impression was that they seemed to only be interested in newer diagnosed people for their trials.* Despite her worsening symptoms and exhausting fatigue, Carissa continued to attend orientation. It got to the point where her spouse actually *had to drive her to and from orientation at that time because she couldn't drive.*

Carissa described herself as *not being a quitter.* She had *started the orientation and she was determined to finish it.* She kept *hanging onto* the fact that *once she got through it, she could go back to normal shifts and have some days off to recuperate.* She struggled

with knowing that had she *dropped out of orientation*, she *probably would have gotten better faster*, but how lack of adequate information made dealing with her relapse more challenging. Carissa discussed how when she first visited the MS clinic they told her to *rest*, but she found that *very vague*. She felt she could have understood better *had they said listen to your body, do what it tells you, you're going to need to sleep, and do it when you feel the need. Don't fight it*. Framing what was happening to her in that way *would have made a little more sense* to her, *because she really had no idea how tired she would be, or how little things would exhaust her*. She also wished that the doctors had *been a little more forthcoming* and clear about the fact that she *needed to be off work*, and there was no other option if she wanted to get better. She reflected on her worry at the time for how if she *didn't know* or wasn't understanding as *a nurse*, then how would *these poor people, who have no medical background, navigate themselves through this stuff*.

Carissa stressed repeatedly that *if she had to do it again*, she *wouldn't have done the orientation*. At the time *it just made sense to get through orientation, so life could get back to what she thought would be normal*. Carissa *got through orientation and things got much better once she started back to her regular, because she had days off where she could recoup*. However, *it took about a year in total to recover from the relapse*. *Mostly everything function wise came back, but Carissa still had some residual issues with her hands*. For a number of years after that first relapse, Carissa *worked normally* with only *little things* in between. Carissa became more aware of *classic MS sort of stuff* that was taking place in her body, but still at certain times she attributed issues to *just being tired and getting old*; she didn't always make the connection *with the MS*. *Fatigue* became more of a *problem if she worked too much or did too much in a row*. She struggled with her hands and *did a lot of dropping of things*. One year in particular she *had three or four UTI's, an infection in her ear, and one in her foot*. It was only *after*, she learned how *with MS you are quite susceptible to infections*. She also seemed to get *way more colds*. Her *limbs* didn't always *work when she wanted them to work*, which would occasionally result in episodes of *tripping or falling*, although not on *any consistent basis*. *Mornings* became *a little slower, because she had and still has uncontrolled spasms, particularly in her right leg when she first gets up*. Although the *limitations* were gradual and not always

present, Carissa became more aware that *routine was really important* and how if she wasn't conscious of her *routine, everything would become difficult*. However, for the most part, *life generally was pretty good* for Carissa, and she *didn't hesitate to call in and take days off if things just became too much*.

Carissa talked a lot about the continuous learning that took place in her life in the years after her first relapse. Not only did she learn how important having a solid *routine* was, but the importance of saying *no*. For example, limiting the *parties* or gatherings she would host for holidays, because she felt bad *if she did a lot of them*. She learned to *slow down, try to avoid stressful situations, and pick and choose what's important in life*. The big lessons for her were knowing her *limitations*, developing an awareness of her body and what it needs, and having to *adjust things in your life* to make yourself feel good. Carissa explained that *until you deal with all the things that happen when you have MS, you don't know what you can and can't do, and it is a learning process*.

One of her attempts to help solidify a routine was to switch to permanent 3-11 afternoon shifts when she was in her late 40s. Her *purpose* in having a *regular shift* was *to develop a routine to feel the best she could*. At the time, Carissa found *mornings* were *difficult to get up, get going, and be to work for 7:00 am*, given that she also had *an hour drive* to work. She explained how it wasn't that she *couldn't have done the 7-3 shift, but it was the shift everyone wanted, so it was more difficult to get*. For both of those reasons she made the *switch to permanent 3-11* afternoons, *so she didn't upset everybody. They didn't want to work that afternoon shift anyway*. She also asked to be *accommodated to only work eight hour shifts*, instead of *twelve*. She requested these changes because otherwise she would be required to *switch between eight and twelve hour, morning and afternoon shifts*. Carissa *couldn't handle those switches anymore, because it wasn't conducive to a routine, and it would mess her up every time*.

For a while the shift *switch* was *working fine, but* Carissa started to find *driving home at 11:00* challenging. She *would try to get a sleep in before she went to work, but it didn't matter how much sleep she got, she was still exhausted by 11:00, and the drive home was becoming more and more difficult*. When she first made the switch, they used to be able

to leave at 10:00 pm, which was not exactly legal. They were allowed to take their last break late in order to go home early at 10:30 pm, but often times, all the patients would be gone by then, and so she could actually get out at 10:00 pm. It wasn't until around two years later when the hammer came down, and policy changed to mandate no break at the end, and staff had to stay right till 11:00. They took that option away, and staff basically had to sit around for the last hour of work doing nothing. That hour really changed things for Carissa, and it wore on her over time. It got to the point that she just couldn't get enough sleep for work, and she continued to go downhill. She was really noticing it difficult to get home at midnight, get up in decent time, have another sleep and get back to work the next day. Inside she just couldn't do it anymore, but she never went to work and said, I need to get out at 9:30 or 10:00 because she felt bad. She explained how part of your job is staying there until 11:00 with everybody else, so that's what you do. Carissa never asked to be accommodated further and was unsure whether they would have accommodated her or not.

Another aspect of the job that made maintaining her routine challenging was call. Between 11:00 pm and 7:00 am there is nobody that does dialysis at the hospital, so if someone comes in through emerge or one of their patients in the hospital needs dialysis, the person on call gets called in to do it. Normally the rotation would be once a month, but Carissa described how that was not turning into twice a month for various reasons. There were some people who couldn't do call so now people were having to pick up more on call shifts. The hospital started utilizing RPN's that couldn't do call, so the people already doing call now had to do even more call. If Carissa was on call and got called in at 3:00 am she would be really messed up for about a week. In fact, she ended up having to call in sick once or twice after she had been on call because she couldn't get herself situated. Again, Carissa knew it wasn't good for her, but never said she couldn't do it. Carissa continued to do call up until she stopped working, which made her feel like she did her part.

As time went on, Carissa started to find that she was tired all the time, and she was starting to lose patience, because things weren't working how she thought they should. Fatigue and having her hands not working normal were some of the biggest challenges

for her. It became especially *frustrating and tiresome* to do things *when your body doesn't do what you want it to do at that time* she explained. She *just put up with it, struggled through, and continued to take days off when she could*. Carissa spoke a lot in the meetings about not wanting to *be a baby and whine, so she continued to go to work even as things got worse and worse*. She described herself on a number of occasions as *not the kind of person who needs or wants sympathy, or special treatment*, and explained how the culture of asking for accommodation *causes ripple effects, and is frowned upon* in her workplace. For example, how leaving the *hour early* on the night shift *sounds a little whiney just over an hour*, and there was nothing to *stop everyone else from saying, she can leave early so why can't I?* She described how at her job there were *lots of people that went off sick or weren't able to lift jugs, because of their back. Sure, people talk about them, that's kind of just how it goes*. She described how *it's just part of the profession or something. Nurses aren't always compassionate towards their coworkers because what you can't do, they have to pick up the slack, and not everybody is willing to do that I guess you could say*. However, in Carissa's case, it was getting to the point where she was struggling greatly *trying to do what was required of her, while not bringing attention to herself as the sick guy at work who can't lift a jug, can't stay there till 11, or can't be on call*. She talked about *how she always wanted to look normal. How if she was there, she could do the job. She didn't want to be that person who couldn't do call anymore because of the MS, or couldn't stay till 11 because of the MS*.

In *the last year* before she left work, *more and more things weren't working, and it was an effort to do everything. Slowly over time she was dragging and dragging, trying to get more sleep, but finding it difficult not getting to bed until 1:00 am*. She was struggling to *get the amount of sleep she needed, but didn't know it at the time*. She continued working and just felt *worse and worse*. Carissa went into work one day and her *charge nurse said, you just look exhausted, and she was*. The *charge nurse* said to her, *I think you should go home, and Carissa didn't argue because she knew she was right*. Carissa went home and *slept for two weeks*. She would even *have a two hour nap everyday just to catch up and feel better*. Carissa talked about how before she left work she *felt horrible*, but explained how *if you start feeling horrible over a period of time, you don't realize how bad you feel until you feel good again*. It was a *big snowball effect* where she didn't even realize it

was happening until *the charge nurse* mentioned it to her. *It was at that time she realized that continuing to work was just too much, and if she wanted to have any kind of retirement she would need to stay off and look after herself.* Ultimately, that was the last shift Carissa worked. She did not return to work after that day.

Similar to when she had her first relapse, Carissa had not been to the MS clinic in a very long time. It had been *13 years* since her last visit and upon calling the clinic they informed her she would need to *get a neurologist*. Unfortunately, they also told her that she wouldn't be able to *see a neurologist* at that time because they would only be *accepting new patients in January or February*, and this was in *June 2016*. Shocked, Carissa informed the clinic staff that she was *not a new patient*, that she already had a *diagnosis*, and that she *just didn't have a doctor* anymore. Her pleas *didn't get her anywhere*, and worries about navigating this process caused a lot of unnecessary stress for Carissa. Not only was she dealing with her symptoms, but she also needed to know what to *tell work* and for some sort of *confirmation of what she was supposed to do* next. Carissa had always *thought that once she had been to the MS clinic, they were always there* for her. She *had no idea her doctor had left*, she was unaware you had to be seen every so often or you *had to get a new referral*, and there was no correspondence with her over the years. Carissa decided to take it upon herself to make something happen. *It was just her luck that she worked at the hospital with access to the company directory, and knew the name of a neurologist to contact directly.* Since the clinic was providing no immediate assistance, Carissa drew on her own resources and *took it upon herself through her job connections to contact the neurologist through email*. Thankfully, he was *lovely and got right back to her*. Unfortunately, he was *busy* and unable to see her. Although she *did need to see somebody*, since her case didn't *sound like an emergency*, he *referred her to his colleague*, and Carissa was able to be seen *within three months*. *At that point, the neurologist thought it was in Carissa's best interest to stay off work, and look after herself in order to get better. At that time they did another MRI that showed progression in Carissa's lesions, and they amended her diagnosis to a progressive form of the disease from the relapsing-remitting type.* This new information solidified in Carissa's *mind that there was no point going back to work and getting herself into the*

state that she was in before she went off, because inevitably that was what would happen again.

Despite clear instructions from the doctor and her new diagnosis information, it was still *a hard decision* on Carissa's part to leave work permanently. She *talked to a lot of* colleagues, friends and family *in terms of what the right thing to do was*. Carissa was afraid of *making the wrong decision*, and all kinds of things were going through her head at the time. She questioned whether she needed *to go to work and continue to make money to know she would be OK* financially, or whether she should *go off and feel better, and worry about the money later*. She didn't want to *go back to work and feel like she couldn't pull her weight, or do some of the things her job required*, things she knew she couldn't do anymore. Now realizing *how terrible she felt* before leaving, she struggled to *see a way to go back and do her job while continuing to feel good*. Carissa also wavered in her confidence about leaving work by worrying that others may be upset she got to leave work early. She explained that she *was only 52 and she was going to stop going to work, who gets to do that? If you're sick enough you get to* she added. She knew that ultimately leaving work *wasn't her choice*, but she held on to the mentality that there would be *other things* if she *couldn't work anymore*. Carissa shared that she always *worked to live, she didn't live to go to work*. Some people live to go to work every day, but she was *never that person*. She *enjoyed her job, loved her job*, and thought she was *pretty good at her job, but she was starting to not be able to be very good at her job* anymore, and she was not *OK with that*.

Carissa came to the decision that *the right thing for her was to be off, get into a routine, and get well. Being healthy and feeling good was more important to her than being able to go out shopping*. She could *learn to live with less*, and felt comfort in knowing that she would *always eat, and have a place to live*. Ultimately it came down to the fact that *retiring at the age of 52 may not have been part of Carissa's plan, but in her profession, if you don't have your health, you don't have anything*. She really didn't *have any other choice but to do what was right for her*, and that helped her feel *good about the decision*. Carissa felt very strongly that *if you can't do the job, you can't do the job, and it came to the point where she couldn't do the job, so she had to go off*. It was *a hard decision to*

make, but once she made it, and came to terms with it, she knew it was the right thing to do. Apart from that, she tries not to worry about leaving work too much, and she's accepted the fact that this is what she has, and this is what is going to happen in her life. The choice was right for her, and it's worked out good. Carissa was able to prolong and work as long as she could.

Carissa has been retired since June 2016. *She feel's great in retirement and she has accepted the situation. She works hard to keep a regular routine, and spoke about how she is feeling wonderful for a person with MS. She recognizes that she will probably never be 100% like a normal person, but she is happy with the fact that she can still walk, and do the things she likes to do. She lives her life at a slower pace now, and frequently needs to stop and rest throughout the day. She is still able to cook her own food, and still go to the bathroom by herself, which is of the utmost importance to her. In the time she has been retired, she has learned to live with less, and is conscious of the fact that she is not making money anymore to spend all the time. Ultimately, Carissa is good with living a simple life. She has a very lovely place to live with just a short walk on the beach, which is good for exercise, and good for her head. She doesn't require a lot to make herself happy.*

Despite accepting the situation and being happy to be retired, Carissa still misses *the social aspect* of work and her *patients*. She shared about how *it was always nice to have good outcomes for your patients, and for them to know that you were there to help them.* However, she also realizes now that there were times when her *patients were in better health than* she was, and when they would be *ordering her around, it could rub her the wrong way, because they didn't know she was a little slower because of the MS.* Carissa would never have shared something personal about herself with the *patients*, but again, it reiterated to her that she wasn't *doing her job the way she used to do it, and she did not want to do a job halfway.*

Carissa spoke about how it can be difficult for her to *feel retired, because she is technically off on disability. Initially* the doctor recommended she be off *for a year to see how things went, and when the year was over in late 2017, Carissa returned to the*

neurologist for re-evaluation. At that time, Carissa *could tell that things were progressing and happening more frequently*. Both Carissa and the doctor *agreed that doing the right things were making her feel really good*, and again, *it was in her best interest to continue that way*. Officially, they are still working on a yearly basis Carissa believes, but *bottom line*, they both agree that Carissa is *not going to get better*. The *reality is that she will continue to get worse at whatever pace that may be*, and hopefully *the slower the better*. Ultimately, *a decision has been made that Carissa will not going to be returning to work although she hesitates to say that out loud, because it seems so permanent*.

There has been quite a lot of stress involved in navigating the disability versus retirement dynamics for Carissa. She knows *that she will not be going back, and that it would be silly to go back*, but really struggles with the finality of it. She believes it is partly due to the fact that she is afraid if she says she is retired, *they are going to stop her disability*. Her disability income is from an optional disability insurance policy that Carissa purchased and paid into back when she began nursing on a part time basis. It is the same disability insurance full time nursing individuals are automatically enrolled in through payroll deductions, but as a part time employee, you have the option to buy. She purchased the insurance *before she even knew she had MS*. Her stress comes from wondering *how long they will continue to pay her disability benefits*, or whether they will force her to *retire at 55*. Carissa has a lot of fear surrounding the situation and doesn't even feel comfortable *to call and inquire*, because she doesn't want to *push them* towards that fact that she could potentially retire at 55 and draw from her nursing pension any earlier than necessary. Her plan is to *wait until she's 55, and see what they do*, with the hope that if they continue to believe she has the potential of *going back to work, they will continue to pay her disability*. She is afraid that if her departure from the workforce is *finalized*, and they learn she will *never return to work, they will look into everything and go OK, you're retired at 55*. Another layer in this difficult situation is that Carissa recently started receiving a fair amount of paperwork and *online learning plan* notices related to renewing *her nursing license*. Having to use the *computer* and navigating all the *paperwork* really *stresses Carissa out*, especially since she is contemplating whether it is worth it to *go through all these hurdles to keep her license if she is not going back*. Carissa also has questions about what letting her license lapse means for her disability,

and *if* she doesn't *keep* her *license*, is she then *not a nurse*, and *could* they *take* her disability away then? Procedurally there are a lot of questions that need to be answered, but Carissa's fear over having the disability income taken away hinders her from being able to have them answered. So unfortunately, for the time being, she continues to live in the uncertainty of what her future holds financially.

Further complicating the situation for Carissa, in the short time between our two meetings, she received even more *paperwork from everybody*. This paperwork included documents for her *pension*, and a *life insurance policy*, both of which the disability benefits have *been covering* while she is off work. They recently informed her *that they are changing the definition* of her *disability from the fact that she can't go back and be a nurse or do her previous job*, and instead *they are looking into whether she capable of going back and doing, or being gainfully employed at any job*. So for the last month, Carissa and the *neurologist* have been looking to see if *there is a job she could go to*, however, neither believe she could *make the money she did prior to being off* at any job that wouldn't force Carissa to be *out and about*, wearing herself *down on a regular basis*. When we last spoke she was just *waiting to hear* their decision, *but* in her mind she had already *decided that if they say she has to find a job, at 55 she will formally retire and take her pension*. She described how she feels *sort of at their mercy*.

Reflecting back on the uncertainty and procedural stress of this time in her retirement, Carissa attributes a lot of it to the difficulty to *coming up with* answers to *the questions* they ask in the *paperwork*. Often times the questions *are vague*, and don't get at the essence of *what life is really like for her* on a daily basis. She gave the example of how one questionnaire asked if she was capable of doing *activities of daily living*. *Of course* she is able to, *but to them that means she is capable, and can go back to work*. She went on to explain how they don't *ask about how much sleep you require, or what exhausts you, or how long does it take you to do a particular task*. *So answering those questions, and completing the paperwork is sometimes very difficult to make them understand what the reality is of trying to do those things*. Specific to her job, it *doesn't mean she can go to work and do someone's buttons up, lift them out of bed, or keep her balance when she's in a hurry to answer a bell; everything takes her a lot longer, because she is*

thinking about it, so she won't trip, or drop things. However, they don't ask those type of questions in the paperwork, so it is very hard to describe what life is like within the confines of their very narrow questions.

Financially, Carissa feels that she has *set* herself up so that she will be *just fine* in retirement. She realizes that she *certainly won't be a millionaire, but* knows that she *won't have to eat Kraft Dinner for the rest of her life.* Her house is *bought and paid for,* so she will always have a place to live, and even though *money may be a little tight,* she *will be able to do it.* She is pragmatic in the sense that she knows the day may come when she *may have to sell her house and move into a facility,* but that is not her current reality, and she feels strongly that *there's no point in worrying until there is something to worry about.* She will be *OK regardless.* There may be some financial changes happening in Carissa's future, however. Her neighbour recently informed her about Canada Pension Plan (CPP) Disability, and she is *going through* the application process *presently.* She shared how she *thought you got CPP when you turned 60 or something,* and how she was unaware *there was a disability* portion if you *were off prior to* old age. No one ever informed her that CPP disability existed or that she should consider applying to supplement her disability pension. Again, the *paperwork* for the CPP process presents its own stress and challenges for Carissa. She expressed how she wished *somebody* could do it for *her,* and that perhaps *had she gone and got herself a social worker, there may have been a little more help.* A *social worker* had been available to her *initially when she was diagnosed at the MS clinic, but she hadn't been there in 13 years, and when she went back, truthfully she just never thought about it again.* On the other hand, *they never offered one up either,* but *perhaps she would have used the assistance of one if she had known about the support for those needs.*

On a more personal note, since retiring Carissa has been dealing with a number of relationship issues with her spouse. It has been *discovered that he is an alcoholic which has produced its own trials,* and there is quite a bit of *stress* related to the situation they are *trying to deal with.* Carissa had noticed for quite some time that his *behaviour was a little bizarre,* but she *couldn't get to the bottom of it.* It wasn't until *he got his DUI* in December 2016 that Carissa learned he had been drinking. The situation was puzzling for

Carissa because she *never saw him drink a lot around the house*, however, she hadn't realized *he had been drinking vodka before he arrived home*. Carissa has only known about the issue for the *two years*, but he has been drinking for longer *he admitted*. He did go to *rehab*, and Carissa *thought they were on the right path, but none of that was effective*, so currently they are back to *square one* dealing with this issue. Her *goal is to get him well and in the meantime, stay well herself*. Carissa shared that the real sadness of the situation is that her spouse has spent his whole career *in healthcare*, and in relation to her MS, *he is very accepting of the whole thing*. She went on to share that *truly, if she was ever to get in trouble, there probably wouldn't be anyone better to look after her than him*. So she is *hoping she is able to get him well, so that perhaps when she needs him, she will have him*. Her future really depends on *if he can quit drinking or not*, and true to Carissa's realistic nature, she knows she *can't project what will happen*. She *can only hope for the best and prepare for the worst*. The outcome of this situation will also have a relatively large impact on Carissa's financial future as her spouse is a financial contributor to the home, and plays a major role in the physical upkeep on their property. Thankfully, Carissa has *a lot of good friends and a lot of support* in her life, so she is able to deal with the difficulties, *do what she has to do*, and find ways to *still enjoy herself*. Despite her positive attitude, the stress is still affecting her. Carissa has been finding that lately she is requiring *a lot of sleep and a nap more often* to manage what they have been going through. She is *tired a lot right now in dealing with the situation, but probably anybody would be*, so she tries to keep that in mind as well. Being off work has given her *the strength to deal with what she's dealing with*, so she often wonders if this is what she's *supposed to be doing* at this point in her life. She realizes that there are *going to be ups and downs, but at this point*, she is doing all she can.

Overall, Carissa *really likes retirement*. She has *limitations* and she has to *know what those are*, but she works hard to maintain her routine, watch *what she's doing*, and tries not to *get herself overtired*. Although it is a challenging time for her family, she finds that *if she gets her sleep, eats properly, and does the normal things you are supposed to do*, she *can feel pretty good* for the most part. Although some financial and family uncertainty exist, Carissa feels happy with the retirement she has, and plans to continue doing things and surrounding herself with people who bring her joy. She really doesn't

feel the *need to talk about* the MS *on a regular basis* which comes back to her desire to *not to wallow* in what may or may not happen in the future, and to not *draw attention to* herself. She focuses on today and tries not to *sweat the small stuff*.

Chapter 6

6 Results

In this chapter, I present four overarching themes from my critical narrative analysis of the five women's narratives on how they came to be retired and what their life is like in retirement. In this chapter, I present each of the themes and corresponding sub themes to reveal the lived consequences of involuntary retirement and how such retirement is socially-politically shaped for these women. The first theme is titled '*Negotiating the Disconnect between Retirement as Imagined, and Retirement as Lived*'. This theme illustrates what the women thought their retirement would be like, and how many of the stories mapped onto 'normative' constructions of retirement. However, their diagnosis of Multiple Sclerosis (MS) was a significant event that altered their expectations of retirement and retirement trajectories. A number of other factors contributed to their need to re-imagine retirement. These included the bodily or cognitive changes produced through MS, their interaction with environments, practices, systems and policies that are unable to accommodate or understand an uncertain or changed body, and how uncertainty was produced for the women in these interactions. I also discuss, in this theme and others, how a number of factors contributed to what I am calling a shortened temporal frame, their need to re-imagine retirement, and the foreclosure of possibilities for them. In the second theme, '*The Production of Consequences in Navigating Ableist Environments Requiring Certainty and the Intersection of Bodily and Financial Uncertainty*,' I explore how uncertainty is produced, how living with uncertainty has impacted the women's ability to plan or prepare for the future, and how the women's engagement with a number of ableist environments that were unable to accommodate or understand their uncertain reality, created challenges for how they are able to survive. Next, in the '*The Failure of Practices, Systems and Policies to Understand the Complex, Intersectional Reality of Women with MS, and the Navigation of Identity Tensions*' theme, I reveal how the women navigate their identity, navigate the disability and retirement policies, systems, and practices they engage with, the tensions or challenges that are produced as they navigate these, and the implications of these interactions for how the women think about and plan for the future. Finally, in '*Filling the Gap*' I discuss the implications of, and

strategies the women employed to fill the medical, financial, social, and psychological ‘gaps’ resulting from practices, systems or policies that marginalized them, failed to meet their needs, or recognize their complex, intersectional reality.

6.1 Theme One - Negotiating the Disconnect Between Retirement as Imagined, and Retirement as Lived

The women’s narratives revealed a number of stories of recollection of what they thought their retirement would be like and when it would occur, prior to the onset of MS. Amanda shared how “I expected that I’d get a really nice one floor condo, open concept, hardwood floors, granite countertops, bar in the kitchen that people could sit at”. Judy talked about how “at the very least, I wanted to be able to do some travelling a little bit, even if it was more local stuff. Yeah, I wanted to have more financial freedom”. Carissa also talked about her expectations. “I think what you expect when you start working and you go into nursing [is] you work till you’re however old. I expected to work till at least 60 and depending on things, 65” but added that she “didn’t really know what it was going to look like”. These examples from the women’s stories highlighted retirement aspirations of ideal housing, abundant leisure and financial resources, and control over the nature and timing of retirement. Their expressed desire towards a particular type of retirement fits nicely with most ‘ideal’ conceptualizations of retirement, what people perceive retirement should or would look like, and how they should plan for retirement based on ‘normative’ conceptions of retirement within the current socio-political context.

However, their stories emphasized the onset of MS as a significant event leading to many changes in their imagined retirement and their retirement trajectories. The women discussed a number of complex, intersecting factors that contributed to the changes in how they were able to think about or plan for retirement. The themes that follow deal with the intersecting factors that led to changes in their trajectory. Unfortunately, in contrast to these ‘ideal’ conceptualizations of retirement, ways of planning for retirement, and the hopeful futures these women had, all these factors have changed their ‘expected’ trajectory of work and retirement, and significantly changed how they live their lives on a daily basis, negotiated work, and how they were ultimately able to think about, plan for and live in retirement.

Judy shared, “I never thought I’d have to get a roommate to help pay for things. [I need] the 400 he provides for his room rental, use of the washer and dryer and the kitchen. So far it’s worked out OK, but that’s ... not what I anticipated of my retirement. You have to adapt to change. That’s the biggest thing I think I’ve learned with this. The adapting to never-ending change”. Judy also explained how, “I don’t have the money to do the things I’d like to do” anymore. “I struggle financially. I used to take my daughter ... around Christmas time every year ... [to] see a live production ... I don’t have the money to do that [anymore] ... which is really sad because that was something we did every year”. She added how “you don’t eat as well as you normally would, and you don’t go out to eat” ever. Even 10 years ago “I thought ... I would have a decent little retirement because I paid into retirement since I was first working as a police officer when I was 25... [but] I didn’t end up with a nice little retirement bundle I guess that I thought I may have”.

For Amanda, “I’ve had to scale back my expectations of our future because I know that he [my husband] is not going to be able to work past 60, and I also know that we are going to have to get out of this house because physically, neither one of us are going to be able keep up with it after my daughter moves out ... I have to drop my expectations that we’re probably going to have to move into an apartment. A lot of that will be because of financial and physical as well”.

Carissa talked about how “it’s a lot earlier than I pictured which doesn’t have to be a bad thing. I feel I’ve made the most of my life doing what I was doing for the last however many years that there isn’t any sort of huge things on my bucket list that I have to do and those things that I would choose to do, I could still do them if I really want to. I just have to save longer given the ability to make the money isn’t ... I don’t have to do without per se”.

What also became evident is that the women are living in what I am calling a shortened temporal frame. I conceptualize a shortened temporal frame as an inability to move forward, to plan or think about the future because their focus, involuntarily, remains on immediate need or circumstance. These women live in a context where ‘normative’ ways of planning for and being in retirement are not possible. A number of the women

discussed how they found it difficult to think beyond the immediate or plan for the future, because so much in their life is uncertain, tenuous, and beyond their control.

Carissa shared how “the social worker had given me papers ... to look into the disease and what it all entailed. I at the time didn’t really want any part of it. Being a nurse I knew, I felt I knew what I needed to know and didn’t...to me there’s sometimes no point in knowing too much ... that’s not me right now. Whether it could be me in the future, it’s not me now, so I choose not to wallow in that” uncertainty. Carissa’s strategy is to “really try to not sweat the small stuff, take what comes, avoid what ifs and deal with [the] present”. Waiting for a decision on whether she could remain off work, Carissa also shared about the stress she felt not knowing what the future held for her and how to plan for it. “It’s on my mind but again, I can’t worry about it until I find out so it’s just going to be the way it is. I’ll deal with it when I hear”. Similarly, Noreen explained, “why worry about something that’s not... don’t waste time now. You have to keep reminding yourself of that ... I’ll deal with the problem when it’s a problem. It’s not a problem right now”.

A number of the women also demonstrated a reluctance to investigate their future. With so much uncertainty in addition to having to navigate environments, practices, systems and policies in ways that do not ‘fit’ their reality, their hesitancy to investigate their future was a strategy the women appeared to enact as a way to survive. According to Carissa, “whether I’m still on disability or whether I have to retire, I guess that will depend on how long they are going to pay this disability for. In which case, I will be forced to retire and start collecting my pension. So in the big picture I’m really covered, so what I’m worried about, I don’t know. I guess I just would like to collect my disability as long as I can so my pension can be OK when I need it ... I don’t want to call and say, how long are you going to pay my disability? and then have them say, oh well you can retire at 55 so that’s what we’ll do. I don’t want to prompt that so that’s why I’ll just sort of wait until I’m 55 and see what they do. I think...to me that’s the better way to do it. Rather than push forward and have them say, well on you know. Because I don’t know if they think that may be going back to work, they will continue to pay my disability. I guess that’s what I’m thinking. As opposed to it being finalized, I’ll never return to work

so they will look into everything and go OK you're retired at 55". Amanda experienced similar uncertainty related to the benefits the drug company initiated for her and paid for initially. "The drug company covered the initial \$3000 deductible [for Trillium]. So fingers crossed that they are going to do that again ... [but] I don't know if they are going to pick it up next year" [or why they did this year].

These stories demonstrate how the women are dealing with what they can at the moment, but the thought of trying to think beyond the immediate is too much. This is often because everything in their lives is so uncertain and they perceive further exploration of an uncertain environment as too risky; choosing not to do it out of fear of jeopardizing their current benefits.

The women's stories reveal how many of them initially had very different conceptualizations of what they thought their retirement would be like. However, due to their diagnosis of MS and a number of reasons, their imagined or anticipated work and retirement trajectories were put off course. Their divergence from their 'expected' retirement changed how they were able to live, work and retire, and shaped their need to re-imagine retirement, because 'normal' ways of thinking about or planning for the future were no longer possible. Having to live in a shortened temporal frame, focused on immediate need, amongst a high degree of uncertainty, led to foreclosed possibilities for these women in planning and preparing for the future. The uncertainty they experienced will be explored in further in the next theme.

6.2 Theme Two - The Production of Consequences in Navigating Ableist Environments Requiring Certainty and the Intersection of Bodily and Financial Uncertainty

6.2.1 The Uncertain Body

The women's narratives highlight living with a pervasive sense of uncertainty in their lives on a daily basis, both prior to and during retirement. For all the women, the body presents itself as an uncertain object. This uncertainty exists at the level of their body, and through their interaction with environments, practices, systems, and policies that value a 'certain' body.

Throughout their narratives, the women spoke to bodily differences produced by MS and the changes that took place in their bodies. Billie discussed how during a flare up her mobility was often affected, and she would start to “walk like a drunk man”. She also had difficulty with her vision and would often “see double” (Billie). Judy, Carissa, and Noreen experienced difficulty in regulating their body temperature. Judy joked that, “I can’t vacation south because my body with MS, I can’t regulate my body temperature. So even if someone paid for my trip to go to Bermuda [LAUGHS] I won’t be going. Carissa shared how “the heat bothers me too [...] and if it gets too much outside I have to come in”. Noreen explained how she has “to rest after I have a shower because the heat makes me [exhausted and how] ... people don’t see me laying on the bed for 20 minutes after I have a shower”. Amanda explained how, “if I do any walking for any length of time ... [my leg] literally starts to drag and I start to lose a bit of control of it”. For Carissa, the “majority of ... [her problem] was fatigue,” explaining how “you don’t realize how bad you feel until you feel good again” and how fatigue is “a big snowball effect and you don’t even realize” the “dragging and dragging” as time goes on. These examples highlight how the often fluctuating nature of MS can produce a number of bodily differences that vary not only between the women, but within the women themselves at different times. In addition to the fluctuating nature of these bodily differences these their examples also highlight the uncertainty associated with how or when they may present, how long they will last, and the impact they have in their daily lives.

Although the women discussed a number of bodily changes they experienced through MS, there were also a number of cognitive changes produced by MS they had to navigate. Amanda explained that “I found myself having to write notes for everything, because I just wasn’t remembering. There were a few times that I slipped up on things because they just totally left my head, so the memory was becoming a bit of an issue”. Noreen shared about how a number of her limitations were not always obvious and pointed out how “because your brain runs everything, it can ... [affect] anything in your body. The signals get screwed up. So an awful lot of that is not necessarily physical. For me, I have cognitive fatigue which means thinking takes three times as much effort. Problem solving, the whole executive functioning that kind of stuff, can’t think of the words, those are all part of it”. These examples demonstrate the additional ‘work’ that an

uncertain and unreliable body creates for the women in managing the body and their abilities, and how many of the limitations they experience may not always be visible.

In addition to the cognitive or bodily changes the women experienced through MS, a change in the relationship that the women had with their bodies also became evident through their narratives. On a number of occasions, the women spoke about how they had lost confidence in their bodies, the reality of what it is like to live, work, and retire with a body they are no longer able to count or depend on, and how they can no longer see themselves as dependable because of the unreliable body and uncertainty they live with.

When discussing her hopes for her future, Judy explained how the uncertainty of her MS limits what she may be able to do down the road. “At the very least I wanted to be able to do some travelling a little bit, even if it was more local stuff. Yeah I wanted to have more financial freedom, but I also wanted the ability to, I’m not predictable with my health, I’m not predictable with the MS. I don’t know how I’m going to feel. What can I book? What can I do ... [where] you have to book anything? Count on your body to be able to hold up? It takes a lot of energy believe it or not to plan a trip or get things together to go away. A lot of mental energy and physical energy which like I say, is not in abundance anymore”.

Despite having little flare ups along the way, Amanda’s relapse was a significant event that really changed the relationship she had and how she felt about her body and her abilities. “I lost complete confidence in my body and what it would do on a day to day basis. I ... stopped doing the Pilates ... it was a struggle, so I stopped going”. Even how Amanda was able to engage in the important relationships in her life changed as her abilities become more unpredictable. “We would walk every Saturday, go for a walk and go for a coffee...when the walking thing will come up now, does anyone want to go for the walk Saturday morning? My answer now will be I’ll meet you for coffee because I know I will hold them back, or I honestly don’t know how far I could go. I would have to push myself to find out. I haven’t tested the waters on that yet”. As a grandparent, a role that brings Amanda much joy, she spoke about how the unpredictability of her MS no longer allows her to be dependable with activities she would like to take part in. “I signed

[NAME OF GRANDSON REMOVED] up for ... rock climbing, but I couldn't be the one to take him to the rock climbing or be the one to climb with him. ... The whole understanding how to do the harnesses and clipping them into the rope ... was kind of a little bit beyond me and just the fact that the hands don't work the way they used to so I couldn't be the one trusted".

Noreen talked about how the unpredictability of her body has changed the expectations she places on herself. "I got qualified in colour Sherwin Williams paint Consultations. I have the whole big thing that decorators have. I was qualified for that twice, but I can't do anything with that. I can't. I'd never expect someone to depend on me to show up for anything. So I think it's the inconsistency. You can have days where you want to do something but not necessarily going to happen".

On a number of occasions, the changes in the women's bodies and their changing relationships with their bodies became particularly problematic for the women within the environments in which they were trying to work, because those environments expected and are built around a particular kind of 'certain' body, that is, one that is consistently able. The women's stories also revealed that these ableist environments often could not understand nor accommodate an uncertain body.

For example, Judy's difficulty regulating temperature made completing the tasks her private investigation (PI) job required difficult at times. "I've read that many MS sufferers, many MS people suffer from overheating... [and] they can't regulate their hot and their cold basically... the job I was doing as a private investigator ... was to ... 'sit on a house' where you are just watching for activity. You can't sit with the car running because then you draw suspicion, right? Anyways, so I'm baking in this car. I was there at 6:45 in the morning and I was supposed to stay there till 5:00 and you know, it was just horrible... I'd report in everyday to my supervisor who wasn't understanding of MS at all and didn't care to understand about MS at all. He just wanted to know the bottom line; did you catch him? Did you get the money shot? Did you catch him doing anything?"

For Noreen as a manufacturing plant line worker and quality control inspector, the unpredictability of a body with MS that produced frequent and often lengthy

exacerbations, was problematic in a work environment that demanded certainty and consistency. “They just gave me my walking papers. I just figured well, I really can’t say too much because ... like my MS was pretty active at that time so I couldn’t say to them well, keep me because my MS is going to go away because it wasn’t going to be doing that. I might as well just forget about it and take early retirement because I don’t like stress and stuff. I don’t like confrontation of any kind”. Noreen went on to explain that “they never had any fault with my work. It was just because I was missing so much time. At that time there was no ... [protection for workers with] MS ... [and] when you miss work ... your job was put in jeopardy”.

When contemplating returning to work after retirement, Amanda was concerned her bodily limitations may be seen as undesirable to her potential employers and was not confident in how to best negotiate sharing her limitations with them. There is “one job that they will probably want to train me in because they only have one person trained for that and it is called ‘the hub’. Its right in the clinic and you work with the nurses, with the doctors, with the anesthetists, directing them. You’ve got all the patients in the rooms and you are sending nurses into this one, doctors into this one. There is a board, and you have to keep track of who is where”. Amanda also explained “that those girls back there are pretty much on their feet all day long and that’s something I can’t do, but I don’t want to go back into this and say [I’m not able to,] so that’s a concern. Amanda was concerned about how forthcoming she should be about her limitations. “It does concern me a little bit wondering [if] they are going to want to hire me because I’m giving them a limitation. Maybe they would rather hire someone who is giving them no limitations? Why am I going to hire her when I can only put her into two jobs, when I can hire this one and put her into four jobs? It could be a factor, I don’t know”.

Living with a body they could no longer count on, depend on, or had faith in, contributed significantly to the uncertainty the women experienced. Having an uncertain body or a changed relationship with their body became even more problematic as the women attempted to negotiate work and retirement within environments that assume a certain, dependable, able-body as ideal, and view someone with an uncertain, unpredictable, or changed body as undesirable. As the women with uncertain or unpredictable bodies

engaged with ableist environments that value able-bodied individuals, it also led to financial uncertainty.

6.2.2 Finances

Throughout the women's stories they discussed their experiences engaging with a number of financial systems both during their working years and in retirement. Their stories demonstrate how many of the systems these women engage with expect that individuals are relatively able-bodied with a certain degree of stability in their employment tenure: and draw attention to how the construction of these systems fail to consider the uncertainty and financial challenges that may be produced when someone with an uncertain body engages them. In the women's stories, financial uncertainty is created at the intersection of women with changed bodies and the systems in which they are trying to work and financially survive, and produced a number of challenges for them.

Noreen's engagement with a pension system that financially penalizes on the basis of early retirement left her feeling defeated for years. Noreen needed and wanted to quit years before she was able to given the financial implications not only for herself, but her family. She spoke frequently about putting her retirement date into the pension system to see how much of a financial loss it would mean for her family. "I remember checking on the computer because we could have access to our pension plan site, and you could put in different dates and see what your pay would be. I was just thinking, please let me quit early, please let me quit early [LAUGHS]. You put the numbers in and every year you go early it's a bigger percentage they dock you in your pension plan and it really is exponential the sooner you go. So my husband wasn't really happy about that one. I don't think he realized how bad it was for me". Noreen conveyed that the weight of the financial impact leaving work early would have on her family further exacerbated her MS symptoms and made her ability to continue working with an uncertain body even more challenging. Eventually Noreen had to access accommodations. However, an intrusive disability half-time application process made her willing to live with less financially in order to enjoy her life and maintain her health. "So then we had to go through ... [the disability half-time application] process again [EMPHASIZES THIS]. We only got a small time before it was time to re-do it and I said we're not doing it! We will put it in,

they will deny us and I'm not appealing it, I can't. If I have to live on half time salary [and] we have to starve, I don't care. We just can't do it; it's making me sicker. So we didn't". Noreen also talked about how managing financially and navigating the application process was only feasible because she had the financial support of a spouse. "I'm just thinking to come up with [large] chunks of cash like that quickly or to say we're not going to bother with the insurance company any more, we're just going to suck it up. [That] ... is always nice to say but when it came down to it, we didn't really want to suck it up. Just too even have that as part of the conversation. Well, we will just live on half your salary because that's just what we have to do. If you're by yourself you don't have that option".

Already living with uncertainty from the changes in her body, Amanda also had to navigate changing financial circumstances and the impact the loss of employment income could have on her family's shared financial situation. Amanda wanted to have ownership over her retirement and for it to come at a time while she was still able to enjoy it given the unpredictability of her MS: however, her husband was adamant that she would need to make up an additional \$500 a month in order to be maintain things financially in the immediate and future as well. Amanda described retirement finances as "going into the unknown. You've never done this. You've worked your entire life; you've had a pay cheque go into your account every two weeks, so the pension cheque goes in once a month and I didn't know if that meant by the end of the month we were going to be eating bacon and eggs how my parents did it. I always knew when we were getting to the end of the month because we were down to bacon and eggs [LAUGHS]. Didn't know how the money was going to work out and that was sort of a key issue in my husband's mind. He keeps saying, every time I ask you these questions you keep saying, I don't know. Because I didn't want to sit down and figure it all out to the enth degree. I just thought if I am going to do it, I just need to do it and I'll figure it out later. But I did know that if they would take me back casually that would help fill in that extra \$500 dollars he seemed to think I was falling short on".

For Carissa, negotiating finances in the face of receiving a diagnosis of MS and the breakup of her marriage led to financial uncertainty and the need for some difficult

decision making in order to financially manage. “At that time given my husband had left, it would have been [financially] beneficial for me to be fulltime, but in knowing I have this MS, even then I knew it was probably in my best interest to stay part time, and I enjoyed part time. So I just stuck with that”.

For Billie, the uncertainty associated with her MS made it difficult to not only maintain her employment, but also consistently make ends meet as a single woman with MS. Billie explained how even though her employer “never had any fault with my work ... [my termination] was just because I was missing so much time”. Her workplace lacked any kind of illness protection for the workers and her repeated absences for her MS exacerbations were not seen favorably by management. Due to these absences and lack of workplace support for someone living with a chronic illness like MS, Billie would consistently struggle to meet her financial needs. “My dad always kept a pretty good eye on me, and he’d help me out whenever I needed help, which was really great, but I just didn’t like having to borrow money or doing anything like that. My dad never [EMPHASIZES THIS] asked me to pay it back which was a really good thing because I could never have paid it back because I was always behind the eight ball ... always got behind in the rent but I always managed to pay it up”. The constant need to ‘catch up’ took away Billie’s ability to save, plan or even consider what her future needs may be and how she would deal with them.

For Amanda, despite having drug benefits through the hospital where she worked, the cost of the medication was too much for her family. “I got off of the study, it ended and then I started to have to buy the drug myself which my drug plan did cover except for \$250 a month. So that was coming out of pocket and I decided I couldn’t afford to do that anymore, so I quit taking it. ... So I wasn’t on any kind of medication. I think there probably was a period that symptoms were surfacing again but that only led me to realize that I needed to be back on some kind of drugs [and wondered how we would pay for that]”. The uncertainty in not knowing how she would pay for necessary medications while receiving partial financial support for drug costs through her work benefits created a lot of anxiety for Amanda about how she could manage when those benefits were lost

upon retirement, and what it would do to her family's shared financial situation if they had to take on an even greater financial load with less.

From the women's stories it is clear how living a life of financial uncertainty limits one's ability to think about and plan for not only their immediate needs, but also future needs. The women stories also demonstrated the extra financial considerations associated with having a spouse or family, and the added complexity or challenges produced when managing financial loss as a single person. It is also important to highlight how existing systems, policies and practices are not supporting these women fully.

In summary, the women experienced a great deal of uncertainty both at the level of their bodies and finances. Throughout the narratives, the women acknowledged that there were changes in their bodies produced through MS, and due to these changes and the uncertainty they experience, their relationship with, and how they view their bodies also changed; bodies they were no longer able to count on, had confidence in or deemed dependable. Their stories also highlighted a number of instances where the environments they interact in could not accommodate or understand an uncertain body, especially given that these environments often require a degree of certainty or consistency and are built around ableist conceptions of a 'normal' body. Although examples from their stories often appeared to problematize an uncertain body, it is important to highlight that the lack of fit between an uncertain body and the ableist environments that body interacts with produces a number of consequences for the women and perpetuate ableism. Financially, the women's engagement with multiple systems constructed around the notion of a 'normal body,' creates opportunities for financial uncertainty when someone with an uncertain body is navigating these environments, practices, systems, and policies. In terms of the future, the uncertainty experienced by these women, the lack of confidence they have in their bodies and abilities, and the financial uncertainty they face, restricts how they negotiate work and life in retirement on a daily basis. It also limits how they are able to think about the future and plan temporally. For a number of the women, living with an uncertain body and the lack of financial certainty has foreclosed a number of possibilities they had for themselves and led to a need to re-imagine what their retirement

will be like. Next, amongst all the uncertainty, the women also had to navigate tensions in their identity and ‘navigate the systems’ on a daily basis.

6.3 Theme Three - The Failure of Practices, Systems and Policies to Understand the Complex, Intersectional Reality of Women with MS, and the Navigation of Identity Tensions

6.3.1 Navigating Identity

The women’s stories reveal how they continually had to navigate their identity as women with MS who are retired, within environments, practices, systems, and policies that do not acknowledge or accommodate an uncertain body or the uncertainty in their lives. A number of the women experienced tensions in navigating their identity. One source of tension was related to knowing that if they were take up the identity of being ‘a disabled person’ they may be able to access certain benefits, receive supports from the systems they interact with, or be eligible for necessary accommodations. However, they also realized that that if they were to take up an identity of being ‘disabled’, they may experience additional or different problems within the systems they interact in, because of the larger negative discourse assigned to disability.

A number of the women expressed their hesitation with being seen as ‘the sick guy’ or ‘playing the MS card’. Their desire to evade this part of their identity appeared to be linked to the negative social meaning assigned to disability or to their hesitancy in being viewed as someone who ‘uses’ the system for their benefit. Amanda shared about how when an interview she participated in for an MS drug unknowingly made her diagnosis public, something she had worked hard to keep private; it was difficult for her. “A lot of people that didn’t know I had MS found out. I didn’t think about that when I did the interview. I didn’t think about the fact that I was putting myself out there. ... It’s like I just came out of the closet”. Amanda went on to explain, “I don’t have fears of sharing. I just don’t want it to be...I’ve never wanted MS to define who I am. I don’t want to use it as an excuse, which is why I don’t talk about it to people. I don’t ever play that card”. Her fear over being perceived as a ‘sick’ person or having her MS define her, even

prevented Amanda from accessing disability financial supports until about two years after retirement. “I wasn’t going back to work, and I had a lot of friends telling me, why don’t you look into it? Look into it. And I think my mantra all along was, I’m not disabled. I don’t need to apply for disability pension. But I was starting to feel a little bit more disabled...and the fact that I couldn’t go back to work [...] [and] I wasn’t going to be able to bring in that extra income is kind of what spurred me on”. She explained further that “I don’t think I would have made my decision earlier because I still wasn’t admitting disability. I mean that’s the other...a lot of it was based on the fact that I wasn’t admitting to it”.

Carissa also expressed her hesitation with sharing her diagnosis or limitations she may be experiencing. “I didn’t want everyone in the world to know I even had MS. I would prefer...it’s not that I’m embarrassed of it, I just didn’t want to play that card. If I was there to do a job, I was there to do a job regardless of anything else, and so I didn’t want to ever announce that factor...I just didn’t want to draw attention to myself I guess you would say”. She went on to explain how “I guess I’m just not that kind of person. I don’t need the sympathy. I don’t need sympathy or special treatment, at least right now and some people feel the need to you know, ask you every day how you are doing. I don’t need to talk about it on a daily basis or even on a regular basis. It’s just there, and I choose not to wallow in it”.

Unfortunately, there were a number of instances in the stories the women shared where they needed to evoke their ‘disability’ status for various reasons, and the tension they associated with doing so. These tensions appeared to relate to the value they placed on projecting themselves as a ‘good’ workers or their desire to be seen as ‘normal’.

Unfortunately, the act of seeking or requesting accommodations or the sharing of limitations, worked against their desire to maintain the normative or ‘good’ worker identities they were trying to live up to.

When considering returning to part time work after retirement, Amanda was concerned over how she could manage a new role with a changing body and new limitations. “I know they need someone in that position. There are other jobs that they could put me into

that would be like registration, putting charts together, where I would be sitting down, [and] I wouldn't be on my feet all day. It does concern me a little bit. Are they going to want to hire me because I'm giving them a limitation? Maybe they would rather hire someone who is giving them no limitations. Why am I going to hire her when I can only put her into two jobs, when I can hire this one and put her into four jobs? It could be a factor, I don't know". Amanda went on to clarify that "I've never played the MS card but I'm afraid I might have to on this because I really don't feel I could handle that job".

Carissa talked about the need to solidify a routine and having to share her limitations in order to do so. However, she was reluctant to ask for any additional supports or accommodations that would have made her job easier to maintain, and the pressure she felt in making that decision. "I didn't go to work and say I need to get out at 9:30 or 10 [instead of 11]. Whether they would have accommodated me or not, I don't know. But I didn't so, of course you feel bad. Part of your job is staying there until 11 with everybody else, so that's what you do". She also spoke about how "that was probably the worst of it all. Trying to do what is required of you and not bringing attention to yourself as being the sick guy at work who can't lift a jug, or can't stay till 11, or can't be on call. You want to be able to...I always wanted to look normal. That if I was there I could do the job. I didn't want to be that person where I can't do call anymore because of my MS, or I can't stay till 11 because of my MS. If you can't do the job to me, you can't do the job and it came to the point where I [could not] ... do the job". Carissa actually spoke a lot about wanting to appear 'normal'. Even now in retirement she explained how "I feel wonderful for a person with MS [but] I'll probably never be 100% like a normal person so I have to keep that in mind".

Other tensions or barriers in the navigation of their identity appeared to stem from instances of discrimination the women had experienced personally or had witnessed against others in similar circumstances given the larger social meanings assigned to disability in that existed within their workplaces.

In sharing her suspected diagnosis of MS and some of the she challenges she was experiencing in her role as a private investigator, Judy's boss was less than supportive.

“I’d report in everyday to my supervisor who wasn’t understanding of MS at all and didn’t care to understand about MS at all. He just wanted to know the bottom line; did you catch him? Did you get the money shot? Did you catch him doing anything?” When expressing some of the limitations she was experiencing completing her role, Judy recalled how he angrily told her “you need to lighten up! Are you playing the sick card? Maybe you’re not cut out for this. If you can’t stand the heat stay out of the kitchen”. In sharing her limitations, Judy was counting on employer support in order to maintain her employment because as a single mother and sole provider, having a job was a necessity. However, she then had to navigate her new reality as a single mother with MS within an environment where she was not “understood, considered, or cared about as an employee”.

Early in her career, Carissa had no choice but to openly share that she was experiencing an MS exacerbation and that she would not be able to attend orientation for her new nursing position. The Nurse Manager’s response to news that Carissa’s would not be coming to orientation was “well, you can sit in a class, can’t you? I said well, yeah, I can’t really write right now but...so you know, I didn’t want to argue about it, so I started orientation which I now realize wasn’t a good thing to do because I got worse”. Carissa explained how “I don’t think she [the nurse manager] knew any more about MS than I did, so I didn’t know enough to say no, I don’t think I can do that. I wasn’t sure if I could do that, so when she suggested could I do it? I thought well, I can try... I should have not continued but you know, inside...I’m here now. Step up and do it. So that’s what I did”. Carissa further explained how “you feel pressure because this is what you signed up for so ... to all of a sudden say no, I can’t do it, puts them in a bad situation and I would have felt bad. So yeah, there was pressure to step up and get the orientation done”. The lack of understanding on behalf of management not only contributed to bodily and cognitive MS exacerbations for Carissa, but created an environment where she felt unable to prioritize her health needs, despite framing it as a mutual learning process for both. This example also touches on particular assumptions underlying the nursing profession where as a nurse, you have particular obligations to care for or about others over yourself.

Later in her career, Carissa spoke again about having to navigate being a woman with MS experiencing limitations and the culture of the nursing profession. She shared how

seeking accommodation is frowned upon within the culture of nursing and how an engrained narrative that it is a nurses 'job' to care and not be cared for, encouraged her hesitancy to ask for what she needed. "We have lots of people that go off sick or can't lift jugs because of their back and sure, people talk about them, that's kind of just how it goes. I think it's just part of the profession or something. Nurses aren't always compassionate towards their coworkers because what you can't do they have to pick up the slack, and that's not always...not everybody is willing to do that I guess you could say". Carissa added how "it sounds a little whiney just over an hour. I think if they started to say, you know you can leave an hour early, what's there to stop everyone else from saying she can leave early so why can't I leave early? It just causes ripple effects and it's frowned upon that sort of stuff, so I just didn't do it".

Noreen's challenges in navigating her identity were tied to the invisible nature of her MS and the lack of understanding she experienced through the process of applying for formalized disability supports. Her story highlighted the suspicion and doubt surrounding disability or illness eligibility or accommodation engrained in both her workplace environment and disability insurance system. During the disability half-time application process, "they follow you, they take your pictures, they take videos, they do all this stuff and then they tell you that you don't get it". Already a marginalizing process where the legitimacy of your illness and needs are questioned and investigated, Noreen explained how "the whole time when you're on ... [disability] you know they are watching you [and it becomes even more] difficult if what you're sick with is invisible. You don't want to look too healthy, because they are going to assume that you are healthy and tell you that you have to work. So if I was having a little bit of pain, I had to make sure it was visible that I had pain. So you find yourself not doing your body any favours by making it visible. Like if you're tired make sure you walk like you're tired. That doesn't do your muscles any good. It backfires, it makes you in more pain". Noreen went on to explain that what so many people do not see or understand is that "if I forget where I'm going and have to take the long way around the block, it's not a safety concern. However, multi-tasking in a classroom...parents get really annoyed if you lose their four year old. Shopping, that would be me dragging myself [out] after three or four weeks of being out of something to the store to pick up my meds. Shopping is not an option". Noreen's

example highlights the struggle of many with MS to legitimize their illness experiences and connects back to the women's hesitancy to 'play the card' for fear of being seen as 'using' the system where real need may not exist.

Another source of identity tension the women had to navigate was surrounding their age and conceptions of a 'normal' retirement. Some of the women discussed their struggle to take on the identity of being a retired person because their retirement was often viewed as 'too early' or 'off-time' by themselves or their peers, or because of the fact that they were not actually receiving or may not qualify for retirement based supports despite being retired.

Carissa shared how she still has a hard time considering herself retired because it is earlier than she planned or wanted, and was beyond her control. "Well I was only 52 and I stopped going to work, you know. Who gets to do that? Well I guess if you're sick enough you get to do that. Some people wouldn't want to do it ... but I was OK with it. I mean, it wasn't my choice". Some of the tension she felt was also tied to the fact that although she was retired, she was actually receiving formalized disability supports due to her age. Carissa very explicitly shared that "I don't even feel retired really because I am off on disability". Amanda spoke about how her early retirement has changed the way she is able to engage in relationships. "I mean relationships certainly have changed. Friends, I'm thinking that maybe they are going to shift again because I have a few coming now into retirement mode so you know, the fact that I still have people working is more difficult because I'm available and they are not".

Finally, another way the women had to navigate their identity was in relation to the other social roles they occupy. More specifically, the women had to navigate their identity in relation to being a wife, mother, spouse, or daughter in the context of being a woman with MS who was working or retired.

Noreen spoke about how it was a difficult process she went through trying to convince her husband that she needed to leave work despite needing and wanting to quit for a very long time. Noreen shared how her husband had "a lack of awareness of what my job is I think, which is normal. Of how much multi-tasking it is". She went on to explain that "I

don't blame him for not knowing that, there were just an awful lot of facets being affected that he ... [did not] see".

In deciding to retire, Amanda talked about how she struggled with prioritizing her health needs and retiring because of those needs, especially given that her husband, who also was experiencing a precarious health situation, was not able to do the same. "I have never been the kind of person who does things for me. You start off and you're a daughter, then you're a wife, then you're a mother... Somewhere in there you kind of get lost. So I've never been the kind of person...I do girls weekends, I do girls getaways, I get together with my girlfriends. That is my guilty pleasure, but I don't do things big in the grand scheme of things for me. So I feel that this retirement was all about me, and I'm having a hard time wrapping my head around that, because I feel bad for him that he can't".

Amanda was also heavily involved in helping her aging parents while simultaneously managing her own limitations. She explained how "my parents have become my hobby and I told them that too. They are now my hobby". Amanda added how "I definitely see a decline in their health which makes me want to be more available to them" going forward. This was a difficult tension for Amanda to navigate given that part of her identity as a retired person now is being a daughter and caregiver to her aging parents, but along with that was the realization and uncertainty surrounding her ability to be able to maintain these roles as her limitations change.

Finally, Amanda spoke of the difficulty in navigating being a mother while managing her own uncertain body, limitations, and future. Speaking about her daughter who still lives in the home, she explained how "she's a huge help to me here, huge [EMPHASIZES THIS] and she gets me. She knows when I've hit a point that I can't do it anymore or...she will pick up the slack and do it without making comments about it, there doesn't need to be a discussion. She just knows. But my mother also pointed out to me, you need to encourage her to move out because the more she sees you [STARTS TO GET EMOTIONAL] ... The more she sees you decline it's harder for her to leave, and I don't want that for her ... I'm not sure how I could handle things around here without her here, but I don't want her to feel that she has to stay here because of me ... True to how I am,

I've probably tried to not seem too dependent. Not let her do as much as she's been doing. Cover it up. I don't need you. I'm fine ... I don't know how accepting of that conversation she would be. I really don't know. I don't want her to feel like I am kicking her out either”.

In summary, the women experienced a number of tensions navigating their identity. They experienced tensions negotiating whether to take up the identity of being a ‘disabled person’ or not, and repeatedly expressed their hesitation to be seen as ‘the sick guy’ or to ‘play the MS card’. Their hesitation in doing so often being linked to the negative social meaning assigned to disability. In navigating their identity they also experienced tensions around evoking their illness status in order to access necessary accommodations or supports, and dealing with the consequences that were, or may be created if they were to do so given the negative discourse around disability, questions about the legitimacy in their illness, and their desire to be seen as ‘normal’ or ‘good’ workers. Often these tensions appeared to stem from the women’s actual experience of, or perceived fear of discrimination within the workplaces and systems they engaged in or from their perception they would be viewed negatively or their needs seen as illegitimate if they asked for accommodations. From a number of the stories it became evident that just because accommodations or supports were available, they were not seen as a right for these women. Instead, the women had to continually navigate how they viewed themselves, how they wanted to be viewed, how they would be perceived by others, and the consequences of accessing these necessary supports within the confines of the environments, policies, systems, and practices they interact in. The women also experienced tensions surrounding how they viewed themselves as ‘retired’ or ‘disabled’ given their retirement often occurred earlier than they had planned or wanted, and many were still receiving disability supports despite being retired. Finally, some women also discussed tension in managing their changing, uncertain bodies and limitations within the social roles they occupy and the tensions they experienced as wives, mothers and daughters. From the women’s stories of navigating their identities amongst changing uncertain bodies, it raises the questions about the adequacy of many of the environments, practices, systems and policies in place to support these women.

6.3.2 Navigating the System

The women's narratives collectively revealed how a number of their specific workplace disability and retirement practices, systems and policies, in addition to formalized ODSP, CPP Disability, and CPP retirement benefits that are supposed to support them, fail to recognize the complexity and intersectional identities these women have. From the women's stories, it is evident how many of the practices, systems, and policies created barriers in navigation for individuals who deviate from the 'normal' trajectories of work and retirement, whether intentionally or inadvertently, and do not recognize the intersectionality of their multiple identities. A number these practices, systems, and policies are also built on the assumption that people are 'well' or able bodied, and assume that realities are relatively homogenous between individuals. This theme exposes how the women navigate existing workplace, retirement and disability practices, systems and policies within the current socio-political context, how the women interact with these practices, systems, and policies, and the possibilities or boundaries they create in their lives. In particular, participants discussed the difficulty in conveying their often complex reality within the confines of standardized questions and applications, and a number of the women highlighted the challenges of applying for and receiving disability-related financial support, the challenges in accessing information on available benefits or supports, differences in how the women are able to navigate options and outcomes depending on the family or social resources they have, and how many of these processes can be quite marginalizing and stigmatizing.

Carissa experienced a lot of frustration and stress when trying to answer the required questions for her disability application. She shared how challenging it can be to make people understand the complex and uncertain reality she lives with on a daily basis. "I think a little bit of the stress with filling out paperwork is coming [from] ... how to answer the questions because they are vague. You know, can you do activities of daily living? Of course I can, but to them that means, OK, so you can go to work. It doesn't. It doesn't ask about how much sleep do you require, or what exhausts you, or how long does it take you to do this that and the other thing? So answering those questions and the paperwork is sometimes difficult to make them understand what it's like trying to do

these things. Just because I can do them, doesn't mean I can go to work and do somebody else's buttons up, or lift them out of bed, or keep my balance when I'm in a hurry to answer a bell. Everything takes me a lot longer because I am thinking about it so I won't trip, so I won't drop things, but they don't ask those type of questions in the paperwork. So you're trying to describe what it's like [for you,] but answering their questions”.

Carissa experienced challenges not only with conveying her reality to others within the narrow confines of their questions, but also in how information was given to her to help her understand and make sense of her reality as well. “When they said rest, that's very vague. Had they said listen to your body, do what it tells you, you're going to need to sleep, and do it when you feel the need. Don't fight it. [That] would have made a little more sense to me, because I had no idea how tired I would be [or] how little things would exhaust me. Yeah, telling me that in the beginning you know, and maybe been a little more forthcoming with yes, you need to be off work, this is what has to be done [to feel better]. They just said perhaps being off work and resting will help. Well, yeah but [LAUGHS] I had no idea how important that was and I'm a nurse. So I'm thinking, if I didn't know, these poor people who have no medical background, how do they navigate themselves through this stuff?” The uncertainty from this interaction created boundaries for Carissa in navigating an already uncertain body and reality. What makes information delivery and comprehension around MS even more challenging is the variability not only within her own body, but across individuals living with a diagnosis of MS. Vague instruction may be a strategy to give individuals a general sense of how to deal with their illness, but its failure to provide any real, meaningful support for individual patients presents further barriers to the management of their illness.

Amanda also found significant difficulty with the disability application process and highlighted how there is a real lack of support through the process. In fact, majority of the women discussed not only lack of support through the process but also having a lack of knowledge about benefits and supports available to them. Amanda described how the “government sites are so confusing” and how “the average person doesn't know where to look. When [HUSBAND'S NAME REMOVED] first said about trying and to do the disability application he literally said to me, you have to come and help me with this,

because I don't understand what they are even asking. It's just a mud pit to try and work your way through it, and there are so many hidden things in there ... there are so many other things hidden under layers that the average person doesn't know is there. They need an advocate. They need someone sitting in an office that they can go to and say, OK, I need to retire, help me plan this out, where do I need to, how do I make this financially feasible. And I'm not talking about investments and banking, I'm talking about disability”.

Carissa also discussed her confusion over available supports. When asking why she never applied for CPP disability she explained, “I had no idea. I didn't know...I thought you got CPP when you turned 60 or something. I didn't know there was a disability [one] if you were off prior”.

Billie found difficulty in even articulating what financial supports she currently receives and the mechanisms underlying her movement between the systems. “Well it was ODSP because when I moved over here [to my apartment] I wasn't making that much money, so they put me on the ODSP which is the Ontario Disability, but since then I've gotten a lot of increases in my pensions and stuff like that. So I switched over to the CPP. CPP disability. I've always been on the CPP disability”. Billie further explained how her financial situation had changed after the loss of her husband and the impact this had for her. “When I was married, [NAME OF HUSBAND REMOVED] and I were both on disability, so we had both his cheque and my cheque, so we were really affluent at that time. But then when he passed away ... I had to resort to just my cheque and you just have to arrange things differently. You concentrate on getting for you, you get for you and you only. It was better when it was both of us, but you just have to adapt”.

Continuous adaptation while already navigating a large degree of uncertainty from her MS contributed to the stress and financial challenges she experienced.

Noreen's experiences with seeking accommodations and disability half-time through her school board were physically, emotionally, and financially draining. She encountered personnel who were less than supportive, was guided away from accommodations

tailored to the complex needs she had, and endured an application process so difficult that going through the process to re-apply was not an option.

When initially seeking accommodations, a woman from the board informed Noreen they could not guarantee or accommodate the consistent routine or changing limitations she presented. Noreen was told “we can do your accommodations for one year, but the nature of the beast is that it’s not guaranteed for beyond that because we get different numbers, the class sizes change, the subjects change, and every year it will be different. There’s no way to guarantee that”. In this situation, even if accommodations had been a plausible solution they still lacked the flexibility required to accommodate the uncertainty and unpredictability associated with a diagnosis of MS and changing limitations.

When she applied for disability half-time instead, she was followed, video-taped and monitored to determine the legitimacy of her illness. Noreen was ultimately rejected but upon appeal her claim was successful. However, the process was so tenuous that re-applying was not an option for her. “Being on disability was making me sick. It was making me sicker because of the whole being aware of whether someone is watching me and following me. I didn’t want to be constantly aware 24/7 of disability. I wanted to actually live my life”. Not to mention the financial toll the process put on her family. Noreen further explained how “I have somebody else bringing money in and that experience of ... [the application process] makes me sicker to be proving to people that I’m worth it. I’d rather just have my good days and enjoy them”. Fortunately a working spouse was a protective factor in allowing Noreen to prioritize her health needs.

Procedurally, Judy’s experiences with ODSP were also mainly negative and she was critical of her experiences and interactions. Although ODSP provided her with a consistent source of income in her retirement, she described the “anger and resentment” with the process of accessing disability supports. Judy described the workers as “callous” and shared how difficult it is to “make ends meet” on what she receives on ODSP as a single woman with MS who is retired, because “it’s never enough”. She felt there was not any real effort to understand the complex factors she was navigating through this process of living with MS, or in understanding what her needs really were. Judy explained how

“you have to pay to get your taxes done every year...you have to pay out of pocket that extra money... [and money] to get a validation tag for your vehicle”. Basically “you have to show up hat in hand looking for any more financial assistance from ODSP... [and] it attacks your pride”.

On a more positive note, upcoming changes to workplace retirement policies for teachers helped Noreen convince her husband she needed to retire, but the changes would mean a significant financial dependency for her family, and brought about the realization that these new plans are built based on the assumption that people are well. “I knew in my current situation where ... [my plan] forks out \$4000 a month on drugs, the plans they were offering retired teachers ... one had an annual limit of \$2000 [and] that was their gold plan. I said well, that does me to the first two weeks of January and then what? I’m \$50,000 a year people [LAUGHS]. I know you don’t want sick people and you don’t like old people because we have drugs, but you really don’t want sick people”. Noreen explained how her choices were limited but there was an option where “you can stay with ... [the] plan you had with your board and just pay 100% of the premiums” out of pocket. For Noreen, this meant “basically the premiums are \$1000 a month, but for me, it’s still worth it, right?”. She went on to explain how this was the only option she had and how these programs “just abandon people when they are retired”.

In summary, from the participant’s stories it is evident that a number of specific workplace disability and retirement practices systems and policies, in addition to the formalized ODSP, CPP Disability, and CPP retirement supports are built on the assumption that people are well and able-bodied. Many of the discussed practices, systems and policies also fail to recognize or account for the women’s complex and intersectional identities, and create a number of barriers to their navigation. The uncertainty produced in the interaction of these women with uncertain bodies, and the practices, systems and policies they engage with, contributes to the ongoing need for navigation of their identity. The uncertainty also contributes to the tensions they face in deciding whether to access supports because of the implications that are, or may be produced.

6.4 Theme Four – Filling the Gap

The women's stories demonstrate how they had to navigate workplace and governmental, retirement and disability practices, systems and policies within the current socio-political context and how these practices, systems, and policies often failed to recognize or account for their complex and intersectional identities. The women encountered a number of challenges navigating these practices, systems, and policies and often felt their needs were not met and their reality not fully understood within them. As the women shared their stories of navigating these systems and the challenges they faced, they also shared the practical things they needed to do in order to 'make ends meet'. This theme discusses the practical solutions the women employed to 'fill the gaps' in the practices, systems and policies because supports were either not available, did not fit their reality, did not meet their needs, or were made so difficult to access that the women had to come up with their own pragmatic solutions.

Judy discussed how there were a number of things she never imagined she would have to do to "make ends meet". She explained, "I've got a mortgage, a small mortgage, but it's a mortgage nonetheless and I've got to make payments. I've got taxes [and] I've got a sick daughter. Thank god I owned my own car at the time, but I ended up having to remortgage my house to make ends meet. That sucks. It's a very scary, very immobilizing fear... [and] you're left to your own devices really trying to figure out how to get ahead, how to manage everything. Looking back at this, how the hell did I do it? I don't know how the hell I did it". Eventually, Judy was forced to work "under the table" due to "financial necessity" because she was unable to survive on what she received as a single woman with MS who was retired on ODSP. "I had to clean a little bit when I had the energy and when I had the opportunity to make a little bit of money to help out. It's been cash, you know. I've had to do it, I had to! Had to! There is no ifs and or buts about it. You have to eat, you have to have a roof over your head, it's as simple as that. So I've had to take cleaning jobs which have branched into kind of being a personal health advocate for some seniors... It gives you a reason to get up every day, [and] the money" is very much needed". She explained how I never thought I would have to "lie about my

income, but what it all comes down to is you do what you have to do. What you absolutely have to do. Omission is lying. It's omitting about how much I bring in".

Despite having two incomes, Amanda's family was unable to afford the cost of her medications even with some financial support from her workplace benefits and they made the difficult decision to stop treatment. "I remember saying to him [the doctor] at one of my appointments that this is really expensive, and I don't think I can do it. Then he said oh ... and he kind of went to a petty change jar and said well the drug company gives us money sometimes to help people and he cut me a cheque for \$1200 or something". This was not the only instance where a drug company became a source of financial support for participants. Knowing her family could not afford the ongoing cost of her medications, Amanda also frequently volunteered to take part in a number of drug studies to offset treatment costs. After assessing her case at the end of a trial Amanda explained how "the study was essentially over but that the drug company had agreed to supply people in the study with another 4 years...also through that they gave me the application through Trillium. So I was accepted into the Trillium Program as well with the deductible...So the drug company picked up the \$3000 cost of the deductible".

Despite the negative nursing culture surrounding accommodation in Carissa's workplace, Carissa knew she needed to prioritize routine in order to manage her limitations and maintain working and took action to do so. "When I went to the permanent 3-11, 8 hour shifts, I knew at that point that the routine was really important. That was my purpose in doing a regular shift, to develop a routine to feel the best I could".

Billie drew on her longstanding faith and attributed her belief in GOD and his protection to how she has been able to deal with the challenges of working and living with MS. "I haven't had any exacerbations since I've been retired. I have not. I can say that ... I believe God has had something to do with that. I can't attribute it all to the pills and stuff like that. I do believe God directs the doctors". Billie added how "I have done very well, and all my worrying was for not, because the lord looks out for his and that's what he's done. It's time to let go and that's what I did ... Let go and let god".

After the marginalizing and challenging disability half-time application and appeal process, because Noreen refused to re-apply for these supports and prioritize her own physical and mental health, she found a way to creatively extend her working tenure at almost her full wage through sick day usage. “Right in the middle of when I was sick, like before I started taking days off ... [they wanted to change] the [sick day] rules. The initial rule was that they would be building in short term disability into your sick days so you would ... only get a certain number of regular sick days a year but then they had this other thing where you could get 60% of your pay for an extension of this many days. In the end ... it worked in my benefit because that meant I could continue to work ... [using] sick days ... at 90% of my salary [because the changes were never implemented]. That wasn’t their intent, but it worked out for me because I don’t think I would have lasted as long because you still need your money right? You have to eat”.

The women also drew on their social capital in certain instances and shared the ways they would work around the system based on who they knew or the connections they had. After not having a flare up in 13 years, Carissa found herself without a neurologist and no longer a patient in the MS Clinic. Needing to be seen desperately and unable to get answers or an appointment, Carissa took matters into her own hands. “They’re telling me I can’t see a neurologist until January or February and [it is June]. I said well, that doesn’t help me because you know, what do I tell work? They are going to want to know my situation and I have to see a neurologist to have that confirmation of what I’m supposed to do. So I took it upon myself through my job and my connections to contact [NAME OF DR REMOVED] at [NAME OF HOSPITAL REMOVED] through email and he was lovely, and he got right back to me”. Carissa explained further that “it was just in my luck that I worked at the hospital and I knew [NAME OF DR REMOVED] how I got in which is I don’t think fair but at that time I needed what I needed so I did it myself”.

In summary, all the women encountered gaps within existing practices, systems, and policies, and needed to use their own pragmatic solutions to fill these gaps in order to meet their immediate needs. This theme is about the implications of having workplaces, practices, systems, and policies that are not built to understand the women’s complex, intersectional reality, or the uncertainty associated with their changed bodies and the

uncertainty produced at the intersections of their changed bodies and environments they do not 'fit' in.

6.5 Conclusion

In conclusion, the women's narratives reveal a number of lived consequences of involuntary retirement and how involuntary retirement and such consequences are shaped within the current socio-political context. Participants conveyed living in a 'shortened temporal frame', experiencing many aspects of their life as tenuous and beyond their control and, in turn, feeling unable to think about and plan for the future. This led to their need to re-imagine what retirement would look like given the multiple levels of uncertainty they had to navigate. The women spoke about how uncertainty existed at the level of their bodies and around finances. They acknowledged how MS produced a changed body and how through MS, they had a changed relationship with their body; one marked by unpredictability, lack of dependability, and loss of confidence. Within workplaces, they experienced challenges given expectations for a 'certain', able body, and inabilities for workplaces to accommodate or understand a changed, uncertain body. A changed or uncertain body was often problematized in ableist environments, and the interaction between someone with an uncertain body and ableist environmental features revealed a lack of fit, and produced a number of consequences for participants. As an example, they discussed the implications of poorly designed practices, systems and policies that privilege able-bodied individuals, and how accommodations or supports were unavailable, or were made so difficult to access they became unfeasible to pursue or realize. These interactions also produced financial uncertainty in various ways for the women. Participants also had to navigate their identity and experienced a number of tensions doing so. They expressed hesitation around being seen as 'the sick guy' or to 'play the MS card', despite realising that there were certain instances where evoking their disability status was necessary in order to receive necessary accommodations or supports. This hesitancy often stemmed from their desire to appear 'normal' or as a 'good' workers, from witnessed or perceived fear of discrimination or marginalization, the negative social meaning assigned to disability, the fear they would be perceived as 'using' the system, and negotiating other social roles such as wife, mother, or provider.

They also experienced tension navigating their identity in relation to age and the other social identities they occupied. The women's stories highlighted that many practices, systems, and policies they encountered failed to understand their complex, intersectional reality of being women with MS who are retired, and showed how these systems and structures failed to meet the needs they had. These practices, systems, and policies are often based on the assumption that people are well, and trajectories of work and retirement or individual needs are relatively homogenous among the population. Finally, the women discussed the strategies and practical solutions they had to employ in order to fill the gaps in the practices, systems, and policies they engaged with. They also discussed the implications of these poorly designed practices, systems and policies that prioritize able-bodied individuals, and how accommodations or supports are either not available, or were made too difficult to access.

Chapter 7

7 Discussion and Conclusion

The main objectives of this thesis were to reveal the lived consequences of involuntary retirement for women with MS who had to leave work before they had planned or were ready to, and to critically interrogate how such retirement and its consequences are shaped by larger social and political practices, systems and policies. Drawing on disability studies perspectives with an intersectional lens and critical life course theory, a critical lens was applied within and across individual narratives to unearth a number of important findings related to how involuntary retirement is socio-politically shaped and a number of lived consequences the participants faced.

In particular, it was found that participants conveyed the need to re-imagine what retirement would look like given the multiple levels of uncertainty they had to navigate. Uncertainty existed at the level of their bodies and around finances. Participants also had to navigate their identity and experienced a number of tensions doing so. Overall, the women's stories highlighted how many existing practices, systems and policies fail to attend to the complex, intersectional reality of being a women with MS as a worker or as a retiree, leading to failures to meet their needs, and ultimately exacerbating or shaping disability and various forms of uncertainty. The women encountered practices, systems, and policies that were often built on the assumption that people are well, able-bodied, and predicated on the belief that individual needs and work and retirement trajectories are relatively homogenous or always within individual control. Finally, in the face of unmet needs, the women discussed the strategies they used to fill the gaps in the practices, systems, and policies. However, despite being able to employ strategies to assist in navigating uncertainty, these women experienced failures in the systems and structures that were designed to support them.

In this chapter, I draw on the critical theoretical perspectives introduced in Chapter three to discuss key findings and illuminate what has been revealed regarding the socio-political shaping of involuntary retirement for women with MS and the lived

consequences of involuntary retirement. Three key points are discussed in relation to the socio-political shaping of retirement. First, I address stigma and marginalization and its implications for if and how workplace accommodations are and can be negotiated. In the second section, I address problematics related to disability policy in Canada. I then turn to how the absence of an intersectional lens within policies leads to further marginalization.

Next, three key points are discussed in relation to the lived consequences of involuntary retirement. First, I discuss how precarity provides a lens to advance understanding of the perpetuation of participants experiences of instability, unpredictability and uncertainty. In the second section, I address how participants have to re-imagine their idealized retirements in the face of existing social policies and discourse embedded with discriminatory conceptualizations. I then turn to how the lives of the participants became increasingly more precarious after involuntary retirement, given the downloading of responsibilities to manage precarity due to gaps in existing systems and structures.

7.1 The Socio-Political Shaping of Involuntary Retirement

Drawing upon a critical disability lens, this study extends current work beyond the dominant biomedical framing around why people with MS struggle to maintain sustainable employment and ultimately leave work (Dyck & Jongbloed, 2000; Edgley, Sullivan, & Dehoux, 1991; Jongbloed, 1996; Julian et al., 2008; Kornblith, LaRocca, & Baum, 1986; LaRocca, Kalb, Scheinberg, & Kendall, 1985; Morales-Gonzales, Benito-Leon, Rivera-Navarro, Mitchell, & GEDMA Study Group, 2004; O'Connor, Cano, Torrenta, Thompson, & Playford, 2005; Smith & Arnett, 2005); showing that involuntary retirement and consequences are socio-politically constructed through ageist, ableist, and sexist, practices, systems and policies. It also fills another significant gap around the articulated need to further attend to gender in relation to experiences and consequences of involuntary retirement for women with disabilities (Denton et al., 2010a). Finally, it responds to the need for critical Canadian based, intersectional, qualitative research to explore the socio-political shaping of 'choices' around work and retirement for women with MS to broaden understandings of the transition out of work and into involuntary

retirement and consequences produced for women with MS within the current socio-political context. In this section, I draw attention to three key aspects of the socio-political shaping of involuntary retirement: the stigma of disability; the narrow conceptualizations of disability pervasive in governmental policy; and the importance of addressing intersectionality in practices, systems, and policies.

7.1.1 The Stigma of Disability: Shaping Reluctance and Constructing Barriers to Workplace Accommodations

Stigma, as defined by Goffman (1963) is a social process that involves having an “attribute that is deeply discrediting” and that reduces someone “from a whole and usual person to a tainted, discounted one” (p. 3). Existing literature has shown that stigmatized individuals, in particular contexts, are those who have or are believed to possess a social identity that is devalued and have characteristics or attributes that position them as inferior (Crocker, Major, & Steele, 1998), ‘spoiled’ or less than ‘normal’ individuals (Dovidio, Major & Crocker, 2000). Ableism highlights the stigma of someone being discredited related to bodily difference. Ableism is “a form of discrimination based on the perception that being able-bodied is the normal human condition and is superior to being disabled” (Hehir, 2005, p. 10). Given the persistence and pervasiveness of ableism in Western society, having MS and not being ‘able-bodied’ was experienced by the women as a discrediting attribute resulting in a number of challenges in the context of work.

Within Western societies, various systems and structures are underpinned by ableism such that chronic illness is marked as non-normative, or something that should be avoided, and thus, often marked out as stigmatizing. In turn, Western societies view illness as ‘abnormal’ and there is a likelihood that if an individual chooses to disclose their chronic illness they may be perceived negatively (Hansen & Philo, 2007; Stone et al., 2014) or face a range of social consequences. Goffman (1963) discussed how individuals may employ various strategies to manage their situation or condition in ways that protect themselves, in relation to self-perception and social identity, against being stigmatized. In the context of this study, this was evident in the ways the participants thought about, investigated, and engaged in decision making regarding accessing accommodations. The stigma that was present often shaped hesitancy to consider

accommodations needed to manage their changing limitations, or when they did access accommodations, fear of discrimination limited the amount or type they would seek. The actual or perceived presence of stigma appeared as a dominant factor shaping their desire to not ‘play the MS card’ because being perceived as a ‘bad worker’, being seen as ‘not normal’, unable to do their job, or having the legitimacy of their illness questioned, reinforced their deviation from ‘normalcy’. In other instances, where the participants did in fact ask for accommodations, some experienced doubt about their need for accommodations from employers. It appears that this occurred because the employers held particular able-bodied expectations and assumptions about the capabilities of workers, and had difficulty reconciling that tasks they considered ‘easy’ for an able bodied person could be difficult or experienced differently by others. This ultimately led to questioning around the legitimacy of their need for accommodation. For example, when Carissa was experiencing a relapse and could not attend orientation, upon notifying her nurse manager she would not be able to attend orientation for her new position, it was questioned what was difficult about just sitting in a chair and why she could not do that. In this instance, Carissa appeared well, and described that the employer did not deem sitting in a chair a necessarily difficult task. However, it appears that what the employer did not understand and was critical of, was that a particular task could be challenging for someone who was experiencing an MS exacerbation even if symptoms were not visible. The employer expected Carissa to act like a ‘normal’ person and be able to do things that a ‘normal’ person would not find difficult. In doing so, Carissa was stigmatized because her body did not function in a particular way. More important, was the apparent failure of the employer to acknowledge and provide accommodation even when a need was expressed; this created a barrier as the employer could not acknowledge or understand the difference.

The findings of this study align with a growing evidence base on the disclosure of chronic illness and stigmatization (Crooks, Chouinard, & Wilton, 2008; Driedger, 2003; Hansen & Philo, 2007; i2i, 2018; Moss & Dyck, 1996; Stone, Crooks, & Owen, 2014). Specifically in relation to MS, Cook, Germano, and Stadler (2016), based on results of a survey conducted with 53 participants, concluded that “many adults living with MS may be concerned that they will be the target of social stigma because of their illness [and

that] these concerns are associated with disease concealment (p. 78). Cook and colleagues (2016) emphasized that although participants did not internalize stigma, they nonetheless engaged in concealment efforts when they anticipated stigma would be experienced from others. These findings highlight how stigma is often imposed on individuals with MS rather than individuals with MS perceiving themselves negatively in that way (Cook, Germano, & Stadler, 2016).

Given the negative social meaning associated with disability and how disability is viewed as 'abnormal' or less than in a Western ableist context, sharing a diagnosis of chronic illness creates the opportunity for anyone who discloses to be regarded negatively (Stone, Crooks, & Owen, 2014) or stigmatized based on these bodily or cognitive differences. This threat of stigma often motivated women with chronic illness to withhold their diagnoses or need for workplace accommodation for fear of ramifications (Driedger, 2003), despite the fact that women who did disclose were sometimes able to access the required accommodations and how sharing removed the need to conceal important parts of their identity (Crooks, Chouinard, & Wilton, 2008). The results of this study align with these findings and demonstrate the tension women experienced around negotiating accommodations. For the participants, stigma appeared to be a driving force behind this tension. The women frequently discussed the tension in trying to balance the need to disclose their diagnosis and/or particular symptoms in order to access necessary accommodations and supports, with their fear of being identified or labelled as a person with a disability. For example, when considering whether she would need to return to work on a part-time basis after retiring, Amanda wrestled with having to let her potential employer know that the job they needed someone to fill was beyond her capabilities physically and cognitively, and the fear she experienced that she would be passed over for the opportunity if they knew she had limitations. This fear was intensified by her economic need and her fear that employers would not re-hire her with limitations when they could easily get someone else to do all four jobs instead of the one or two she was capable of.

This study, and the stories of the participants, illustrate that ableism extends beyond stigma involved in discourse and interpersonal relations in the workplace, and is in fact,

built into the very systems purportedly designed to support continued work for those with chronic illness. This is enlivened in Noreen's story, who found the process of applying for supports so traumatizing she refused to even consider re-applying despite her need for continued accommodations. The difficult and marginalizing investigation processes, designed around visible, permanent illnesses, could not account for her invisible, chronic illness; calling into question the legitimacy of her illness and forcing her to go without the supports she needed in order to prioritize her own physical health and mental well-being. This example demonstrates how attitudes and practices involving questioning the legitimacy of illness and the need for accommodations were built into the very processes or systems for accessing accommodations. Recently, The MS in the 21st Century initiative has sought to raise awareness and encourage dialogue between persons with MS (PwMS) and health care practitioners (HCPs) around a number of challenges and unmet needs identified from both perspectives, including the invisibility of symptoms (Rieckmann et al., 2018). Through a series of open forum workshops, PwMS identified challenges around the communication, identification, monitoring and detection of the invisible/'hidden' symptoms of MS during standard medical consultations as an unmet need (Rieckmann et al., 2018). Consistent with the findings of this study, this group called for, a greater recognition and consideration of the impact of invisible/'hidden' symptoms as necessary to promote positive QOL for PwMS and address unmet needs (Rieckmann et al., 2018). This study extends the call for a greater awareness of and attention to the invisible/hidden symptoms within MS disease management (Rieckmann et al., 2018) and in workplace management and accommodation systems.

Taken together, the findings of this study demonstrate how women with MS experienced stigma and were socially marginalized through interactions with peers and employers, and discursively marginalized as they navigated negative constructed meanings around having a chronic illness, being seen as a 'bad worker' or 'not normal'. Furthermore, findings show how participants were systematically marginalized by systems designed and made available to support them when in need of accommodation; leaving them without the resources necessary to continue their employment, and shaping their ultimate exit from the workforce.

In Chapter two I outlined the need for flexible employment options and the implementation of workplace and governmental accommodations to support the ongoing employment of individuals with chronic illness in general (Denton, Plenderleith, & Chowhan, 2013b) and women with MS specifically (Jongbloed, 1996:1998). This study further illuminates gaps in the accommodation process, and demonstrates the inability and inflexibility of the current processes and systems to accommodate the complex lived realities of intermittent chronic illness like MS or the uncertain body it produces. These accommodations are organized around particular conceptualizations of disability as permanent, sustained, visible, and predictable; changing needs and uncertainty are not accounted for in this conceptualization of disability. As a result, the inflexibility left the women with little opportunity to have accommodations that were responsive to their changing needs within a system that could not account for the distinct needs of women with MS. This misfit results in their needs being dismissed, obscured and unmet. The inability of systems to account for the lived realities of women MS had significant consequences for participants including the exacerbation of their illness, feelings of isolation and vulnerability, and the narrowing of options for remaining in the workforce. For example, when Noreen tried accessing accommodations before applying for half time disability, she was steered away from accommodations as an option because her changing limitations would make them difficult to secure and execute, and they could not be guaranteed beyond the immediate school term.

The challenges associated with accommodating chronic illness in the workplace are well documented in the literature (Banks, Chaykowski, & Slotsve, 2013; Lysaght & Krupa, 2014). Accommodation policy and processes are complex and shaped by the variable nature of chronic illness and the dynamic nature of the work environment (Lysaght & Krupa, 2014). Existing research substantiates the complexity associated with accommodating chronic illnesses in the workplace. For example, discussed in the literature are challenges around the individuality of chronic illness and how it may manifest differently over time; the impact of an illness on specific tasks being dependent upon specific job demands and the nature of the workplace; and the capacity of a workplace to respond to accommodation needs are based on a multitude of factors including but not limited to financial stability, policy structure, and experience (Lysaght

& Krupa, 2014). The complexity of accommodation has resulted in a troubling “accommodation gap,” whereby around 35% of Canadians do not receive necessary accommodation in order to work productively or at all in Canadian workplaces (Banks et al., 2013). This gap is produced by the “shortfall between those accommodations which persons with disabilities require in order to work, and those workplace accommodations which they actually receive” (Banks et al., 2013, p. 295). They also found that as age and severity of the illness increased, so did the magnitude of the accommodation gap (Banks et al., 2013). This existing literature sheds light on some of the challenging aspects of accommodating individuals with unpredictable chronic illnesses like MS, and despite the nature of illness itself often being problematized, it reveals the systemic nature of the problem (Banks et al., 2013).

The results of this study locate the problem as the interaction of a person with chronic illness within systems and structures that posit a narrow conceptualization of disability as a static state that creates accommodations, policies, and mechanisms that do not support individuals with intermittent and unpredictable illnesses. Ultimately, what this means for the Canadian workforce is that “potentially productive workers are being lost” (Banks et al., 2013, p. 301) as individuals are having to retire involuntarily. As a possible solution, recognizing that the needs of an individual and the nature of chronic illness itself may change or fluctuate over time, in their book chapter, Popiel, Porch, and Dolan (2014) discuss how accommodations in the workplace should be routinely reviewed, re-evaluated and include individually tailored plans given that each employee context is unique. Unfortunately, within the context of this study, that was not the case for participants.

7.1.2 Problematics in Canadian Disability Policy: Narrow Conceptualizations of Disability and Inflexibility

Disability policy in Canada has been described as fragmented, incoherent, challenging to navigate and a ‘hit-or-miss’ affair (Cameron & Valentine, 2001; Jongbloed, 2003; McColl & Jongbloed, 2006; Prince, 2004) causing frustration and disappointment (Prince, 2004) for many. For over 40 years, research has pointed to challenges within Canadian Disability Policy. For example, Brown (1977) points to the “lively awareness

of the many deficiencies in policies for disabled people in Canada” (p. 548). More recently, the literature has highlighted how narrow or restrictive conceptualizations of disability in existing social policy can have a wide range of negative effects (Smith-Carrier et al., 2020). From the participant’s stories, it is clear that disability policy is falling short.

One of the key ways existing federal and provincial disability policy is falling short for individuals with intermittent chronic illnesses is through its narrow conceptualizations of disability. As previously discussed in Chapter one, there is considerable discussion in the literature surrounding eligibility for governmental disability programs such as the Ontario Disability Support Program (ODSP) (provincial) and Canada Pension Plan (CPP) Disability (federal), and how narrow conceptualizations of disability inform the development of restrictive criteria (Longfield & Bennett, 2003; May, 2019; Smith-Carrier et al., 2020; The Standing Senate Committee on Social Affairs, Science and Technology, 2006) which often restricts and excludes individuals with intermittent chronic illnesses like MS

One key critique has been that these policies incorporate conceptualizations of disability that are dichotomous, that is, an individual is either disabled or not. For example, the definition of disability embedded in CPP Disability requires that a mental or physical disability regularly stops an individual from doing any kind of substantially gainful work and that the disability is long-term, of indefinite duration, or will probably result in death (Government of Canada, 2020a). Problematically, particularly for persons with MS, the assumption that individuals are either consistently disabled or not, does not align for those who move unpredictably between periods of illness and wellness, because “life with episodic disabilities is not that black and white” (May, 2019, p. 22). Aligned with this argument, the MS Society of Canada (2008) has pointed to the ways in which the episodic nature of MS means that many individuals are excluded from particular programs, such as CPP disability, given the lack of sensitivity to the nature of MS.

The exclusions created by such definitions means that individuals may also be excluded from the benefits and supports provided to those who are deemed ‘disabled’ (Longfield &

Bennett, 2003; May, 2019; Smith-Carrier et al., 2020; The Standing Senate Committee on Social Affairs, Science and Technology, 2006). This type of exclusion is documented in the literature (Lightman, Vick, Herd, & Mitchell, 2009; May, 2019; Jackson, 2005) and aligns with the findings of this study. For example, Lightman and Colleagues (2009) argue that “since there are no official categories for persons with episodic disabilities to fit in because they are not entirely well (and employable) nor entirely sick (and unemployable), they are [often] judged as 'not disabled enough' within the existing parameters of assistance” (para. 1) and their lived realities are excluded. Similarly, Jackson (2005) points to how individuals living with chronic illness “threaten the logic of [classificatory] system[s] by straddling boundaries [where they] are neither properly well nor properly sick[, which] puts them betwixt and between the statuses of sickness and well” (p. 345).

The dichotomous definitions of disability in existing social policy have been challenged by academic literature showing a space ‘in between’ illness and wellness where the lived realities of people living with intermittent chronic illnesses exist, and the need for non-dichotomous conceptualizations of disability. However, there is limited existing literature that attempts to theorize the space in between wellness and illness (Vick & Lightman, 2010; Vick, 2012). Moss and Dyck (2002) theorize that women with chronic illness exist

“in-between” hegemonic discourses— not quite ill but not quite healthy, almost disabled, and almost abled, very nearly normal yet nearly deviant. [Such] women are unassimilated others, existing at the interstices of specific identities (pp. 33-34).

Vick (2012) acknowledges how a state of ‘in-between’ forces recognition of the need to theorize disability diversely and question how bodies have been traditionally been interpreted in society. Finally, Asenjo (1988) discusses how when we explore the contact of two words such as disability/ability and two realities such as health/illness, a middle, hidden one emerges ... In the landscape of in-between, nothing has fixed boundaries, nor is anything closed; terms are open doors, paths crisscrossed by countless other paths ... a blended inclusion [of] every possible standpoint. (p. 44-62).

The reality is that “experientially, women with complex episodic disabilities live in two seemingly contradictory worlds: the world of the healthy (and sometimes employable) and the world of the ill (and sometimes unemployable)” (Vick & Lightman, 2010, p. 77). Moss and Dyck (2002) draw attention to the shifting nature of chronic illness and how the reality of living with chronic illness can be like being sick and healthy at the same time.

[The] capricious movement inherent in chronic illness sets up individuals to experience both vigour and lethargy, remissions and flare-ups, “good days” and “bad days” – sometimes months apart, sometimes within minutes of each other, sometimes in tandem. For most chronic illness, recurrence of sickness or health is indeterminable ... for the most part chronic illness is laced with uncertainty (Moss & Dyck, 2002, p. 14-16).

Marks (1997) talks about how the lived realities of individuals with chronic illness are a challenging group to categorize because they seem to permeate the boundaries between sickness and wellness by violating the terms of the sick role with never fully recovering, and at the same time, not always capable of full participation.

Despite literature highlighting the existence of a space ‘in between’ illness and wellness and the challenges these lived realities may present in relation to social policy, there remains a failure on the part of social policy makers, in a Canadian context, to address this space ‘in between’ or modify to understand or accommodate these lived realities. From a disability policy perspective, this is uncharted territory because considering realities that fall ‘in-between’ are not the way systems and structures have been designed to support, or conditioned to think about disability. From a government report on improving the lives of individuals with episodic disabilities, one of the speakers very eloquently states how “what I learned then, which is still relevant today, is that the current disability income and support programs in Canada were not designed with episodic disability in mind” (May, 2019, p. 20). This notion of lived realities that reside somewhere ‘in-between’ sickness and health challenges the ways things have always been done.

The implications of this pervasive dichotomous approach to disability within federal and provincial disability policy are highlighted in stories shared by women in this study. For example, Carissa spoke about filling out her application for CPP disability benefits and the difficulty she faced trying to convey her reality within the narrow confines of the disability application; specifically how standard yes or no questions are insufficient and excluding. She explained how asking if she could perform activities of daily living was not a simple yes or no answer, much like how she is not ‘sick’ or ‘well’ consistently. Her inability to convey an honest account of her lived reality meant that in order to access benefits she very much needed; she was forced to withhold pieces of her identity as a woman with MS.

Another key way disability policy is falling short is through how they restrict flexible movement in and out of the workforce for individuals with intermittent chronic illness. Unlike more traditionally stable health conditions like spinal cord injuries where the production of bodily differences may remain relatively static, episodic disabilities can cycle between periods of illness and wellness that may require people to leave the workforce suddenly and return unexpectedly as symptoms resolve or improve (Canadian Working Group on HIV and Rehabilitation, 2007). As they are currently set up, existing policies and programs do not allow for the flexible movement in and out of the workforce and onto disability supports as circumstances change, and “these programs fail to match the unpredictability of the impact of episodic disability with a corresponding flexibility” (May, 2019, p. 25). In recent years, ODSP has introduced a rapid reinstatement option that would allow previously qualified recipients to bypass the disability adjudication process in an attempt to streamline this process, however, this process is not without limitation. Individuals are only eligible to take part in this process “if the Application for Assistance Part 1 is less than one year old or was updated within the last 12 months” (Government of Ontario, 2020e) and they meet other specific financial and eligibility criteria. This process was introduced “as an incentive for ODSP recipients to become employed by reducing the risk of not re-qualifying for ODSP if the employment does not work out” (Government of Ontario, 2020e, ¶6). However, what it does not consider is that due to exacerbations in particular chronic illnesses like MS, individuals may need to, repeatedly and unpredictably, cycle in and out of the workforce, and these periods may or

may not occur within the 12 month period of a previous application. What this means for individuals with episodic illnesses is that there is a risk that once they leave ODSP during a period of improvement in their chronic illness, it is possible that they may not be eligible for future supports should they experience another exacerbation or health challenge; creating barriers to supporting continued employment of people with episodic chronic illnesses and potentially creating a disincentive to leaving ODSP.

The participants in this study experienced tension around the lack of flexible movement between work and disability benefits first hand. For example, Judy discussed her desire to still contribute in a meaningful way when she was feeling 'well', however, she had to do so in secret because if ODSP found out she was 'capable' of working, they would take her benefits away. Carissa also shared the guilt she felt on 'good' days while off on disability and struggled with whether she should return to work, however, she always came back to the fact that things could get bad again suddenly and there were no processes in place that would allow her to take the time she would need to recover.

Taken together, narrow conceptualizations of disability in Canadian social policy position disability as dichotomous, and fail to realize or accommodate the need for flexible movement in and out of the workforce for individuals living with an episodic chronic illness like MS; ultimately leaving individuals with no other options but to leave work, and further perpetuating uncertainty in their lives. The findings of this study serve to unveil the challenges of living amongst such uncertainty. The 'shortened temporal frame' the women found themselves living in made thinking about and planning for the future challenging due to the uncertainty produced in disability policies and systems that did not address the nature of MS, and ultimately led to a number of consequences for them.

Already navigating a considerable amount of uncertainty, trying to convey the complexity of their reality within systems and structures that are not designed for experiences outside the 'normal' characterizations of disability and illness created an additional layer of discrimination within disability itself. The women in this study discussed extensively the challenges around the inflexibility of accommodations and supports, the difficulty conveying their reality within the confines of standardized assessments, and how overwhelming it was to navigate gathering information about

available resources and the process of applying for them. Ultimately, many were left to come up with their own pragmatic solutions in order to get by and fill these gaps. Individuals with fluctuating illnesses like MS may become further disadvantaged as they are left to ‘fall through the cracks’ from periods of cycling in and out of the workforce (Mayson, Vander Plaats, & Wintermute, 2005; Driedger, 2003). The findings complement existing literature that points to the inflexibility of existing systems and structures and how they are incongruent with intermittent types of chronic illnesses like MS (Lightman et al., 2009; Longfield & Bennett, 2003; Standing Committee on Human Resources Development and the Status of Persons with Disabilities, 2001). Findings from this study also highlight how experiences of disability are not homogenous, and point to the need to consider multiple experiences of disability resulting from the intersections of different identity markers.

7.1.3 Intersectional Lived Realities: The Importance of Addressing Intersectionality in Practices, Systems, And Policies

The results of this study illustrate the complex, intersectional nature of the lives of women with MS. Intersectionality describes how individuals simultaneously occupy multiple social identities, for example, age, race, gender, disability, sexual orientation, and class (Crenshaw, 1989:1991). These social identities intersect or overlap with one another to produce varying experiences of privilege or marginalization. Intersectionality attempts to “understand what is created and experienced at the intersection of two or more axes of oppression” (Hankivsky et al., 2010, p. 3) and is a lens to examine how systems of oppression (e.g. ageism, sexism, racism, etc.) overlap or intersect to produce unique and distinct experiences of marginalization for individuals and collectives who are facing multiple forms of discrimination (Crenshaw, 2016).

In addition to lack of fit within systems designed in ways aligned with ableism, the results of this study highlight how many of these systems also consider disability in isolation from other aspects of the women’s lives. Chapter two outlined the clear need to expand understanding around the intersection of disability with other social identities in order to understand the multiple lived realities of women with chronic illness. From Chapter three, it was also discussed how perhaps the most important reason to study

disability and the meaning of disability, is to understand human difference and how the concept of disability is central to understanding the social construction of other identity markers such as gender, race, class, and other ways that individuals differentiate themselves from one another (Ferguson & Nusbaum, 2012). This study's findings further reinforce the imperative of taking an intersectional lens to illustrate how, unfortunately, existing systems and structures fail to take into consideration the interplay between social categories such as age, race, gender, class, and other social categories with disability.

As one example, the findings of this study attend to ways in which the lived realities produced at the intersection of age and disability status are incongruent with socially constructed expectations of retirement timing, and who counts as retired built into policy frameworks. Not only are they incongruent with the lived realities the participants in this study are facing, but in fact, ideal constructions of the life course they are expected to attain are still linked to the work and retirement constructions of able-bodied, Caucasian, men (Priestly, 2000). Socially constructed expectations also unfairly construct homogenous social categorizations, both in practice and rhetoric, that privilege some older adults (Krekula & Vickerstaff, 2020) and particular kinds of illness or 'disability' over others. The results of this study echoed these findings and demonstrated that participants faced challenges that arose from the intersection of age and disability. While participants considered themselves 'retired', they described navigating feelings of being 'off-time' because many of their peers were not yet retired. This was because their retirement came earlier in life than they had planned, wanted or were ready for, and they could no longer meet the 'normative' conceptualizations of what a retiree is expected to look like, and at what age retirement 'should' occur. Furthermore, for many, despite considering themselves 'retired', retirement benefits could not be accessed until the age of 60 or 65, reinforcing that despite how they viewed themselves, when they were considered 'retired' was shaped by 'normative' conceptualizations of retirement tied to age markers and a model of retirement predicated on an able-bodied, normative life course.

Women's experiences of involuntary retirement were also shaped at the intersection of gender and disability. Discussed in the literature is the concept of the "second shift"

where women are ‘on duty’ in their daytime employment roles outside the household and then come home and are ‘on duty’ again with the demands of caregiving and family (Hochschild & Machung, 2012). What this means for women with chronic illness is that the socially constructed responsibility for caring by women never goes away, and in the presence of chronic illness, produces tensions around how women negotiate caring for themselves and maintaining employment on top of caregiving demands. In Chapter two, I illustrated how gendered responsibilities for care reduced the options women had to restructure work environments, ultimately impeding their ability to maintain employment and increasing their vulnerability (Dyck & Jongbloed, 2000). However, the results from this thesis extend the existing literature by demonstrating it is in fact far more complex, and that aspects of identity beyond gender and disability, like age, marital status and class, also shape women’s experiences of involuntary retirement. For example, Judy’s story illustrates that intersections of gender, disability, age, marital status and class, shaped how she navigated her employment and retirement as a single mother and sole provider with MS. Judy’s story highlights how the options for her life narrowed significantly after the breakdown of her marriage, devastating and costly divorce process, her daughter’s illness, loss of employment and associated financial challenges, and her diagnosis of MS.

In summary, this study’s findings illustrate the complex intersections of social categories in the lives of women with MS. In turn, systems and structures that assume individuals belong to only one identity category are unlikely to address the complexities of intersectionality, highlighting why these are important to address in policies, systems, and practices. The challenge remains that “policy frames ... people as all the same and therefore recommends solutions ... that disadvantage certain groups and are likely to lead to widening inequalities amongst those in retirement” (Krekula & Vickerstaff, 2020, p. 39). Broadening our understanding of the multiple, complex lived realities that people face is the first step in creating effective policy that meets the needs of individuals that are currently excluded by its singular focus.

7.2 The Lived Consequences of Involuntary Retirement

Extending beyond the social and political shaping of involuntarily retirement, the participants' narratives raised awareness of the lived consequences of involuntary retirement, particularly in terms of on-going tensions and prolonged implications. Three consequences are discussed in this section: the socio-political production of multi-faced precarity; the need to retreat from an imagined, idealized retirement; and the production of unmet needs and 'filling the gaps' due to systemic failures.

7.2.1 The Socio-Political Production of Multi-Faced Precarity

After their diagnosis of MS, the women's lives became increasingly unstable, uncertain, and unpredictable, in ways not necessitated by their body, but produced through social and political forces. The concept of precarity can be used as a lens to make sense of this instability, uncertainty, and unpredictability, and to articulate how vulnerability was perpetuated in their lives. Precarity is defined as "possessing insufficient material resources ... [and] an existence defined by insecurity and unpredictability, which can influence people's thoughts and behaviors" (Craciun & Flick, 2014, p. 79). Grenier and Colleagues (2017) echo that to be precarious is to be vulnerable or at risk, further highlighting precarity as multidimensional and socio-politically produced: "precarity is multidimensional, may emerge at particular social locations, and/or extend from particular transitions or intersecting disadvantages carried into late life" (Grenier et al., 2019, p. 2). Within contemporary socio-political contexts, critical scholarship has highlighted how precarity is produced through social and political forces within contemporary neoliberal contexts that increasingly individualize responsibility for maintenance of security amongst declining social protection (Grenier & Phillipson, 2018; Grenier et al., 2019).

A number of studies describe the experience of uncertainty amongst persons with MS (Alschuler & Beier, 2015; Courts, Buchanan, & Werstlein, 2004; Dennison, Smith, Bradbury, & Galea, 2016; Stone et al., 2014; Olsson, Lexell, & Söderberg, 2008). A large source of uncertainty for the women in this study was at the level of their body. They

described how there were a number of bodily and cognitive changes produced through MS, how they had a changed relationship with their bodies, and how they no longer felt able to count on their body or see themselves as dependable. They spoke to the difficulties of living with an uncertain body. These findings are consistent with literature related to the MS body. In their phenomenological study, van der Meide, Teunissen, Collard, Visse, and Visser (2018) discuss the uncertainty associated with the changing nature of the MS body. They identify how individuals with MS may shift between four experiential dimensions of their body: bodily uncertainty, having a precious body, being a different body, and the mindful body (van der Meide et al., 2018). Highlighting the changing nature of the MS body over time, results showed: how the body may not behave naturally or as expected, necessitating on-going planning in daily life and important moments; incongruence between what the body can do and what the individual (or self) wants to do, leading to previously inherent movements or actions becoming conscious acts requiring careful attention; differences between, and difficulty reconciling, the body as it has lived in the past and how it is experienced in the present; and living in a state of continuous body alertness, encompassing on-going adaptation to a changing body (van der Meide et al., 2018). Carel (2016) argues how for most individuals, “we do not normally question that our body will continue to function in a similar fashion to the way in which it has in the past” (p. 89), however, similar to findings by van der Meide and Colleagues (2018), participants in this thesis were constantly aware not only of their body and its limitations, but how they live amongst multiple layers of uncertainty.

Participants in this study, not only experienced uncertainty at the level of their bodies, but also in relation to finances, benefits and supports, relationships, and housing. In other words, for women in this study, living with a precarious body led to a precarious life. This was because of their interaction with discriminatory, ableist, ageist and sexist policies, systems and practices, leading to a misfit between people with precarious bodies within these systems and structures unable to accommodate an uncertain body.

Grenier and Phillipson (2018) have proposed that uncertainty and instability “when experienced over time and in relation to conditions such as austerity, can deepen disadvantage” (p. S15). Precarity may become more apparent in single living situations

(Grenier et al., 2017; Portacolone, 2013), when individuals require care (Grenier et al., 2017; Grenier & Phillipson, 2018; Polivka & Luo, 2017), or deepen as ongoing unmet needs continue to disadvantage (Evans & McBride, 2017). This was evident in the women's stories. Their stories included numerous instances of experiencing deepening disadvantage and highlighted the relationship between disadvantage and varying social and political circumstances and resources in their lives. The women spoke about how over time they were forced to make difficult choices out of necessity, learned to live with less, went without necessary medications, food and social participation, and had to do things they never thought they would have to in order to make ends meet. Their stories demonstrate the socio-political production of precarity in the ways their experiences of disadvantage and marginalization deepened after they were forced to leave work involuntarily. Their stories also show their layered experiences of uncertainty and disadvantage after MS, as they attempted to negotiate within systems that marginalized on the basis of intersecting social locations, produced the precarious life they are now living. In reality, their choices were constrained which perpetuated their precarity, because they lacked or were unable to attain necessary resources to resolve their precarity.

Reinforcing the centrality of an intersectional lens, results showed that experiences of precarity also varied among participants as they were quite heterogenous in their work, social, financial, educational, family and marital situations. There was variation among the women at what point in their careers they had to leave work involuntarily and the level of disadvantage they experienced. All participants voiced that they had to leave before they had planned, wanted or were ready to, and described how their lives became increasingly more precarious after involuntary retirement. Three of the participants were either married or in a common law partnership, while two were single. All partnered participants spoke of the protective impact of having a spouse, however, this was of course dependent on the health and capacities of their spouse. For example, Noreen's spouse and his income provided the space to choose not to re-apply for disability half time a second time and take on the burden of paying 100% of drug cost deductibles (\$1000 per month) after retirement to avoid the loss of essential benefits. Carissa on the other hand, was grateful for the income her spouse provided, but expressed fear over the

future and level of continued support she would have if he was not willing to deal with his alcoholism. Billie, whose spouse was also on disability before his passing, spoke of him as a major source of support for her and how financially, his lost income means she has to make things stretch now.

The results of this study also illustrate how precarity was produced through the ways drug benefits were structured. For example, knowing she would not be able to afford the cost of her medications, Amanda would frequently sign up for drug trials so the medication costs would be covered upon the loss of employment benefits. However, she repeatedly expressed her concerns for when those ended and whether she would be left without needed medications because she could not cover the out of pocket costs and no other sources of financial support were available to her. In this instance, age and lack of eligibility for retirement supports also contributed to precarity given restrictions in what she could apply for or have covered. From these examples, it is apparent how increasing precariousness in the participants lives was “an intrinsic sense of instability and insecurity stemming from a lack of, or difficulty to, access essential resources” (Portacolone, 2013, p. 166), and how precarity is produced when individuals encounter retreating public resources and find themselves individually responsible for their situation (Portacolone, 2013). Using precarity as a lens to examine the unmet needs and multidimensional uncertainty in the participant’s lives “provides language to explain how altered social conditions and disadvantage over time may expose ... people to greater risk of injury, unmet need, and neglect” (Grenier & Phillipson, 2018, p. S16).

7.2.2 The Need to Retreat from an Imagined, Idealized Retirement

According to Pickard (2016), “the life course ... [remains] one of the most powerful vehicles of an age system that is key to the governing, ordering and meaning-making processes of society” (p. 66). From a critical life course perspective, retirement itself is proposed to be a discursively constructed, socio-politically shaped aspect of the life course (Kohli, 1986). In Western societies, since the 1950s and 1960s, ways of thinking about planning for retirement, embedded in social policies, media and social expectations, have largely been built around a ‘normative’ male-focused conceptualization of a Fordist life course with distinct, age-based transitions throughout

the life course characterized by a period of education, followed by long tenured, full time employment until reaching a pensioned retirement (Kohli, 2007). Within this study, another consequence of involuntary retirement was the need to retreat from an imagined, idealized retirement, and subsequently re-imagine or accept a less idealized retirement.

This life course has been critiqued for its gendered, ableist nature. Critical scholars point out that what many fail to consider is that normative conceptualizations of the life course, at any point, have never adequately captured the reality of many individuals including women and those living with chronic illness. In fact, Priestley (2000) discussed how “it is the image of [a] non-disabled white, heterosexual, male adult that has been central to the idealised life course constructions” (Priestley, 2000, p. 426) and therefore, “it is, thus, men who constitute the norm that women, [the aged, and those living with chronic illness] are expected to strive to imitate” (Krekula & Vickerstaff, 2020, p. 35).

The ways such ‘idealized’ conceptualizations of the life course are embedded in both policy and in discourse further marginalized the participants. Within this study, participants conveyed living within what I described as a ‘shortened temporal frame’. This was defined as the inability to move forward, to plan or think about the future because their focus, involuntarily, remains on immediate need or circumstance as so much in their life is uncertain, tenuous, and beyond their control. Retirement feels very different for these women because they are having to navigate an understanding of retirement and the life course that does not align with the ‘ideal’ framed by societal discourse and embedded in policies. This concept builds on and further explicates the previous work of Bishop and Hobson (2015) who described a ‘shortened planning horizon’ amongst people living with long term physical disability. In this earlier study, when asking participants whether they were confident or concerned about their futures, many described how they had not thought about it. Charmaz (2006) also discussed a similar concept, specifically that of ‘living one day at a time’. She discussed how in her qualitative work done with persons with chronic illness, “people frequently referred to living one day at a time when they ... faced continued uncertainty” (p. 83). For Charmaz (2006), “living one day at a time pulls the person into the present and pushes back past futures (the futures the person projected before illness or before this round of illness)” (p.

83). The results from the current study highlight not only the participants' inability to plan, but adds further dimension to these concepts by highlighting how the multiple layers of uncertainty that exist, contribute to a precarious life that does not afford participants the ability to think about and plan for retirement in 'normative' ways.

The women also shared stories about the expectations they had for themselves in retirement and how those are no longer realizable. Critical scholars have proposed that the increasing individualization of retirement, and the promotion of 'positive aging', informed by neoliberal rationality has exacerbated inequities between those with the resources and conditions that enable idealized forms of retirement, and those without (Laliberte Rudman, 2015). For the participants, MS was a significant aspect of their lives that changed the way they were able to think about and plan for the future. In retirement discourse there is an assumption that "planning for retirement will lead to positive outcomes" (Noone, Stephens, & Alpass, 2009, p. 296). However, from the findings of this study, typical ways of thinking about, planning and preparing for retirement were abruptly interrupted and were not recoverable even when some had taken part in previous planning. The findings also show that for the women in the study who live with multiple layers of uncertainty in various aspects of their lives, these assumptions are particularly problematic because they assume that individuals are able to plan for or anticipate uncertainty, have an unwavering degree of control over their futures, and the resources to 'age well' and 'successfully' into retirement by normative standards. What has become problematic is the way these assumptions have been taken up in social policy and influenced public policy changes around age eligibility and extending the working lives of individuals. Changes to existing Canadian social policies have created favorable conditions for individuals who can plan for and are willing and able to continue working past 'standard' retirement ages (Krekula & Vickerstaff, 2017:2020; Krekula, Engström, & Alvinus, 2017; Smeaton & White, 2016; Vickerstaff & Loretto, 2017). Unfortunately, this approach "neglect[s] ... growing differences in longevity [and positions] ... privileged aging as the starting point" (Krekula & Vickerstaff, 2020, p. 29).

In summary, the participants articulated a number of ways they were considered, or considered themselves, 'off-time' from 'normative' pathways of the life course. Although

individuals living with chronic illnesses may share common occurrences, milestones, or experiences with able-bodied individuals, they do also have distinct experiences and trajectories (Yorkston, McMullan, Molton, & Jensen, 2010; Zarb, 1993). For these individuals, gendered, ableist, or ageist systems and structures can actually deepen the disadvantage they already face. Unfortunately, according to social standards, the individuals who are unable to meet ‘normative’ standards of work and retirement transitions continue to be viewed as ‘less than’ or problematic because “normative concepts of age appropriateness (or generational location) have ... [become a] yardstick by which to measure [...] people’s human rights” (Priestley, 2001, p. 247).

7.2.3 ‘Filling the Gaps’ Due to Systemic Failures

Within their increasingly precarious lives, participants attempted to find practical solutions to unmet needs created through systemic failures. Consistent with “the neoliberal ideology of downloading responsibility onto citizens” (Pinkerton & Davis, 2015, p. 308), this study exemplifies how the responsibility for managing precarity was placed on the women themselves, and the challenges associated with this. Findings reveal the efforts they took to manage their precarity, pointing to strengths of the women but also to failures of systems and structures that were designed to support them.

What this meant for the women in this study was that they had to negotiate and manage precarity at an individual level where they often found themselves shouldering the “impossible task of finding biographical solutions to systematic contradictions” (Beck, 2007, p. 685) where “the consequences of the action are borne by the subject alone, who is also solely responsible for them” (Lemke, 2001, p. 201). The results of this study revealed how social problems are being shifted to individuals who may not have resources or capabilities to be considered productive, responsible citizens in accord with neoliberal logic. It is important to highlight that not only could the women in this study not live up to these standards, but that these standards themselves are exclusionary. The stories participants shared were filled with instances where the systems and structures they interacted with failed them, and how they were left to fill the gaps themselves in order to meet the needs they had. For example, unable to afford her medications, Amanda found unlikely support in the drug companies that offered to offset the costs of her

medications and take care of the Trillium application process and deductible for her. Similarly, after expressing the financial hardship of MS medication costs, Carissa's doctor gave her \$1200 to cover medication expenses on behalf of the drug company. Judy worked under the table cleaning and as a personal care advocate when she was feeling well enough to earn extra money because she was unable to live on her ODSP income. Finally, Billie sought financial support from her parents when she was struggling because she had no other options. These results are particularly concerning because they highlight how neoliberal rationalities create issues of disparity and raise inequities among already marginalized individuals (Laliberte Rudman, 2013).

7.3 Boundaries and Strengths

This thesis is not without boundaries. This was a critical narrative study done within a particular context at a particular time in history. The aim of the study was not for generalizability, but to raise insights about the socio-political context in which these women with MS live, and to highlight ways in which lived consequences of involuntary retirement were socially and politically shaped. There is no claim that the lives of these women can be generalized to all women with MS in Canada or in any other context. My claim is that by investigating the lives of these women and situating them in a particular context, using critical theory, I can point to problems in systems and structures. This thesis is not about sharing these women's lives in an unmediated way; it is an analysis of their lives from a critical viewpoint that served to reveal problems in existing systems and structures, and raise awareness of the consequences they produce in people's lives.

Another boundary was the limit on what intersections I could address in the thesis. For example, all participants self-identified as white, heterosexual, non-immigrants which limited my ability to explore how social identities including, but not limited to, race, sexual orientation, and immigration status may influence the experience of involuntary retirement and the consequences produced. Although multiple intersections were present in the lives of participants, it is important to recognize that there were particular intersections I was not able to attend to that could shape or produce different outcomes.

Despite these boundaries, this study also had a number of strengths. Although only five women were included in this study, the highly immersive, in-depth, multi-stage data collection and analysis, and collaborative co-construction process ensured rich data and a particular depth to the analysis. A particular strength of this critical narrative study was, despite the limits noted in the above paragraph, the variety of women's experiences that provided both a contrasting and complementary rich narrative sample. Had recruitment and time challenges not presented themselves, and other financial resources been available, the findings could have been further enriched by the narratives of other women. This study also makes an important contribution to the limited body of Canadian research around involuntary retirement for people living with chronic illness. More so, it fills important gaps in the literature: it explores involuntary retirement qualitatively through an intersectional and critical perspective to provide rich accounts of what retirement for women with MS in Ontario, Canada may look like. In doing so, this study has pushed understanding of this issue beyond the biomedical framing of symptoms as the dominant predictor of work outcomes and provided an opportunity to interrogate the impact of social and political forces in people's lives.

7.4 Implications

Critical scholarship aims to reveal the effects that taken-for-granted assumptions, expectations, and values have on individual lives, as a means to raise critical awareness of the socio-political production of inequities and the need for social change (Given, 2008). In this section, I will address implications of this work for research, policy, and critical scholarship.

7.4.1 Research Implications

Choosing to use critical narrative inquiry as a methodology was very important to me as a researcher because not only did it allow me to co-construct rich, participant narratives, but it also enabled a space for the women to tell their stories in the way they wanted to tell them. According to Ferguson and Nusbaum (2012), research around illness and disability is full of contributions from individuals living without chronic illness or experiences of disability and that 'people with disabilities' and their families need to

participate, influence, and do the research; not just be researched. Methodologically, this study employed a tailor made data collection and analysis approach to achieve this goal, with the addition of a phase for consultation and co-construction. The addition of this stage allowed for discussion and refinement of the narrative, and gave me and the participants an opportunity to complete the process together. Approaching this topic using a critical narrative format also allowed me to achieve a particular depth in my analysis and richness in my data, because of the immersive involvement of the participants as we constructed the narratives together. This process also created an opportunity for the voices of women with MS to be heard, and an entire space within this thesis for their narratives to exist on their own. Further research should involve and expand upon building collaborations with persons with chronic illness in this way, to further the collaborative nature of research outlined as essential within disability studies (Ferguson & Nusbaum, 2012).

The results of this study also show how the participants, who had to retire before the ordained time in policy, were put into a liminal place marked by precarity, and demonstrates how ‘normative’ constructions of the life course do not fit. As previously stated in this chapter, there is a lack of research around this theoretical space between illness and wellness (Vick & Lightman, 2010; 2012), despite it being the place where the lived realities of many people living with complex, episodic chronic illnesses reside (Ironside et al., 2003; Vick & Lightman, 2010; Vick, 2012). Further research needs to continue to focus efforts towards critically exploring the lived realities of people living with chronic illness, and the theoretical space between illness and wellness where these complex, intersectional lived realities exist.

7.4.2 Policy Implications: Workplace Accommodations and Social Policy

The results of this study add to the body of critical literature highlighting the need for changes in workplace practices, systems, and policies, as well as broader governmental social policies. In relation to workplace practices, systems, and policies, there is a need to modify accommodations in workplaces to acknowledge and address the unpredictable, uncertain nature of episodic chronic illnesses like MS for individuals. Future research

around the investigation, development, and implementation of accommodations that allow for degrees of flexibility in order to accommodate the uncertain lived realities of persons with chronic illness is needed. Existing literature has articulated the need for better services and policies to support re-entry, and maintenance of employment (Rumrill Jr. et al., 2016), while calling for increased flexibility in workplace and governmental accommodations, and employment options for individuals with disabilities (Denton et al., 2013b) and those with MS (Jongbloed, 1996:1998). However, when contextualized with what is shared in the participant's stories, many of these problematics persist or have not been addressed. Also needed is more focused attention on the ways in which stigma and ableism are actually embedded within existing processes purportedly designed to support continued presence in the workforce. In their book on Stigma, Brewis and Wutich (2019) spoke about how

just noticing our own stigmatizing thoughts and behaviours is the first, and sometimes trickiest, crucial step [,] ... knowing that social norms can change - and becoming part of the vanguard making that change happen – is the next step...[, and that] knowledge about stigma isn't enough. We need empathy and action, too [in order for things to change moving forward] (p. 205).

They also discuss how it is the pervasive and unquestioned nature of stigma that makes it so insidious, and how the persistence of stigmatizing ideas and actions as 'normal' or 'right', will continue to sustain the design and implementation of interventions that reinforce intersecting stigmas (Brewis & Wutich, 2019); further disadvantaging the already vulnerable. Hansen and Philo (2007) argue the need to find new ways of attending to the lived realities of the impaired body within non-disabled spaces. Their work encourages thinking around the need to shift away from the notion of accommodations that aim to have disabled people do things 'normatively' as able-bodied individuals would do them, or to fit impaired bodies within the shape and expectations of non-disabled spaces; to thinking about how spaces can be created to do things differently (Hansen & Philo, 2007). This thesis has shown a number of instances where these workplace systems and structures perpetuated vulnerability and further marginalized the participants. More careful examination of these practices, and the important role they

play in shaping the lives of individuals with chronic illness who are navigating them, is needed.

In relation to social policy, these results illuminate the need for policy reformation informed by an intersectional lens. As noted above, participant's stories demonstrate diverse challenges that arose from the intersection of multiple social identities, and unmet needs arose from the lack of consideration of such intersections within policies and inter-related systems. As well, there is a need to question the dominance of dichotomous classifications in disability policy in order to enhance responsiveness to the changing and unpredictable nature of chronic illness; particularly because the intermittent nature of episodic disabilities can leave individuals ineligible for the most common income support options. For example, CPP Disability most likely will not be an option for many persons with intermittent illness because of the severity condition and expectation for a long duration (May, 2019). Further work is needed to know what those changes would look like, and to apply an intersectional lens in the reconfiguration of systems and policies.

The findings from this study also add to the growing body of literature revealing the contradictions and lived consequences of neoliberalism for those citizens unable to take up its activating agenda. As the needs of participants continued to go unmet over the long term, there was an ongoing production and perpetuation of precarity. This precarity was multidimensional and interlinked in these women's lives, highlighting the impossibility of taking up individual responsibility to resolve socially produced issues. Neoliberalism assumes that individuals should be able to manage risk, exercise choice and ensure their own futures (Rose, 1999), but the findings of this thesis demonstrate that is not the case; showing a contradiction of neoliberalism in that it obscures people who, no matter what they do as an individual, cannot overcome the risks that they are experiencing. Similar critiques exist for older adults as a group who has been left out of the neoliberal definition of a good citizen deserving of support (Grenier et al., 2019). This study highlights a particular group that has become invisible, and who are not considered when social policies are conceptualized or put into place. Finally, this work raises questions about how the policies on which existing systems and structures are based and those

theories or political rationalities that underpin them, should best serve people living with chronic illness moving forward.

7.4.3 Implications for Critical Scholarship

The results from this study show how a critical lens enables a shift away from biomedical determinism, highlighting the need for continued work that shifts the dominant tendency to locate challenges of maintaining employment in symptomatology of MS, and attends to social and political factors shaping involuntary retirement and associated consequences. Applying a critical life course lens also enabled me to place individual lives in socio-political constructed normative expectations, and in the policies and systems built on such expectations. I suggest that this lens be used in future research in this area to further situate individual ‘choice’ within socio-political conditions. A disability studies lens enabled me to further augment the need to shift away from biomedicalization and towards the socio-political shaping of workforce exit and involuntary retirement in MS while acknowledging ‘difference’, and the complexity associated with ‘difference’ through the addition of an intersectional lens. Disability studies perspectives provided a critical lens to examine how existing social mechanisms marginalize and exclude disabled people (Cameron & Moore, 2014). With the integration of an intersectional lens to study difference, it helped to problematize the ways ‘difference’ is managed or attended to within existing disability systems and structures in the current socio-political context. Future research should continue to integrate an intersectional lens into research around the production and experience of disability (Ferguson & Nusbaum, 2012; Goethals, De Schauwer, & Van Hove, 2015) in order to broaden understanding of the production of disability and its consequences.

7.5 Return to Reflexivity

My critical voice. I have struggled to find my critical voice and it is an ongoing struggle. To this day, I do not even know if I have it right. Over the course of this thesis, my supervisor and I had plenty of discussions about my struggle and excitement in finding my critical voice and using a critical lens; however, I would say that even at the end of this thesis, I am still struggling. This has been the most difficult process for me, and I was

not prepared for the continued failure of ‘not being critical enough’ and having to re-work sections over and over again. If I am being honest, this entire thesis took a major toll on my confidence. I have questioned my abilities as a researcher, because some of the challenges I have encountered in this thesis have been very difficult. Taking on this new lens has been a real struggle. I have shed many tears in this process and felt foggy and lost. Yet, I could never stop. I knew deep down I could complete this, that I had to finish, and I had to create a space for these stories to exist and a way for these problems to be revealed and examined. When I listen to other critical researchers speak and I hear them so naturally be able to say exactly what is wrong with ‘a thing’ and speak so eloquently and ‘critically’, I wonder if I will ever get to that point. On version 15 of the literature review, I was seriously questioning whether it would ever get to the place I needed it to; this can be a difficult thing to face and not something that many people speak about in grad school. At the very end when you are so close, you have invested so much, and you feel and know so many different things, sometimes it is difficult to see through the fog. My advice at this point – keep going and you can do it.

On another note, studying women with chronic illness and being the child of a mother with chronic illness, I knew, but never fully realized how complex chronic illness can be and how it may have complicated so many things in our lives beyond what I understood. As a mother myself, it has challenged some of the ableist assumptions I had about decisions that were made when I was a child, or instances where my mother was not able to do the things I wanted. I think that when I began to study these women’s lives, I began to realize how I myself may have been holding onto some ableist assumptions, even to this day, that I was trying to critique. These experiences with my participants helped me to understand some things that I personalized when, perhaps, there were some broader things happening there; making me grateful for the ability to understand better and reflect even after so many years. It has also given me a deeper appreciation for all the things and the wonderful life my mother gave us, despite everything else she must have been navigating and struggling with that we never knew about.

7.6 Conclusion

This critical narrative study presented the narratives of five women with MS living in Ontario, Canada to reveal the lived consequences of involuntary retirement and unpack how these lived consequences and such retirement were shaped within the current socio-political context. Informed by critical life course theory and disability studies perspectives with an intersectional lens, findings revealed four overarching themes. These included: 1) ‘Negotiating the Disconnect between Retirement as Imagined, and Retirement as Lived’; 2) ‘The Production of Consequences in Navigating Ableist Environments Requiring Certainty and the Intersection of Bodily and Financial Uncertainty,’ 3) ‘The Failure of Practices, Systems and Policies to Understand the Complex, Intersectional Reality of Women with MS, and the Navigation of Identity Tensions’; and 4) ‘Filling the Gap’. In addition to responding to calls to add a critical lens to this area of study, implications for research, policy and future use of critical theoretical lens are forwarded.

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Appendices

Appendix 1: Ethics Approval



**Western
Research**

Research Ethics

**Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice**

Principal Investigator: Dr. Debbie Rudman
Department & Institution: Health Sciences/Occupational Therapy,

Review Type: Delegated
HSREB File Number: 107737
Study Title: The Socio-Political Shaping and Lived Consequences of Involuntary Retirement for Women with Multiple Sclerosis in Ontario: A Critical Narrative Study

HSREB Initial Approval Date: April 21, 2016
HSREB Expiry Date: April 21, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Letter of Information & Consent	Revised Letter of Information and Consent (Appendix 3) - Clean Version	2016/03/14
Other	Appendix 11 - References - January 25, 2016	2016/01/25
Data Collection Form/Case Report Form	Appendix 10 - Participant Information Sheet and General Inclusion Criteria Checklist - January 25, 2016	2016/01/25
Recruitment Items	Appendix 8 - Recruitment Social Media and Listserv Ad - January 25, 2016	2016/01/25
Recruitment Items	Appendix 9 - Recruitment Mailing Letter of Invitation - January 25, 2016	2016/01/25
Recruitment Items	Appendix 6 - Recruitment Newspaper Ad - January 25, 2016	2016/01/25
Recruitment Items	Appendix 7 - Recruitment Email Letter of Invitation - January 25, 2016	2016/01/25
Recruitment Items	Appendix 5 - Recruitment Postcard PDF - January 25, 2016	2016/01/25
Recruitment Items	Appendix 5 - Recruitment Postcard PPT - January 25, 2016	2016/01/25
Recruitment Items	Appendix 4 - Recruitment Flyer - January 25, 2016	2016/01/25
Other	Appendix 2 - MS and Non-MS Support Services - January 25, 2016	2016/01/25
Data Collection Form/Case Report Form	Appendix 1 - Demographic Questionnaire - January 25, 2016	2016/01/25
Western University Protocol		2016/03/14

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer to Contact for Further Information: Erika Basile ___ Nicole Kaniki ___ Grace Kelly ___ Katelyn Harris ___ Vikki Tran

Appendix 2: Letter of Information (LOI) and Consent Form



LETTER OF INFORMATION AND CONSENT

STUDY TITLE: The Socio-Political Shaping and Lived Consequences of Involuntary Retirement for Women with Multiple Sclerosis in Ontario: A Critical Narrative Study

PRINCIPAL INVESTIGATOR: Dr. Debbie Rudman, PhD, OT Reg. (Ont.), Western University, School of Occupational Therapy, Phone: (XXX) XXX-XXXX xXXXXX, Email: XXXXXXXX@uwo.ca

CO-INVESTIGATORS: Kristen A. Bishop, PhD (Cand.) Western University, Phone: (XXX) XXX-XXXX, Email: XXXXXXXX@uwo.ca and Professor Sandra Hobson MAEd, LLD, OT Reg, FCAOT, Western University, Email: XXXXXXXX@uwo.ca

EMERGENCY CONTACT NUMBER: (XXX) XXX-XXX

Invitation for Participation:

You are being invited to participate in this research study focused on understanding the lived consequences of involuntary retirement for women with MS in Ontario. This study aims to increase understanding about the consequences of having to leave work and retire involuntarily for women aging with MS, and raise awareness of how involuntary retirement and these consequences are influenced by current social and political practices, systems, and policies. This study is being conducted by a research team headed by Debbie Rudman as the principal investigator, Kristen Bishop as the student investigator, and Professor Sandra Hobson as a co-investigator.

Purpose of this Letter:

The purpose of this letter is to provide you with the information required for you to make an informed decision regarding participation in this research. Please take the time to read this carefully and feel free to ask questions if anything is unclear. This study will involve three interviews with five to eight women with MS in London, Ontario or surrounding areas.

You are being asked to participate as an individual who has the following characteristics:

- 1) Female,
- 2) Diagnosed with Multiple Sclerosis (MS) or probable MS,
- 3) Consider yourself to be 'retired',

- 4) Has spent at least 6 years in the paid labour force, and
- 5) Had to leave work before you had planned, wanted or were ready to.

You may not be able to participant in this study if you:

- 1) Have any congenital, developmental, or psychiatric disabilities
- 2) If you do not speak English or do not have the cognitive abilities to provide informed consent or take part in an in-depth interview

Background of this Study:

Previous research demonstrates that women with MS often face challenges related to work and retirement due to the combined effects of gender, aging, and having a chronic illness. For example, women with MS experience involuntary or early retirement at higher rates than the general population and often have to leave work before they had planned, leading to a number of financial and lived consequences. Exploring the lived consequences, including and beyond finances, of early or involuntary retirement for women with MS and how these consequences and involuntary retirement are shaped within existing social and political practices, policies and systems is an important part of this project.

Purpose of this Study:

The purposes of this study are to 1) critically examine how the process of involuntary retirement is socially-politically shaped for women with MS, and 2) raise awareness of the lived consequences of involuntary retirement.

Enrollment and Length of Study:

You will be asked to take part in three interviews to build a narrative about how you came to be retired and your life after retirement.

Five to eight participants will be recruited for this study, and the overall study will take approximately two years to complete. However, it is expected that each participant will be involved in the study for a period of three to four months in order to complete four data collection sessions.

Study Design and Procedures:

This study uses critical narrative inquiry, an approach to research that focuses on stories and how people share their experiences through stories. This approach will be used to understand how women experience the involuntary retirement process and what their life is like after retirement.

To build a narrative with you, you will be asked to participate in three audio-taped interview sessions with the student investigator. Each interview will last between one and two and a half hours and will take place at a location mutually agreed upon by you and the student investigator. In order to ensure the accuracy and completeness of the information gathered, the interviews will be audio-recorded.

During the first interview, the study investigator will ask you two questions. The first question is asked to hear your story about how you came to be retired and the second will ask for information about what your life is like after retirement. During the same visit, once you are finished sharing your story and answering the two questions, a break for both participant and study investigator will be taken. After the break, the interview will continue and the investigator will ask for more story about the topics already discussed. In addition, you will be asked to complete a demographic questionnaire that collects information about some basic descriptive characteristics, and can choose to do this on your own or with the study investigator.

Finally, we will collect your contact information, so we are able to keep contact with you throughout the study (e.g. reminders of upcoming meetings), and to share the completed narratives and study results after they have been completed and published if you wish to receive a copy. This first session is expected to last between one and two and a half hours.

In the second interview, you will be asked additional questions based on the content of your first interview. The parameters of the questions will always be tied back to the research questions and how you came to be retired and life in retirement. This interview is expected to last between one and two and a half hours and will be completed at least a week after the first interview is completed.

Prior to the third and final interview, you will receive a copy of the completed narrative created from information gathered in the first and second interview, and will be given time to reflect on it. This final interview creates an opportunity to discuss the narrative and gain comments, feedback, or suggestions for editing. After this process is completed, the narrative will be amended by the investigator based on the discussion.

Risks:

There is minimal risk to participation. You are free to choose what you will and will not share with the study investigator. In telling your story, you may reflect on situations in your life that were difficult and this could trigger a variety of emotions. You are free to discontinue your participation at any time. Contact information for local counselling or support services will also be made available, if requested.

Any personal information that may identify you as a participant will be kept confidential, and you will have control over when and where data collection occurs. In the final study report and all publications or presentations related to this study, your name and personal information will never be used. Pseudonyms will be used in all documents, publications, and presentations.

Benefits:

There are no known direct benefits to you associated with your participation in this research. Your participation may help us enhance understanding related to the lived consequences of involuntary retirement and how the social and political environments impact and shape the experiences of women with MS who have to leave work involuntarily. We also hope that the findings from this study can be used to demonstrate how the current Canadian socio-political

context may create inequality for how women are negotiating leaving work and transitioning into retirement.

Audio Recording:

For the purpose of data collection, interviews will be audio recorded using a digital audio recording device. These recordings will then be transcribed by a member of the research team in order to complete the analysis of the data.

Compensation:

There will be no cost to you as a result of taking part in this study. If you decide to take part in this study, you will receive a stipend in the form of \$10 in Tim Horton's gift card (\$5 at the initial visit and \$5 at the last visit) to thank you for your valuable time, input, and dedication to the study. If you withdraw early, you will get to keep the \$5 gift card provided at the initial visit.

Privacy & Confidentiality:

All data collected will remain confidential and accessible only to the investigators of this study. When the results are presented or published, your name or identifying information will not appear.

All research data will be locked in a secure office at the Western University. All study materials will have identifying information removed and will be stored in a locked filing cabinet in a secure office or on a data key under password protection and encryption. Pseudonyms will be used in the final thesis, any study reports, publications, and presentations to protect your identity. If we find information we are required by law to disclose, we cannot guarantee confidentiality. All research data will be destroyed after 5 years. If you would like to review your interview transcripts any notes made during your interview, please let the study investigator know.

All printed data obtained from this study will be kept locked in the file cabinets and all electronic files will be saved in a password protected computer for at least 5 years after the study data (results) are published or presented.

Voluntary Participation:

You do not waive any legal rights by signing the consent form.

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. You may decide not to be in this study, or to be in the study now and then change your mind later. If you choose to enter the study and then decide to withdraw at a later time, all data collected about you during your participation in the study will be retained and used as part of the findings. Your decision to participate or not in this study will not affect your relationship with your physician, future care received, or MS organization contacts.

Contacts and Further Information:

If you have any questions about this study please contact Kristen Bishop at telephone number (XXX)-XXX-XXXX or by email at XXXXXXXX@uwo.ca or Dr. Debbie L. Rudman at (XXX)

XXX-XXXX ext. XXXXX. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Additionally, representative of the Lawson Quality Assurance (QA) Education program may look at study data for QA purposes.

If you have any questions about your rights as a research participant or the conduct of the study you may contact The Office of Research Ethics at Western University at XXX-XXX-XXXX or by email at XXXXXX@uwo.ca.

Publication:

If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please contact the research team.

Please keep this copy of the Information/Consent letter for your records.

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

STUDY TITLE: The Socio-Political Shaping and Lived Consequences of Involuntary Retirement for Women with Multiple Sclerosis in Ontario: A Critical Narrative Study

PRINCIPAL INVESTIGATOR: Dr. Debbie Rudman, PhD, OT Reg. (Ont.), Western University, School of Occupational Therapy, Phone: (XXX) XXX-XXXX xXXXXX, Email: XXXXXXXX@uwo.ca

CO-INVESTIGATORS: Kristen Bishop, PhD (Cand.) Western University, Phone: (XXX) XXX-XXXX, Email: XXXXXXXX@uwo.ca and Professor Sandra Hobson MAEd, LLD, OT Reg, FCAOT, Western University, Email: XXXXXXXX@uwo.ca

I have read the Letter of Information/Consent, I have had the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

Research participant or legally authorized representative:

Print name: _____ Signature: _____

Date: _____

Person responsible for obtaining informed consent:

Print name: _____ Signature: _____

Date: _____

Appendix 3: Participant Demographic Questionnaire

Age: _____

1) Relationship status (check all that apply):

- Single
- Married
- Common Law
- In a Relationship
- Separated
- Divorced
- Never partnered

2) Children

- None
- One
- Two
- Three
- Four
- Five or more

3) Year of onset of symptoms associated with MS:

4) Age at diagnosis or onset of MS (Please circle which item you are providing an age for):

5) At what age did you have to leave work?

6) Mobility Devices (Please check all that apply):

- None
- One Cane
- Two Canes
- One Crutch
- Two Crutches
- Walker
- Wheelchair
- Power Scooter

7) Education (Highest grade level completed)

- Less than high school
- High School
- Some College or university
- College Degree or Diploma (Please circle which)
- Bachelor's Degree
- Master's Degree
- PhD

8) Previous Field of Employment or Job Type

9) Date of 'retirement'

10) Current Income Sources (Please check all that apply)

- Registered Retirement Savings Plan (RRSP)
- Spousal Support/alimony
- Savings
- Ontario Disability Support Program (ODSP)
- Worker's Compensation (WSIB)
- Old Age Security (OAS)
- Guarantee Annual Income System (GAINS)
- Guaranteed Income Supplement (GIS)
- Canada Pension Plan Disability (CPP Disability)
- Canada Pension Plan Retirement (CPP Retirement)
- Inheritance from family or friend
- Assistance from family members
- Financial support from local organizations
- Other (please specify) _____

11) Financial Resources (Please describe the most suitable answer describing your financial resources)

I have:

- More than enough** money for what I want and need to do
- Enough** money for what I want and need to do
- Just barely enough** money for what I want and need to do
- Not enough** money for what I want and need to do

Curriculum Vitae

Name: Kristen A. Bishop

Post-secondary Education and Degrees: University of Western Ontario
London, Ontario, Canada
2005-2009 BHSc (Hons).

The University of Western Ontario
London, Ontario, Canada
2009-2011 MSc

The University of Western Ontario
London, Ontario, Canada
2011-2021 PhD

Honours and Awards: **Western Graduate Research Scholarship**
2009-2015

Canadian Association on Gerontology Divisional Best Poster
Vancouver, British Columbia, Canada
2012

Accelerating Translation of Knowledge to Community Practices Grant
Gerontological Society of America, Washington, D.C
2014

Related Work Experience

Graduate Teaching Assistant
The University of Western Ontario
2010-2014

Research Assistant
The University of Western Ontario
2009-2014

Research Associate
St. Joseph's Health Care, London, Ontario
2013-2014

Research Coordinator
St. Joseph's Health Care, London, Ontario
2015-2018

Research Assistant

The University of Western Ontario
2015-2016, 2019-Present

Research Associate

The University of Western Ontario
2020-Present

Publications:

Taneja, R., Sibbald, R., Elliott, L., Burke, E., **Bishop, K.A.**, Jones, P., & Goldszmidt, M. Exploring and reconciling discordance between documented and preferred resuscitation preferences for hospitalized patients: A Quality Improvement Study. *Canadian Journal of Anesthesia*, 26, 530-540. DOI: CAAN-D-20-00627R1

Taneja, R., Faden, L.Y., Schulz, V., Rawal, A., Miller, K., **Bishop, K.A.**, & Lingard, L. (2019). Advance care planning in community dwellers: A constructivist grounded theory study of values, preferences and conflicts. *Palliative Medicine*, 3(1), 66-73. DOI: 10.1177/0269216318803487

Freeman, S., **Bishop, K.A.**, Spirgiene, L., Koopmans, E., Botelho, F.C., Fyfe, T., Xiong, B., Patchett, S., & MacLeod, M. (2017). Factors affecting residents transition from long term care facilities to the community: a scoping review, *BMC Health Services Research*, 17: 689. DOI:10.1186/s12913-017-2571-y

Gutmanis, I., Hay, M., Shadd, J., Byrne, J., McCallum, S., **Bishop, K.A.**, Whitfield, P., & Faulds, C. (2017). Understanding bladder management on a palliative care unit: a grounded theory study, *International Journal of Palliative Care Nursing*, 23(3): 144-151. doi: 10.12968/ijpn.2017.23.3.144

Marston, H.R., Freeman, S., **Bishop, K.A.**, & Beech, C. (2016). A scoping review of digital gaming research involving older adults aged 85 and older. *Games for Health Journal*, 5(3): 157-74. doi: 10.1089/g4h.2015.0087

Bishop, K.A., & Hobson, S. (2015). Perceptions of the process of aging with adult-onset disability. *Perspectives Journal of the Canadian Gerontological Nursing Association*, 37(4), 6-19.

Bishop, K.A., & Hobson, S. (2012). Aging with an adult-onset physical disability: A scoping review (extended abstract). *International Journal of Integrated Care*, 12, 16 November.