Bodies in Transition: Geographies and Experiences of Men Living with Chronic Physical Illness

By Yuk Shing Tan, B.S.C. B.A

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree Master of Arts

McMaster University MASTER OF ARTS (2025) Hamilton, Ontario

TITLE: Bodies in Transition: Geographies and Experiences of Men Living with Chronic Physical Illness

AUTHOR: Yuk Shing Tan, B.S.C., B.A. (McMaster University)

SUPERVISOR: Dr. Robert Wilton

NUMBER OF PAGES: 124

Abstract

Culturally valued norms of masculinity are shaped by what disability scholars conceptualize as compulsory able-bodiedness/able-mindedness (McRuer, 2006; Kafer, 2013). For those living with disabilities and chronic illness, negotiating these cultural norms can be difficult. On one hand, there is pressure to approximate these norms in the pursuit of a valued social identity. On the other, bodily and mental constraints can make such a performance unsustainable, necessitating other approaches to the presentation of the self. Drawing from post-structural feminist geography and critical men's studies, my research contributes to the growing literature on the geographies of disabled masculinities. I seek to shed light on the practice of gender by men living with chronic illness, drawing from in-depth interviews with eleven respondents diagnosed with either Multiple Sclerosis or Fibromyalgia. Of these eleven participants, ten also engaged in a visual arts activity focused on illustrating their lived experiences. The men's stories reveal interconnected and evolving landscapes as their identities are called into question. Through strategic patterns of practice in the face of shifting and uncertain circumstances, the intersection of illness thus requires the men to craft (and recraft) a workable sense of self as they engage within and across spaces like the home, workplace, and social encounters. As such, my research highlights the embodied and relational nature of masculinity within a geographic context. Moreover, it demonstrates how alternate masculinities emerge alongside the contestation and reformulation of dominant, socially recognized forms, as men navigate their everyday lives as gendered individuals in a social world.

Key words: men, masculinity, geography, chronic illness, disability, identity

Acknowledgements

The journey behind the course of writing this thesis will forever be part of my life history that I will not forget. To the people who have journeyed with me through the entire process: such are the memories and stories I will share for years to come.

To the eleven respondents who participated in my research, thank you for taking the time and effort to share your stories and experiences. You are the foundation upon which this work is built, and without your contributions, this work would not be possible. Thank you also to April for facilitating many of the artworks. Your patience, care, and openness to communicate is evident to all.

To Dr. Rob Wilton, no words can express my gratitude to your continued patience and guidance. This thesis was by no means a short journey, but you have supported me all the way through. Thank you also for introducing me into this field of study where I learned the importance of listening to people's stories and recognizing its value therein.

Finally, a big thanks to friends and family. To Ryan and Jeremy, thank you for keeping me accountable and pushing me through the finish line.

To my parents, you are the best support a son could ask for.

Table of Contents

Chapter 1: Introduction

Over the past few decades, increasing scholarship has approached gender as a social construct—a critical and feminist lens that understands gender as produced and reproduced through relational and practice-based interactions within hierarchies of power, legitimacy, and oppression (Connell, 2005; Connell & Messerschmidt, 2005; Courtenay, 2009; Messerschmidt, 2016; Garland-Thomson, 2020). Through this framework, gendered practices are recognized as multiple and fluid, continually negotiated and renegotiated as they are embodied and shaped through personal experience, social interaction, spaces, and time. More specifically, scholarly work from the geographies of men's health and critical men's studies alike have emphasized the need to attend to the intersections of race, ethnicity, class, sexuality, and age in shaping gendered practices and relations (Brownlow, 2005; Hopkins, 2006; Garland-Thomson, 2020). Yet among these intersections, disability remains underexamined—especially as it is often framed as the antithesis of normative masculinity (Shakespeare 1999; Shuttleworth et al., 2012; Barret 2014; Wilton and Schormans, 2025).

From a critical perspective, disability is defined as the attribution of embodied deviance. However, it is not determined by the properties of bodies themselves but rather shaped by cultural expectations of what bodies should be or do (Garland-Thomson, 2020). As Shuttleworth et al. (2012) observe, disability and masculinity are often positioned as opposites—linked respectively with notions of (in)dependence and autonomy. Yet, conceptual work has increasingly moved beyond these static, binary definitions to embrace a more dynamic understanding of how gender and disability are lived and embodied. Nonetheless, by positioning disability as fundamentally at odds with all that the "ideal male" represents, it continues to be cast—often as a generic category—as a form of symbolic castration, associated with economic, social, and political exclusion and vulnerability that dominant constructions of masculinity are expected to reject (Shakespeare, 1999; Barrett, 2014). As Murphy (2001) notes, "dependency invades and erodes the very compact upon which association between adults is premised" (p. 199), threatening not only social relationships but also one's identity. These narratives not only marginalize disabled bodies but reinforce societal anxieties around frailty and mortality, positioning disability as something to be feared, pitied, or disavowed.

The lived experiences of day-to-day life, then, are shaped by pressures for men to embody hegemonic notions of economic productivity, virility, strength, and independence—pressures that serve to also isolate those who cannot or do not conform (Murphy, 2001). As such, navigating disabled masculinity complicates and challenges longstanding beliefs of gender that are seemingly at odds with each other, hence the need to approach such discourses from and with a range of lived experiences (Shuttleworth et al., 2012). This extends across all spaces of everyday living, including, for instance, the dynamics of care and emotional expression within the home, navigating the breadwinner role in the workplace, and managing the presentation of oneself through various manhood acts across a variety of social encounters and experiences of illness.

In its early stages, research and narratives on masculinity and disability have largely focused on men with acquired physical impairments, such as spinal cord injuries (Gerschick & Miller, 1997; Murphy, 2001). While foundational, this body of work has been critiqued for often positioning disability as a homogeneous category (Shuttleworth et al., 2012). As the field has developed, however, such monolithic portrayals of both gender and disability have been increasingly challenged—particularly as research has become more interdisciplinary, drawing on feminist geographical and sociological perspectives that approach these experiences through critical and intersectional lenses. In response to these limitations, scholars have called for greater sensitivity to how masculinities are lived and relationally embodied across a wider range of impairments, identities, and spaces (Connell & Messerschmidt, 2005; Manderson & Peake, 2005; Gorman-Murray & Hopkins, 2014)

For men living with chronic illnesses such as multiple sclerosis (MS) and fibromyalgia (FM), cultural relations of gender, power, and embodiment create tension between societal expectations of masculinity and the everyday realities of their conditions. Unlike visible or static impairments such as spinal cord injury, chronic physical illnesses are often marked by fluctuating symptoms, relapse, remission, and other changes—at times degenerative—that are not plainly noticeable. In this way, the presence of chronic illness introduces ongoing uncertainty and change into the lives of those affected, as well as the people around them. Indeed, men living with chronic illnesses must continuously renegotiate their identities and roles in response to changes in physical and mental capacity. The results are a set of unique experiences that hold the potential to complicate dominant narratives of both disability and masculinity alike, exposing the limits of socially constructed and normalized ideals of illness and gender. and pointing toward more flexible, adaptive, and often contested ways of being a man (Gibson et al., 2007).

In his personal narrative, the Body Silent, Murphy (2001) writes about how his experiences with degenerative illness—a benign yet invasive and growing tumour in his upper spinal cord that led to quadriplegia—has affected his everyday life. While the manifestation of his impairment was paralysis, Murphy describes his experience as an inevitable "metamorphosis" (p. 55) as his bodily capacity decreased over time. In his account, the introduction of illness permeated all aspects of life, including the identity he embodied in places like work, the home, and broader social spaces.

In the chapter on love and dependency, Murphy (2001) highlights the rigidity of cultural expectations around roles such as marriage and employment, arguing that men's social standing—particularly within the family—is closely tied to their ability to work. He notes how this norm continues to shape perceptions of masculinity despite shifts in family structures and labor participation. For disabled men, who may become economically dependent due to their impairments, this dependency further undermines their social status as men: a man who stays home is still widely seen as a failure, whereas a woman who does the same is viewed as a homemaker. In her essay, *The Right Not to Work*, Taylor (2004) expands on this connection between work and worth, highlighting how disabled people are often forced to adapt to—or exit—systems that fail to accommodate their embodied realities. Taylor questions why financial

independence remains so tightly bound to a person's value, as though economic productivity has become the primary marker of legitimate personhood.

This goes to illustrate the multiple and interrelated dimensions of embodying gender. Especially in the context of navigating disability, diverse, plural, and fluid experiences cannot be reduced to fixed characterizations or generalizations. As scholars such as Connell (2005) argue, the concept of masculinity is itself not a singular ideal or description, but multiple, contested, and always changing as it is performed across the reproductive arena. In this way, gender is the medium through which social practice is ordered, defined, and always in response to shifting contexts and lived experiences within structures of social relations and spaces (Connell, 2020). To this end, scholarship on masculinity and disability alike in recent years has continued to expand, exploring the intersections of, for instance, health-related practices, sport, and aging.

Research objectives

This thesis further addresses these gaps by focusing on men living with chronic physical illnesses and examining how they navigate masculinity within the constraints and possibilities created by their conditions. The objective of my research is to learn more about the lived experiences of these men and the extent to which their identities align with, resist, or reconfigure prevailing norms of masculinity in Canadian society. Specifically, my study seeks to understand the activities, perceptions, and relationships that shape their everyday lives and inform their sense of what it means to be a man. By investigating these lived experiences, this research interrogates—through a feminist geographical lens—the cultural assumptions underpinning hegemonic masculinity, exploring how men with chronic illnesses reimagine and embody their gendered identities in response to bodily limitations and societal expectations across various spaces and places.

Connell's (2005) framework of multiple masculinities provides the foundation for understanding the practice-based and hierarchical relation of gender. Hegemonic masculinity operates as a culturally exalted ideal, marginalizing those who do not align with its standards. As mentioned earlier, this creates a precarious position for disabled men, as their lived realities often challenge their capacity to embody such ideals. Yet, masculinity is neither static nor monolithic, and such fluidity and plurality opens opportunities for transformation and alternative masculinities to emerge.

Moreover, Gerschick and Miller's (1997) 3R framework—reformulation, reliance, and rejection—serves as a framework in approaching such processes. Some men reformulate their understanding of masculinity to align with their current capacities, while others rely on hegemonic norms as a means of maintaining identity and status. For others still, there is the potential for the rejection of hegemonic ideals, offering a critique that contests the very foundations of the gender order. These strategies reflect the complexity of living with chronic illness in a world structured by rigid expectations of normative masculinity. Even so, as scholars such as Light (2007) have warned, traditional hegemonic masculine discourses may sometimes

be entrenched in a given cultural space, leaving little room for new forms and practices of masculinity.

To achieve my research objectives, this study adopts a feminist and geographical approach to disability and gender, foregrounding perspectives that challenge societal structures of oppression rooted in unequal power relations within and across different spaces. Again, feminist critiques of gender, alongside critical approaches to health and disability, emphasize the distinction between impairment as a medical condition and disability as a socially constructed category. This perspective highlights, for instance, not only physical but also social barriers that limit the full inclusion and participation of those marked as Other. By shifting focus to the social processes that produce and sustain inequality, this research highlights how men with chronic illnesses navigate, resist, and reimagine their masculinities, while emphasizing the fluid and embodied nature of both gender and disability. As Shakespeare (1999) emphasizes, the intersection of masculinity and disability not only challenges normative gender ideals but also highlights the relational and constructed nature of both categories.

By examining how societal narratives around, for example, sexual performance and independence marginalize disabled men, this research opens room to reimagine masculinities that accommodates the full range of embodiments and experiences. In doing so, this work contributes to ongoing conversations in feminist geography, critical disability studies, and masculinity studies, offering a more nuanced understanding into the strategic and dynamic process of reshaping gendered identities as men (Broughton, 2008). Ultimately, this research furthers current scholarship on how men with chronic illnesses navigate the intersections of their bodies, social relationships, and cultural expectations in their everyday lives.

As the respondents' lived experiences will demonstrate, they must navigate not only the uncertainties of life but also the changing realities of their own bodies and minds. The intersection of illness and gender is one that permeates through all areas of life, disrupting foundations thought unchangeable, and calling them to reimagine and reconstruct identities and relationships with themselves and others. As their bodily and mental capacities continue to change, so too do their bodies transition through various spaces. This reflects a process that is at once fraught with tension yet alive with possibility.

Chapter 2: Literature Review

2.1 Introduction to Overarching Themes

To go beyond a cursory explanation of masculinity remains a significant challenge, as contemporary definitions leave the boundaries of the term unsatisfactorily vague. For instance, Merriam-Webster (2025) defines masculinity as "the quality or nature of the male sex: the quality, state, or degree of being masculine or manly." Similarly, the New Oxford American Dictionary (2025) describes masculinity as "qualities or attributes regarded as characteristic of men or boys: handsome, muscled, and driven, he's a prime example of masculinity." Such definitions of masculinity, however, are increasingly scrutinized—particularly in the fields of gender and health studies—for their oversimplification of the plural, fluid, embodied and relational aspects of what it means to think, feel, and act masculine.

As Connell (2005) emphasizes in her book *Masculinities*, the concept of masculinity is a relatively recent historical construct. Moreover, Connell notes that the social construct of masculinity has resisted being reduced into a coherent science, writing, "This does not reveal the failure of the scientists so much as the impossibility of the task" (p. 67). Indeed, Connell argues that masculinity is not a fixed, isolated, or generalizable attribute (such as a quality, character type, or behavioural norm), but rather is best understood through its principle of connection—the dynamic processes and relationships through which men and women conduct gendered lives.

Masculinity, then, according to Connell, is "simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices in bodily experience, personality and culture" (p. 71). Moreover, Connell highlights the broader social structures within which masculinity is located. These structures have a profound role in shaping how gender is understood, performed, and embodied. Among these broader structures, Connell identifies the system of patriarchy as a key catalyst for the construction and maintenance of masculinity. As men continue to hold power and dominate the sociocultural, economic, and political spheres, expectations around masculine performance likewise shift to reinforce, and are simultaneously reinforced by, power dynamics that privilege men over women. Connell refers to these patterns of gender relations as the gender order, a hierarchy in which men and women are positioned relative to each other.

As a social construct, masculinity is susceptible to change over time as dominant idealizations of its performance are contested and social norms evolve. For example, the rise of feminism has pushed (some) men to rethink their roles and attitudes, encouraging them to embrace women's rights and agency, as well as their participation in previously male dominated fields of work and spaces of leisure alike. Changing societal expectations for the role of men within the household too, have posed a threat to traditional notions of gender roles, forcing men

to reevaluate their place within the home and their identity as a family member, especially in the contexts of family living, intimate relationships, parenting, and even aging.

Yet, despite all these changes, many people still believe that masculinity is instinctive. As Edley (2017, p. 23) notes, "we live in a world in which the existence of men (and women) is taken utterly for granted," reinforcing the idea that masculinity is easily recognizable. In this way, socially constructed expectations of masculinity are normalized, and to challenge these assumptions is to question common sense, as men's behaviour has become to be understood as the product or consequence of them being male. However, the reality is much more nuanced and complex. This is further disrupted through the experience of chronic illness, in which the body becomes positioned as a constant and evolving site of struggle.

Beginning with a discussion on the theorization of masculinity, this literature review will explore feminist and geographical perspectives, especially as it relates to notions of power and control within and across spaces such as the home, work, and public spaces. The chapter will conclude with a discussion on the role of chronic illness, and its impact on intersecting dimensions of everyday life.

2.2 Five Theses of Masculinity

With a growing body of literature covering the subject of men and masculinity, concepts of sex and gender are becoming increasingly complex as discourse develops. It is thus important to recognize the various ideas that have emerged. To this end, Edley (2017) outlines five theses of masculinity—distinctive answers stemming from a variety of theoretical perspectives that address the substance of masculinity.

Masculinity as an Expression of the Body

One way of approaching masculinity is through the characteristics of the body categorized as belonging to the male sex. Through this perspective, the substance of masculinity is determined and defined by the expression of the condition of being male. Masculinity is often seen as tied to outward traits such as genital anatomy (i.e., having a penis), internal sex organs (i.e., producing predetermined quantities of testosterone), and genetic markers (i.e., XY chromosomes). These characteristics of the biological male sex are taken as natural indicators. However, as Edley (2017) notes, the perspective of masculinity as an outward expression of the body is not without its limitations. To begin, the aforementioned traits are themselves not rigid or consistent in scope and scale. The presence or lack of the male sex organ, for instance, is not guaranteed to correspond with characteristics of the other traits that are designated as male. Furthermore, binary categorizations of male and female on grounds of biological expression ignores the roles of environmental and societal contexts. Finally, Edley also cautions against the

sensationalization of scientific findings such as the supposed discovery of the "warrior gene" that positions behavioural differences among men as rooted in genetic factors.

Masculinity as a Psychic Structure

A second perspective positions the substance of masculinity as psychological. A number of models, for example, place an individual's affect and behaviour as already formed in early childhood, as well as rooted in relationships. Here, Edley (2017) explores Freudian perspectives that highlight the significance of the unconscious: people, including children, are sexual beings, and as such exhibit sexual desires that are repressed or otherwise manifest through sublimation. Such perspectives point to general discomforts when discussing subjects of sex and sexuality (such as incest), connecting them to theories such as the Oedipus Complex as evidence for repressed desires. In this way, psychoanalysts point to men's seemingly instinctual avoidance of anything and everything associated with femininity as evidence of repression.

Other models, such as Object Relations theory, portray the development of character, and by extension, masculinity, as the product of the quality of relationships in early childhood, primarily with the mother, and the subsequent processes of Individualization in which the child recognizes their sense of self. Greenson (1968), for example, writes that "the male child, in order to attain a healthy sense of maleness, must replace the primary object of his identification, the mother, and must identify instead with the father" (p. 260). Difficulties in this process of Dis-identification and Counter-identification are posited to be the cause of problems associated with men's gender identity.

While these perspectives offer insights into the character of maleness and factors contributing to constructing male gender identity, psychoanalytical theories often leave little room for change as the unconscious is developed from a young age. Furthermore, while Freudian models of psychoanalysis remain undoubtedly influential, its rhetoric and discourse have and continue to mature with time. Transvestism and fetishism, for example, were positioned as predominantly male diseases (Greenson, 1968). Furthermore, psychological theorizations of the male sex role have also shifted since the 1980s and 1990s (Thompson Jr. & Bennett, 2015).

Masculinity as a Trained Response

As Edley (2017) outlines, with the rise of first wave feminism came the shift in discourse that the substance of masculinity is something learned, rather than solely biologically or psychologically predetermined. This perspective marks a shift in the way masculinity and by extension, gender relations, is approached as the role of environment is called into consideration. Unlike previously explored notions of psychoanalytical theory which also emphasize the significance of nurture, this understanding of masculinity places it as a social construct—that society decides what it means to think, feel, and act masculine. To this end, the expression of gender and expectations of gendered roles are not inherent within the individual but learned from the places within which

they are situated. This process of Becoming is explored by authors such as Simone de Beauvoir (2011), who, in *The Second Sex*, critiques the social othering of women. She rejects the notion of biological determinism, focusing instead on the implications of socially constructed institutions—such as marriage, employment, and religion—in reinforcing women's dependence on men and, consequently, their subordination. As she writes, "One is not born, but rather becomes, a woman" (p. 234).

Models such as *sex-role theory* employ such an understanding of masculinity, suggesting that boys and men learn to adopt and exhibit sex appropriate attitudes and behaviour through periods of inscription. Moreover, the performance of masculinity is trained within key institutions such as the family, school, and media, in which gendered stereotypical behaviour is produced and reproduced. Especially within and across spaces such as social media and forums where regulatory policies—-on, for instance, sexist and misogynistic content—are less stringent. Online spaces are increasingly recognized as spaces where gendered tensions and anxieties are reproduced as a result of exaggerated expressions and expectations of performance and conformity.

Masculinity as Power

For later feminist thinkers, power is at the heart of what it means to be masculine. Specifically, masculinity is defined by and built upon unequal relations of power in which a social hierarchy is constructed and maintained. From this perspective, sex roles become markers, or descriptions, of an individual's character and behaviour, whereas gender roles refer to the normalization of such beliefs. However, sex roles are also regarded as not only descriptive but also prescriptive—that is, there is a degree of imposition in which men and women are expected to conduct gendered lives. Citing Connell (2020), Edley comments that in this context, "norms stand not for what is typical or commonplace but for what is normative or ideal" (p. 41). From the lens of masculinity as power, models such as the aforementioned sex-role theory are critiqued as lacking the consideration of power relations. Critical to movements such as radical feminism, the role of power is foundational as gender norms and the fight for emancipation remains a site of struggle, resistance, and violence.

From this perspective, the notions of exclusion and marginalization extend beyond gender as it intersects with other aspects of an individual's identity. This includes the intersection of race, class, life stage, sexuality, and (of particular interest to this thesis) dis/ability and illness, as the degree to which hegemonic privilege extends varies in relation to each person's unique lived experience and position within the social hierarchy.

Returning to the context of gender, masculinity as power is central to the idealized construction of manhood that is both exalted and largely unchallenged in society. This form of masculinity is widely recognized as *hegemonic masculinity*, a term developed by Connell (2005) to explain the intersection of power in gendered relations—both between men and women, as

well as among different groups of men. In patriarchal societies, this normative approach to masculinity promises privileges to men, with some men enjoying greater advantages than others (Thompson Jr. & Bennett, 2015). While this concept will be explored in greater detail later in the paper, hegemonic masculinity, in brief, represents the most culturally exalted *form* of masculinity, exerting dominance over other expressions (Connell, 2005). Meanwhile, alternate forms of masculinity that deviate from hegemonic ideals—such as those associated with homosexuality or disability which contradict standards of heterosexuality and able-bodiedness respectively—represent subordinate masculinities that are actively and intentionally sidelined. While hegemonic masculinity is not something most men can fully achieve; individuals can nonetheless enjoy some of its privileges through complicity in benefiting from the patriarchal dividend.

In sum, masculinity as power is deeply relational, as its acquisition and use involve the engagement of multiple groups. Within the context of gender, patriarchy has historically elevated men through the subordination of women—positioning them as categorically inferior or under the authority of a male representative or guardian. Yet postmodern and intersectional feminist perspectives have cautioned against binary, monolithic representations of gender. Indeed, the portrayal of disability as a generic category, along with the overrepresentation of white, middle-class experiences, has similarly drawn critique (Shuttleworth et al., 2012; Bell, 2017). Even within relational dynamics among men, scholars have expressed concern over both intentional and unintentional reinforcement—sometimes found within gender scholarship itself—of narratives that rely on cultural assumptions positioning a static image of young and middle-age men as the standard for manhood (Spector-Mersel, 2006; Saxton & Cole, 2012).

Masculinity as Practice

While masculinity is often discussed in terms of ideologies and societal expectations, another approach is to understand its nature as fundamentally tied to practices—actions that men engage in that express and reinforce their gender identity. This perspective shifts the focus away from viewing masculinity as a static, internalized essence. Rather, displays of gendered practices, such as violence, control, insensitivity, and sexual insatiability (which other perspectives might position as symptoms or expressions of masculinity), do not provide insight into the source of masculinity, but constitutes the substance of the concept itself (Edley, 2017). Masculinity, then, is something men *do* rather than just something they *are*—their behaviours reflecting not only societal expectations and norms, but also its performative demands. In this way, masculinity is demonstrated through repeated actions that solidify one's identity as a man; their construction of the type of man he seeks to embody. This framework is especially relevant in the context of chronic illness, where men must continuously adapt their performances of masculinity in response to their changing bodily and mental capacities.

The performative aspect of conducting gendered lives has and continues to be explored (West & Zimmerman, 1987; Messner, 1992; Connell, 2005, 2020; Gerschick, 2000; Manderson & Peake, 2005; Courtenay, 2000a, 2009, 2011; Paccaud & Marcellini, 2022). For instance, Teinemaa and Unt (2022) illustrates the potential of older men to be relieved from expectations of hegemonic masculinity. Even so, their identities remained closely tied to the roles they performed—particularly in the shift from breadwinning to providing care. While themes of interdependence and care beyond the nuclear family are introduced, the hierarchical constraints of hegemonic masculinity continue to shape how men negotiate their identities in later life, especially in relation to aging and disability.

The notion of masculinity as practice has also gained significant attention within feminist critiques of unequal gender relations. From this perspective, masculinity as practice is closely tied to masculinity as power. The configuration of gendered practices and the stratification of men and women are deeply embedded within patriarchal structures, where symbolic representations of gender roles are not only reinforced but embodied in everyday behaviour. These practices do not exist in isolation—they are part of a broader system that reproduces and legitimizes gendered power. As such, the dynamics between masculinity and femininity, and between men and women, become further entrenched and normalized through repetition.

To this end, scholars such as Schrock and Schwalbe (2009) have argued that research on masculinity should prioritize examining the social construction of gender and the reproduction of gender inequality. Their work emphasizes the importance of gendered practices and processes—including how men engage in identity work to claim membership in the dominant gender group. This includes affirming the reality of that group, eliciting deference from others, and maintaining privileges over women.

This shift toward understanding masculinity as practice offers valuable insights into the fluidity of gender and the possibility for change. If masculinity is something men do, it implies that it can be redefined or altered over time. Nonetheless, these performances are not individual acts but rely on the participation and recognition of others. Thus, while masculinity as practice highlights the potential for transformation, it also recognizes and underscores the constraints imposed by societal norms and the collaborative, relational nature of gender construction.

2.3 Connell's Organization of Masculinity

As highlighted in the previous section, the substance of masculinity has been interpreted through various lenses, including biological, psychological, and social perspectives, as well as through notions of power and practice. This section now turns to Connell's framework as the relational-practice based model of masculinity. As defined earlier, Connell (2005) views masculinity as a configuration of gendered practices within society. Deeply relational and rooted in power dynamics, masculinity is contestable, and its dominance is never absolute.

Multiple Masculinities

As I have explored, masculinity remains a fluid and contested concept. It has been theorized across a range of frameworks—as expressions of the body and mind, as a trained response within society, as inherent essences within men, and as defined through positivist, normative, or semiotic lenses. It is also understood through perspectives of power and practice. What becomes evident is that masculinity cannot be captured as a singular, fixed entity.

From this maturing foundation, I turn to Connell's (2005) concept of *multiple masculinities*. As Connell observes, recognizing the existence of different forms of masculinity is a prerequisite for understanding how these configurations of practices relate to each other within the gender order. With its relational approach and emphasis on embodied and unequal power dynamics, this critical perspective also offers a different way to understand how masculinity intersects with the full range of individual lived experiences and intersecting identities such as race, class, sexuality, and dis/ability. This approach acknowledges that masculinity is not monolithic, but rather hierarchically structured within the gender order—with hegemonic masculinity occupying the dominant position, while subordinated and marginalized forms are pushed to the periphery. In this context, the following section will explore Connell's theory of multiple masculinities, focusing on how masculinity is shaped by power dynamics and intersects with other axes of identity.

Hegemonic Masculinity

The term hegemonic masculinity has already been mentioned and briefly defined a number of times prior—its frequent occurrence a sign of its importance. Indeed, this concept is fundamental to Connell's theory of multiple masculinities, representing the culturally exalted form of masculinity that legitimizes patriarchy and sustains men's dominance over women, as well as over other men. This form of masculinity is not necessarily the most prevalent, nor is it embodied by most men. As Connell states, men in positions of power don't necessarily embody hegemonic notions of masculinity; rather, it is the placement of hegemony at the apex of the gender hierarchy that guarantees privileges to men. Thus, rooted in notions of unequal power relations, hegemony often concentrates within top levels of corporations and government in what Connell describes as.a "corporate display" of masculinity (p. 77). In this process, an intimate intertwining of cultural ideals and institutional power becomes the medium by which configurations of gendered practices become recognized and exalted—the successful claim to power and the violence found therein markers of its hegemonic status.

In this way, Connell defines hegemonic masculinity as the "configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy,

which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women" (p. 77).

Subordinated Masculinities

While hegemony represents the top of the hierarchy, it necessarily implies the existence of other configurations of gender that exist in its shadow. Moreover, although hegemony reflects the current response to patriarchy (i.e., men's dominance over women), equally significant are the relations of dominance and subordination among different groups of men.

In particular, Connell emphasizes the dominance of heterosexual men and the subordination of homosexual men, noting that this intersection of sexuality goes beyond cultural stigmatization. For Connell, the subordination of gay men is a matter of everyday life, manifesting in discrimination and exclusion across social, economic, and political spheres, as well as in violence. From the perspective of hegemonic masculinity, gay men are seen to embody gender configurations coded as feminine, and are therefore violently rejected

Homosexuality embodies but one of many intersecting identities that are rejected and subordinated—many of which symbolically overlap with femininity. Connell highlights other characteristics that, like gayness, are positioned as lesser, including manifestations of disability that impact an individual's physical or mental capacity. To this end, subordinated masculinities are essential for maintaining the power of hegemonic masculinity. These subordinated forms act as the *other* against which hegemonic masculinity asserts its dominance.

Like the other forms of masculinity, subordination is defined in relation to hegemony, representing what is expelled from the circle of legitimacy and positioned at the bottom of the gender hierarchy among men. This process of *othering* is particularly poignant in response to socially constructed ideologies perceived to align with the feminine, compelling men to distance themselves from such identities and configurations of practice.

Complicit Masculinities

This component of Connell's framework represents that of the masses—the conglomerate configurations of practice that upholds and sustains the gender hierarchy. Here, the relationship of complicit masculinity within the hegemonic project is twofold. First, it yields privileges to men who do not embody hegemonic ideals, allowing them to benefit from the patriarchal dividend without the risks associated with being on the frontlines of this contested site of struggle. Second, it is through this collective complicity that the patriarchal dividend is realized.

Complicit masculinity is significant as it illustrates how most men, despite not meeting the hegemonic norm, still gain from the privileges associated with being male through the overall subordination of women. Through complicity, such masculinities enforce and further legitimizes hegemony masculinity's answer to patriarchy, leading to men enjoying advantages such as, for

instance, higher wages and political representation. Moreover, such privileges extend beyond material and political power as men also dominate spaces such as within the home.

Connell's analysis of complicity shows that patriarchy is maintained not only through overt domination but also through society's consent, whereby men contribute to the maintenance of the gender order by not challenging it. This dynamic is critical to understanding the resilience of patriarchy, as it suggests that even men who do not conform to hegemonic masculinity may have little incentive to resist it, given the benefits they receive from the broader system of male dominance.

Marginalized Masculinities

While hegemony, subordination, and complicity refer to configurations of practice that exist "internal to" the gender order, there remains a horizontal interplay between gender and other structures that add to its complexity. In particular, Connell explores the relationship between masculinities and how they shape, and are shaped by, race and class relations—aspects of lived experiences that play a critical role in constructing and reinforcing gender expectations and practices.

As an example, Connell highlights the marginalization of Black masculinities within a White-supremacist context to illustrate this dynamic. For instance, while Black athletes may embody hegemonic ideals of strength and toughness, enduring stereotypes like that of the Black rapist remain deeply embedded in White sexual politics. In this way, the individual success of Black athletes, while embodying certain hegemonic traits, does not translate into broader social authority for Black men. Rather, the construction and performance of Black masculinities are embedded within institutional structures and systems of power that have historically positioned them as *other.* Connell further emphasizes how the intersection of race and class influences these dynamics, noting in particular the disproportionate rates of Black unemployment and poverty—products of institutional racism that powerfully shapes the making and doing of masculinity within these communities.

Although Connell initially applied the concept of marginalized masculinities primarily to race and class, this notion of marginalization—relational, defined in contrast to hegemonic ideals, and interspersed within the the gender order—can also extend to other identities, such as sexuality and disability, within the context of other configurations of gender practice. Indeed, in discussing gender as a structure of social practice, Connell acknowledges the ways by which gender "interacts" with other social structures (p. 75). This relational framework aligns with intersectionality, a concept that is gaining increasing recognition for its ability to reveal the interconnected nature of identity categories and how they shape power and inequality within the gender order.

2.4 The Multiple Intersections of Masculinity

The intersection of masculinity and disability presents unique challenges to the hegemonic ideals that shape societal notions of manhood. Gerschick and Miller (1997) examine how men with physical disabilities navigate their gender identities within a system that marginalizes both their bodies and their masculinity. Building on Connell's concept of hegemonic masculinity, the authors highlight how bodily limitations and social stigma restrict men with disabilities from embodying dominant masculine ideals. As a result, these men find themselves subordinated within the gender hierarchy—a complex position that the authors describe as a "double bind" (p. 471). On one hand, they are expected to conform to hegemonic masculinity, defined by expressions of strength, aggression, and independence (values the authors note are often more rooted in fantasy than reality); on the other, they contend with the societal image of disability as weakness, passivity, and dependence.

This intersection of gender and health not only challenges their position as men but also reveals the limits of hegemonic masculinity's reach. In this way, Gerschick and Miller focus on how men with physical disabilities "find happiness, fulfillment, and a sense of self-worth in a culture that has, in essence, denied them the right to their own identity, including their own masculinity" (p. 457).

The authors identify three dominant patterns of practice: reformulation, reliance, and rejection. Referred to as the *three "R" framework*, these strategies reflect how men actively engage with their sense of self at the crossroads of masculinity and physical disability. Each strategy represents a process of negotiation, where men come to terms with their identities in relation to the expectations and definitions of their geography—the construction of gender embedded in local relations of power and broader systems of oppression alike. This geographical approach to gender relations and politics is later expanded by scholars such as Connell and Messerschmidt (2005), who emphasize the consideration of the local, regional, and global levels as significant areas of study.

Even so, these patterns within the three "R" framework are not rigid or exclusive strategies—that is, no individual relies entirely on just one response. Indeed, Gerschick and Miller advise to consider the "major and minor" ways by which men employ these patterns (p. 457). For example, a reliance on ideals of independence may lead to risk taking behaviour as demonstrations of bodily capacity. However, the same individual may reformulate other aspects of his identity, such as attitudes towards sexuality and occupational attainment, redefining his masculinity in line with the limits of his abilities. As such, the authors highlight that there are no "reformulators," "reliers," or "rejectors" (p. 471). Rather than compartmentalizing men's responses into arbitrary categories, Gerschick and Miller foreground the prevalent means by which disabled men respond to hegemonic ideals, while acknowledging the greater complexities involved in navigating life as a disabled man.

The following section will explore each of the three patterns comprising the three "R" framework.

Reformulation

The pattern of reformulation begins with the conscious or unconscious recognition of the body or mind's inability to meet—or pass within—the standards set by hegemonic masculinity. Men who engage in reformulation do not directly challenge these dominant ideals but instead redefine them in ways that align with their own physical and cognitive capacities and self-perceptions.

In their study, Gerschick and Miller highlight how some men reformulate traditional concepts of masculine control and independence. Despite their reliance on personal care assistants (PCAs)—a setup that might typically be viewed as dependency—these men reframed the experience as one of control. They emphasized their authority in directing the labour of their PCAs and managing the material context of their care—namely, their position as employers and "acting through others" (p. 458). In this way, the relations of gender, disability, and class intersect as the men assert a redefined understanding of independence and control within their life circumstances.

Reformulation, in this sense, reflects a form of complicity with culturally dominant masculine ideals, as men recast hegemonic notions into new, personalized configurations of masculine practice. Even so, there is a degree of resistance as men confront and navigate prevailing standards of masculinity on their own terms, distancing themselves from such notions in the process. However, Gerschick and Miller posit that the pattern of reformulation does not present an adequate challenge to the gender order as it remains a subjective and independent project.

Reliance

As with reformulation, the pattern of reliance begins with recognizing one's inability to meet hegemonic standards of masculinity. However, rather than reshaping these ideals to suit their own capacities, men who adopt reliance instead internalize dominant masculine norms, adhering to them despite the constraints of their circumstances. As Gerschick and Miller note, these men exist in a state of conflict: "they embrace dominant conceptions of masculinity as a way to gain acceptance from themselves and from others. Yet, they are continuously reminded in their interactions with others that they are incomplete" (p. 461). This double bind undermines their sense of masculinity, leading to a contested yet decisive erosion of identity as they struggle to embody these prevailing norms.

Returning to the notion of "masculine" independence, Gerschick and Miller illustrate how some men rely on this strategy by refusing to ask for or accept help. Highly conscious of their appearance and the way others perceive them, some men describe how physical disability

renders them "genderless"—a direct threat to their identity, as their sexuality and autonomy are symbolically stripped away. This form of emasculation, or symbolic castration, is particularly pronounced in cases where the physical manifestations of disability are highly visible. One participant describes his interactions with others as transactional, noting that his inclusion is conditional, permitted only in contexts where he maintains a dependent position.

As a pattern of practice, reliance is rooted in hegemonic ideals of control, independence, strength, and outward appearance. The desire—yet inability—to embody these ideals often leads to feelings of inadequacy and, as a result, compensatory behaviours such as risk-taking or an adamant refusal to seek help. These behaviours, the authors warn, come with "major costs" associated with the reliance paradigm. Furthermore, as this conflict is located on the individual level, viewed as a personal failing rather than as a product of social structures, Gerschick and Miller thus conclude that reliance ultimately serves to reinforce the existing gender order.

Rejection

Unlike the previous strategies of reformulation and reliance, the rejection paradigm operates horizontally to the expectations set by the social hierarchy. Rejection involves the creation of alternative masculine identities that deliberately diverge from—and thereby reject—traditional gender norms. Moreover, Gerschick and Miller argue that rejection requires both a cognitive shift and a source of social support; it calls for a different reference point from which to view masculinity, along with the resources necessary to engage with it on these terms. Rejection, then, encompasses viewing the notion of difference—be it perceived or real—as inherently valuable rather than deviant.

Gerschick and Miller illustrate this with examples of men who establish new standards of masculinity in place of those they have divested—or never internalized due to the early onset of their disability. One participant, for example, rejects the procreative imperatives embedded in traditional fatherhood. Meanwhile, another individual expresses his denial of normative expectations surrounding dependency and care, adopting instead a person-first approach that centers his humanity above both his gender and disability.

As Gerschick and Miller note, such attitudes are deeply aligned with the ethos of the Disability Rights Movement, which prioritizes individual rights and agency. In this way, the rejection strategy poses the greatest threat to the gender order, situating masculinity as a social construct and offering a pathway by which hegemonic configurations can be questioned and transformed. However, of the three patterns of practice, rejection is also the least represented.

2.5 Beyond the three "R" framework

Gerschick and Miller's (1997) three "R" framework—reformulating, relying on, or rejecting dominant norms of masculinity—offered a critical starting point in theorizing how disabled men

navigate masculine identity. Their work was foundational in mapping out the range of strategies that men use in negotiating new identities after acquiring impairments. It created space for recognizing that masculinity is neither abandoned nor automatically retained in the face of disability; rather, it is reworked through complex, intentional, and situated configurations of practice.

Even so, the framework has limitations. While helpful in categorizing men's responses, it risks oversimplifying the fluidity and relational nature of identity as it suggests stable, identifiable strategies rather than capturing the often contradictory and shifting ways men engage with masculinity over time. Importantly, the men in their study did not fit into a single response pattern, nor are they quantified into reduced categories of reformulators, reliers, and rejectors. Later scholarship, including Gerschick's (2000) own work, builds on this foundation to offer a more nuanced theoretical account that incorporates broader social dynamics to consider the intersectional aspects of gender and disability.

In "Toward a Theory of Disability and Gender," Gerschick (2000) introduces three interrelated dynamics that shape the experiences of disabled individuals: (1) the stigma assigned to disability, (2) gender as an interactional process, and (3) the importance of the body in enacting gender. These dynamics help shift the focus from individual adaptation to broader questions about power, recognition, and the social meaning of the body.

Citing Goffman (1963), Gerschick affirms that disability is not solely a physical or mental condition but a deeply social and stigmatized identity. In this way, the process of stigmatization and distance between the able-bodied and their disabled counterparts—the relation between the socially constructed normative and Other—is therefore one characterized by avoidance, fear, and, at times, hostility. Reflecting on this imposed image, Murphy (2001) writes that the "stigmatization is less a by-product of disability than its substance," in which the "greatest impediment to a person's taking full part in his society are not [their] physical flaws, but rather the tissue of myths, fears, and misunderstandings that society attaches to them" (p. 113). As such, the presence of disability is rendered socially significant in terms of how it disrupts normative expectations of the body, capability, and personhood.

On the notion of gender as an interactional process, West and Zimmerman (1987), writes that it is something people "do" in the context of everyday social interactions, rather than something they simply "have" or "are." It is not a fixed trait or role that exists independently of social life—it is continuously produced, maintained, and recognized through interaction with others. In this way, West and Zimmerman argue that people "do gender" by engaging in behaviors that others recognize as appropriately masculine or feminine. These behaviors include how one speaks, dresses, moves, and interacts with others. Thus, gender is a routine, intentional, and recurring accomplishment embedded in everyday activities. As the authors note, "Doing gender involves a complex of socially guided perceptual, interactional, and micropolitical activities…" (p. 126).

Because gender is enacted in interaction, it is inherently relational—its success depends on how it is read and affirmed by others. When others fail to recognize one's performance as

appropriately gendered, it can result in embarrassment, humiliation, or exclusion. Gender performance, then, reinforces the social order, and as such, there is pressure to enact gender in ways that elicit validation. Where affirmation grants status and inclusion, rejection compounds marginalization. As Gerschick (2000) points out, the presence of disability complicates this interactional process, placing disabled individuals—especially men—in an "asymmetrical power relationship with their temporarily able-bodied counterparts" (p. 1264). Their ability to do gender in culturally legible ways, such as the demands of its hegemonic or complicit forms, is often compromised by the social meaning attached to bodies deemed deviant and Other.

On the body and embodiment, Gerschick (2000) notes that it operates socially as canvases on which gender is displayed and the means by which it is enacted. In this way, the body functions both materially and symbolically—it enables and constrains how gender is expressed and read. This echoes the Foucauldian body in which the body serves as the surface or stage on which social norms, power, and knowledge are inscribed. However, more recent work has challenged the view of the body as merely a passive cultural text. Davis (2007) argues that bodies are not only shaped by culture but are also lived, anatomical, physiological, and experiential entities that age, suffer, become injured or ill, and experience shifts in capacity over time. Acknowledging the body's vulnerability enables the resistance of essentialist understandings of ability and gender. The specifics of embodiment, then, are subjectively experienced. It is not fixed; rather, it is fluid in that it shifts through interactions with the environment and social relations, the passing of time, and the context of places.

In the context of disability, however, these processes of embodiment are challenged as disability calls into question how such bodies are socially recognized as appropriately masculine or feminine. This is all the more confounded by factors such as the form of illness or disability, its severity, and its visibility—all of which influences the extent to which the disabled body is "socially compromised" (Gerschick, 2000, p. 1264). These elements influence not only how others respond to the individual but also the strategies the individual adopts to perform gender.

Goffman (1963) draws attention to this role of visibility in shaping stigma. He breaks this down into components: the degree to which a stigmatizing attribute is known , its obtrusiveness in social contexts, and whether it becomes the perceived focus within interactions. Importantly, stigma and visibility are closely tied to the notion of passing—the extent to which someone can conceal or minimize their difference to be read as "normal." As Goffman explains, "the consequence of a presentation that is perforce made to the public at large may be small in particular contacts, but in every contact there will be some consequences…" (pp. 77–78). As such, the visibility of disability carries cumulative effects—each interaction becomes a site where gendered and ableist expectations are negotiated and performed.

An intersectional approach

To examine the lived realities of gender and disability, scholars have increasingly called for intersectional and critical perspectives—approaches that center the interplay of subjective identities while shifting the focus away from the individual as the site of "the problem." Instead,

disability is understood as produced and maintained through socially constructed beliefs and practices. These include taken-for-granted norms around gender and embodiment, as well as access barriers that generate exclusion, stigma, and the positioning of disabled people as *Other*. Recognizing that disability is not a personal deficit but a consequence of inaccessible and unequal systems of power and privilege is fundamental to this line of thinking.

Within these broader critiques, first-hand accounts from persons with disabilities are essential, as such narratives offer not only insight into their lived experience, but reveal how broader social forces shape identity at the level of the everyday. In the context of chronic illness and masculinity, these accounts foreground how men navigate bodily changes, shifting capacities, and the external gaze of others across various contexts and places. Coined by Kimberlé Crenshaw, intersectionality emphasizes that identity is multidimensional and dynamic—race, ethnicity, gender, disability, class, and sexual preference do not operate independently, but interact in ways that shape both how individuals move through the world and how they are perceived and treated by others. When exploring experiences of gender and disability, it is thus crucial to center those who live at this intersection—to trace how their identities are perceived and embodied through practice, how those identities are interpreted by others, and how they shift across time, space, and social interaction. Indeed, scholars have noted the trend towards approaching masculinity and its mutually constitutive dynamics with other axes of identity (Berg & Longhurst, 2003; Connell & Messerschmidt, 2005) .

For example, aging has increasingly been recognized as a critical intersection in the formation of gender identity. As Tarrant (2013) highlights, grandfathering encompasses a transition into a new life course from that of a father. This leads to changes in conduct when engaging in social interactions, but also spatio-temporal changes as they interact with different gendered care spaces.

Alternatively, Bennett's (2007) research on widowed men reveals that, rather than identifying as "widowers"—a term marked by loss and passivity—many choose instead to describe themselves as "bachelors". Such labels maintain associations with (hetero)sexuality, autonomy, and the "lone wolf" typology associated with notions of threat and danger. Moreover, as the research addresses the sensitive topic of loss and bereavement, the ways in which these men navigate emotional stress, control, and suppression are particularly compelling, especially given that certain behaviours are permitted in private spaces but not in public. In this way, scholars have highlighted the gap in literature recognizing that aging men and women have and continue to do gender (Thompson Jr, 2006; Van den Hoonaard, 2007; Becker et al., 2013; Thompson Jr & Langendoerfer, 2016). Much like the intersection of aging and masculinity, the presence of disability often disrupts the performance of gender, especially in cases where it renders individuals as genderless or "not real men" (Gerschick & Miller, 1997; Manderson & Peake, 2005). Other avenues relating to men and aging have also been explored, such as Calasanti's (2004) investigation of gendered health outcomes among older men, as well as work by Smith et al. (2007) examining independence as a marker of successful aging.

In addition, Courtenay (2000a, 2000b, 2011) has written extensively on men's health-related beliefs and behaviours as demonstrations of gender. Practices that are detrimental to health are positioned not simply as individual shortcomings, but as responses to cultural pressures—including messages embedded in social and institutional structures such as the media and the healthcare system itself—that reinforce stereotypical notions of masculinity and femininity. Courtenay argues that men and boys are not passive victims of socially prescribed roles, rather, they exercise agency in actively constructing and enacting gendered identities—the variety of gendered roles reflective of the socially fostered concepts of masculinity and femininity that they adopt from their environment (Courtenay, 2000b). Gender, then, is not something that resides within the individual, but emerges through social transactions coded and recognized as gendered. In this sense, men and women are not simply socialized by their cultures, but are active agents in constructing and legitimizing dominant forms of masculinity and femininity.

Drawing on social constructionist and feminist frameworks, Courtenay highlights that many behaviours commonly regarded as harmful—such as avoiding medical care, minimizing symptoms, or engaging in high-risk activities—are better understood as strategic enactments of hegemonic masculinity. Acts such as delaying treatment, dismissing vulnerability, or rejecting emotional expression are performed not just in opposition to femininity, but as affirmations of masculine identity. Moreover, these behaviours are enacted relationally—not only in relation to women, but in interaction with other men. As Courtenay (2000a) notes, masculine identity is secured and reinforced within hierarchical social structures of power, where particular behaviours are rewarded with status and legitimacy. In this way, men's health behaviours are deeply embedded within systems of gendered power.

In the case of marginalized men—whether on the grounds of class, race, ethnicity, sexual preference, disability, or other aspects of identity deemed incompatible with hegemonic masculinity—the constant negation of their manhood may prompt compensatory displays of hypermasculinity. These behaviours, Courtenay (2000a) notes, such as exaggerated sexual conquest among gay and bisexual men or the emphasis on appearing tough or "cool" among inner-city African American men, may be framed as assertions of masculine legitimacy but are not hegemonic in themselves. Pyke (1996) similarly describes such actions as compensatory strategies, particularly among lower-class men who engage in behaviours like drug and alcohol use or sexual carousing in response to their subordinated status within the hierarchy of employment. As Courtenay notes, these expressions of masculinity have been variously described in the literature as *compulsive* (Majors & Billson, 1992), *oppositional* (Messerschmidt, 1993), or *protest* (Connell, 2005) masculinities—each representing alternative routes through which marginalized men seek to assert and claim gendered power, even if at significant personal or social cost.

From the perspective of disability, an intersectional approach also requires attention to other dimensions and forms of difference, including bodily, cognitive, intellectual, and behavioural impairments (Gerschick, 2000; Shuttleworth et al., 2012). As Shuttleworth et al.

argue, disability should not be treated as a singular or generic category. Rather, scholarship on masculinity must consider how different forms of impairment intersect with other masculinities and axes of identity, shaping diverse and uneven experiences of what it means to "do" masculinity. In this case, the integration of disability within frameworks of intersectionality has been shown to offer valuable insight into life course transitions and gender, particularly as it relates to doing masculinity, the body, technology, and other social contexts (Paccaud & Marcellini, 2022).

Feminist and critical disability perspectives further complicate these understandings by interrogating the power relations that define which bodies are considered normal and which are not. Pointing to the aforementioned factors of race, class, and sexuality—social inequalities "inextricably" linked with gender—Calasanti (2004, p. 5306) establishes that such hierarchies "comprises power relations in which the privilege of one group is tied, intentionally or not, to the oppression of the other." Moreover, these are neither additive nor separate, as such inequalities are interlocking and experienced holistically.

Importantly, feminist theory is not solely about women's issues, rather, it positions gender as relational: the social meanings attached to women and femininity are always produced in relation to those attached to men and masculinity (Connell, 2005; Calasanti, 2004). Through this lens, disability is not only gendered but also a site through which dominant gender norms are reinforced, reformulated, and, at times, subverted. Indeed, a feminist framework approaches masculinity from a critical standpoint, asking what it means to think, feel, and do masculinity within a broader system of social power (Schrock & Schwalbe, 2009). It situates masculinity within intersecting systems of inequality—systems structured by dominance and subordination—and foregrounds how gendered practices emerge within and across gender relations. These practices often work to uphold hegemonic and complicit forms of masculinity while subordinating not only femininities but also alternative or non-dominant masculinities. In this way, a feminist critique of masculinities, then, is concerned not only with how men relate to women, but also with how men relate to other men within hierarchies of gendered power.

These dynamics are especially visible in the context of sport, where gender and disability intersect in complex and often contradictory ways. Sport has emerged as a key site in which disabled men resist negative associations attached to their bodies—particularly those linked to previously explored notions of dependence, weakness, or a lack of agency. As Manderson and Peake (2005) argue, participation in competitive sport offers disabled men an opportunity to reclaim a sense of wholeness and social legitimacy through the embodiment of hypermasculine ideals. In this way, the athletic body becomes both a strategy for resisting stigma and a performance of culturally sanctioned masculinity. Yet this strategy is not without tension. While sport may offer a means of empowerment—and in some cases, rehabilitation—it also has the potential to reify patriarchal notions of gender by reproducing exclusionary ideals and re-centering able-bodied norms of masculinity (Lindemann & Cherney, 2008). This warning extends beyond the context of sport to include broader interpretations or presentations of disability that frame it either as an individual failure to be overcome or, conversely, as a personal

triumph of willpower. Such narratives—such as in film, media, and other cultural representations—risk reducing disability to a monolithic experience or symbolic metaphor, thus obscuring the structural and material realities of discrimination, inaccessibility, and social exclusion that people with disabilities navigate on a daily basis (Meeuf, 2009). This extends also to portrayal of masculinity, especially which forms are privileged or celebrated, and how others are misrepresented, marginalized, or rendered invisible altogether (Clarke et al., 2014).

2.6 Placing Masculinities

Regarding the intersection of masculinity and place, Gorman-Murray and Hopkins (2014) trace its development through two interconnected bodies of literature: the geographies of masculinities, and the broader field of critical men's studies. The former, grounded in feminist social and cultural geography, has focused on inequality and injustice as they occur within and across gendered structures, processes, and spaces (Jackson, 1991, 1994; Berg & Longhurst, 2003; Hopkins & Noble, 2009; McDowell, 2003; van Hoven & Hörschelmann, 2005). The latter—critical men's studies—is noted as predating geography-specific inquiries and has increasingly embraced interdisciplinary approaches to masculinity, appearing across the social sciences, humanities, and other fields (Kimmel, 1987; Whitehead, 2002; Connell et al., 2005). While shaped by different traditions and appearing distinct, both lines of scholarship are closely connected in their focus on approaching everyday gendered experiences through a feminist lens—framing masculinities as socially constructed, variable, and deeply gendered, while critically engaging with how power and control are enacted, questioned, and challenged. Unsurprisingly, masculinity—and its place within geography—remains a dynamic and expanding area of discussion (Hopkins & Giazitzoglu, 2025).

As feminist geographers have long argued, geography as a discipline has historically privileged men's perspectives—a discipline dominated by men and about men; presenting itself as universal or otherwise comprehensive (Rose, 1993; van Hoven & Hörschelmann, 2005). The critique here is not only about the absence of women in academic contributions or fieldwork narratives, but about how masculinism structures teaching, learning, career progression, and knowledge production (Bonnett, 1999). While strides have been made to disrupt these assumptions and practices, much work remains to be done to transform such unequal relations of gendered power, as well as examining how such experiences are materialized and lived within and across different spatial contexts (Seager, 2000; Crang, 2003; van Hoven & Hörschelmann, 2005; Maddrell et al., 2016). In this way, feminist geographers have challenged masculinist traditions, opening up new avenues of conversations for understanding the social and spatial construction of masculinities (McDowell, 1993, 2022; Massey, 1994; Gorman-Murray, 2008, 2013; Gorman-Murray and Hopkins, 2014). Indeed, as Berg and Longhurst (2003) note, masculinities are temporarily and geographically contingent. Just as the body is more than a passive canvas or vessel on which meaning is inscribed, so too are spaces more than just passive backdrops. Rather, the spaces in which people are situated—and the places they become,

whether the home, workplace, or broader social environments—actively shape the contours of identity, visibility, power, and belonging.

It is this intersection between space, place, and identity that feminist geographers have brought to the forefront. As Gorman-Murray and Hopkins (2014) writes, the range of feminist methodological and conceptual interventions—ranging from reflexive engagement with positionally to attention to emotion, ethics, and the politics of research (Bondi et al., 2002; England, 1994; Katz, 1994; Mohammad, 2001; Kobayashi, 1994; Moss, 2002)—has destabilized masculinist assumptions and opened new space for the critical study of masculinities.

As van Hoven and Hörschelmann (2005, p. 7) observe, feminist work has been crucial in challenging "homogenous" understandings of gender and sexuality, demanding attention to how masculine identities are formed in relation to space and place. Moreover, they argue that masculinities are not simply attached to male bodies but can circulate through "bodies, objects, places and spaces well beyond the apparent confines of biology and sex" (p. 10).

The geographies of masculinities thus center on how masculine identities are constructed, negotiated, and contested within a variety of places. This includes workplaces (McDowell, 2003, 2009; Massey, 1996), homes (Murphy, 2001; Gorman-Murray, 2008, 2011, 2013), places of sport (Messner, 1992; Hall, 2005; Waitt, 2006), commercial spaces (Law, 1997; Caluya, 2008), as well as digital spaces (Bonner-Thompson & McDowell, 2021). Rural areas, urban neighborhoods, and migration contexts have also been explored as important sites of masculine identity formation (Warren & Gibson, 2011; Bryant & Pini, 2010; Pini & Mayes, 2013; Walsh, 2011; McDowell et al., 2022). What emerges from this body of work is a shared understanding that masculinity is not just performed in space—it is in part also produced by space. Masculinity is done in ways that are tied to place, and those places are in turn implicated in the regulation, reproduction, and contestation of gender, as well as its change over time.

Importantly, this research underscores that masculinities are always spatially and temporally contingent. In this way, masculinity as configurations of gendered relations and practice can be further characterized as the interplay of embodiment, values, and meanings, situated and realized in space (van Hoven & Hörschelmann, 2005). Nayak (2006) and Hopkins and Noble (2009) thus write that it is only in the analysis of "actual men in actual places that we can grasp the shifting dynamics of power" (Hopkins and Noble, 2009, p. 813). Returning to feminist and intersectional frameworks, this form of grounded, place-based inquiry reveals how certain masculinities—often white, middle-class, heterosexual, and able-bodied—are privileged in particular spaces, while others are marginalized or rendered invisible. As such, the spatial landscape is not neutral; it is deeply embedded with gendered hierarchies that inform whose masculinities are made legible, rewarded, or stigmatized.

Finally, with regard to research, new and exciting directions have been proposed by scholars at the intersection of masculinity and geography. These include experiences and practices pertaining to bodies and embodiment, sexual identity, and the broader framework of multiple and intersecting identities (Waitt & Stanes, 2015; Rosenberg, 2023; Giazitzoglu, 2024; Tarrant, 2013). Within this is the consideration of disability. As Murphy (2001) invokes in The

Body Silent, it is crucial to consider what it means to navigate social and physical spaces that are not built with disabled people in mind—how barriers and inaccessibility are encountered, even in private and intimate settings such as the home, how these spaces actively shape and reproduce social relations for disabled men, and notably how the body responds in turn. Other notable areas of study include the intersection of places of work and employment, migration, violence, and environmental considerations such as climate change and sustainability (Orman et al., 2024; Mazei et al., 2021; Wilson & Chu, 2020; Pease, 2021)

Within geography, Hopkins and Giazitzoglu (2025) offer a recent review of work on hegemonic masculinity. They argue for more attention to the body and to processes of embodiment, describing this intersection of masculinities and place as a fruitful area of scholarship. Moreover, while disability is absent from their review, the authors argue that:

> Research could usefully continue to explore the ways in which hegemonic masculinity can be gained, lost, and re-secured for different bodies and in relation to different processes of embodiment (p.90).

In the context of this thesis, I see research on experiences of disability and chronic illness as making an important contribution to current discourse revolving the embodied, relational, placed-based negotiations of doing gender.

Chapter 3: Methodology

3.1 Research Design and Objectives

This study examines how men with chronic physical illnesses navigate masculinity in the context of their embodied and relational experiences and societal expectations. As discussed in the introduction, masculinity in Western cultures remains closely tied to cultural ideals of independence, strength, and productivity—qualities that chronic illnesses such as MS and FM complicate due to their unpredictable and fluctuating, if not degenerative, nature. While early research on masculinity and disability had focused on men with acquired physical impairments, such as spinal cord injuries, this study shifts attention to the distinct challenges posed by chronic illness, where bodily capacity is not static but continuously shifting. In this way, the research aims to explore how men with chronic illness understand and enact masculinity in their daily lives, focusing in particular on the strategies they employ to navigate their new and changing identities as disabled men.

To explore these dynamics, the study employs a qualitative research design informed by a feminist geographical perspective. This approach recognizes that gender is not only relational and embodied, but also spatially situated and rooted in unequal power relations, unfolding across different contexts such as the home, workplace, and public spaces. The study draws on semi-structured interviews to examine how participants perceive and enact masculinity in their everyday lives. It also incorporates a participant-directed drawing activity, which provides an alternative means for the respondents to express and communicate aspects of their experiences that may otherwise be difficult to articulate through words alone.

As part of the research design, Connell's (2005) framework of multiple masculinities and Gerschick and Miller's (1997) 3R framework—reformulation, reliance, and rejection—serve as analytical tools to interpret how participants negotiate masculinity in response to their illness.

Ethics clearance for this study was obtained from the McMaster Research Ethics Board (MREB). Ensuring informed consent and maintaining confidentiality were central to the research process. A summarized outline of the study was provided in the recruitment poster, accompanied by a more detailed letter of information, all written in plain language. Information about participant expectations, confidentiality, ownership of created works, honorariums, and the right to withdraw was made readily accessible. These details were reinforced verbally at the start of each interview, ensuring clarity and transparency. Given the sensitive nature of the research topic, avenues of support, such as help hotlines, were also considered to address any potential anxiety or discomfort. In this way, flexibility was embedded into the research design (including the arts component) to ensure participants could engage with the data and activities in ways that suited their preferences.

By addressing these questions, this study contributes to feminist geography, gender studies, and critical disability studies, offering insights into how gender norms are reinforced, contested, and adapted in the context of chronic illness within various geographies, while remaining socially relational and enacted through embodied performance.

3.2 Recruitment

The study focuses on Canadian men living with chronic physical illnesses, specifically MS and FM. While the original proposal centered on what Del Casino (2009) describes as the "taken-for-granted mid-life" (p. 5) of adulthood, the scope expanded to include older men, allowing for a broader exploration of their experiences. Recruitment combined purposive and snowball sampling strategies to ensure the inclusion of participants meeting the study's criteria.

Initial recruitment efforts were conducted through formal contacts with MS and FM support groups within the Greater Toronto and Hamilton Area (GTHA). For instance, the local chapter of the Multiple Sclerosis Society distributed information about the research project to its membership. Materials shared included the study's Letter of Information and a Recruitment Poster, which detailed, among other items, the research objectives, the interview and art-making components, the accompanying honorarium, confidentiality measures, the right to withdraw, and contact information.

With the recruitment of several initial participants, snowball sampling was then employed to identify additional eligible respondents. This approach presented challenges, as establishing contact, gauging interest, and coordinating schedules proved more difficult than anticipated. Nevertheless, the research unexpectedly gained traction in online spaces, such as Facebook and Reddit, from which at least one respondent was recruited. In total, 11 men participated in the study, of which 10 also participated in the arts component.

3.3 Data Collection

The research involves two stages of qualitative data collection. As a note, the effects of the COVID-19 pandemic must be acknowledged, as they significantly reshaped how the research was conducted, particularly the data collection process. The details of these impacts will be fully discussed in the limitations section.

To begin, the first stage focuses on in-depth, semi-structured interviews with individual men. The study conducted 11 interviews, guided by the principles of theoretical saturation (Morse, 2000; Charmaz, 2006). These interviews were designed to explore how participants understood and enacted masculinity within the contexts of their everyday lives, with discussions directed toward three interconnected themes: (1) bodily differences, encompassing physical, mental, intellectual, and emotional performance, (2) men's practices within the social geographies that structured their daily lives, including homes, workplaces, and recreational spaces, and (3) relational dynamics, such as giving and receiving care, intimacy, family relationships, and friendships.

The interview guide provided a structured yet conversational framework, allowing for a natural flow while leaving space for participants to expand on areas of particular relevance to their lived experiences. All interviews were confidential and lasted approximately one hour. With participants' consent, all interviews were digitally recorded and fully transcribed for analysis.

The second stage of the research involves a participant-directed drawing activity, with all participants from the first stage invited to take part. Drawing on the work of Guillemin (2004), Kearney and Hyle (2004), and Guillemin and Drew (2010), this method utilizes visual techniques—such as photo-elicitation and video—where the creation and engagement with visual images serve as research data. A significant advantage of this approach is its capacity to help participants articulate aspects of their lives that they may not have previously considered in depth (Guillemin and Drew, 2010, p. 178). This makes it particularly suited for a topic like masculinity, where men are asked to reflect on their bodies, practices, and social relationships. As Guillemin and Drew (2010) argue, visual methods can broaden the scope of data collection and offer insights into the complexities of the phenomenon being studied. Additionally, such methods may benefit participants by fostering a sense of involvement in the research and enabling them to express what is often difficult to convey through words alone. From a disability perspective, art-making offers a way to move beyond reliance on "authentic" narratives of subjective experience (Macpherson, 2009, p. 1052). Moreover, as demonstrated in work by Wilton, Fudge-Schormans, and Marquis (2018), art-making and the availability of facilitators serves as a "collective meaning making and mapping practice" (p. 238) through which experiences can be further explored (see also Wilton & Fudge-Schormans, 2020 and Feldman et al., 2020).

However, practical challenges accompany this approach, including participants' potential 'performance anxiety' about drawing (Kearney & Hyle, 2004). To address this, participants were informed about the drawing exercise well in advance, allowing time to raise questions and alleviate concerns. Rapport established during the first round of interviews and feedback meetings further supported this process. During the art-making stage, participants were encouraged to work at their own pace and comfort level. They were informed verbally and through an Art Activity Outline that their image could represent anything or anyone they chose, so long as it related to the topic. Emphasis was placed on self-expression rather than artistic skill, focusing on how participants think and feel about their experiences of chronic illness as men.

Participants were also informed that they could take as much time as needed to complete the activity and use any materials of their choosing, including pencils, paints, markers, cut-out images, computer graphics, or any combination thereof. Recognizing the diverse abilities of participants, alternatives were provided for those unable to create art independently. A trained visual arts facilitator was available to assist these participants in realizing their vision. In such cases, meetings were conducted via telephone and email, where participants described their ideas for the artwork. The facilitator created drafts based on these descriptions, incorporating participants' feedback until they were satisfied with the final piece. Completed artwork was delivered to participants by mail or in person. Of the 10 men who participated in the art component, 4 pieces were co-created with the arts facilitator.

Once the artwork was completed, participants were invited to discuss their pieces during a phone conversation, sharing what their images meant to them. It was again emphasized that there were no right or wrong answers and that participants were free to share as much or as little

as they felt comfortable. These conversations were audio recorded and transcribed for analysis. The visual images, along with their interpretations, generate data that can be compared and contrasted with the themes emerging from the individual interviews.

To acknowledge the value of participants' time, honorariums were provided: $30 for each individual interview and feedback session, and $100 for the art component, reflecting the longer time commitment required.

3.4 Data Analysis

The research employs a thematic analysis of the individual and group interview transcripts, progressing from the identification of specific codes within the data to the defining and naming of broader conceptual themes (Braun & Clarke, 2006). In line with Guillemin and Drew (2010), the visual data is treated as inherently linked to the men's interpretations of their drawings, necessitating a "simultaneous and not separate analysis" (p. 184). The analysis of the drawings adopts Rose's (2022) critical visual methodology, which emphasizes the production, content, and composition of the drawings while incorporating the interpretations of both participants and researchers (Schormans, 2011, 2015).

Following the multiple rounds of data collection and its full transcription, the data was organized into themes reflecting how different aspects of the men's lives were affected by chronic illness. Initially, the data was categorized based on different areas of life, including but not limited to employment, intimacy, family, and social relationships. However, this structure was later revised to focus on themes based on place—that is, the workplace, the home, and social spaces. This reorganization better reflects the geographical perspective, highlighting how the respondents' embodied and relational experiences and practices were shaped by the specific contexts of these settings, while also capturing the breadth of their experiences with gender and disability across different aspects of their everyday lives.

3.5 Position Statement

I approached this research as someone who also identifies as having a chronic physical illness. Prior to this work, I regarded my own disability—degenerative myopia—as a marked difference, something that set me apart from others. In this way, engaging with the literature was truly eye-opening, especially as someone who came from a science-based undergraduate program. Learning about the lived, human aspects of geography (after I have studied its physical and natural dimensions) revealed a more fluid, contested, and reflexive approach not only to my studies but also to how I engage with myself and society more broadly. Here, concepts such as intersectionality and the embodied and relational aspects of gender were particularly relevant as I reflected on my own identity as a cisgender, heterosexual, immigrant who has experienced much privilege. Engaging with this work also led me to see my own experiences with disability not just as something that I must navigate daily, but as an integral and essential part of my intersecting identity. In this way, the implications of this research—and the writing of this thesis—have been deeply personal. The collaborative process of knowledge production was more than collecting

data for research, but a true learning experience as reflected on the sharing of the 11 respondents, some of whom have lived with chronic illness for most of their lives. I am grateful to each one of the respondents.

As such, I have tried to reflect their experiences as accurately as possible, highlighting the complexities of their everyday lives in relation to gender, disability, and space—hence the length of this thesis. Even so, I am aware that despite my efforts to preserve and reflect their stories as they were shared, there are inevitably gaps. The respondents themselves remain the true experts of their own bodies and experiences as they continue to navigate the lives and identities as men living with chronic illness.

3.6 Respondent Profiles

P1, now in his early 60s, has spent decades living with fibromyalgia, a "catch-all" condition he suspects stems from early-life trauma. While he continues to experience muscle weakness and cognitive challenges, P1 emphasizes the impact of a surgery that he had earlier in life in greatly improving his breathing, sleep, and overall quality of life. Although he holds a university degree, health limitations led him to move between roles in retail and service work, and he currently relies on ODSP for financial support. Moreover, access to stable subsidized housing has enabled him to live independently. Describing his family relationships as complex and often strained, P1 maintains a selective approach to social engagement, preferring intellectual discussions while finding close relationships difficult to sustain. He expresses a strong critique of traditional masculine roles—particularly the expectation of self-sufficiency and the overemphasis on breadwinning—and advocates for a more realistic, interdependent view of masculinity. P1 now focuses on volunteer work, writing, and social advocacy and, with recent access to a degree of financial stability, is exploring the possibility of travel.

P2 is in his late 30s and was diagnosed with MS a few years ago. Working full-time in finance, he balances the demands of his role with the unpredictable symptoms of MS, including fatigue, muscle tension, and cognitive challenges. These symptoms have led him to advocate for necessary adjustments at work. However, even though his workplace has been, to a degree, accommodating, P2 recognizes how his self-advocacy may affect his employer's perceptions of him. An immigrant to Canada, P2 now lives together with his long-term male partner, who has been a steady source of support throughout his journey with MS. As a result of his chronic illness, P2 notes how he must approach life more strategically. Spontaneous engagements are increasingly replaced by a balance of caution and planning—elements of exploration and stability that permeate all aspects of his life from travel to intimacy.

P3 is in his mid-40s, diagnosed with MS over a decade ago after a long period of undiagnosed symptoms. His symptoms, including fatigue, cognitive difficulties, and physical limitations, led to significant challenges in his marketing career, which he had to prematurely end as the demands and pace of work were unsustainable. Since then, he has focused on managing daily life

around the home and identity as a husband and father—playing a more active role in supporting and caring for his wife and child. In this way, P3 now assumes responsibilities that keep him present at home. Moreover, His shifting physical capacity requires adaptive strategies in daily activities and interactions within his community, where he has become more socially isolated. Though he finds himself distanced from his former work and social life, he maintains a reflective outlook on adapting to these changes, finding ways to stay active and engaged within his current physical limits, particularly in the home with his family..

P4 is in his early 70s and has been living with MS for over 40 years. Initially diagnosed with relapsing-remitting MS, his condition has gradually transitioned to secondary progressive MS, which now significantly impacts his mobility (the different forms of MS will be detailed in the following chapter). Early symptoms included intermittent episodes of arm weakness and sensory changes that often went unnoticed by others. However, as the disease progressed, he began relying on a cane or walker and used an adult tricycle to maintain some degree of independence outdoors. With a long career in education, P4 reportedly retired before his MS had a major impact on his work life. At home, his wife has taken on more physically demanding tasks, while he continues to contribute to outdoor work when possible. For tasks beyond their capacity, they rely on assistance from helpful neighbours or hire outside services. Socially, P4 remains active in his community, volunteering and participating in MS peer support groups where he shares advice and connects with others facing similar challenges.

P5 is in his late 50s and was diagnosed with primary progressive MS around eleven years ago. The illness began subtly with symptoms like foot drop, but it gradually intensified, leading him to leave his career in prematurely as walking and cognitive fatigue became more difficult to manage. The condition has since progressed to a point where he relies on a walker for shorter distances and a scooter for longer outings. P5 noted the high-energy nature of his career—a demand that he was increasingly unable to fulfill due to his diagnosis. On the suggestion of his employer, P5 transitioned to long-term disability support, which has alleviated some financial pressures of managing MS. As a husband and father, P5 has a close relationship with his wife and children, yet he also values autonomy. He now lives independently, an arrangement which suits his needs as well as the concerns of his family. In the community, P5 values friendships where he’s seen beyond his illness.

P6 is in his mid-60s and has been managing relapsing-remitting MS for over two decades, a condition that has gradually shifted to secondary progressive MS. Early on, his symptoms—such as headaches as well as sensory changes in vision and taste—were unpredictable but manageable, allowing him to sustain a career as a writer and trainer. Over time, however, the frequency and intensity of his symptoms have increased, with chronic fatigue, muscle weakness, and persistent headaches prompting P6 to gradually reduce his in-person work. Now retired, P6 still occasionally conducts online workshops. Living with his wife, who manages many of the

physical tasks around the house, he describes their partnership as crucial to preserving his sense of autonomy, though he acknowledges the increasing role her support plays. Nonetheless, he takes pride in the things he can still do, such as walking the dog twice daily—a routine that grounds his sense of ability as well as keeping him active in the neighbourhood. Moreover, he appreciates friends who understand the realities of MS, though he has seen some friendships fade as his limitations grew. Finally, being part of an MS support group provides him with a space to connect with others facing similar experiences.

P7 is in his late 50s and has been managing fibromyalgia for nearly 40 years, a condition that was initially difficult to identify and continues to shape his daily life. Similar to other respondents, P7 notes the gradually intensifying of his symptoms, which include chronic pain, fatigue, and occasional cognitive difficulties. As a result, he describes the impact on his physical capacity as a constant balancing act—striving to do as much as possible on good days while being cautious not to overextend and trigger setbacks. Formerly employed in a foundry, P7 left the physically demanding work due to the limitations imposed by his illness and now relies on disability support while living independently. Nonetheless, he remains involved with his family and community. Although divorced, P7 maintains a close relationship with his daughters, and leads a fibromyalgia support group, where he brings people together to share experiences and strategies for living well with chronic illness—a condition that he believes can be overcome through positivity and setting of achievable goals through self advocacy and resilience.

P8 is in his late 70s and was diagnosed with MS in the early 1990s, which has gradually transitioned to its secondary progressive form over the following years. Throughout his life, he has faced various health issues, both related and unrelated to MS, that have shaped his overall life course. P8 notes how the multiple health challenges initially obscured his MS diagnosis, delaying identification. Despite these difficulties, P8 continues to maintain his independence, living alone in an apartment. He balances self-care with the help of home support services for tasks like cooking and bathing—an arrangement he identifies as giving him opportunities to do what he can. Formerly an accountant, he had to leave his career when cognitive issues made continuing work impossible. His condition has also impacted his social life; while he stays connected with friends and family through phone and email, he no longer attends social gatherings involving noise and large crowds—activities he once enjoyed but now finds overwhelming. P8 takes pride in his resilience, focusing on what he can do each day and emphasizing the importance of living fully within his abilities.

P9 is in his late 40s and was diagnosed with MS over a decade ago after experiencing a range of symptoms since the early 2000s. His initial symptoms which include numbness in his hands, speech difficulties, and persistent nerve pain, were initially difficult to attribute to MS. The condition gradually impacted his career as a university lecturer, particularly due to speech and fatigue issues. Although he pivoted to research for a time, he ultimately had to retire prematurely

as his MS progressed and transitioned to long-term disability support. Now living alone in a condo, P9 manages daily life with the help of friends and relatives for tasks such as shopping. He has developed strategies to cope with the unpredictable nature of MS, modifying activities based on his energy levels and focusing on his body's needs to avoid exacerbating symptoms. Despite these challenges, he maintains strong connections with friends and participates in a local MS support group, finding value in shared experiences and staying informed about potential treatment options. Volunteering was also significant for him at one point, providing a morale boost despite being unrelated to his profession. P9 frames his experiences in economic terms, viewing MS as an explanatory variable that influences life's decision.

P10 is in his late 30s and was diagnosed with fibromyalgia in the mid-2010s after experiencing progressively worsening symptoms since his late 20s. Initially marked by fatigue, muscle pain, and other manifestations of illness, the symptoms made it increasingly difficult to manage an intense career as a lawyer. The demanding 60- to 80-hour work weeks were unsustainable, leading him to come to terms with his physical and mental limitations. Following diagnosis, P10 implemented lifestyle changes such as giving up alcohol and starting to work out—adjustments that helped him better balance the demands of work and health. This was accompanied with a transition to a less stressful, though well-paying, legal position. Nonetheless, he admits feeling under-challenged and notes that he may not be working to his full potential. At home, he shares responsibilities with his supportive spouse and takes pride in being present for his family. Despite the unpredictable nature of fibromyalgia, he strives to live fully, finding purpose beyond professional ambitions. This new perspective allowed him to let go of certain pressures and pursuits he could no longer sustain, directing his efforts instead toward activities that were meaningful and achievable within his current capacity.

P11 is in his late 40s and was diagnosed with relapsing-remitting MS nearly 20 years ago, a condition that has recently progressed to its secondary progressive form. Initially, he experienced muscle weakness, balance issues, and vision problems—symptoms that were inconvenient yet manageable. However, as the illness progressed, the symptoms became more severe and notably, visible. For instance, he is aware of how his reliance of a cane to aid walking has drawn attention from those around him. More recently, he has been advised to use a rollator, which he resists due to the stigma of appearing older. His current symptoms include chronic fatigue, balance difficulties, and a foot drop. The impact of his diagnosis led P11 to transition from full-time work to a part-time role as a driver. While this job is less demanding, the effects of his illness can still be felt, such as becoming out of breath when walking longer distances. At the time of the interview, he was living independently—an arrangement that, while not permanent, provides a sense of community and support among fellow residents. Even so, independence remains crucial for P11, who expresses frustration when having to rely on others for tasks that he believes a man should be able to do, such as yard work or car maintenance. Moreover, P11 values his ability to drive and remain active, which he sees as essential for maintaining his identity as a

man—noting in particular that if his license were taken away, he would feel that life would lose its meaning, Although he continues to adapt to his physical limitations, he notes that some activities once taken for granted, such as skiing or participating in large social events, are now out of reach.

Chapter 4: Analysis

This chapter contains the results of the qualitative analysis. As was suggested in Chapter 2, the focus of the analysis is on examining how gender and disability intersect in the context of specific places that comprise participants' social geographies. This focus provides an opportunity to examine the changing place-based 'configurations of practice' that sustain masculinity as a relational accomplishment (Connell, 2005). While the bulk of this chapter is concerned with participants' experiences in the workplace, home, community and other significant places, I begin by examining the nature of the illness experience.

4.1 The Illness Experience

The Nature of Multiple Sclerosis and Fibromyalgia

To understand how MS and FM shapes identity and masculinity, it is important to consider the nature of these illnesses, as well as the specific challenges they pose. Both conditions are marked by unpredictability, with symptoms varying widely in severity, duration, and progression. These illnesses disrupt daily life and force individuals to navigate new realities that challenge their sense of self. Here, I do not seek to delve in depth about the illness' breadth, depth, and complexities. Rather, the purpose is to provide a brief summary of what each illness entails, as to set the stage for the understanding how living with such chronic illness may interact with the participant's everyday lives and identities as men.

According to the National Multiple Sclerosis Society (2024), MS is defined as a chronic, yet unpredictable, disease of the central nervous system (CNS), in which the body's immune system attacks its own healthy tissue. Inflammation and damage to the CNS disrupts communication between the brain and spinal cord, as well as to other parts of the body, manifest in symptoms of various forms.

There are three main types of Multiple Sclerosis. Relapsing-Remitting MS (RR-MS) is characterized by the presence of new or increasing neurologic symptoms—referred to as relapses or exacerbations—followed by periods of remission, partial, or full recovery. Around 85% of individuals with MS are first diagnosed with RR-MS.

One of the respondents diagnosed with RR-MS was P2, who described his first relapse which was marked by sudden double vision—an event that led him to seek medical attention and receive a diagnosis.

The progression of RR-MS may lead to the diagnosis of Secondary-Progressive MS (SP-MS), a track of the MS disease course marked by declining neurologic function between periods of relapses and remissions. For P11, this progression brought lasting mobility challenges. As I will explore in the following sections, P11's experiences with chronic illness go beyond mobility concerns. They also involve the embodied and relational implications of using assistive mobility devices at a younger age than what is socially expected, as well as the challenges this presents in other areas of his life.

Finally, Primary-Progressive MS (PP-MS) is characterized by declining neurologic function or disability at the onset of new symptoms. Accounting for 15% of individuals with MS,

there are no early relapses or remissions as part of this MS disease course. Moreover, changes are difficult to track, as increasing disability may occur with or without new relapses.

Among the participants, P5 was one such individual diagnosed with PP-MS. He described grappling with symptoms like foot drop and cognitive fatigue—symptoms that steadily worsened from the onset. Reflecting on his experience, he said, "When you get a new symptom, you have to make friends with it, 'cause it's not going away."

FM remains a poorly understood disorder characterized by chronic pain, tenderness, fatigue, and cognitive difficulties (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2024). Unlike MS, FM lacks clear biological markers, often resulting in misdiagnoses or skepticism from others. Regarding the diagnosis and prevalence of FM, P7 highlighted how FM was historically underdiagnosed in men. Similarly, P1 expressed frustration with the diagnosis, calling it an unsatisfactory "catch-all" term that oversimplified his experiences. Even so, the symptoms of FM have substantial implications on the men's lives. For P10, the sudden onset of fatigue disrupted his ability to maintain the demanding pace of his work and personal life. As I will also present in later sections, the tension between the invisible and hyper-visible aspects of FM (and MS) were critical components of the men's experiences with chronic illness. The disruption to the flow of everyday life called into question their capacity to embody what previously defined their identity and masculinity.

Diagnosis, Symptoms, and Unique Experiences

Living with chronic illness begins well before a formal diagnosis. However, as symptoms are often varied, unpredictable, and not clearly defined, receiving a formal diagnosis becomes essential to legitimizing the symptoms that the respondents experience in their daily lives. A diagnosis not only validates the reality of the illness to others but can also affirm the experience for the men, providing clarity and paving the way for more informed decision-making. This is particularly significant for those who have lived with symptoms over extended periods, grappling with unexpected changes to their physical and mental capacities without a clear understanding of the underlying cause.

The diagnostic process is further complicated by historical gaps in understanding chronic illnesses. These gaps have led to frequent misdiagnoses or even outright dismissal of symptoms, adding an additional burden to an already vulnerable population. For instance, P1 reflected on his lifelong suspicion that something was wrong with his body, suggesting he may have lived with FM for much longer than initially recognized. Despite persistent concerns, his symptoms were dismissed by numerous doctors, who assured him that "everything is perfect." In his experiences, this lack of validation resulted in stigmatization, with P1 recalling being accused of being "just another lazy bastard" or lying about his condition. The betrayal was particularly profound as even those expected to care for him rejected his concerns.

Similarly, P9 endured nearly a decade of uncertainty, feeling through his body that something was amiss. It was only after receiving a formal diagnosis that he was able to name his experiences. By that point, however, significant damage had already been inflicted on his body.

Nonetheless, the diagnosis marked a turning point, enabling him to pursue more targeted and informed treatments.

For P8, the journey to diagnosis was complicated by a list of health problems—including tuberculosis and liver failure. While many of his conditions had identifiable names, his experience with MS stood apart. The gradual progression of symptoms—such as frequent stumbling, increasing weakness, and difficulty holding objects—lacked a clear explanation for years. It wasn't until a severe trembling episode occurred that he finally received a diagnosis of secondary-progressive MS (SP-MS). For P8, having a name for his condition was transformative:

> "When they told me I had Multiple Sclerosis in 1990, I was overjoyed… There's a name for what's wrong with me. I've been suffering from this problem since I was five years old. I've been suffering from health problems, and now there's a name. It's a horrible name, it's a horrible disease, but I have a name for it."

For these men, a formal diagnosis legitimized their conditions, confirming the reality of their illnesses and offering a foundation for approaching this new reality. Yet, the range of experiences—shaped by the diversity of symptoms and the age of onset—complicates how this new identity intersects with their established lives. For P11, confronting a potential chronic illness at the age of 22 was particularly challenging. The results of his MRI left him with two possible diagnoses: a tumor or MS. The uncertainty was "scary," especially as he lacked knowledge about either condition. He was forced to come to terms with the diagnosis despite his lack of preparation.

Challenges with Naming Illness

While a formal diagnosis is essential for recognizing and legitimizing chronic illness, the process of naming the illness is not always straightforward. Due to the varied and often ambiguous array of symptoms, the first signs of an illness are not always recognized for what they are—if they are recognized at all. Symptoms can overlap with those of other, more common illnesses, complicating the path to diagnosis. Among the eleven men in this study, there are many examples of delays, misdiagnoses, and challenges in getting a proper diagnosis.

This was illustrated in P5's experiences. In 2012, he began noticing problems with his right foot, which slapped the ground whenever he walked. After visiting a sports clinic, it was initially thought that the issue was caused by a pinched muscle or nerve. He underwent several rounds of treatment and therapy, but there was no improvement. It wasn't until the head of the clinic suggested an MRI that P5 finally received a diagnosis of primary-progressive MS (PP-MS).

P4's story was another example. When his symptoms first appeared in the early 1970s, he was misdiagnosed with lupus. Over time, however, his symptoms worsened, and after further testing, his diagnosis was updated to that of MS. Reflecting on this, he mentioned that getting a diagnosis back then was much harder than it is today.

Such challenges with receiving a timely and accurate diagnosis was also voiced by P1. His experiences highlight not only the difficulties of identifying illness, but also his concerns of being labeled with mental illness:

> "What's really dangerous about it is people who start singling you out as crazy. It gets really dangerous. You know, I was in very dangerous situations a couple of times with people trying to get me labeled as schizophrenic, you know? And finally, I got—fortunately, I got the right doctors, and got the right sort of documentation. Look, this guy is not mentally ill, you know, and he needs proper help."

These examples show how challenging the process of naming chronic illnesses can be. While a formal diagnosis is a crucial step, it is often not as simple as it might seem. Delays and setbacks take a toll, whether in time, money, or added stress and worry.

That said, diagnostic processes have improved over time, as reflected in the experiences of some of the more recently diagnosed participants. Consider P2's experience in 2018, when he was diagnosed with relapse-remitting MS (RR-MS). His first symptom, double vision, led him to visit a walk-in clinic. From there, he was referred to an ophthalmologist, sent for an MRI, and then seen by a neuro-ophthalmologist before being referred to an MS clinic—all within a relatively short period. P2 described the process as "fairly quick" and "quite a good service response,"—a sharp contrast to the longer and more complicated journeys others had faced.

Variability in Symptoms

Further complicating the experience of illness were the variability of symptoms. Among participants with both MS and FM, each individual's experience of chronic illness was unique—not only in the types of symptoms they faced but also in the frequency, duration, and progression of those symptoms. This variability influences not only how the men's lives are shaped by illness but also how they navigate and adapt to its ongoing challenges. Among the respondents, symptoms ranged from brief, isolated episodes to recurring relapses and permanent, progressive changes. Understanding this spectrum is critical for appreciating how these illnesses affect each of the men's perception and embodiment of identity and masculinity.

Temporary symptoms, such as sensory disturbances or fatigue, often appeared suddenly and resolved without lasting effects. Even though these symptoms were brief, their unpredictability disrupted the men's sense of control and caused anxiety about their potential recurrence. P2, for example, recalled experiencing a sharp pain in his face years before his formal diagnosis, which he later suspected might have been his first relapse—occurring even before the double vision that led him to seek medical attention. While these symptoms resolved, the uncertainty about what might come next added to the challenges participants faced.

For others, symptoms were temporary but recurring, appearing at irregular intervals and disrupting routines. These included periodic fatigue or flare-ups of pain that, while not constant, nonetheless interfered with daily life. P6, a writer, adapted by restructuring his work habits to match his fluctuating energy levels. He saved demanding tasks for better days, allowing him to

maintain productivity while managing his symptoms. However, this approach required constant adjustment, as the timing and intensity of relapses were difficult to predict.

Permanent symptoms, such as mobility challenges and cognitive difficulties, added another layer of complexity. These symptoms became persistent features of the respondents' lives, requiring significant lifestyle adjustments. P11, for instance, described how his transition to SP-MS led to lasting changes in his physical capabilities, which altered how he was perceived by others. The visible nature of these symptoms sometimes invited judgment or misunderstanding, further complicating his efforts to maintain a sense of normalcy and independence.

At the most severe end of the spectrum were permanent-degenerative symptoms, which involved a steady decline. For P5, the gradual worsening of mobility and cognitive function required ongoing adaptation. He reflected on the emotional toll of accommodating these changes, noting (as was mentioned earlier) the need to "make friends" with symptoms that would not go away. These progressive symptoms often challenged the men's roles and identities, particularly when they limited independence or the ability to fulfill traditional societal expectations.

The variability of symptoms across this spectrum underscores the unpredictable nature of MS and FM. This unpredictability forced participants to continually re-evaluate their abilities and adjust their priorities. While the severity of symptoms varied, the shared challenge was finding ways to adapt and maintain a sense of self. Notably, these categorizations are not distinct or mutually exclusive, as the participants often experienced a mix of symptom types. Some faced sudden, temporary episodes that resolved on their own, while also managing persistent or degenerative symptoms requiring significant lifestyle adjustments. For example, intermittent fatigue disrupted routines unpredictably, while ongoing challenges like foot drop permanently affected mobility. This complex interplay of temporary to chronic and degenerative symptoms added another layer of difficulty, as the men balanced immediate needs with the long-term implications of their illnesses.

4.2 The Place of Work

In Western cultures, employment represents a key way for men to enact culturally valued forms of masculinity as it satisfies the socially constructed values of productivity and competition (e.g, Thébaud, 2010). The prestige associated with certain positions as well as the opportunity to earn an income provides avenues for men to demonstrate their capabilities–especially in competition with other men. Paid work also enables men to fulfill the traditional gendered role of breadwinner and provider, reinforcing cultural ideals of masculinity. As Zuo (2004, p. 814) states:

> [B]readwinning serves as a powerful ideological device in forming individuals' self-identity, and in producing and reproducing gendered behavior and activities.

In this project, the value placed on employment was significant across all eleven respondents, who were all currently or previously employed. However, this relationship with paid work was

disrupted with the onset of chronic illness. This section begins with an exploration of the men's current and past relationships with paid work, followed by a discussion of disclosure and accommodations. It concludes with an examination of the significance of paid work in their lives as a reflection of their identities as men.

Men Who Left the Labour Force

Eight participants had left the labour force as a direct result of their chronic illness. Their experiences varied significantly, shaped by factors such as the age of onset, the combination of symptoms they experienced, and the nature and demands of their work. The experiences of P1 and P4 represented two ends of the spectrum. For P1, the early onset of his illness during high school made it difficult to secure stable paid employment. After graduating, he primarily drove cabs for a living, appreciating the flexibility the job offered. Reflecting on the challenges of adhering to rigid schedules, P1 shared, "I had days when I couldn't sleep at all, and at eight o'clock, I'd be sort of knifed right out." For him, the combination of early illness onset and debilitating symptoms contributed to his struggle to find his place within paid employment. Over time, P1 decided to stop driving cabs, explaining, "Eventually I just didn't want to continue with that. I just didn't want to be a moving target for some people and all the corruption that was going on with the cab business and all."

In contrast, P4 was able to experience what he described as a "natural" retirement. Having worked for over 30 years as an elementary school teacher, he described his MS as manageable while at work. He shared, "No one would've known unless they saw me get out of my car in the parking lot… I don't think I missed a day as a result of my MS." When asked if his MS influenced his decision to retire, P4 downplayed its role, citing financial incentives instead: "It was the minimal discount on my pension and the opportunity was there. I went out on a high." For P4, the later onset of illness, coupled with manageable symptoms and a supportive workplace, allowed him to retire in a way that aligned with traditional masculine ideals of career longevity and success.

Six other participants recounted premature and often difficult departures from paid work. For P3, who worked in the advertising industry, the onset of MS significantly impacted his ability to perform professionally. Using a sports analogy, he described his experience as, "if you're playing basketball at a high level like LeBron James, and some change in your brain causes you to release the ball differently." Symptoms such as cognitive decline and loss of bowel control made work increasingly stressful. "I wouldn't leave the house until I'd gone because the risk of defecating yourself on the way to work, on the subway, was extremely stressful," he explained. These challenges, combined with other life stressors, led P3 to describe his situation as "doing the job while walking a high wire and juggling cats." "I was a problem [at work]," he reflected.

Similarly, P5, also in advertising, described the physical and cognitive toll of his PP-MS diagnosis. "It just became too much…" he said, "I'd be walking to the color printer and trying to

mask the limp in my leg. I just couldn't do it anymore." For him, the demanding nature of his career, which required extensive travel and creativity, became too difficult to sustain.

For P8, who worked as an accountant, cognitive symptoms were the main barrier. "I had to totally stop because my mind couldn't function," he explained. Despite retaining his knowledge and expertise, he found himself unable to execute tasks due to impaired cognitive flexibility. "I couldn't remember what to do. I knew what had to be done, but my mind wouldn't allow me to put two and two together to get four."

Physical and mental limitations also forced P7, a foundry labourer, to leave his physically demanding job. After 18 years in a role where stamina and physicality were essential, chronic pain and fatigue likewise left him unable to meet the demands of his work. "It came to the point where I couldn't do that, right? Every day?" he reflected.

P9, a university lecturer, found his ability to teach compromised by worsening MS symptoms, including difficulties with speech and physical fatigue. Although he transitioned to research-based roles for a time, he ultimately had to stop working as his condition similarly became unsustainable.

Finally, P6, a writer and trainer with a 40-year career, expressed frustration at no longer being able to fulfill his professional responsibilities. "I have the ability to write the job; what I don't have is the ability to talk to you about it on the phone, listen to what you say, absorb, and then regurgitate what you need." Although P6 retired at an age more in line with societal expectations, he nonetheless expressed disappointment at having to give up the work he loved and a career he built for himself: "It pisses me off that I can't do it anymore."

Men Who Were Still Employed

The remaining three participants were engaged in paid work at the time of their interviews. While continuing employment provided a means of maintaining aspects of a breadwinning identity, the participants also faced ongoing challenges in negotiating their work in relation to the physical and cognitive changes brought about by chronic illness.

To begin, P2, who had been living with MS for three years and worked as an accountant, described how his symptoms impacted his work: "I've been working with numbers almost all my life, and I'm not as expert or competent as I used to be before." Among the symptoms he experienced, those most affecting his ability to work included double vision, muscle tension, fatigue, and declining cognitive capacity. Despite these challenges, he explained, "I have no problems delivering, but it's going to take me longer." For P2, maintaining employment required careful negotiation with his employer, particularly around disclosure and accommodations. "It's tough though, [especially] from an employer's point of view, like holy shit… So we need to have a discussion beforehand, and usually, it's alright," he said. When asked how MS had influenced his career aspirations, P2 acknowledged how his decisions had become more cautious:

> "Would I go to a start-up? Absolutely not. It would have to be something established… something calculated. So to answer your question, yes, the MS does impact the decisions, now more than ever."

P10 also had to adjust his career to accommodate the impact of chronic illness. Previously a private practice lawyer, he transitioned to a less demanding role as in-house counsel after his FM symptoms made the 50-60 hour work weeks unsustainable. He described how this shift affected both his career and his sense of self: "All of this work I had done to establish a career and to establish myself… all of a sudden that became very tenuous." While P10 appreciated the greater stability of his new position, he found the work less fulfilling. "I can kind of do it with my eyes closed. Like it's very simple compared to the work I used to do," he explained. The loss of challenge and prestige in his new role significantly impacted his professional identity:

> "I'm doing much less challenging things than I used to, and [my current] work is not the thing that gives me that sense of pride and identity."

For P11, a decline in health led to a shift from full-time to part-time work at a car rental company. This change was driven by the need to balance his passion for driving with the limitations imposed by his illness. "I've always been a car guy," he said, noting that he could still drive because his symptoms primarily affected his left leg. While his current role was less physically demanding than previous positions, P11 recounted challenges he had faced at other jobs, including a period at a hotel where his declining health caused significant concern among colleagues. Reflecting on this, he shared, "I didn't feel good at all… slept the entire day," prompting his boss to check on him. Despite his efforts to stay employed, P11 felt that his illness affected how he was treated at work. He recounted how tasks were assigned to other employees despite his capabilities—an observation of being passed over as a result of his apparent difference or incapacity.

> "You know, I have a driver's license because otherwise, I wouldn't be able to work here. Why do you never ask me? … Is it because you see I have a disability?"

For P11, this perceived unfairness was an affront to his identity and pride as a man—an area of discussion that will be further explored in later chapters:

> "I'm just as much a man as he is… They think because I can't drive standard, I'm not a man. Well, let's get out in a car and race—you'll see who wins."

Disability Disclosure in the Workplace

Participants' experiences with paid work and, for some, their departures from it, were shaped in part by the extent to which they felt able to disclose their illness and request accommodations. As existing research demonstrates, disclosure is a particularly complex decision, impacting people's workplace security and their sense of identity (Wilton, 2006; Lindsay et al., 2018). For participants in this research, disclosure involved confronting vulnerabilities—not only in terms of their relationships with employers, but also in acknowledging their own limitations in a professional setting.

Deciding whether, how, and how much to disclose about their illness required careful consideration of the potential risks and benefits. P10 summarized this tension:

> "It's an assessment of the relative risk. Assessment of the person I'm talking to, right? How trustworthy they are. There's such an immense vulnerability in making that disclosure."

Despite the risks, some participants, like P2, felt compelled to disclose. "It wouldn't be professional for me not to tell," he said. For him, disclosure was as much about accountability to his employer as it was about professional ethics. However, he carefully weighed how much information to share: "I disclose information as needed, [on a] as-needed basis. If they need to know, yeah, I can tell, but if not, then too much information isn't necessary sometimes." This approach allowed him to navigate both his professional obligations and comfort level. As he explained, "I have to be transparent with them."

P5 also disclosed his condition to his employer, explaining, "I made it very clear I had MS, and straight away." His decision to disclose was partly strategic, ensuring he was financially protected. "I knew I had to let my work know so I was covered," he said.

For other participants, negative experiences with disclosure led to more guarded attitudes. P11, for example, avoided sharing his diagnosis unless absolutely necessary. "I don't feel the need to have to say anything, and they don't really ask," he said. His approach was shaped by a prior job where he believed disclosing his illness contributed to his termination. "I don't want to [disclose] 'cause I'm afraid," he explained.

Rather than disclosing their diagnosis outright, some participants chose to share specific symptoms instead, as this was often easier for colleagues and employers to understand. To illustrate this point, I return to the experiences of P2 and P11. Beginning with P2, he explained, "Hey guys, I'm having double vision, and if I'm having double vision, I should not be managing budgets [and] forecasts." He added, "It's an easy symptom to understand. Double vision is way easier to grasp than cognition."

Meanwhile, P11 adopted more creative strategies to avoid linking their symptoms to their diagnosis entirely."Sometimes, I don't want to explain it. I'll tell them I was in a car accident… [or that] I was born with nerve damage in my leg," he said.

The decision to disclose often carried significant consequences, both positive and negative. While some employers were accommodating, others responded in ways that created challenges for participants, including termination.

P5's experience highlights this complexity. Although his decision to disclose ensured his financial security, it also led to his dismissal. "Basically, I was let go. I was relatively high up, my position at work, and so it was a big kind of issue," he said. After informing his employer of his MS, P5 was terminated, prompting a "back-and-forth legal proceeding." Ultimately, he secured long-term disability benefits and "a good portion of [his] salary until [age] 65." Even though his decision to disclose his illness led to the forced departure from a career he loved, P5

was glad he made the decision—especially from the perspective of financial security which he described as being "in good shape."

As previously mentioned, P11 had a similar experience, though without the resources to take legal action. He recounted being let go from his job after disclosing his illness, though he could not prove it was the reason for his termination. "I can't prove it; it's just a theory that I have," he said. "I worked for… a payroll company for 5 years… and [when] they did layoffs, my termination letter had the wrong salary on it." He explained that he believed his employers began to harbor "second thoughts" after his disclosure, perceiving him as a financial liability. "I think they were going to terminate somebody else and changed their mind and terminated me because I was out of my MS there," he said.

These examples underscore the difficult and deeply personal nature of disclosure for participants. While some found ways to navigate these challenges strategically, the risks involved highlight the broader vulnerabilities men with chronic illnesses face in the workplace, particularly when their health challenges disrupt traditional expectations of masculine independence and professional reliability.

Accessing Workplace Accommodations

While disclosure was a complex and strategically made decision, informing employers did not always result in meaningful accommodations. This was particularly evident in the experiences of participants in corporate positions, where the demands of the work environment often conflicted with the impacts of chronic illness. Faced with these obstacles, many participants devised strategies to work around their changing capacities.

For example, P2 encountered limited support in his workplace. When asked about accommodations, he responded, "Oh, that doesn't exist." Instead, P2 resorted to working longer hours to meet the demands of his role, explaining, "I think I'm working like twelve hours a day." Despite only having been diagnosed with MS for two years, he understood the precariousness of his situation. "There are people who [say to me], 'oh you're so lucky that you have a job,'" he said, adding, "It's pretty tense." For P2, his extended work hours reflected both his commitment to his role and the pressures to remain employed.

On the other hand, he also expressed the need to be his own advocate in the workplace. "You need to voice what you need, which I'm really bad for because I'm not the… vulnerable type [of] person." In this way, P2 talked about simple requests that would make a big difference—small changes such as receiving money remotely, especially since the team was working from home anyway due to the pandemic.

In the case of P3, without formal accommodations, he was able to continue working for a time with the support of a colleague. This partnership helped with tasks such as remembering creative ideas, which were crucial in his advertising career. He described the collaboration as having "saved" him at times. While this informal support allowed P3 to remain in his role for longer, the combined demands of the job and the worsening effects of MS eventually became unsustainable. Reflecting on this period, P3 noted that he should have retired two years earlier,

but it was difficult to make that decision at the time. He described himself as a "crack addict" in relation to his work and summarized the experience as, "At the end of the day… I was hanging by a thread."

In contrast, participants in public-sector roles described greater access to accommodations. P10, who, as a reminder, transitioned to work as in-house counsel for a labour union, noted that his workplace's willingness to accommodate employees reflected its values. "It would otherwise be very, very hypocritical and bizarre if we were not accommodated," he said. However, P10 nonetheless chose to not go forward with requesting accommodations, as another team member was already permanently accommodated. "It would have been too much of a burden on the department," he said, adding, "I just didn't want to do that to my colleagues."

P4 also shared his experiences with accommodations, though it was centered around him finding continued success without it. When he temporarily lost the use of his right arm while writing report cards, he was offered support by the school. "I dictated my results to the secretary, and she wrote them out. And so, I was accommodated that one and only time," he explained. Reflecting on this, he added, "I don't think I asked, but it was suggested strongly and given to me."

Meanwhile, participants who were self-employed described the flexibility of their roles as a form of accommodation in itself. P6, a freelance writer and editor, shared how self-employment allowed him to adapt to the unpredictable nature of his symptoms. "I knew symptoms came and went," he said. This flexibility enabled him to balance productivity with his health:

> "When I was feeling good, I'd do more marketing in the area of training… because if you were a client, and I'm writing for you, and if what I'm writing is due Friday, and I'm having a bad Tuesday, you don't need to know that. I'm hoping I feel better on Wednesday and Thursday so I can get the job done."

Self-employment also allowed P6 to choose where to work, often from home. He described how aspects of his job, such as conducting webinars and workshops or writing, could be done online. However, this flexibility also blurred the lines when it came to retirement. Eventually, P6 reached a point where even the adaptability of self-employment was no longer enough. "I was able to work around it," he said, "now I can't work around it [anymore], I can't do it, but you know, I had a good fifteen years with MS where I was able to work around it."

Work and Identity

For many respondents, their job and the ability to work were deeply tied to their gender identity. Employment represented not only their achievements but also their capacity to provide for themselves and their families. For P3, his work reflected his creativity; for P4 and P9, their ability to instruct; and for P7, his physical strength and endurance. Paid work also served as a source of pride and fulfillment. However, career changes—particularly shifts to less demanding roles—often led men like P10 to lose the sense of pride and identity they once derived from their

earlier accomplishments. For others, such as P11, being employed was primarily about financial stability: a reliable income and the ability to maintain independence.

The impact of chronic illness can call into question the men's capacity to perform—that is, to be productive and financially independent. Yet, their professional careers remained central to their identities as men. Their jobs reflected not only what they did but also who they were. For instance, P2 described himself as a "risk taker," an identity he tied to his work in finance: "I wouldn't be working in finance if I were not a risk-taker," he explained.

Reflecting on his career as a self-employed writer, P6 stated, "This is what I want to do, this is what I've chosen to do. I loved what I was doing."

Similarly, P10 described his career as deeply tied to his ego: "My ego was invested in and it gave my ego what it needed." He added, "I'm prideful about my work. I was very ambitious, despite pretenses that I wasn't."

P10 reflected on the societal pressures around masculinity and work, noting how the role of being a "provider" is central to many men's sense of self-worth. He described how his earlier career aligned closely with these expectations, providing him with a sense of accomplishment, independence, and financial security. However, the onset of FM disrupted this alignment, forcing him to confront the vulnerability and dependence that accompanied his chronic illness. This shift included turning down lucrative and prestigious opportunities as his capacity changed:

> "I had to, again, confront my incapacity in this, you know, devastating way. And I had to give up, you know, an insane amount of financial security or financial privilege really… It was a pretty painful experience because I had to look at, you know, having my dream job again as an in-house labor lawyer doing litigation. I really loved litigation. But knowing that the stress of it, the precarity of my health, it just wasn't going to work."

For many of the respondents, leaving paid work—especially prematurely—was a difficult process. P1, for instance, chose to stop working due to health concerns during a period of uncertainty about his illness, prioritizing instead on seeking the help he needs and figuring out his diagnosis.

For others, such as P7, leaving work was accompanied by a profound sense of loss. He shared the difficulty of adjusting to life after leaving his physically demanding job. He described going from "[working] twelve-hour shifts and stuff like that to a person who can't even work part-time." Losing the capacity to work, he felt "devalued" and struggled with feelings of "being less of a person," a period he called "very trying."

For participants like P7, P3, and P5, departing from work also required redefining their sense of self. Drawing on P5's experiences, he reflected on the process of renegotiating his understanding of himself after leaving work. He described the central role his career had played in shaping his identity: "I found a lot of my identity, my confidence, my sense of self, it came from work and so, losing that was a very hard thing for me." Using the metaphor of a suit of armour, P5's imagery foregrounds how central his career was in defining and maintaining his identity:

> "It's kind of like my head's just spinning, well who am I now, you know? It was like a suit of armour I wore. And then that's stripped away. So if you take work out of the equation, what's left?"

As these experiences demonstrate, the presence of chronic illness intersects deeply with employment and culturally valorized notions of productivity and financial independence. Departure from the workplace thus carried significant implications, not the least of which was time spent at home.

4.3 Home

As was suggested in the previous section, the departure from paid work for many participants means that they are spending more time at home. The home thus becomes important as it is a place of comfort and familiarity where the men act with relative privacy. It is also a place to provide and receive care as well as exercise control and independence. The impact of chronic illness means that they are often in need of additional care and support. At the same time, some were also engaged in providing care and support to others. More broadly, the analysis highlights the ways in which chronic illness impacts on gender relations and gender identity at home. Julie Livingston (2015, p. 3) argues that debility "troubles, mobilizes, and intensifies social relations." In this way:

> [T]he question of our responsibilities toward one another becomes more overt. Safety nets and moral economies are tested. Key relationships undergo both public and private scrutiny. The deep relationship of the body to the person is exposed, both for the subject and those around [them].

This is visible in the experiences of participants. In some instances, relationships at home are changed or enhanced. This may have particular implications with respect to the gender division of labour at home. In other instances, relationships can be fractured or broken.

This section is organized around the distinctive experiences of two groups of participants – those whose domestic relationships (with spouses and partners) continued in the presence of chronic illness, and those whose relationships ended at least in part because of chronic illness.

Negotiating Domestic Relationships

The first group of individuals (6) consisted of those who remained married or were in an active relationship. For these participants, there was an understanding that their relationships had changed as a result of chronic illness. Yet, despite the impact of their chronic illness, these relationships endured—and in some cases—became even stronger. "I actually feel like it (the MS) brought us even closer," said P2. Likewise, P10 said, "We become a stronger dependent unit." This was also voiced by P5, who said, "We are very close."

The men's living arrangements and their engagement with networks of care and support emerged as significant aspects of their experiences within the home. Alongside these, relations of

intimacy also became key points of discussion. For this group of men—and each in their own way—their relationships evolved and matured as both partners adapted to the challenges posed by chronic illness. The illness thus affected not only the men themselves, but also their romantic and intimate relationships, requiring ongoing negotiation and adaptation from both parties.

P2, for example, shared extensively about the supportiveness of his partner of six years. "I feel it brought him more closer to me. I mean he's been my support person all this journey," he said, "He's been the best person I could've ever dreamed about. Amazing, amazing, incredible guy." When prompted further about his evolving relationship with his partner, he said, "It's tough, but hey, I mean, to him, he hasn't freaked out or anything… I'm sure we can—I'm sure we'll be alright."

This increase in closeness—of chronic illness bringing the relationship closer together—is similarly echoed by P6. Following his diagnosis, he had a conversation with his partner:

> "Early on, when I was first diagnosed with it, I said to my wife, 'If you want to go or want me to go, I understand. Well, I can't go dig a hole and bury myself, you should find somebody who's healthy.' I can swear, she told me to fuck off (laughs). She said, 'We are going to deal with this together.' and she's doing great."

P6 also described how his wife's support was appreciated as the two navigated the effects of illness together. He shared about a major renovation that he and his wife undertook, and how, throughout the whole process, his wife was the one to handle most of the work. "I did nothing," he said, "I couldn't help." "She was basically the self-contractor… My job was to… make sure we had good stuff to watch on TV, while she sat on the couch exhausted, you know?"

Intersecting with notions of independence, P6 thus pivots to discuss how his "MS is taking independence from [him]." For the renovation job, he felt "dependent upon" his wife for the contracting, organization, and cleanup. However, he believes that he is still able to exercise a degree of independence, reflecting that on day-to-day living, "I don't feel like I'm dependent on her, but if she wasn't here, my life would change dramatically.

In the case of P4, he described a long-standing and positive relationship with his wife, similarly marked by mutual support and adaptations necessitated by his MS. However, his experiences stand out from the other men as he considers himself to be directing the process of his wife taking on greater responsibilities, especially within the home. For example, P4 noted that his wife has taken on more physical responsibilities, such as yard work, which he attributed to his reduced capacity in recent years. However, he also acknowledged her increased role with appreciation and viewed it as a positive development for her, saying, "I think it's forced her, to her benefit, to do much of it, so… it's made her a better person in that respect."

In addition to physical tasks, P4 also mentioned teaching his wife how to handle certain administrative responsibilities, including paperwork and financial matters. However, he emphasized that their relationship has remained on good terms despite the challenges posed by MS, saying: "I don't think it has really, maybe it has made us closer over time, I'm not sure."

Nonetheless, he emphasizes also the many things he continues to do: “I get up every morning, I greet my wife… I spend time with my grandchildren, I go out, I do things, I talk to people…”

Moreover, and similar to P6, P4 also reflected on his changing independence in relation to his reliance on his wife’s support. In this regard, P4 asserts that his wife is “more concerned about the things [he] might do.” Moreover, he adds that, “she doesn’t help me, or she thinks she needs to help me, but I can manage for the most part on my own.”

As P2 touched upon, the notion of support and working around his changing body together with his partner was something he greatly valued. This is also reflected in P10’s marriage, where the onset of FM made it so both parties had to reach out in mutual support of each other. Even so, there were circumstances when he had to rely more on his partner, which ultimately brought them closer:

> “We understand that we’re both relying on each other in a really profound way,I think that because we’re both in this situation of such immense dependence. You do work really hard to make sure that you don’t take things for granted.”

Nonetheless, P10 is wary not to overburden his spouse. Though the dynamics of his marriage are clearly impacted, communication and appreciation in navigating the challenges has become all the more important. “I think you start to really appreciate the things that the other person does for you,” he explained, “You try and be more mindful and you try and be more gracious.” As presented earlier, however, P10 also expressed a sense of guilt over the increased burden he placed on his spouse.

> “I feel an immense amount of guilt because I think that I shouldn’t render that other person responsible for me in any way. But I suffer a lot of guilt; she has to do a lot of things that if I was healthy, she wouldn’t have to.”

The wide range of feelings and attitudes these men had towards their partners can be understood in relation to events unfolding around them, such as in comparison to others’ experiences. For instance, several participants noted the different ways that other people with MS had experienced breakdowns in their marriages and/or relationships. Such outcomes are what P6 commented as being “one of the saddest things” about living with MS because “the person with MS is now sort of out there and feels like [they] have been rejected because of [their condition].” To this end, P6 was cognizant of his position and felt lucky to not have to experience such rejection. “I never had to feel that—I had to feel a little bit because I know a few friends left us because of my MS,” he said, “but my wife and I are together. She’s very supportive”

P2 echoed this sentiment, saying, “Of course not. I wouldn’t want to be in my shoes at the moment.” In his case, his partner also demonstrated support through encouragement. “My partner gave me a lecture, we spoke about it,” he shared, “We work around it so both of us can be happy.”

P10 also shared how he and his wife had to learn to navigate through his illness together. “I think with my spouse,” he began, “we both had kind of resigned ourselves to living a very laid

back, you know, peaceful life." Referencing the stories shared on social media, he spoke of the many struggles that people with FM go through. "They are utterly miserable like their lives are tough," he said, "Most of them are like struggling with disability claims, struggling with unsupportive spouses, you know, lots of suicidal [inclinations]." As such, he concluded, "I'm not there, and so I kind of feel really lucky."

Finally, P3 shared how his relationship with his wife evolved following his MS diagnosis. Like the other men in this group, their relationship experienced moments of tension and required adjustments to support one another. He described how fatigue from work often left him too exhausted to engage with his wife: "By the time I got home, I'd just shut down." This withdrawal sometimes led to misunderstandings, as it could be interpreted as a lack of interest in spending time together.

Adjustments also included a shift in roles within the relationship. P3, who had previously taken charge of planning trips and managing household responsibilities, found himself relying more on his wife to take on those tasks:

> "The old me would be booking a trip to Vegas, booking the hotel, booking front row seats to Tom Jones, money no object. Now, it's my wife booking the camping trip, and it's about figuring out 'how do I support her.'"

The change in roles also affected P3's identity as a father. Rather than being physically active with his son, he shifted his focus to being emotionally present and finding alternative ways to engage. Such adjustments illustrate how P3 adapted his role within the family while continuing to support and connect with his son.

> "It was about figuring out how to still be fun dad but finding other ways of doing that. So maybe it's about playing Lego Marvel video games with him rather than being physically active. I used the expression 'being the rocket fuel now rather than the rocket."

For the group of men who remained married or were in a relationship, their newfound constraints and limitations, imposed by their changing physical and mental capacities, resulted in the spouse or partner taking on a larger share of responsibilities. Moreover, this was a shared experience among all six of the men who comprised this group. As P5 aptly summarized, "A single person doesn't get MS, the whole family gets MS. It affects everybody."

In the face of living with chronic illness, the men described the division of labour as collaborative, even as the healthy partner may have to shoulder a larger share of the work. For P4, he tries to contribute where he could. With respect to yard work, he said, "I still try, even though my wife does most of the physical work in the garden area." However, he added that his physical contributions of labour on the property have declined over the years.

With respect to yard work, P4's experiences—alongside those of others such as P11—reflect attitudes that position such tasks as men's work. Activities like mowing the lawn or performing car maintenance are treated as gendered forms of labour. However, small changes like the inability to mow the lawn and to engage in other forms of traditionally masculine yard

work (Hagaman, 2023), upset a gendered domestic geography that underpin existing performances of masculinity.

Returning to P4, he notes that, following his diagnosis, his wife has been "doing everything around the house." Even so, he explained that he would help his wife in whatever capacity he could. "So, she's doing something, and needs me to hold something so she can reach and repair [it]," he began, "I can stand there and hold it, you know. I lean against the wall holding something." As such, P6 has adopted a more supportive role within the relationship with respect to labour:

> "I'm tired, I've walked the dog, she's cooked a nice meal, I take a deep breath, and I clean up. Throw them in the dishwasher, wash the pots and pans, and then go and collapse on the couch. Then I'll say to her, 'I hope there is nothing else that has to happen because I'm not getting off the couch.'"

In the case of P3 and P10, both of whom were corporate workers, their focus has shifted from employment and breadwinning to more so of a family-orientated, caregiving, capacity—especially in terms of parenting. "A lot of my efforts now are family," said P10, and likewise, P3 shared that he became much more active as a caregiver for his son.

Even so, P10 admitted that his wife remained "inequitably burdened," and thus he was mindful to reciprocate support. He gave an example of how he and his spouse negotiated a schedule around childcare. "'We can have kids but I need to protect my sleep schedule,'" he said, "and so, what we agreed is that she would stay up in the night and then I would get up in the morning."

With respect to parenting in particular, P10 felt that his wife "suffers way more than other mothers." As he was not able to provide the care and support that other mothers would typically receive from their spouses, P10 felt "really guilty" as he perceived this to be the result of him not being healthy.

Meanwhile, P3 described his new roles in the family as threefold: parenting his son, supporting his wife, and keeping his mother happy and supported in the final years of her life. "That's a full-time job with MS," he said.

As such, he also sees this work in terms of being a "provider" for his family. By "providing smiles [and] drives," As I will further explore in the next section, P3 used the expression "being the rocket fuel now rather than the rocket" to describe his new place within his family. "It was an important role whether I wanted it or not," he said. Even so, he also said that he couldn't do all of the care work by himself with the MS—his wife helped him out with it also.

Separation

While some participants and their partners had found ways to sustain relationships, four others had their marriages or long-term partnerships end—all of which occurred after the men received their formal diagnosis, while one had decided to move out and live separately from his family. Their experiences reflect a long-standing belief that debility tests existing relationships, and not

all survive. While this was justifiably a difficult topic to discuss, the respondents in this group shared about their experiences be it directly or implicitly. They linked the failing of relationships to a number of factors, including a lack of understanding on the part of the healthy partner, and the inability to tolerate or accept the new reality of their once-healthy partner—their changing needs and capacities.

In this way, P7 felt that his wife and family simply did not appreciate the pain and fatigue that he experienced as a result of his FM. This lack of understanding led to irreconcilable conflict and tension. Reflecting on this, he said, "If your wife or ex-wife or family could only experience it so they have an understanding, right?"

With respect to needs and capacities, the men commented that their partners had found it difficult to accept the changing nature of their relationships. As mentioned above, the presence of chronic illness and manifestation of symptoms can be strenuous even in situations where the marriages or relationships remained together. In some cases, however, the prospect and implications of living with chronic illness may be too severe for the healthy partner to accept. This was the case for P8's marriage;

> "I'll mention this, I was married… and my wife, she also knew I was going to get a wheelchair, and she didn't want to be in a house with a wheelchair, so she left me."

While P9's marriage also ended in separation following his diagnosis, his approach to understanding his then partner's reasoning was one of logic, describing the choice as a "rational calculation."

Being the sensitive and personal topic that it is, the three men ultimately had little to say about their divorce. However, this separation nonetheless had a lasting impact on the men and meaningfully contributed to their process of reworking their identity both as a person and as men—a section that will be explored later.

P11 had been in a long-term dating relationship. When describing this relationship, he strongly suspects his worsening symptoms led his partner to leave after 17 years. He reflected that his relationship started out strong, with his partner fully aware of his illness:

> "For the relationship? Yeah, I think the MS had a good—played a big part in the role… [But] I don't think he'll ever admit it."

P11 noted that his condition was something his partner initially supported. "You take that chance when you take me, that's how it started basically" he said, "[My condition] was well known from the beginning."

However, P11 explained that his relationship with his boyfriend, who he described as once being "supportive," faltered alongside his changing health. "I just felt that when I started to go downhill that things started to change with us, and I think that's what eventually killed it," he said.

P11 continued to explain how not being able to do things with his partner was the key issue at play, as he said, "I think he really didn't want to be in that relationship because we

couldn't do [a lot of things together]." This inability to do things together was what helped to "destroy" the relationship.

At the time of the interview, P11 said he felt that the impacts of chronic illness also made it unlikely he would find a new partner:

> "Yeah. I don't know if I'll ever be in a relationship [again] because what do I have to bring to the table? Not a whole lot."

For some of the men, this endeavour was more challenging than others. For instance, P8 notes that "living" differently had become a routine that he had to confront on a daily basis. For him, even basic, taken-for-granted tasks become time-consuming endeavors."It takes me anywhere from two to three hours to get dressed in the day," he said, "... [but I] do whatever I have to do in order to live."

P8 voiced that this was part of what he does as a man—that even though he lives alone, he remains in charge of taking care of his basic needs as any person does in order to to "function" and "live." The daily routine of "living" was thus a part of his identity as a man, grounded on his capacity to plan ahead and take action:

> "Does that change the fact that I am a man? No. it just is part of the fatigue problem that I go through, because of the MS, [but] I do what I can… I wash my hands, I wash my face, I wash my eyes, and I start functioning and I start living. I come out and depending on how tired I am, and whether pain woke me up or not, I start functioning and do whatever I have to do in order to live."

P5's experiences represented a distinct case of separation and independent living in that he had made the decision to move out of the family home. While he expressed gratitude and appreciation for the support of his partner, living alone allowed him to take responsibility for his day-to-day arrangements and maintain a degree of independence. Moreover, this arrangement eased his wife's concerns, as he explained how she would worry when she found him pushing his limits at home—things that "drive [his] wife crazy." He explained how he would do things simply because they were "difficult," and how his wife expressed constant worry about him injuring himself.

P5, shared that "I go out and shop… and I prepare my food and stuff—like again, it's challenging." Even so, he interpreted this as an opportunity to exercise independence, mentioning, "I can do what I want, when I want… I can go on my own schedule." P5 had chosen to move out of the family home, noted the freedom of this arrangement as not having to "worry" his family:

> "It's not ideal, but it's the better situation I think. They worry about me, and we are very close. We get together a lot, talk all the time, it's kind of that day-to-day walking up the stairs and they're worried that I'll fall, that puts stress in their lives and it puts stress in my life. And when I'm alone, it's very peaceful."

For P5 and his family, living alone was a compromise as well as a financial investment. However, as he also notes that such an arrangement is "peace for them, and it's peace for me, and we still get together when we can, and I think it's better that way, I really do… it's hard, but it's better."

At the same time, P5 worried about his changing body, and what would happen if he did not push himself even to the point of danger. He said, "I'm just scared about it, but as soon as you stop, you're done." The decision to live independently therefore, while remaining together and in close connection with his wife and family, was an adjustment that he is thankful for. Moreover, despite living separately, P5 reflected that this setup has brought them closer, allowing their relationship to grow in new ways. They still meet regularly, though P5 acknowledged that with his energy levels, "That's all I can take anyway." Reflecting on his situation, he reflects that " it's certainly different, but this disease is different too. I have to adapt the best way I can."

This notion of self advocacy was echoed by P7, who was also living independently. For him, P7 notes that he had to become his "own advocate," as "too many people think their doctors are going to fix them."Living on his own, P7 faced challenges in confronting and accepting the changes brought about by his chronic illness—disruptions that affected many aspects of his home life, including his marriage. For him, managing his illness involves not only controlling the symptoms but also maintaining his mental well-being. As a support group facilitator, he now draws on these experiences to support others navigating similar struggles:

> "I try to push forward to get better and also show joy and pride if I can help other people not have to go through what I've gone through."

P9 described the challenges of living alone in his condo, noting that his condition often left him too fatigued to manage daily tasks like cooking and shopping. To adapt, he simplified his routine, stating, "I am a little bit independent now. I am figuring out, but sometimes, you know, you feel so tired and you are not able to make shopping and I'm not able to cook well… so I have a strategy of drinking juice only, and not cooking often."

Turning to the experiences of P11, he shared that he was temporarily living in a trailer park, expressing a sense of comfort with the arrangement while also acknowledging the uncertainty it created regarding his long-term housing security. Reflecting on his precarious situation, he said, "If I'm not settled by [date], I'll probably be back on my parents' couch." Despite this uncertainty, P11 found a sense of community within the trailer park, describing it as "like our own little family." He shared how residents helped each other with tasks, recounting a time when he needed a ratchet for a spark plug and quickly received offers of assistance through the community's Facebook group. He also highlighted moments of connection, such as impromptu shared meals:

> "We just managed to get this dinner together, impromptu, like boom boom boom."

However, P11's living situation intersected with broader concerns about his health and his ability to maintain stable housing and care. The uncertainty surrounding his financial future weighed

heavily on him. “My future is unknown, so it’s a little scary,” he admitted. In his case and others, their experiences of living alone were shaped by economic (in)security, be it mentioned explicitly or implicitly.

Additional sources of care and support

While living with a spouse or partner was a key pillar of support and care, this was not the only source, especially for the men who were living alone. Besides the methods and strategies already mentioned, the following is a showcase of the numerous other ways that the men living alone find and secure care and support.

Support workers. One of the participants, P8, occasionally received assistance from support workers. “I have workers come in, both female and male workers that come in and help me shower,” he shared. He also notes that there are people who come in to help with cooking and dishes. However, he also affirmed that he was not wholly reliant on their aid, doing what he can manage on his own. He said, “For me, on days I don’t get a shower, I have to wash. I wash all the parts of my body, the same as you do if you don’t get a shower.”

Relatives. P9, shared that his relatives were an appreciated source of support. “I have some relatives who can help me,” he said, “and I can see them sometimes for shopping.” He continued, “Given the current condition that I have, they understand what it means, and they know what’s going on.” Similar to the other respondents, P9 also described his situation as a demonstration of independence. “I am figuring [things] out, but sometimes, you know, you feel so tired,” he said.

Neighbours. Neighbours were yet another source of support for some of the men. For two of the participants, P4 and P11, their neighbours provided support in terms of yard work. P4, who was living with his wife, said, “I’m very fortunate to have a wonderful neighbor who cuts my lawn and does my snow.” P4 explained that his neighbour’s help was in response to their acknowledgment of his chronic illness, but also that it was an expected act of courtesy as yard maintenance was a required responsibility. “This is over the last ten years because he realizes my lessening of capabilities, and he’s really good about it,” he said, “It’s a job for him, when he cuts his lawn, he cuts mine. So in some respects, it’s made life easier for me.”

In contrast, P11 enlisted the help of his neighbour’s son. “I was paying my friend’s kid who’s 16 to cut my grass,” he said. Occasionally, P11 would also ask him to help with other tasks, such as refueling his car on a hot day—services that he would tip. For P11, however, not having the capacity to do these things himself was frustrating as it called his masculinity into question. “I [would] gave him a tip,” he shared, “but in my head, I was thinking, it’s so pathetic to ask someone just to do that because I just didn’t have the energy to do it.”

Other hired help. Contracting outside help was another strategy employed by some of the men, especially those who were advancing in age. P6, for example, shared how “[if this is] fifteen years ago… [and] my wife is saying, ‘the garage trim needs cleaning and doors need painting.’ I could do that. If she asks me that today, we’ll get a quote (laughs), I can no longer do that.” P6 added that “[We] have to look for alternatives… I can’t ask her to do absolutely everything.”

Becoming (More) Dependent

For the men, receiving care and support came with mixed feelings. While the men expressed gratitude and appreciation for those who provided care, such as their spouses, partners, family, neighbours, or hired help, there remain times when the men felt at odds with getting help for something they were once able to do, or feel that they should be able to do. As mentioned earlier, these feelings sometimes resulted in guilt, such P10 who felt responsible for overburdening his spouse. However, there are other feelings, such as guilt directed towards the self for not being able to do things, especially things that a "man" should be able to do. While these feelings of emasculation are presented here in the receiving and giving of care and support, they will also be further explored in a later section on encountering others. Here, I briefly explore the experiences of P4 and P11.

Beginning with P4, as much as he appreciated his wife's care and support, he shared that her concern can sometimes be overbearing. "She doesn't help me, or she thinks she needs to help me," he said, "but I can manage, for the most part, on my own." To this end, P4 explained that he sometimes felt frustrated by her constant concern. He gave some examples: "In her eyes anyway, 'take it easy, you don't need to go over there, you don't need to take the ramp, you don't have to walk up the steps.'"

P4's feelings of emasculation were shared by P11 who, despite being separated and living alone, felt that his masculinity was challenged by his need to depend on others' care. "You don't feel like a man when you have to ask for help for things that are basic, that anyone should be able to do," he said. Even more so, however, was when other people started to assume he needed help when he didn't. To this, he gave an example:

> "When there was a guy who used to live across the street from here at the trailer, and every time I see him, he'll come running out to help, and it was just instant because he knew that I had MS, and it's like, wait a minute, there was a lot of times when I was like, 'you know what, [name], when I need help, I'll ask for help,' and that made me feel like less of a man, that he was always coming over to give me help… Is [this] something that's important to me? Yeah, because I mean, otherwise, I'll just have [a] sex change (laughs)... I feel emasculated sometimes because it's like, [I can't do] things that a man should be able to do like, cut the grass… and I feel guilty, I feel guilty,"

Finally, I turn to P1, who offered a unique perspective in sharing that his celibate lifestyle was a deliberate choice. Having lived with symptoms of chronic illness from a young age and confronted a broad lack of social acceptance, his experiences were different in that how it was difficult for him to form bonds with other people. "It's hard to trust people, hard to form any kind of social relationship," he said.

On the matter of intimacy and relationships, he responded that seeking a spouse or partner was not something that he had the energy to pursue:

> "I've tried to develop some sort of platonic relationship with women, just to have a friend, somebody who's gonna arrange a funeral or like that, I don't know. But you know, it always turns out, turns into some sort of tension or drama, you know, and just doesn't really work out."

P1 reflected that it is hard to find relationships for "people like me," and as a result, he has decided to remain single. "I'd rather live alone than have to get mixed up in foolish psychological drama." This strategy of isolation in the face of other people's hostility was something that featured prominently in P1's artwork.

Figure 1. P1's Artwork

At the same time, P1 acknowledged that he had once dreamed of a "version" of him which had a family of his own. "I would've loved to have some kind of a family," he said. Reflecting ON notions of marriage and fatherhood, he added, "when I was younger, I was dreaming about [how] I need to get over all this and live a normal life, get a wife and kids, and that kind of thing."

For P1, he believed "that [it] isn't gonna happen" because of his chronic illness. "I wouldn't have been a very good parent anyway." he said, "I just wouldn't have been able to provide a good environment." For him, it was all "very depressing."

As for the six men who were living alone, including one individual who was living independently by choice away from his spouse and family, navigating daily life—be it grocery

shopping or maintaining personal hygiene—was a core part of their lives that they must navigate independently on their own time and by their own means.

For men like P1, living alone was important to him because it allowed him to be independent and manage his condition in a space where he feels fully in charge. This is depicted in his artwork, where he described his home as a "safe space," emphasizing its importance as a retreat where he could maintain his autonomy. Reflecting on his art, he said, "Sometimes it's just necessary to go up, create a fortress around yourself, climb up the tree, pull up the ladder—and just wait for these idiots to go away," he said.

Living alone also intersects with how P1 receives care and support. Like a number of other respondents, he relies on programs like ODSP and subsidized housing to maintain his independence, emphasizing their critical role in his day-to-day life. Reflecting on the importance of securing a place to live, he noted, "The key to be able to survive and have a decent life is getting that freaking surgery done… but also having a system of affordable housing." Even so, P1 expressed frustration over the state of the welfare system, noting that they are "focused on maintaining you at minimum cost."

4.4 Encountering others

This section focuses on participants' experiences in a variety of community spaces. Again, departure for paid work has meant that participants spend more time in other social spaces. Some of these are spaces occupied by members of a larger public: e.g., grocery stores, public parks and sidewalks. Others are spaces that are primarily designed for communities of people experiencing chronic illness: e,g, support groups and voluntary organizations. In both cases, participants negotiate encounters with others in the presence of chronic illness. As they note, the way they perceive and engage the world has changed, as has the way they are perceived and engaged by others.

Encountering others in community space

As Bigby and Wiesel (2019, p. 40) have argued, "encounters are important to the way social differences are socially constructed and experienced." Encounters are also central to the politics of place - they represent a response to the question of how we live together (Massey, 2005). In the analysis, participants' experiences point to the ways in which assumptions about gender and (dis)ability - held by participants themselves and those around them – shape the nature of these experiences. In spaces where participants meet members of a broader public, they noted that encounters are shaped by a complex interplay between invisibility and hypervisibility.

From visible and invisible changes in physical and mental capacity, the men reported being misunderstood and judged as a result of their chronic illness. One shared aspect of their daily lives that the men need to confront, however, is navigating social encounters. Be it their changing physical capacities, or level of fatigue, the way that the men interacted with others had to be reexamined. As P5 voiced, "I had to kind of un-learn [needing to be liked]... [I] realize… I'm not going to be seen in the way I like being seen by a lot of people, with this disease."

Meanwhile, P11 recounted the changing social encounters with people as his walking disability progressed and became more visible. His comments reflect the overlapping intersection of his chronic illness with societal expectations, especially that of a young man. "[At the time,] I had no visible signs of needing to park in the handicap spot," he began, "and I had a lot of people throughout the years question me, 'what's a young man like you parking there?'"

This, however, would change when he began using a cane some years later. He describes the cane as a visible signal of his condition, and thus, difference. "But [when] they saw a cane, then they think you have a disability, or there's something wrong with you, but if they don't see anything, immediately it's 'you're in the wrong.'" As a result of these experiences, P11 felt like a "book [judged] by its cover."

Similarly, invisible symptoms such as chronic fatigue and pain were easily misunderstood and misattributed as representative of one's character. In this way, P1 recounted several negative experiences where he was harassed and labeled by others. "They'll say, 'oh you're just another lazy bastard,'" he said, "I'm not just some stupid, lazy, crazy, individual. There's an actual condition there."

Having lived with his chronic illness for a long time, P1 was the recipient of much criticism. "They assume I must be a drug addict or an alcoholic," he said. As such, P1 often felt "attacked," and coupled with a perceived lack of support from his doctors, as well as members of his family, he harboured feelings of resentment:

> "Other people seem to react hostile to it, very hostile to it, at least some of my relatives, also certain members of the medical community… What's really dangerous about this is people who—people start singling you out as crazy… [And then they'll say], 'you're being hostile to everybody, and you're not being friendly at all.'"

As demonstrated, a wide range of symptoms and manifestations of illness were met with the broad issue of misunderstanding. This was shared by P6 and P7, who discussed how the varied symptoms and manifestations of MS made it difficult to intuitively understand. As P7 said, "When [we're] having a bad day, [we] don't bloat. So, most people say, 'oh you don't look sick' cause they only see you on your good days, right? People… they physically can't see it."

This was echoed by P6. "Yeah, because we don't look any different," he said "we should all turn purple or something, and they'll see the manifestation of my MS. People will know we have something."

Even so, highly conspicuous symptoms are not immune to misunderstanding and judgment either. While there may be a level of understanding between friends and family, as explored previously, the dynamics in encountering others may play out differently. As P8 shared, "The people that know me don't have a problem, They know what I go through because they talk to me. It's the people that don't know me." Despite the conspicuousness of his wheelchair and specialized eyewear, there remained moments of tension and insensitivity as P8 navigated social spaces. He described an incident in a local store:

> "And I was in the store, and I have to go apparently contrary to the arrows, and this other customer got mad at me and said, 'can't you see the arrows?' And I said, 'no I am blind, can't you see my white cane?' And she got mad at me and said, 'well you're going the wrong way.' I said, 'my body doesn't work on the right side so apparently, I can't follow the arrows like you can because I'm not able-bodied like you.'"

Others, meanwhile, reflected on the visibility of their condition in other ways. P4, for instance, shared how his walker marks him apart from others. He described a time when he had a shiny new walker: "[I was] the only person with it," he explained, "and wow, people knew me—well as a result of my personality but also that, me pushing that around." To him, the conspicuous walker was a conversation starter for people who want to engage with him: "I enjoyed the fact that it gave me an opportunity to converse with a lot of people," he said. Even so, the walker served a double purpose — as a mobility aid and tool to facilitate discussion through its visibility. "It made me stand out in the crowd," he said. On this note, P4 also reflects that there will be others who do not want to be "involved" with him, but he notes that "those are the sort of people… who veer far away… would do that anyways."

At the same time, P4 had given up membership of a choral and caroling group that performed at various public spaces including around the city centre. Reflecting on this activity, he said, "I did that for thirty-five years," describing how the group performed at various events, including house parties and Christmas jobs. While he was still able to sing, he felt that his reliance on a walker/rollator meant that he no longer fit in with respect to the choral performance:

> "First, for two years, I had a cane, and then the last year I used my walker to go through the mall. I kind of tucked it behind me when we stopped and sang, but I felt that it was infringing on the group, so I stepped down."

This interplay of visible and invisible surfaced at the forefront of P5's sharing, as well as in his art piece. Featuring a faded silhouette of a man on his scooter in the midst of a crowd, this piece captures the visibility aspect of his illness experience. "I'm here, but I'm not here," he said. To begin, P5 shared how he felt invisible in the sense that he wasn't seen by others as a man or even a person. "I feel like, when I go out in my mobility scooter, I feel like I'm much more mobility scooter than I am a person. I'm an obstacle to walk around," he said, "When someone sees you, you're not a man, you're a man on a scooter."

Figure 5c. P5's Artwork (Scooter)

Contrarily, P5 also explained that, because of his MS, he was very visible in that his ill-health was evident for all to see. "It's very jarring for people to see someone so sick, who isn't supposed to be sick," he said, "and people don't want to see that." Having worked in advertising for three decades, he described himself as a walking billboard that people avoided. Significantly, he also described the gendered and relational process between himself and other men:

> "You're almost like a billboard for death. Because, you're basically an image, a reminder of what's gonna happen to everybody, but it's happening a lot faster for you, and people don't want to see that. We live in a world that celebrates youth and beauty… In a sense, you're always bringing bad news to people, and this might be self-inflicted, but it's like,

> people don't want to see you… Men avert their eyes, they don't look you in the eye. Especially middle-aged or older men, they don't want to see—especially a younger person—in a mobility scooter."

The awkward mix of sympathy and discomfort was also identified by other participants. P11, for example, shared how people would react whenever he goes out with his rollator. "People [are] feeling sorry for you and that's something I hate," he said. He continued:

> "People are like, 'oh, what's that for?' and I'm like, 'Oh, I have MS.' Or they're like, 'when do you get rid of your cane?' or, 'how was the injury?' I'm like, 'No, it's permanent, I have MS," 'Oh, I'm sorry!' It's like, 'don't be sorry,' just, I don't know, whatever."

P11 was frustrated at the linearity and awkwardness of many of his conversations with strangers, especially when the topic of discussion shifted to his chronic illness. which was usually met with the expression of some form of sympathy.

Likewise, P9 shared a similar statement. "I don't want to show them [that I have MS] so that they are not bothered," he said, "so that they are not—they don't feel comfortable talking to me." Being treated specially, in the sense that others do not know how to approach and talk to you, because of having chronic illness was a common experience among the men. For example, P5 shared:

> "So often with other people, I find you get one of two things, there's the person whose aunt's sister's niece's brother has MS and they're gonna tell you about a cure for it and what you should do. And the second, 'Oh please don't tell me about your MS.'"

With respect to gender, some men also talked about feeling belittled or devalued as a result of their chronic illness. P5 and P11, for example, were frustrated when people offered help that they felt was unneeded, especially when they believed the task should be done themselves. For P5, he shared about an incident when he was at a restaurant with his wife, in which the waiter not only directed conversation towards his wife, but positioned him as a third person, rather than an active participant in the conversation:

> "There's been times—I was in a restaurant, like last year, I was in a restaurant with my wife, and the waiter, he said, 'What would he have?' to my wife. That is insulting. That is insulting."

Encounters such as these were a serious affront to his dignity as a person and as a man. However, he also shared that he was learning to accept help from others, and to not be so easily insulted.

Finally, P5 also shared about this sense of emasculation when navigating conversations with women, and how his illness has affected the way others perceive him. He described how, as a man who is six-foot-two but confined to a scooter, he feels that women are more comfortable engaging with him. "Women are much more comfortable around you… they approach you much

more, and they smile at you, much more than I had before," he said. While acknowledging that this could be seen as positive, he also framed it as somewhat frustrating, explaining how these interactions often stripped him of being perceived as a sexual or masculine person.

Encountering others living with chronic illness

While the previous section focused on encounters in broader community spaces, many participants were also engaged with support groups and organizations for people with chronic illness. In one sense, these groups and organizations might be understood as sites of inclusion and belonging (Hall, 2010). They represent spaces in which there is a shared understanding of the nature and lived experience of chronic illness that is often absent in the context of 'mainstream' community spaces. They also offer advice and support for people, and opportunities to get involved. At the same time, some participants are uncomfortable with these spaces to the extent that they challenge particularly masculine ways of living and coping with illness.

P9 attended a local MS support group, which had been important in terms of sharing information and building community. He reflected:

> "We have an MS support group. We help each other. We make meetings every month and I am also part of the MS Society of Canada, and I read a lot about MS and so it's all about having confidence."

P4 was also actively involved with the MS Society, particularly in peer support initiatives where he enjoys the opportunity to "talk on the phone with people with MS, both males and females." In this way, P4 reflected on how his chronic illness had shifted the landscape of his social life, noting both limitations and new opportunities. "Getting back to the question, how has it affected me, well in some respects, it's opened up some aspects of my social life, and it's cut off others," he said. While some traditional avenues for social engagement had become less accessible, volunteering and peer support offered him meaningful ways to build relationships and remain socially connected.

Participation in a support group was also central to P7's discussion on not only his social engagement, but his outlook on life. His role as a leader in a FM support group significantly shaped his social interactions and provided him with a sense of purpose. As the group's facilitator, he took pride in fostering a space where people could connect and support one another through shared experiences. Reflecting on the importance of these interactions, P7 explained, "When you're at your worst, the best place you could be is to come to a meeting, cause everybody there will understand and be able to relate to you, and there's no better place to be than with people who understand you."

Through his leadership, P7 actively worked to create an environment where members could find comfort and understanding. He viewed his role as both a responsibility and an opportunity to make a difference in the lives of others. His engagement with others thus also reflects his own journey with FM:

> "I try to push forward to get better and also show joy and pride if I can help other people not have to go through what I've gone through."

P7 also spoke about the value of connection and mutual learning within the group. "People can come and express themselves to each other, and learn with each other," he shared, emphasizing the supportive dynamic he helped foster. This role not only allowed him to build meaningful social connections but also reinforced his sense of identity and resilience as he balanced the challenges of his illness with his commitment to the group's well-being.

At the same time, some participants were concerned that support groups were too focused on complaining. This reaction is interesting in thinking about stoicism as a core attribute of hegemonic masculinity, which discourages emotional expression (Martin, 2016).

For example, P1 signaled his reluctance to attend organized support groups for people with FM, in part because they are too often focused on complaining about the illness. He commented:

> "There's limited usefulness with that kind of a group. You can get together and exchange information, but as a lot of people have noted, it has become a wailing wall that gradually peters out … and there's only so much you can do."

P3 noted that he held off going to support groups for a long time, but was glad he did go in the end. He said that sometimes there is a sense of doom in those groups. He noted: "Most people just want to complain but that's not for me".

And while P4 did attend a group, he noted that the feel of this group was different to many he had encountered in the past:

> "Fortunately the group we have is a positive group, and there are so many, or many that I've run into over time, women especially, they go, oh woe is me, I have MS, and it's a shock, and they want sympathy deluxe."

Disconnecting from Social Space

Finally, it is important to note that for some men, changing physical and mental capacities, coupled with the awkwardness of social encounters, has led them to reduce or limit time in community spaces and social interactions.

On social engagements, P8, for instance, said, "I still have now, but not to the extent I used to. I used to go to bars, but the moment I stopped drinking, a lot of my friends didn't want to associate with me anymore."

Likewise, P6 said, "I've got a few friends who [I] don't see anymore because I have MS." In contrast to his other friends who accepted him and his new limitations, P6 explained how this group of friends was unable to reach a "compromise" with his chronic illness. "We used to go out for dinner and then go to the show," he said, "[Now] there are times I can't do that, but to them, they would think this is some big compromise. So we just don't see each other anymore."

Some of the other men shared how they simply lacked the energy to entertain friends. P2, for example, said, "I'm not going out to visit friends as much as before, just because of the energy demand that's required."

Similarly, another participant, P9, explained how he was a lot less active as a precaution to take care of himself. "Whenever something happens," he said, "I have to take care of myself, I withdraw instead of being active." He understood the strains on these relationships as a rational outcome of his MS, comparing it to "a cost-benefit analysis."

These varying experiences demonstrate that the range of social relations are shaped by factors that are within as well as out of the men's control. Here, P1 shared about his choice to isolate from broader society. He recounted his experiences back when he was a student: "Everybody in the class noticed I was rather ill… I just wanted to not be bothered and stay by myself," he explained, "I don't need people trying to help me make some friends or something like that. I just don't have the mental energy to maintain any kind of relationship anyway." As presented earlier, as well as through his artwork depicting him in his fortress, P1 has made the deliberate choice to distance from people who, as he describes, are always "attack, attack, attack."

There was also P3, who had become increasingly socially isolated since he stopped working. He talked about wanting and needing to disconnect from what he described as a "hyper-connected world"—a "system" that "does not grow organically," and a place that he wanted to have no part of. "I don't want to see it," he said. As such, P3 shared that he planned to "gracefully and continually detach from the system." Furthermore, he said that "he is on a road to zero," deliberately losing touch with friends from before: "I have 8 friends on social media right now and that will probably be down to 5 by the end of this year." However, now as a "free man," P3 explained that his focus had now shifted to supporting his family—a redefinition of his identity that he described as having "saved his soul."

4.5 (Re)negotiating Identity

Having explored the impact of chronic illness on various aspects of the eleven respondents' lives, I turn to present the intentional, relational, and involved process that is the (re)construction of a new workable sense of self over spaces and time. Having already experienced changes in both physical and cognitive capacities, the men must also come to terms with an uncertain future as a result of the chronic nature of their diagnosis. As such, they were uniquely positioned to confront their ever-shifting capacities, which in turn informed and continues to inform their understanding of masculinity and identities as disabled men—especially in relation to other men and women.

Longitudinal Uncertainty

The men often reflected on the dual challenge of chronic illness: its unpredictable nature and enduring presence. For those diagnosed with progressive forms of MS, this unpredictability led

to a significant struggle with control and independence. P5, discussing how his PP-MS impacted his career and sense of agency, remarked:

"The single thing about this career—no, about this disease, is that it's just so crushing. It takes away… you have to make friends with uncertainty, you know? Especially with any kind of MS, especially progressive MS, you're waiting to see what's happening to you next. You don't have a lot of control."

This concern was not limited to progressive MS, as participants living with RR-MS and FM also expressed an acute awareness of the precarity imposed by their conditions. P10 described how FM created a heightened sense of instability in his life: "The unpredictability of the symptoms and the impact of fibro means that things could change… I know that at any time my health could get worse."

Echoing similar concerns, P2 referred to his RR-MS as "unpredictable" and "frustrating," particularly because of its impact on his personal relationships.

P2 further conveyed the weight of this uncertainty through his artwork. Created in collaboration with the arts facilitator, April, his piece depicted dark bars and ticking clocks in melancholic blue hues, symbolizing his feeling of being "imprisoned" by MS. Yet, he also emphasized hope, represented by a central tree in warm, bright tones, inspired by the strength he derived from his relationship with his boyfriend. "It's going to be a lifelong process for me to really get to terms with it," he explained.

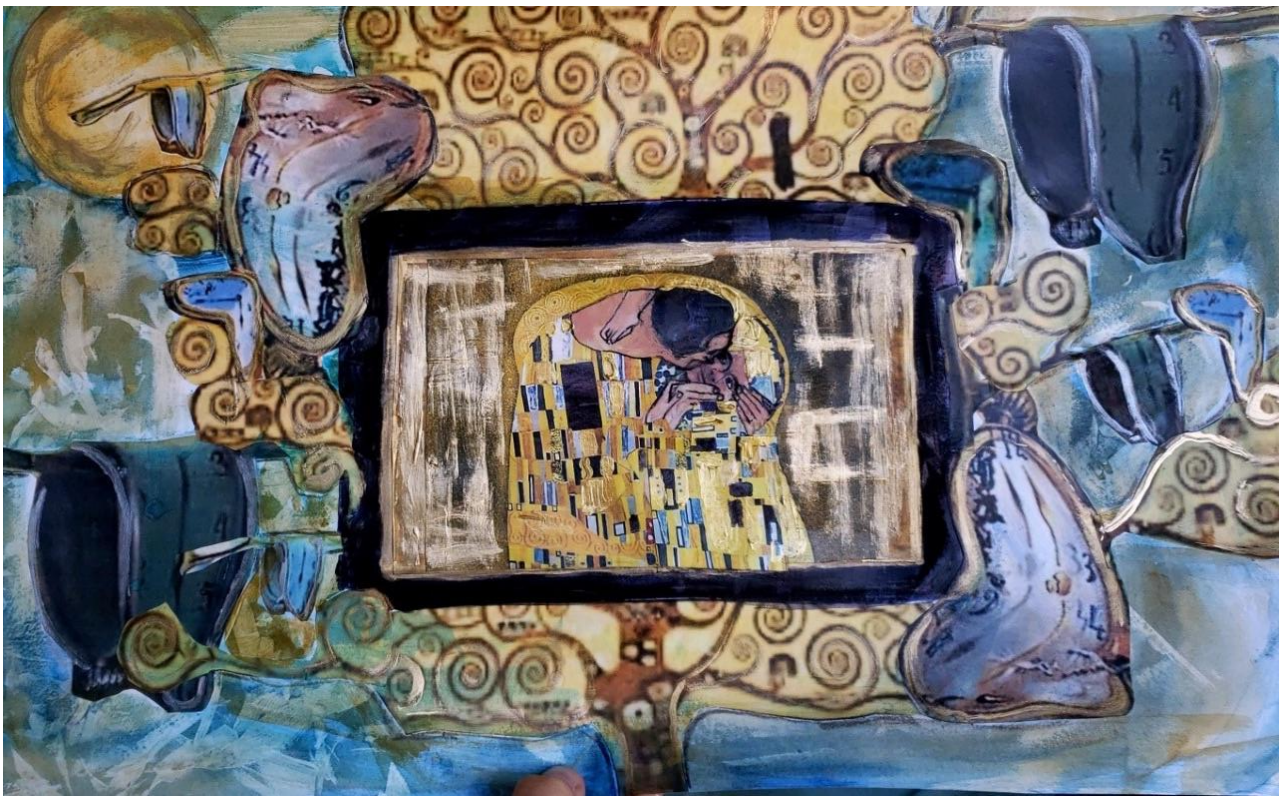

Figure 2. P2's Artwork (Collaboration with April)

For all participants, the experience of uncertainty shaped their sense of self and influenced how they navigated change over time. However, how they perceived and responded to these changes varied significantly.

Navigating Change

The respondents varied in how they approached and accepted changes brought by their illnesses. For P4, whose later-onset MS had relatively mild symptoms, the changes were not perceived as overwhelmingly disruptive. “My life has not changed too much other than the limitations that the actual MS has caused,” he shared. Reflecting on his acceptance of these changes, he noted the gendered as well as longitudinal aspects that comprised his identity: “I think I am what I am. I think I’m my father’s son, and I carry on.”

P1, on the other hand, emphasized a more self-reliant approach. “I had to use my head a lot more,” he explained. “I had to make the best of every possible break I could get.”

Among the eleven respondents, there was a recurring notion of learning to acknowledge and confront their chronic illness—a process that is both long-term, changing, and uncertain. Even so, there was an element of pragmatism as the men prepared for the inevitability of change. P2, for instance, reflected, “I have to accept the fact that maybe I’m not the person I used to be.” Adopting a practical mindset, he remarked, “How can you solve a problem if you don’t approach the problem? You have to acknowledge there is a problem and maybe see if there’s an action you can take to solve it.”

For P5, it took several years for him to come to terms with his diagnosis. He illustrated this shift using an analogy of circles:

> “For the first five or six years of the MS… MS [was] a big circle… I was a little tiny lump of that circle, like I was a part of MS. I finally turned around, went to the point where MS is part of me. I’m the big circle, and MS is part of my life—who I am, but it doesn’t define who I am.”

Similarly, P6 described his initial response as a refusal to acknowledge the illness: “Early on, I said to my wife… you can’t tell anybody. And I didn’t talk to anybody about it.” Over time, however, he came to recognize the impact this had on his relationship. At first, he was only comfortable with his wife confiding in close friends privately. But as time passed, he chose to be more open and expressive about his new reality. “I woke up one day and thought, screw this, I’m going to tell the world,” he said, “I’m not embarrassed, I’m not ashamed.”

Even so, for P6 and many respondents, moving forward involves confronting their changing capacities and taking ownership of their conditions—a process that takes time. As P6 reflected, “I’m not going to say it’s been easy… It’s been an evolution.”

Carrying On and Moving Forward

For some men, emphasis was placed on maintaining parts of their identity and passions despite the onset of chronic illness. P3, for example, recreated the sensations he once enjoyed through activities like snowboarding:

> "I can still be out in nature. I can sit by the creek and enjoy nature. I can play snowboarding video games and still enjoy that rush. As to the feel of the wind in my face, I can drive on the highway with the car windows down and get that same feeling."

Others, meanwhile, responded by seeking to overcome their challenges, reflected in terminology such as survival, liberation, moving forward, and success. To illustrate this point, P7 described himself as someone who had "been over the road." "The first goal is how to learn to be positive, to move forward with what we have and what we are," he explained. "I accept [my fibromyalgia], and understand it… the only way I can go is forward."

P1 similarly emphasized survival as the means to "have a decent life." If not for the choices he made, such as advocating for certain medical treatments, P1 reflected that "I don't think I'd be alive by now, and it's [been] a terrible fight."

P2 also saw his condition as a "process," a "new normal," and "life-long… very forever."

P8, having lived with illness for over fifty years, likewise described his perspective as one of survival. "You know, that's life. So what? Why get depressed over it? Why get stressed out over it? That's the way life is for me," he said, " I do what I have to in order to survive."

In this way, carrying on, adapting, and finding new sources of strength were recurring themes. For P7, this growth was embodied in his desire to live positivity. He reflected on his efforts to develop what he called a "natural smile," stating:

> "It's sometimes hard if you're depressed or have anxiety, or you're in pain constantly to try to become upbeat… but a positive mental attitude would create more miracles than any liquid or wonder drug."

Regarding his personal journey of finding his natural smile, P7 explained that it was not a front as it is something he's become.

> "[My health issues and] chronic pain was something I've had to learn to live with… I've become worldly.. I learned to speak my mind, and every day, I learn to grow better and make better decisions."

His art piece, also created in collaboration with April, symbolized his journey of recovery and progress. The imagery of the warrior, phoenix, and barbed wire, as well as through the use of colour, reflected themes of tenacity, rebirth, and finding beauty amidst pain as it occurs through time.

Figure 7. P7's Artwork (Collaboration with April)

Referencing the popular movie series Star Wars, P7 quoted: "do or do not, there is no try." To P7, the choice to move forward and come to terms with chronic illness rests in positive affirmation—a process of learning to love and accept oneself; a journey waiting to be embarked; a lifelong battle to be won.

The Intersection with Age

Age added complexity to how the men understood and responded to their changing physical capacities, particularly in distinguishing between the effects of chronic illness and the natural aging process. Two themes emerged from their accounts: (1) the blurred boundaries between chronic illness symptoms and aging, and (2) perceptions of age-appropriate behavior in relation to socially acceptable norms.

Several men, particularly those approaching or were already beyond retirement age, expressed confusion and frustration about whether their physical changes were due to illness or age. P6 reflected on this uncertainty, saying, "I have experienced people, healthy people, aging naturally, and I look at that and I think, that will never be my life. I will never experience that." He explained further, "My hips are a little sore, but I don't know if I'm sore because of my MS or because of my age."

For him, this ambiguity led to a sense of loss: "She [my wife] can put her finger on the aging process. I can't do that." As such, he felt "ripped off" by MS.

P4 shared similar experiences but framed the changes in his body as more attributable to aging than his illness. "I'm independent," he noted, "but at the same time, age, rather than handicap, I think is changing things."

For younger participants, managing age-related perceptions of illness and disability presented different challenges. P11 spoke about how societal expectations influenced his decision not to use a rollator despite needing one: "Using a rollator makes you look old." He felt that people would immediately associate him with aging if they saw him using the device. "The first thing [when] people see a rollator," he explained, "they think old people."

The respondents also discussed how aging influenced their activities and priorities, reflected in P7 comments such as: "I'm not twenty anymore, so I can't do what I did when I was twenty."

Similarly, P8 described how his lifestyle had shifted as he got older:

> "I don't drink anymore, I don't smoke anymore, so I don't go to bars. I can't handle that sort of life anymore. With the medication I take, I'm not supposed to drink… It's not something I want to do. I don't want to go out to that kind of thing."

On Doing and Being

Finally, many respondents spoke about how they managed change through embodied experience and a focus on doing—the active engagement with their physical capacities and daily routines. Sometimes, this takes place by simply being less physically strong and capable. P9, for instance, reflected that, "being a man with MS makes [him] different and not as strong as someone without MS."

Moreover, as their independence shifted, men like P11 and P2 reflected on how it impacted their sense of masculinity. P11's attitude of wanting to demonstrate capacity through acting independently was explored in previous sections. However, it is worthwhile to reiterate in this section of identity that he sometimes feels "emasculated" when receiving the support of others:

> "It's so pathetic to ask someone just to do [something] because I just didn't have the energy to do it… I think more so when you don't feel like a man is when you have to ask for help for things that are basic—that anyone should be able to do… I cut my grass—twice—so I can do it. And that's what makes me feel like a man, by cutting the grass: 'See, I can do it!' But now, the smart thing to do, for a person with MS, is to get someone else to do it. It sucks to have to ask because I should be able to do it myself, because I am a man."

P11 also spoke about his fear of losing confidence in his body and the consequences this had on his ability to engage with family:

> "My nephew had a baby, and I used to take care of him, carry him around, walk around the house, you know what I mean? And now, I have this fear, holding this kid when I'm not sitting down; because if I trip and, you know, go down with the baby in my arms—that's kind of like, a shame. It's kind of depressing actually."

Similarly, P3 described a balance between safety and maintaining control over his life. He explained that he uses trekking poles for stability but still pushes boundaries: "I'll still go on my longboard skateboard. Don't tell my neurologist!" For him, pushing himself was a deliberate and calculated—a gendered choice that involves weighing the risk of injury against the need to feel in control:

> "I'll still do that even though my wife and my mom say I shouldn't. Given my bone density, if I fall, I could really injure myself, but I'm a man. I need to do that. I need that… I lost snowboarding and skiing. It's a real risk, but I love it."

Others, such as P10, emphasized how his physical limitations shaped his engagement with his children, though he continued to find ways to participate fully in their activities. "I just struggle with that," he admitted. In this case, despite pushing himself, P10's choice reflected a deliberate blending of responsibilities towards his children as a father, and to himself by seeking opportunities to remain active:

> "I push myself also—so that I'm not being derelict. I play with them a lot. We're always going to parks. One of the benefits is that I need to exercise in order to mitigate my symptoms, so I have to incorporate that into the way I play with them. I do a lot of chasing games and playing outside. I guess I'm pushing myself through the pain and fatigue."

Similarly, P5 reflected on how physical challenges became a means of self-motivation. "Sometimes you do it because it's difficult—or in spite of it being difficult. But there's real value in pushing yourself. Any physical challenge I can find, I'll welcome it," he said. To illustrate this point, he shared this story:

> "When my wife picks me up in the car, she always offers to put my walker in the back for me. And I understand her intent. But I insist on doing it myself because I can. There's going to be a point in the future when I can't anymore, and I'll tell you when that hits me. But right now, yeah, it's hard for me, but… there's real value in doing things even if they're hard. The alternative is you're not doing anything."

In this way, challenging himself physically represented his battle to keep his independence:

> "Once you get in a wheelchair, there's no coming back. So I'm doing everything I can to avoid going in a wheelchair. It really comes down to independence—that fight, you know?"

For P6, staying physically active was central to his identity and mental well-being:

> "If I couldn't walk my dog, if I have to wake up and basically sit on the couch, sit on my chair in front of my computer all day… if that was my life (sighs)… as much as I enjoy eating good food, and watching some good TV, and reading some good books, if I couldn't get out of the house, my life might as well be over."

He observed that other people with MS find ways to maintain their independence:

> "People with walkers, scooters, or in wheelchairs—we see them carrying on every day. They found their equivalent of me walking my dog. I don't know what that would be for me, but hopefully I'd find it if things got worse. Right now, I'm trying to be optimistic—saying, 'I can still walk my dog, I can get outside, I make my breakfast and lunch. My wife makes dinner. I go out and buy peanut butter and bread for breakfast. I can still do that stuff.' I don't know what life would be like if that was taken away from me. I honestly don't know."

In this way, his capacity to *do* and to *be*—to embody and and be able to perform the things he believes to be basic—was essential to informing his identity. He summarized his outlook by saying:

> "So, you do what you can do and, I think, for mentally, physically, emotionally, there are barriers that prevent you from going even further—and some people go really far. But I feel I'm doing what I can do knowing who I am and under my circumstances to ward off the worst of the MS."

Finally, consider P4's perception of himself as rooted in the things he does. Here, the emphasis of doing and not doing was central to his understanding of himself as a man and was likewise reflected in his artwork. Also produced in collaboration with our artist, April, P4 foregrounded the range of outdoor activities that he engaged in, such as walking and riding his bike. He shared also about the social and relational elements inherent within such activities—a area of focus that will be explored in the next section:

> "When I get off the bike, if you were to look at me and I walk a few paces, it's very obvious that I suffer from mobility problems, and people can pick up, 'oh he has MS' from the dragging of the one leg and the one foot—I am not embarrassed in any way, shape or form by that. So is that a masculine thing? I think it is. I'm going to carry on with my life to the best I can, with whatever I have."

P4's artwork also captured the temporal aspect of reworking identity which was presented in the previous section. From the changing of seasons, to the blurring of his bike as he transitioned from a two-wheeler to a three-wheeler due to his changing body, P4 thus emphasized his "masculine" ability to adapt and change as he's a "cup half full kind of person." He shared: "Walking, riding my bike—riding a two-wheeler was a thing I used to do, and the idea was to

put the two-wheeler in there, but with it blurring so that it was in the past. I've gone from that to the three-wheeler. To me, it's as masculine as it can be."

Figure 4. P4's Artwork (Collaboration with April)

On Life, Living, Death, and Dying

Finally, I consider the blurred boundary that is between living and dying. This, too, was a recurring theme and approached from a variety of perspectives, as the men reflected on how chronic illness called into question what it meant to truly live.

Among the respondents, several explicitly made the connection between their chronic illness and their quality of life—with some even exploring the implications of their illness on living and dying. For P8, despite being arguably the participant with the most severe symptoms, he described his MS as merely an "inconvenience" to his everyday life as a man.

Others, such as P7, positioned their chronic illness as something that he had to make friends with and overcome through positivity. On this note, P6 described that. "[I] have MS," he said, "[but] that doesn't mean my life should end."

On this topic, P8 shared a story about a younger man with MS who had become overwhelmed by his recent diagnosis of MS. While this narrative presents the experiences of someone who has seemingly given up, defeated by his condition, P8 also employed this story as a contrast to how he faces his daily challenges head-on:

> "He sits there and he's panicking. He says, 'What do I do? My life is dead.' It's not. You still function, you still do things… But he had to quit his job, give up his apartment, and move back with his mum. And I can imagine she's pulling her hair out by the roots because he considers himself dead."

Even so, the fear of losing autonomy and dignity was also a shared major concern. This was evident in some of the men's sharing about their changing physical and mental capacity. However, it is also exemplified in their reflections regarding a potential point of no return.

P11, for instance, made it clear that he did not want to live in a state of dependency: "Well, I always told my partner that if I ended up like Richard Pryor when Elizabeth Taylor was talking to him, cause I saw this once on TV and she was saying to him, 'do you want something to eat, sweetie?' Okay? And she's talking to him like he was a baby? I said if I ever get to that point, just kill me, because I don't want to be living like that."

P5 echoed a similar sentiment, placing emphasis on the quality of life over its length. He said, "I want to keep growing and getting stronger in the ways I can. I know I'll get weaker in other ways, but once I get to the point where they want to stick tubes in me in the hospital, I have no interest. I'm not concerned about how long I live, but I am concerned with how I live."

This notion is reflected in one of the art pieces he created, depicting a tombstone that reads "Dead at 40, Buried at 80."

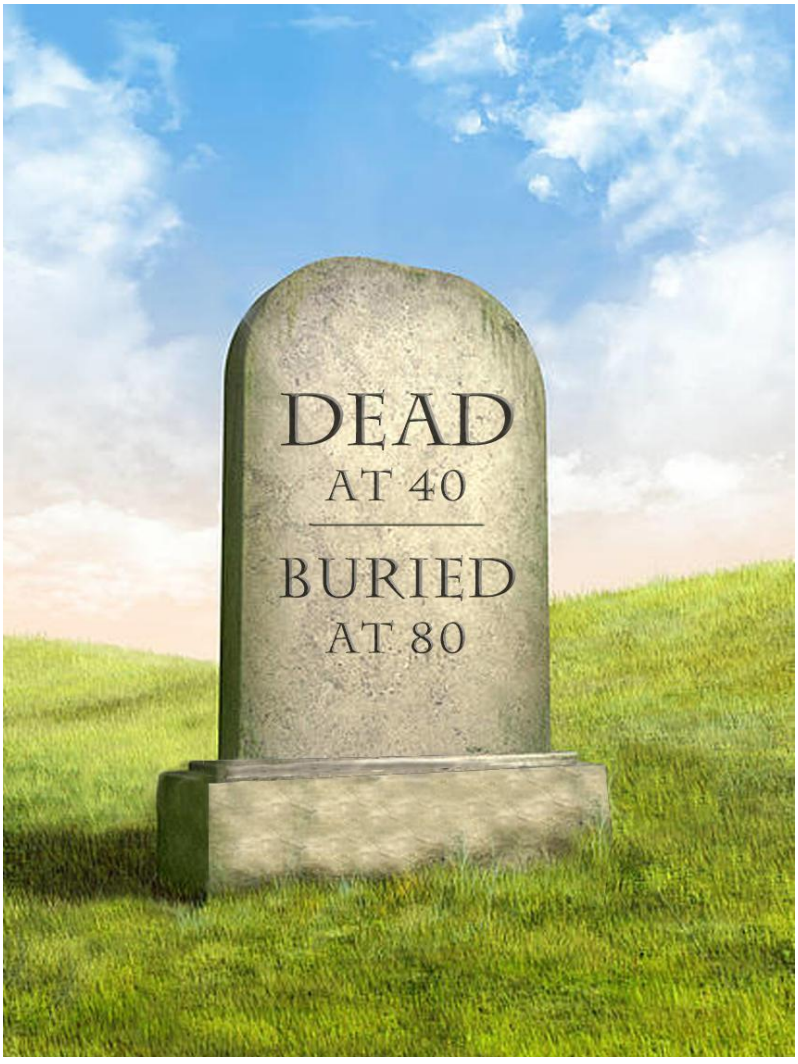

Figure 5b. P5's Artwork (Tombstone)

A Relational Experience

As alluded to earlier, the process of recreating a workable sense of self is also a relational one. In my conversations with the eleven respondents, the men often positioned themselves in relation to other men as well as women. While the previous section on Encountering Others explored the intersection of chronic illness with the men's social relations, this section further illustrates how such intersections are also gendered as well as embodied, influencing their sense of identity and masculinity.

A recurring theme was the act of comparing oneself to others, which often shaped feelings of luck, gratitude, or distinction. Five participants explicitly voiced attitudes of feeling fortunate or unique in contrast to others with similar conditions.

For instance, P5 reflected on his position relative to other people with MS:

> "Oh, I'm telling you, as I said, I'm at this group I go to every couple of weeks with MS, and people—I feel just awful. So many people are living in one-room apartments… it makes me sad, you know? These are the people I know though, then you think about all the people that are shut-ins, that you don't know about, that don't have a voice, that aren't online, that don't [get to share their stories], you know? Living pay cheque to pay cheque? I'm really very lucky. I'm lying here in this nice condo right now, and yeah, I think it's really important to keep that sense of gratefulness… And I'm very aware of that, you know? Even though I got dealt a crappy hand with this disease, I'm blessed in a lot of other ways, so I'm always aware of being grateful with what I have. I think that's really important."

Similarly, P6 expressed empathy for those whose experiences with MS were more severe than his own, saying, "I feel sorry for people with MS who lose… their partner."

However, he also acknowledged his own fortune, saying, "I didn't know how lucky I was. Yeah, like people with primary progressive, they are in wheelchairs. Hell, there are some people I know with primary progressive, they're dead. You know?"

This sense of positioning was not limited to those with less severe symptoms. Participants with more advanced conditions, such as P8 and P7, framed their positivity as a defining characteristic. P8, for instance, described the numerous symptoms and hardships he had faced but emphasized his positive outlook, believing it to set him apart from others—even among men in the study:

> "Well, I don't know who else you're going to get in this study, but I will be very surprised if they had the attitude I do, because I've talked to a tremendous number of people who have MS, and they are all either stressed or depressed. And, like, people just look at me and say, 'How can you be so cheerful and happy? You've got a chronic disease that's going to kill you one day.' I say, 'That's fine, one day it will, so what? It's not today.'"

Similarly, P7 described himself as having achieved a "natural smile," which he saw as a unique asset that enabled him to help others:

> "I'm a unique case, because of the fact I've made myself understand it, right? I try to push forward to get better and also show joy and pride if I can help other people not have to go through what I've gone through."

While some of the respondents framed their identity through positivity, others focused on how the loss of capacity impacted their self-perception in social contexts. In this way, P11 described a bowling experience where he suspected being pitied by his peers and how it affected his pride:

> "Just last year, I went bowling for the first time, and because I feel a little bit more confident I can take a few steps without pain… I used to do 156, [but now] I didn't even break 100. I couldn't even break 80! Like, it's just—that made me feel like, wow. Yeah, it's like, 'wow, I can't even like' whatever. Then I felt pretty crappy. And then I beat the two guys I was playing with in the second game, and I said, 'Did you just do that out of pity?' Of course, they said no. That hurts the ego, like a little bit."

This blow to ego was also described by some of the other respondents, particularly in situations where they feel passed up, insulted, or regarded as non-threatening as a result of their chronic illness.

P5, for instance, reflected on how his use of a scooter made him feel small. "I'm a big guy. I'm six foot two, but when I'm in a scooter, I'm like three foot six, right?" he said.

P5 shared another encounter where he felt undermined as a person:

> "A woman in front of me started unloading my basket, and so I just said, 'Oh, that's okay, thank you, I appreciate that, but I'm good,' 'cause I can stand up and still do that. But she kept on going… [and] it really bummed me out."

However, P5 also noted how he is learning—and continues to learn—how to see such encounters in a different light:

> "My instincts normally would've been a lot worse. Like, how dare she. I would've been insulted… But I remember thinking, as I was leaving, you know, that's a really nice woman. She thought she was helping. And you know, don't be insulted so easily, you know? The person who was trying to help me in the store—I've learned, or I'm learning at least, I'm learning to not get so upset and offended so easily."

Similarly, P2 reflected on the importance of vulnerability and adaptability in managing social interactions, particularly while traveling with his partner:

> "For example, we like to travel once a year… Last year, we went to Portugal. It's beautiful, it's incredible, but it's hilly. And the hills are really, really tough. And [my partner said,] 'remember for next time, to stay far away from the hills. We need to create conditions in which you can see.'"

He, too, explained how his perspective had shifted over time:

> "Maybe a year ago I felt like, who the fuck gives you directions, right? Who the hell do you think you are? Who do you think you are to tell me that? But nowadays the way that we look at it, you know what though, it's something for the both of us to have a good time."

On Feelings of Masculinity

Many participants reflected on their embodied actions as a way to demonstrate masculinity in relation to others. However, their control over these actions was often limited by the effects of chronic illness. This was evident in P9's desire to "handle" his MS and maintain his social stature. He emphasized that his interactions with others were shaped by a need to appear competent and equal to men without MS.

"I have MS and I want to handle it… I am optimistic that I can handle myself," he explained. "What I mean is that I can talk to them face to face, I can make bilateral discussions… I don't want to show that a man is stronger than me."

Meanwhile, for P9, his ability to control his body had direct implications for his personal identity and the way others perceived him.

Similarly, P7 noted that he rarely outwardly expressed his pain:

> "Most people don't think I have pain, or don't look like I have [pain]. They've never actually seen me express pain."

Respondents like P6 shared how their chronic illness restricted them from performing activities they associated with masculinity, such as physical labor and yard work. "These are things that I, as a man, would have done; I'm not doing them, I can't do them," he explained.

P11 also spoke about the frustration of being unable to perform tasks he saw as part of being a man. "All these things that a man should do, so to speak, I can't… because [either I can't, or] it will take ten years (laughs)—that's an exaggeration," he said.

Moreover, he reflected on how others might view his limitations, noting that his body did not align with societal expectations of masculinity:

> "I probably could [do some things], but it would look like, whatever, it would look like I'm a loser. You know, men are masculine and muscular, and you know, I know they're not all like that but, (laughs)."

Interestingly, P11 discussed not only what a man *should* do but also what a man might *want* to do, particularly athletic activities. He also connects the notion of *doing* with the embodiment of gender specifically.

> "It influenced me to the way where I don't think I can feel I can do what most men would want to do, like even hiking, climbing, like mountain climbing. Yeah, so stuff like that I

> can't do… Is it something that's important to me? Yeah, because I mean, otherwise, I'll just have sex change (laughs)."

P11's emphasis on athleticism was echoed by P10, who took up competitive tennis after being diagnosed with FM. He explained that the sport became a way to demonstrate his masculinity through competition and dominance.

> "I mean, it's a curious thing—the thing I do is take up a highly competitive sport. A highly competitive [strenuous] sport and throw myself into it 6-8 hours a week to demonstrate my virility. And you know, I can't lie about that. But like, if there's something there, right? That is about showing that capacity where I'm still trying to compete with other people, right? Where I'm still trying to demonstrate some measure of dominance, a measure of mastery and stuff, right? And it's sort of pathological, I think (laughs). It's also like demonstrating that I'm not defeated."

Respondents such as P6 and P4 also demonstrated how their embodied identities were shaped by comparisons to both men and women. For P6, this was expressed through positioning himself as more capable than other men with MS. "I know somebody who's on the MS diet… I can outwalk him," he said. "You know, he speaks with a kind of wobbly voice, and he has difficulty walking far, but he's doing all he can do, and to him, that's the diet. I'm not on the diet."

P4, by contrast, positioned himself as atypically masculine. He described how his love for singing, his career as a primary school teacher, and his interest in music—embodied characteristics that might not fit traditional masculine norms—shaped his self-perception as such a lifestyle may have been regarded as "unmasculine" at an "earlier era."

> "I'm not a very macho guy… You're talking to probably one of the least manly man that you'll talk to… I'm wearing a pastel pink fuchsia t-shirt at the moment, ah, when we hang up, I'll turn on the radio and listen to a show-tune station because I do like show tunes… Other people—other males might think, 'Ehh?' I love opera. There we go, I'm open more so than many."

Furthermore, P4 explained how his masculine response to adversity was influenced by the behaviors he observed in others at support groups. "Fortunately, the [support] group we have is a positive group," he said. "[But] there are so many, or many that I've run into over time—women especially—they go, 'Oh woe is me, I have MS,' and it's a shock, and they want sympathy, deluxe."

Meanwhile, he positioned his response to his chronic illness as a contrast to what he perceived as a more emotional or passive response:

> "Other people that I know… [they] moaned and groaned about it so the whole world sympathized with them. That was not my way of doing that… I guess it's more of a connection to my father, yeah. This sort of thing, you carry on. You're—I didn't complain. I looked at the bright side of life and always have."

As such, these narratives reveal the complex and varied ways that men negotiated masculinity in the context of their chronic illness. For some, like P8, there was a rejection of hegemonic portrayals of masculinity. He embraced the roles he had to as a father, for example, including acts of caregiving that are traditionally normalized to be done by women.

> "My son has a child. Yeah, I've changed his diaper. There. I've helped him on the toilet, with his bodily functions. Like I couldn't show him how to pee because I couldn't pee, and he's seen me naked and it's not a problem with him or my son. Ah, and he's seen the tubes hanging out of me, and that's not a problem with them. But I've helped him when he was younger. I've changed his diaper, I've wiped his bum. I showed him how to pee, I showed him what to do and everything, this sort of thing. I cook meals, I do housework. Does that make me less of a man?"

Other men, like P10, were strategic in navigating and constructing their daily lives. For him, there were times when he wanted to demonstrate his capacity to compete. However, he shared that, on a whole, his priorities have shifted towards aiming to divert unwanted attention:

> "I think, and I honestly do think that, that the way I dress, the way I present myself—like most people when they met me 10 years ago thought, 'this individual was gay,' right. I was kind of an effeminate and there was a certain purpose in this too. Now I think, like, since I've been sick, I think I don't want to draw attention to myself… I don't want my presentation to draw any more attention to myself."

Such tensions of adaptation, conformity, and resistance thus illustrate the interconnected lives that the men experience as they confront a social world while coming to terms with their chronic illness. From the varied responses, it is clear that there was no one pattern that the men employed, but their gendered and embodied lives remain one that is subjectively favoured as it is strategically navigated.

I conclude this section with a longer narrative shared by P4, as he positions himself in relation to masculinity through comparing himself to another man who he characterized as "extremely masculine." A comparison grounded on embodied and gendered aspects of understanding and doing masculinity, this relational reflection also captured many of the previous themes as presented throughout the entirety of this chapter.

> "I'm in a peer support group and it's a one-on-one, and I'm sitting with a fellow, who I'm going to say was mid-early-fifties, um, extremely masculine, sort of in the old-fashioned way, um, rough guy, … he was involved in boxing as well, and he sent me a picture with [famous boxer] and there he was, he was a brute of a guy. Now, in talking to him over the course of several months, the reason he needed this, he found out recently you know, a couple years, that he had MS. And it was about his family, his ex-wife, his adult children, accepting the fact that, yeah, 'come on dad, there's nothing wrong with you,' … he wanted them to realize that yeah, there were times that he was tired, and he couldn't do

the things that he once did, so here's a guy that… I would've met in a local bar and he's the sort of guy that you'd start talking to and rough, vulgar-sounding guy and, he wanted a little bit of sympathy and understanding from his kids, from his family, from me.

There's an example of an old-fashioned, tough masculine in the old way of looking, and yeah, the old way of looking at things who's really, is really affected by the MS because it's bothering him, and changing him into a male that he was, and you know… This guy, this guy was having real, real problems accepting his dilemma with having MS later in life and the way his family accepting it and, I could just see him with his muscles and his, you know with tears in his eyes and crying and being very un-masculine even though he was a, a real masculine looking character."

Chapter 5: Discussion

Overall, the lived experiences shared by the eleven respondents offered a diverse yet rich account of life as men navigating chronic illness. While each participant is uniquely positioned through the intersection of various identities—such as age, occupation, and family structure—common themes emerged in how chronic illness shaped their perceptions and enactment of masculinity. These themes reveal how illness influences not only how the men understand and embody gender but also how they interact with broader societal expectations and how society, in turn, perceives and treats them. The ability to perform and maintain control—relating to notions of power and independence—was a recurring point of tension in their narratives, as was the relational nature of these experiences, where identity is constantly shaped in interaction with others and their surroundings. This chapter will provide a summary of the men's experiences as presented in the Results chapter, followed by a discussion of its connection to literature. Finally, I will conclude by exploring several limitations of this research and my thoughts on future research directions.

5.1 Summary of Findings

The Place of Work

Beginning with paid work, the participants emphasized how employment held significant meaning as a site for performing culturally valued forms of masculinity. In Western contexts, paid work often symbolizes productivity, competition, and independence—qualities deeply tied to the breadwinner role and traditional ideals of masculinity. For many respondents, their careers were a source of pride and identity, offering validation through status, accomplishment, and financial stability. However, chronic illness disrupted their capacity to embody these ideals, forcing participants to renegotiate their relationship with work.

Eight of the eleven men had left the labour force due to changes in their physical and/or mental capacities, though their experiences varied based on factors such as the timing of illness onset and the nature of their jobs. While the majority of the men had to prematurely retire, there were others who had longer careers, with some even finding extra employment after retirement. For the men who were forced to retire early, such departures were often described as difficult and detrimental to their identity. For the three men who remained employed, work was a space of ongoing negotiation, requiring constant and strategic planning. Symptoms such as cognitive changes, fatigue, and physical limitations required careful—yet time sensitive—decisions regarding action such as disclosure and seeking of accommodations.

Disclosure was particularly complex as the men navigated uncertainty around potential discrimination, judgement, or even job loss. Moreover, meaningful accommodations were not always available, with access seeming to differ between private versus public sector work—though this was further complicated by the varying urgency and degree to which accommodations were needed.

Meanwhile, being self-employed or self-directed offered the most flexibility around scheduling and delivering work. The freedom of a flexible schedule allowed them to work and

adapt around the symptoms of their illness, including the possibility of working from the comfort of home. However, even this adaptability had limits, as men in this type of employment were eventually forced to reduce or end their work prematurely. Nonetheless, across the narratives, work remained central to participants' sense of self, with its loss calling to question a part of their identity that they had chosen, pursued, and constructed. Employment, to one of the respondents, was described as his "suit of armour."

As such, the findings on paid work illustrate how chronic illness challenges the core societal expectations placed on men to be productive, independent, and successful providers. Participants' experiences reveal both the structural limitations of workplace support and the personal impact of losing the ability to perform roles that, for some, were deeply valued. To those who were still employed, a shift to alternative forms of work was interpreted as a departure from their full professional potential. However, even for men who did not closely tie their employment to their working of identity, financial pressures—often as result from the lack of work—remained an area of concern.

The Place of Home

Next, the home emerged as a significant space for the participants. In the results chapter, this space was explored through aspects such as domestic living in relation to themes of intimacy, care, and support.

Regarding the intersection of care work, the men's experiences revealed a complex interplay on how such shifts in the giving and receiving of support shaped their sense of masculinity and identity, especially as it relates to notions of independence and capacity. As chronic illness altered their physical and emotional dynamics of home life, so too were the men's roles within such spaces changed. For those living with partners or spouses, this often meant a shift in the division of labour, with the able-bodied partners taking on greater responsibilities. However, the men continued to emphasize their desire to contribute where possible, be it from the desire to contribute their fair share, or as a means to maintain a sense of control and independence by doing what they are able, when they are able, and however they are able. This was especially poignant in particularly gendered work such as yard work and vehicle maintenance.

For the five participants living with a partner or spouse, the evolving dynamics of support and embodied roles often involved ongoing negotiation and compromise as they navigated the effects of chronic illness together. In many cases, the men reported relying more on their partners, though emphasis was also placed on how they continued to contribute in varying capacities. These experiences reflect a spectrum of compromise: feelings of guilt and emasculation were voiced but were often accompanied by gratitude and appreciation—at times by the same men. Moreover, this aspect of shared living at times overlapped with notions of fatherhood and parenting. In such cases, communication and compromise became all the more important as the men balanced their health and energy with spending quality time with family.

For the six men living alone, independence was both a source of pride as well as an ongoing challenge. Some of the respondents described such arrangements as affording them greater control over their daily routines, having the freedom to “do what I want, when I want.” Moreover, managing living space on their own terms transformed the place of home into a “safe space,” or “fortress.” Even so, managing responsibilities such as personal hygiene, grocery shopping, and cooking can sometimes become difficult, with some of the men relying on aid from support workers, family, or friends. The realities of living alone also highlighted other needs of external support, including subsidized housing and income assistance.

Next, when discussing the place of home, the topic of romantic and intimate relationships emerged as a critical component of the men’s identities—one that was significantly impacted by chronic illness. Of the eleven participants, five remained married and one was in an ongoing relationship, while the remaining five were either divorced, separated, or single.

Here also, there was a range of reported experiences. On one hand, the men in relationships reported that their illnesses had deepened their bonds with their partners through continued support, communication, and compromise. However, not all relationships withstood the pressures of chronic illness. Four men experienced divorce or separation following their diagnoses, with factors such as a lack of understanding and difficulty adapting to the new realities of illness contributing to the separation. For one of the respondents, remaining single was a deliberate choice as romantic relationships would only contribute to “tensions” or “drama.”

Finally, sexual intimacy was another area where illness affected participants' perceptions of masculinity. For some, sexual intimacy remained largely unaffected, while others had to adjust expectations and plan ahead due to fatigue and other symptoms. For a few of the participants, sex was described as having long been off the table. In this case, a respondent rejected the societal perception of sexual performance as central to masculinity, instead emphasizing his role and responsibilities as a father caring for his adopted son and his ability to provide in other ways. In contrast, others described their inability to maintain an erection as a "knock down" to masculinity.

Social spaces

Another aspect of the men’s lives affected by chronic illness was how they encountered others—particularly through the mutual navigation of engagement and perception across social spaces. As their experiences revealed, these encounters—whether with friends, family, neighbours, or strangers—were closely intertwined with how they understood and enacted masculinity. Factors such as visibility and energy, for instance, had far-reaching implications for how the men approached social interaction. This was further complicated by the nature of the relationship, such as a spouse or partner versus a coworker or passerby. Shaped in large by the degree to which they felt socially included, these experiences held important implications for how the men understood their identities and their broader disposition toward society,

To begin, the challenges of being caught between invisibility and hypervisibility were voiced by many participants. As in the home and workplace, manifestations of illness—particularly invisible symptoms like pain and fatigue—were often misunderstood or dismissed. In social settings, such responses were described by participants as a source of frustration and tension.

Here, the visibility of the men's condition shaped how they interacted with others. The presence of a cane, for instance, served to legitimize illness, yet was also a symbol of disability. Beyond the notion of visibility, however, is how the men's actions reflect gendered behaviours. To draw again on the example of the cane, a respondent mentioned choosing to use such a tool rather than a rollator. To him, a man his age should not be using such mobility aids as it makes him appear old. In many cases, the respondents were highly aware of how their symptoms appeared to others, that is, publicly invisible and yet unavoidably conspicuous.

Such discomfort within social settings also extended to more immediate encounters, such as conversations and the accompanying notion of sympathy. In some cases, the men described how conversations became awkward once illness was mentioned. Two common reactions were noted: people either offered unsolicited advice about cures or became visibly uncomfortable and avoided the topic altogether.

This sense of discomfort is also closely related to feeling emasculated or otherwise overlooked. Participants recounted events where a waiter, for example, addressed the wife, asking "'What would he have?" or employers who would call upon other employees for work that the respondent can manage. Emasculation also surfaced in encounters with neighbours who would constantly and unsolicitedly offer help. Notably, the intersection of illness and gender reshaped socially normalized privileges typically afforded to men—privileges that, in some cases, were redirected toward women, as exemplified by the interaction with the waiter.

Moreover, such experiences of emasculation also reflect a sense of loss in terms of sexual presence or otherwise sexually non-threatening. For one of the participants, being wheelchair bound led women to perceive him as harmless and to act friendlier toward him. While he appreciated the more open communication this brought, he reflects that he nonetheless wants to be seen as more than a "safe guy" as he feels he is no longer seen as a sexual person at all.

Energy also played a significant role in shaping the men's social encounters across various spaces. As previously discussed in relation to home and work, fatigue and pain remained limiting factors—manifesting in practices such as resting early to protect sleep schedules, anxiety over missing or being late to work, an inability to complete tasks, or concerns that partners might misinterpret exhaustion as disinterest. Similar dynamics extended into social spaces, where limited energy or other health-related concerns prevented the men from participating in activities they once shared with friends and peers, leading to a decline of social interaction—be it intentional or incidental.

Even so, some of the men remained active in seeking ways to maintain social connections. Here, the presence of a spouse or partner helped to facilitate gatherings with friends

or neighbours. Some of the men also took initiative in maintaining their own social circles, be it over coffee or activities like sport.

For others, meanwhile, social engagement took on new forms. Participation in such events represented new doors of opportunity opened by their experiences with chronic illness, and a number of the men have found a sense of place volunteering with charitable organizations and facilitating support groups.

Encounters and relationships within social spaces thus remained an area of the men's lives that was as complex as it was varied and fluid. Their experiences reveal the interconnected ways in which chronic illness shapes and reshapes such relations—both in terms of how they perceive and engage with others, and how others, in turn, perceive and engage with them. In this way, the men confronted at times seemingly opposed, challenges such as visibility and hypervisibility, independence and vulnerability, seeking new connections and detachment, as well as navigating the doors that were opened and closed as a result of their new realities. Such experiences also illustrate the scope of interactions and relations that take place within and across various spaces. With their identity called into question, the men must confront and navigate not only their changing bodies but also their place within the social world.

Illness and Identity

As evident through the intersection of chronic illness and gender across various spaces, the process of navigating their changing bodies and minds shaped not only the participants' physical experiences, but also their evolving sense of self and masculinity. Many men reflected on the significance of receiving a diagnosis—an event that, while often delayed and fraught with misunderstanding and misdiagnoses, ultimately legitimized their experiences. Receiving a formal diagnosis was thus recognized as crucial, as without this formal recognition, symptoms such as pain, fatigue, and other physical or cognitive changes were often dismissed by others—exacerbating feelings of frustration and alienation.

In terms of its effects, the men's experiences suggest that the intersection of illness extends deeply into many aspects of their lives—including their sense of identity and how they navigate and live out their gendered lives as men. Participants living with more aggressive conditions spoke of learning to "make friends with uncertainty." Even so, the men are uniquely positioned to adapt to new limitations while striving to maintain a sense of continuity in the ongoing gendered reconstruction of who they are and who they may yet become.

For many, this adaptation involved a gradual process of acceptance and self-advocacy. These experiences often take the form of making friends with, or otherwise incorporating, their conditions as part of their identity, rather than being defined by their illness. Whether aimed at preserving previous capacities or redefining themselves along new lines, the ways in which the men practiced gender were performances that spanned the scope of their lived experiences. Some approaches were creative and collaborative; others, risky and isolating. The one through line was the deliberate and strategic steps the men took to make it happen.

On the topic of changing bodily and mental capacities, age emerged as a complicating factor as it added layers of complexity onto how participants perceived and navigated their illness, particularly when symptoms overlapped with the natural aging process. Older participants reflected on how their changing bodies were shaped as much by age as by chronic illness. In contrast, younger men expressed anxieties about the visible markers of disability—such as using a rollator—which they feared would make them appear prematurely aged or dependent. Sexuality also emerged as a point of interest as one participant noted that he already did not fit certain societal expectations as a gay man.

At the core of these narratives was the embodied negotiation of masculinity. Many participants described how their physical limitations challenged their ability to perform tasks they associated with being a man. This was compounded by their shifting capacities or experiences of emasculation, prompting various responses aimed at reclaiming. affirming, or exerting control over their masculinity. These include engaging in activities such as competitive sports, video games, house work, and car maintenance.

Moreover, the relational dimension of identity work also played a critical role. Participants frequently compared themselves to others with chronic illnesses, positioning themselves within a spectrum of capability and fortune. It was common, for instance, for the men to share similar stories about feeling lucky or blessed in comparison to the hardships and loss faced by others. For the men who remained in committed relationships, there was a strong sense of gratitude for the continued support and connection with their spouse or partner. Meanwhile, those who were single or divorced also expressed a sense of being fortunate—if only for the fact that they were still alive and able to do what they could to make the most of their circumstances.

Conversely, the respondents also expressed sentiments of frustration and anger—be it from the loss of capacity, to the limited ways they are able to engage with their family, friends, work, and the broader social world. This range of experiences, however, illustrates the complex interplay between chronic illness and gender as the men continue to move forward in their everyday lives. In this way, the men navigated a dynamic process of loss and adaptation as they sought to maintain their autonomy and sense of self in the face of shifting physical and mental realities.

What is clear, however, was that there was no singular path that defined or determined their responses. Just as the men voiced themes of perseverance, redefinition, and relational positioning as they took on new roles, so too did they, in other aspects of their embodied and relational lives, continue to rely on and recreate opportunities that defined their previous experiences. For these men, the intersection of chronic illness was not only a health condition but a deeply relational and embodied experience—it became their new normal that called into question all aspects of their gendered lives. This experience demanded not only a thorough and ongoing reconsideration of how they perceived and enacted themselves as men, but also their sense of identity and place in the world.

5.2 Connecting Findings to the Literature

The narratives presented in this study both affirm and complicate existing scholarship on masculinity, disability, and chronic illness. In line with Connell's (2005) conceptualization of masculinity as a plural and relational configuration of practices, respondents' accounts demonstrate that lives as gendered beings are complex and dynamic. The presence of chronic physical illness poses a challenge to the demands of normative masculinity—a form of symbolic castration and emasculation that positions them as less than men (Shakespeare, 1999; Valentine, 2005; Shuttleworth et al., 2012). Indeed, these feelings were common among the respondents as they confronted a loss of their established identity and autonomy alongside changes to their bodily and mental capacities.

My findings extend Gerschick and Miller's (1997) framework of reliance on, rejection of, or reformulation of dominant masculine norms. In their paper, they have outlined that these patterns of practice reflect the strategies men employ and are not mutually exclusive. While most practices reflected patterns of reformulation and reliance, My research affirms this framework as depending on situational demands, most participants moved fluidly between strategies. For example, maintaining involvement in traditionally masculine tasks such as yard work or vehicle maintenance reflected a reliance on gendered norms, while redefining fatherhood or pushing intimacy outside the centrality of sexual performance (as in the case of P8) exemplified reformulation and rejection. Such fluid and context-specific strategies emphasize the situational nature of gender performance among disabled men—a reminder that such socially constructed categories encompass a diverse range of experiences (Hopkins, 2006; Gerschick, 2000; Shuttleworth et al., 2012). The call to move beyond static, monolithic portrayals of gender and disability is also discussed by Garland-Thomson (2020) who calls for integrating disability into feminist theory as a vital analytical category, noting that such integration exposes the ways power operates on bodies and identities differently depending on social context.

Another facet of my research is the affirmation that masculinity is lived and embodied as it is relationally shaped and reshaped. As Schrock and Schwalbe (2009) discuss, framing masculinity as action—that is, collective male practice—provides an avenue for understanding the manhood acts that define the "male" category and its constituent members. The social construction of gender hierarchy is thus determined by embodied action and how they distinguish themselves apart from others. These actions include the claiming of privilege, resistance to exploitation, and "what men do to create, maintain, and claim membership in a dominant gender group" (p. 281). Indeed, men's choices are shaped by gendered social practices that are deeply embedded in cultural expectations and power relations (Courtenay, 2009). In response to questions such as "what does it mean to be a man," statements such as "I move forward" or "I get up every morning [and] I greet my wife" reflect performative and heterosexual norms of masculinity—even as the men themselves were labeled or perceived as disabled and non-normative.

Such practices of distinguishing oneself apart from others were also exemplified in the ways the respondents consider themselves to be lucky—a statement often made in comparison to

individuals in less favourable positions. For the men who remained married, for instance, they were thankful for having a spouse or partner. Meanwhile, for the men who were single or divorced, they mentioned they were lucky to still be capable of doing the things they want to do. Finally, for the men who were living with limited mobility and/or constant pain, even they said they were lucky, if only to still be alive.

Another aspect of embodiment relates to a more relational aspect, as manhood acts can fail if they are not recognized as legitimate by audiences, demonstrating the social construct of masculinity as contingent and contestable. In practice, this can result in men's reluctance to alter health behaviours to protect masculine credibility within peer groups (O'Brien et al., 2009), as their masculine identity hinges on others' validation or rejection of their gender performance (West & Zimmerman, 1987, Gerschick, 2000). In other cases, the performance of manhood acts include the suppression of fear and downplaying symptoms, such as the exaggerated masculinities of young men who draw upon notions of fearlessness and aggression in response to "coping with the fears and risks of becoming a man in the inner-city" (Brownlow, 2005, p. 590). From choosing not to use a mobility device to not appear old, to playing snowboarding video games that simulate the rush, the respondents' actions and self-presentation demonstrate the highly performative nature of enacting masculinity, both in terms of gaining recognition from others and personal satisfaction alike. Such embodied and relational dynamics emphasize the practices and process of shaping masculinity as well as the actors who simultaneously belong within such categories and while being its makers.

Social spaces

The geographies of masculinities remains a critical element of my study as gender is not only inscribed onto, but performed by, bodies across different spaces (Browne 2005; Gorman-Murray 2012; Longhurst 2005). Indeed, the role of place emerged as critical areas that shape and are shaped by performances of masculinity as they are lived or otherwise imagined. As Wilton et al. (2014) highlights, spaces have the power to reinforce harmful norms, but also the potential to facilitate change.

In continuation of my discussion on the embodied and relational nature of doing gender, public spaces emerged as a recurring arena where manhood acts were performed and evaluated. As Valentine (2005) writes, public environments—such as streets, shops, and areas or facilities of leisure—are often designed around able-bodied norms. As such, the presence of chronic illness intersects with these spaces as sites of surveillance and othering, where their bodies are read as deviant or in need of help. Such social encounters were common among the respondents, manifesting as the subject of others' gaze or deterred glances. In conversation with strangers, the respondents shared stories of awkwardness around the topic of illness and unsolicited offers of assistance alike. Even so, there are other, more pleasant experiences where markers of difference—such as a cane or mobility device—served as opportunities for conversation.

In some cases, public interactions can reinforce feelings of emasculation, such as one respondent's experience of being passed up by a waiter who instead, addressed his wife. Still, in

other cases, social spaces can be empowering, as in the case of P7, who applied his experiences with illness in his advocacy work and facilitating support groups. Indeed, alongside subjective experiences of aging, illness, and fatherhood, peer networks, work environments, and community are important spaces that play a role in reinforcing or challenging masculine norms (O'Brien et al., 2009).

The place of home

Home emerged as a central site in the men's accounts, especially as they moved away from the workplace. While socially constructed as women's domain (Gorman-Murray, 2011), the home became a place where masculinity was reworked. Some men continued to perform manhood acts—such as P4 drawing on his teaching experience to take a leadership role—while others shifted toward domestic labour and family care, reshaping identity, wellbeing, and intimate relationships. This supports Gorman-Murray's (2011) view that "home has become the primary site of belonging—of emotional attachment, self-worth and ontological security" (p. 218). It also echoes Courtenay's (2009) example of alternative masculinities that challenge or depart from traditional hegemonic norms.

As Valentine (2005) notes, the home can be a space of both autonomy and vulnerability. It offers opportunities to reassert control and adapt the environment to one's needs. Yet it can also be a site of dependency and compromise—particularly in the exchange of care and emotional support within families. This was especially significant for fathers in this study, who had to rework how they engaged with their children, sometimes by embodying valued masculine traits, other times by adopting non-traditional forms of support (Pini & Conway, 2017). One participant aptly captured this shift as "being the rocket fuel now rather than the rocket." Thus, negotiation of domestic labour and emotional relationships within the home illustrates how chronic illness reshapes everyday gender practices in ways that are deeply relational, extending well beyond the individual.

For men living alone, independence was framed as both a source of pride and a logistical challenge from managing self care to securing groceries. Such arrangements also foreground the intersection with class as those with financial resources could maintain separate households, while others relied on subsidized housing and external support.

The workplace

Paid work emerged in this study as a critical site on which the men's identity was partially constructed. This reflects scholarly work linking traditional models of hegemonic masculinity to dedication to paid work, with men's identities often structured around the breadwinner ideal (Connell, 2005; Gorman-Murray, 2011; Pini & Conway, 2017). For participants, work provided not only material security but also a sense of purpose, status, and social validation. Moreover, it serves to place one's capacities in competition against other actors. As Barrett (2014) notes, the continued gendered division of labour ties employment to masculinity, shaping how it is defined and legitimated. Yet, standardized systems of embodiment and environment built for able-bodied

masculinity often result in their material and social exclusion (Gibson et al., 2007). As such, Barrett (2014) comments: "disabled men were simultaneously both required to participate in the labour market by virtue of their gender, and excluded from it by virtue of their disability" (p. 41). This gendered dilemma is also voiced by Murphy (2001) who writes: "A man who stays home is a loafer and a failure, but a woman who stays home is a homemaker. Women may work, but men must work" (p. 204).

As with Gerschick and Miller's (1997) framework, strategies of reliance, rejection, and reformulation were visible here: while some participants sought to preserve their professional roles as long as possible, others adapted responsibilities or working patterns to align with changing capacities, or redefined success outside employment altogether.

While some of the respondents have or are continuing to experience conventional career trajectories, the common experience of premature departures from the workforce reflects the structural and personal impacts of illness. For those still employed, decisions around disclosure and accommodation reflected a balancing act between maintaining professionalism and voicing vulnerability. As noted by Dalessandro et al. (2019), this form of strategic silence is a way for men to maintain positions of dominance and prestige while avoiding perceived threats to their masculine identity. In addition, the choice of disclosure and seeking accommodation is multi-faceted as doing so may jeopardize their careers. This was the case with P11, for instance, who had negative experiences being upfront with his illness. These accounts affirm that the workplace remains a powerful arena where masculinity is enacted and contested. With their professional identities and capacities called into question, the men must negotiate their new position within or outside of it.

5.3 Limitations

Regarding the limitations encountered in my study, the onset of the COVID-19 pandemic necessitated significant adjustments to the original research design, particularly the shift away from in-person interviews. Initially planned as video conferencing sessions, interviews were ultimately conducted over the telephone to safeguard participant confidentiality and privacy. Similarly, the original group-based art-making component was revised into individual activities to prioritize participant safety while maintaining engagement. While the group format would have fostered opportunities for participants to connect and share experiences, the individualized approach offered greater flexibility and allowed participants to complete the activity at their own pace and comfort level.

A key limitation of the research was the time constraints inherent to completing a master's degree. The compressed timeline for conducting and analyzing the research affected certain aspects of the process, such as the ability to return to participants for feedback, clarification, or follow-up. Furthermore, the limited timeframe curtailed opportunities for broader knowledge mobilization—such as advocacy efforts or public dissemination of findings through non-academic mediums. In hindsight, greater emphasis on these components would have

enriched the study, particularly given the socio-geographical, feminist, and participant-centered focus of the research.

My own inexperience as a researcher also emerged as a limitation. As the interviews consisted of back-and-forth conversation, my role as the interviewer was to guide and facilitate discussions. Even with the interview guide, a better job could have been done in keeping my conversations focused on addressing the research question. As such, recognizing ways to prompt, as well as when and how to appropriately interject, proved to be a valuable learning experience. Moreover, another aspect of the interviews was navigating tension. In such situations, the interviewer's ability to empathize with the respondents—recognizing personal and emotional moments of vulnerability—was critical for conducting a discussion that is professional, yet sensitive and respectful to the participant's voice.

Finally, there are limitations regarding representation. To begin, only two of the 11 participants were living with FM. While the gender disparity in FM prevalence is greater than that of MS, it remains important to prioritize reaching out to men with FM for this study. In this way, future research should place greater emphasis on recruiting men with FM to better understand their experiences. Moreover, MS and FM, while valuable for exploring chronic, unpredictable, and often degenerative conditions, do not capture the full range of chronic illnesses. Many other conditions—across the full physical/cognitive spectrum, visible and/or invisible—remain a core part of people's everyday lives—comprising their lived realities and identities that are no less significant than what is considered here in this research.

On this note, the study did not fully account for the spectrum of intersectionality. The intersections of race and class, for example, were not specifically factored into the research design. This limitation is particularly significant as intersectionality has become widely acknowledged as critical by both academic and non-academic groups, including human geographers, critical disability studies scholars, feminist scholars, and social justice advocates alike, for its essential role in shaping a person's lived experiences.

Intersectionality informs us that individuals embody interconnected dimensions of identity, shaping the way individuals perceive and interact with society, and how society reciprocates. This framework also describes the systems of inequality embedded within society as it relates to the intersection of gender, race, ethnicity, class, sexuality, disability, and other identities. It speaks to experiences of power, privilege, and oppression, as well as to the processes of legitimization that produces inequality. The interconnected and inseparable mosaic of intersecting identities thus becomes a contested site of struggle wherein discrimination and disadvantage are disproportionately produced, reinforced, and experienced. As such, the interplay of intersecting identities and the disabling state of society become critical components to consider, especially in the context of examining men's experiences with chronic illness and their perceptions and enactment of masculinity within and across spaces and relations. It is, ultimately, a gendered and social construct and problem.

Another limitation was the small sample size which, while a recognized limitation, was mitigated by the depth and richness of data collected through interviews and art activities.

However, relying primarily on support organizations for recruitment inadvertently excluded men who do not engage with these programs. While the study's visibility on social media partially addressed this gap, a greater push for snowball sampling would have engaged a wider population. The inclusion of these men would better reflect the experiences of living with MS and FM from a more holistic perspective.

As such, while the sample was not intended to be representative of the broader population, the research aimed to achieve theoretical saturation across both the interviews and art-making components (Morse 2000; Charmaz 2006). Nonetheless, there remains a clear need for future research to expand on this work. Specifically, further studies should explore how men with chronic illness navigate their identities, challenges, and futures in ways that center their lived experiences and reflect the dynamics of power, social relations, and space.

In summary, this research seeks to provide a deeper understanding of the diverse perspectives, experiences, and creative capacities of Canadian men living with chronic illness. By examining the intersections of disability and masculinity, the study sheds light on how men navigate their identities within the context of contested spaces such as the body, home, workplace, and public life. It explores how chronic illness disrupts traditional masculine ideals of strength, independence, and productivity, while also revealing the strategies men use to negotiate these disruptions. In doing so, the research contributes to broader conversations about gender, disability, and identity, challenging assumptions about what it means to be "able" and expanding discourse on how masculinity is lived and redefined in the face of chronic illness.

5.4 Future Directions

This research has highlighted the complexities of the men's lives, shedding light on how chronic illness affects their perceptions and enactments of masculinity. Yet, I feel that this study only begins to scratch the surface of these experiences. Chronic illness is not a static condition—it dynamically interacts with multiple aspects of identity and social life. This research project is part of a larger study that aims to compare lived experiences across different groups, including individuals with intellectual disabilities. The broader project also considers the experiences of non-disabled men, offering a comparative perspective on how health intersects with gender. Together, these varied experiences help build a more comprehensive understanding of how gender, disability, and health interrelate.

Based on my research interests, I would like to further explore how various intersecting identities influence gender. The men in this study led diverse lives, and their experiences cannot be reduced to static categories. Nevertheless, factors such as race, class, sexuality, immigrant status, and religion likely shape how they respond to their illnesses. While some of these intersections emerged during the interviews, they were not the primary focus and were not explored in a targeted way.

For example, participants with greater access to financial resources appeared to enjoy more flexibility in how they managed their illness and its impact on their daily lives. This observation suggests that material conditions and access to wealth may play a significant role in

shaping experiences of chronic illness. As such, a direction that future research can take is focusing explicitly on the impact of class structures and materiality, examining how these factors intersect with chronic illness and masculinity. Class is intricately linked to power and social relations, which may, in turn, influence men's strategies for navigating illness and their capacity to maintain or redefine their gender identities. Understanding these dynamics will contribute to a richer, intersectional analysis of chronic illness and masculinity, providing deeper insight into the socio-economic and cultural forces at play.

Additionally, the inclusion of multiple research methods has demonstrated its effectiveness in social research by offering different perspectives on participants' lives. In this study, the works of art created or directed by participants provided an alternative angle into their experiences, complementing the interviews. These artworks also serve as a valuable means of research dissemination. Unlike a lengthy academic thesis, art can be understood and appreciated by a broader audience, transcending the constraints of formal writing. I believe that accessible communication and advocacy are crucial for the success of making voices heard, and art has proven to be a powerful and effective medium for both.

References

Barrett, T. (2014). Disabled masculinities: A review and suggestions for further research. *Masculinities & Social Change*, *3*(1), 36-61. https://doi.org/10.4471/mcs.2014.41

Becker, C. B., Diedrichs, P. C., Jankowski, G., & Werchan, C. (2013). I'm not just fat, I'm old: has the study of body image overlooked "old talk"?. *Journal of eating disorders*, *1*, 1-12. https://doi.org/10.1186/2050-2974-1-6

Bell, C. (2017). Is disability studies actually white disability studies? In L.J. Davis (Ed.). *The Disability Studies Reader* (pp. 422–431). Routledge. https://doi.org/10.4324/9781315680668-38

Berg, L. D., & Longhurst, R. (2003). Placing Masculinities and Geography. *Gender, Place and Culture: A Journal of Feminist Geography*, *10*(4), 351–360. https://doi.org/10.1080/0966369032000153322

Bondi, L., Avis, H., Bankey, R., Bingley, A., Davidson, J., Duffy, R., Einagel, V., Green, A-M, Johnston, L., Lilley, S., Listerborn, C., Marshy, M., McEwan, S., O'Connor, N., Rose, G., Vivat, B. & Wood, N. (2002). *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research*. Oxford: Rowman and Littlefield.

Bonnett, A. (1999). Masculinity/masculinities/masculinism. In L. McDowell and J. Sharp (Eds.), *A Feminist Glossary of Human Geography* (pp. 159-162). Routledge. https://doi.org/10.4324/9781315832449

Bonner-Thompson, C., & McDowell, L. (2021). Digital geographies of austerity: Young men's material, affective and everyday relationships with the digital. *Geoforum*, *120*, 113-121. https://doi.org/10.1016/j.geoforum.2021.01.023

Brannon, R. (1976). Looking at the Male Role. *Contemporary Psychology*, *21*(11), 795–796. https://doi.org/10.1037/014712

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Broughton, C. (2008). MIGRATION AS ENGENDERED PRACTICE: Mexican Men, Masculinity, and Northward Migration. *Gender & Society*, *22*(5), 568–589. https://doi.org/10.1177/0891243208321275

Brownlow, A. (2005). A geography of men's fears. *Geoforum 36*(5), 581-592. https://doi.org/10.1016/j.geoforum.2004.11.005

Bryant, L., & Pini, B. (2010). *Gender and rurality*. Routledge. https://doi.org/10.4324/9780203848289

Calasanti, T. (2004). Feminist gerontology and old men. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *59*(6), S305-S314. https://doi.org/10.1093/geronb/59.6.S305

Caluya, G. (2008). 'The rice steamer': race, desire and affect in Sydney's gay scene. *Australian Geographer*, *39*(3), 283–292. https://doi.org/10.1080/00049180802270481

Charmaz, K. (2008). Grounded theory as an emergent method. In S. N. Hesse-Biber and P. Leavy (Eds), *Handbook of Emergent Methods* (pp. 155-172).

Clarke, L. H., Bennett, E. V., & Liu, C. (2014). Aging and masculinity: Portrayals in men's magazines. *Journal of Aging Studies*, *31*, 26–33. https://doi.org/10.1016/j.jaging.2014.08.002

Connell, R. W. (2005). *Masculinities* (2nd edition). Routledge. https://doi.org/10.4324/9781003116479

Connell, R. W. (2008). Gender as a Social Practice. In J. C. Alexander & S. Seldman (Eds.), *The New Social Theory Reader* (2nd ed., pp. 369–375). Routledge. https://doi.org/10.4324/9781003060963-62

Connell, R. W. (2020). The Social Organization of Masculinity. In *Feminist Theory Reader* (5th ed., pp. 192–200). Routledge. https://doi.org/10.4324/9781003001201-23

Connell, R. W., & Messerschmidt, J. W. (2005). Hegemonic Masculinity: Rethinking the Concept. *Gender & Society*, *19*(6), 829-859. https://doi.org/10.1177/0891243205278639

Connell, R., Hearn, J., & Kimmel, M. (2005). Introduction. In M. S. Kimmel, J. Hearn, R. W. Connell (Eds.), *Handbook of studies on men and masculinities* (pp. 1-12). Sage Publications, https://doi.org/10.4135/9781452233833.n1

Courtenay, W. H. (2000a). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine*, *50*(10), 1385–1401. https://doi.org/10.1016/S0277-9536(99)00390-1

Courtenay, W. H. (2000b). Engendering Health: A Social Constructionist Examination of Men's Health Beliefs and Behaviors. *Psychology of Men & Masculinity*, *1*(1), 4–15. https://doi.org/10.1037/1524-9220.1.1.4

Courtenay, W. H. (2009). Theorising masculinity and men's health. *Men's health: Body, identity and social context*, 9-32.

Courtenay, W. H. (2011). Dying to be Men. In *Dying to Be Men*. Taylor & Francis Group.

Crang, M. (2003). Malestream Geography: Gender Patterns among UK Geography Faculty. *Environment and Planning. A*, *35*(10), 1711–1716. https://doi.org/10.1068/a3699

Davis, K. (2007). Reclaiming women's bodies: Colonialist trope or critical epistemology? *The Sociological Review (Keele)*, *55*(s1), 50–64. https://doi.org/10.1111/j.1467-954X.2007.00692.x

De Beauvoir, S. (2011). *The Second Sex* (First Vintage Books edition). Vintage Books

Edley, N. (2017). *Men and masculinity: The basics*. Routledge. https://doi.org/10.4324/9781315764245

England, K. V. (1994). Getting personal: Reflexivity, positionality, and feminist research. *The professional geographer*, *46*(1), 80-89. https://doi.org/10.1111/j.0033-0124.1994.00080.x

Feldman, B., Wilton, R., & Fudge Schormans, A. (2020). Including people with intellectual disabilities in the mobilities turn: mobile interviews in Toronto, Canada. *Mobilities*, *15*(3), 362–379. https://doi.org/10.1080/17450101.2020.1723929

Garland-Thomson, R. (2020). Integrating Disability, Transforming Feminist Theory. In *Feminist Theory Reader* (5th ed., pp. 334-354). Routledge. https://doi.org/10.4324/9781003001201-22

Gerschick, T. J. (2000). Toward a Theory of Disability and Gender. *Signs: Journal of Women in Culture and Society*, *25*(4), 1263–1268. https://doi.org/10.1086/495558

Gerschick, T. J., and Miller, A. S. (1997). Gender Identities at the Crossroads of Masculinity and Physical Disability. In *Toward a New Psychology of Gender* (1st ed., pp. 455–475). Routledge.

Giazitzoglu, A. (2024). Masculinity, embodiment and identity-work: how do organisational members use their bodies as identity resources to (re) accomplish hegemonic masculinity? *Organization 31*(1): 139–162. https://doi.org/10.1177/13505084221074041

Gibson, B. E., Young, N. L., Upshur, R. E. G., & McKeever, P. (2007). Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy. *Social Science & Medicine (1982)*, *65*(3), 505–517. https://doi.org/10.1016/j.socscimed.2007.03.043

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

Gorman-Murray, A. (2008). Masculinity and the home: a critical review and conceptual framework. *Australian Geographer*, *39*(2), 367–379. https://doi.org/10.1080/00049180802270556

Gorman-Murray, A. (2011). Economic crises and emotional fallout: work, home and men's senses of belonging in post-GFC Sydney. *Emotion, Space and Society*, *4*(4), 211–220. https://doi.org/10.1016/j.emospa.2010.06.003

Gorman-Murray, A. (2013). Urban homebodies: embodiment, masculinity and domesticity in inner Sydney. *Geographical Research*, *51*(2), 137–144. https://doi.org/10.1111/j.1745-5871.2011.00750.x

Gorman-Murray, A., & Hopkins, P. (2014). Introduction: Masculinities and Place. In *Masculinities and Place* (1st ed., pp. 1–24). Routledge. https://doi.org/10.4324/9781315594118

Greenson, R. (1968). Dis-Identifying from Mother: Its Special Importance for the Boy. *International Journal of Psychoanalysis*, *49*(2), 370–374.

Guillemin, M. (2004). Understanding illness: Using drawings as a research method. *Qualitative health research*, *14*(2), 272-289. https://doi.org/10.1177/1049732303260445

Guillemin, M., & Drew, S. (2010). Questions of process in participant-generated visual methodologies. *Visual Studies*, *25*(2), 175-188. https://doi.org/10.1080/1472586X.2010.502676

Hall, C. M. (2005). Shifting spaces of masculinity: from Carisbrooke to the MCG. In B. van Hoven and K. Hörschelmann (Eds.), *Spaces of Masculinities* (pp. 143-152). Routledge. https://doi.org/10.4324/9780203507254

Hopkins, P. (2006). Youthful Muslim masculinities: gender and generational relations. *Transactions of the Institute of British Geographers, 31*(3), 337-352. https://doi.org/10.1111/j.1475-5661.2006.00206.x

Hopkins, P., & Giazitzoglu, A. (2025). Hegemonic masculinity: new spaces, practices, and relations. *Progress in Human Geography*, *49*(1), 84–98. https://doi.org/10.1177/03091325241307387

Hopkins, P., & Noble, G. (2009). Masculinities in place: situated identities, relations and intersectionality. *Social & Cultural Geography*, *10*(8), 811–819. https://doi.org/10.1080/14649360903305817

Jackson, P. (1991). The cultural politics of masculinity: towards a social geography. *Transactions of the Institute of British Geographers*, *16*(2), 199–213.

Jackson, P. (1994). Black male: advertising and the cultural politics of masculinity. *Gender, Place and Culture: A Journal of Feminist Geography*, *1*(1), 49–59.

Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.

Katz, C. (1994). Playing the field: questions of fieldwork in geography. *Professional Geographer*, *46*(1), 67–72. https://doi.org/10.1111/j.0033-0124.1994.00067.x

Kearney, K. S., and Hyle, A. E. (2004). Drawing out emotions: The use of participant-produced drawings in qualitative inquiry. *Qualitative Research*, *4*(3), 361-382. https://doi.org/10.1177/1468794104047234

Kimmel, M. (1987). Rethinking "masculinity": new directions in research. In M. Kimmel (Ed.), *Changing Men: New Directions in Research on Men and Masculinity* (pp. 9-24). Sage Publications.

Kobayashi, A. (1994). Coloring the field: gender, 'race', and the politics of fieldwork. *Professional Geographer*, *46*(1), 73–80. https://doi.org/10.1111/j.0033-0124.1994.00073.x

Law, R. (1997). Masculinity, place, and beer advertising in New Zealand: The Southern Man campaign. *New Zealand Geographer*, *53*(2), 22–28. https://doi.org/10.1111/j.1745-7939.1997.tb00495.x

Light, R. (2007). Re-examining Hegemonic Masculinity in High School Rugby: The Body, Compliance and Resistance. *Quest (National Association for Kinesiology in Higher Education)*, *59*(3), 323–338. https://doi.org/10.1080/00336297.2007.10483556

Lindemann, K., & Cherney, J. L. (2008). Communicating in and through "Murderball": Masculinity and disability in wheelchair rugby. *Western Journal of Communication*, *72*(2), 107-125. https://doi.org/10.1080/10570310802038382

Macpherson, H. (2009). The intercorporeal emergence of landscape: Negotiating sight, blindness, and ideas of landscape in the British countryside. *Environment and Planning A: Economy and Space*, *41*(5), 1042-1054. https://doi.org/10.1068/a40365

Maddrell, A., Strauss, K., Thomas, N. J., & Wyse, S. (2016). Mind the gap: Gender disparities still to be addressed in UK higher education geography. *Area*, *48*(1), 48-56. https://doi.org/10.1111/area.12223

Majors, R., & Billson, J. M. (1992). *Cool pose: the dilemmas of black manhood in America*. Lexington Books.

Manderson, L., & Peake, S. (2005). Men in motion: Disability and the performance of masculinity. In C. Sandahl & P. Auslander (Eds.), *Bodies in commotion: Disability and performance* (pp. 230–242). University of Michigan Press. https://doi.org/10.3998/mpub.92455

Massey, D. (1994). *Space, place, and gender*. University of Minnesota Press.

Massey, D. (1996). Masculinity, dualisms and high technology. In N. Duncan (Ed.), *BodySpace: Destabilizing Geographies of Gender and Sexuality* (pp. 109-126). Routledge.

Mazei, J., Zerres, A., & Hüffmeier, J. (2021). Masculinity at the Negotiation Table: A Theory of Men's Negotiation Behaviors and Outcomes. *The Academy of Management Review*, *46*(1), 108–127. https://doi.org/10.5465/amr.2017.0570

McDowell, L. (1993). Space, place and gender relations: Part I. Feminist empiricism and the geography of social relations. *Progress in Human Geography*, *17*(2), 157–179. https://doi.org/10.1177/030913259301700202

McDowell, L. (1999). *Gender, identity, and place: understanding feminist geographies*. University of Minnesota Press.

McDowell, L. (2003). *Redundant masculinities?: Employment change and white working class youth*. Blackwell Pub.

McDowell, L., Bonner-Thompson, C., & Harris, A. (2022). On the margins: Young men's mundane experiences of austerity in English coastal towns. *Social & cultural geography*, *23*(4), 620-637. https://doi.org/10.1080/14649365.2020.1795233

McRuer, R. (2006). Introduction: compulsory able-bodiedness and queer/disabled existence. In *Crip theory* (pp. 1-32). New York University Press.

Meeuf, R. (2009). John Wayne as" Supercrip": Disabled Bodies and the Construction of "Hard" Masculinity in "The Wings of Eagles". *Cinema Journal*, 88-113.

Merriam-Webster. (2025). Masculinity. In Merriam-Webster.com dictionary. Retrieved from https://www.merriam-webster.com/dictionary/masculinity

Messerschmidt, J. W. (1993). *Masculinities and crime: Critique and reconceptualization of theory*. Rowman & Littlefield.

Messerschmidt, J. W. (2016). *Masculinities in the making: from local to global*. Rowman & Littlefield.

Messner, M. A. (1992). *Power at play : sports and the problem of masculinity*. Beacon Press.

Mohammad, R. (2001). "Insiders" and/or "outsiders": Positionality, theory and praxis. In M. Limb and C. Dwyer (Eds.), *Qualitative Methodologies for Geographers: Issues and Debates* (pp. 101-120).

Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research*, *5*(2), 147-149.https://doi.org/10.1177/104973239500500201

Moss, P (Ed.). (2002). *Feminist Geography in Practice: Research and Methods*. London: Blackwell.

Murphy, R. F. (2001). *Body silent: The different world of the disabled*. WW Norton & Company.

Nayak, A. (2006). Displaced masculinities: chavs, youth and class in the post-industrial city. *Sociology*, *40*(5), 813–831. https://doi.org/10.1177/0038038506067508

New Oxford American Dictionary. (2025). Masculinity.

O'Brien, R., Hunt, K., & Hart, G. (2009). 'The average Scottish man has a cigarette hanging out of his mouth, lying there with a portion of chips': prospects for change in Scottish men's

constructions of masculinity and their health-related beliefs and behaviours. *Critical Public Health*, *19*(3–4), 363–381. https://doi.org/10.1080/09581590902939774

Orman, E., McGuirk, P., and Warren, A. (2024). Emergent time-spaces of working from home: lessons from pandemic geographies. *Geographical Research 62*(1): 28–44. https://doi.org/10.1111/1745-5871.12602

Paccaud, L., & Marcellini, A. (2022). How to be a man differently: The intersection of gender and disability in the life course of a powerchair athlete. *Men and masculinities*, *25*(4), 581-601. https://doi.org/10.1177/1097184X211064320

Pease, B. (2021). *Facing patriarchy: from a violent gender order to a culture of peace*. Zed Books. https://doi.org/10.5040/9781350220027

Pini, B., and Conway, M. (2017). Masculinity and fathering in the lives of rural men with a disability. *Journal of Rural Studies 51,* 267-274. https://doi.org/10.1016/j.jrurstud.2016.12.005

Pini, B., & Mayes, R. (2012). Gender, sexuality, and rurality in the mining industry. *Sexuality, rurality and geography*, 187-198. https://doi.org/10.1177/0022185613514206

Pyke, K. D. (1996). Class-Based Masculinities: The Interdependence of Gender, Class, and Interpersonal Power. *Gender & Society*, *10*(5), 527–549. https://doi.org/10.1177/089124396010005003

Rose, G. (1993). *Feminism & geography: The limits of geographical knowledge*. University of Minnesota Press.

Rose, G. (2022). *Visual methodologies: An introduction to researching with visual materials*. Sage Publication.

Rosenberg, R. (2023). Geographies of hegemonic gay masculinity: interplays of trans and racialized in/exclusions in the gay village of Toronto. *Annals of the Association of American Geographers 113*(9):2219–2236. https://doi.org/10.1080/24694452.2023.2211141

Saxton, B., & Cole, T. R. (2012). No Country for Old Men: a search for masculinity in later life. *International Journal of Ageing and Later Life: IJAL*, *7*(2), 97–116. https://doi.org/10.3384/ijal.1652-8670.1272a5

Schormans, B. A. F. (2011). *The right or responsibility of inspection: Social work, photography, and people with intellectual disabilities* (Doctoral dissertation).

Schormans, A. F. (2015). People with intellectual disabilities (visually) reimagine care. In T. Brannelly, L. Widdie, and N. Ward (Eds.), *Ethics of Care* (pp. 179-194). Policy Press. https://doi.org/10.1332/policypress/9781447316510.003.0014

Schrock, D., & Schwalbe, M. (2009). Men, masculinity, and manhood acts. *Annual review of sociology*, *35*(1), 277-295. https://doi.org/10.1146/annurev-soc-070308-115933

Seager, J. (2000). "And a charming wife": Gender, marriage, and manhood in the job search process. *The Professional Geographer*, *52*(4), 709-721. https://doi.org/10.1111/0033-0124.00260

Shakespeare, T. (1999). The sexual politics of disabled masculinity. *Sexuality and Disability*, *17*(1), 53–64. https://doi.org/10.1023/A:1021403829826

Shuttleworth, R., Wedgwood, N., & Wilson, N. J. (2012). The dilemma of disabled masculinity. *Men and masculinities*, *15*(2), 174-194. https://doi.org/10.1177/1097184X12439879

Smith, J. A., Braunack-Mayer, A., Wittert, G., & Warin, M. (2007). "I've been independent for so damn long!": Independence, masculinity and aging in a help seeking context. *Journal of Aging Studies*, *21*(4), 325–335. https://doi.org/10.1016/j.jaging.2007.05.004

Spector-Mersel, G. (2006). Never-aging stories: Western hegemonic masculinity scripts. *Journal of Gender Studies*, *15*(1), 67–82. https://doi.org/10.1080/09589230500486934

Tarrant, A. (2013). Grandfathering as spatio–temporal practice: conceptualizing performances of aging masculinities in contemporary familial carescapes. *Social & Cultural Geography 14*(2): 192–210. https://doi.org/10.1080/14649365.2012.740501

Taylor, S. (2004). T*he Right Not to Work: Power and Disability*. Monthly Review. https://monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/

Teinemaa, T., & Unt, M. (2022). Contradictions of hegemonic masculinity and the (hopeful) potential of old age and caring masculinity in Estonian society and in films *A Friend of Mine* (2011) and *Tangerines* (2013). *Journal of Aging Studies*, *63*, 101034–101034. https://doi.org/10.1016/j.jaging.2022.101034

Thompson Jr, E. H. (2006). Images of old men's masculinity: Still a man?. *Sex roles*, *55*(9), 633-648. https://doi.org/10.1007/s11199-006-9119-7

Thompson Jr, E. H., & Bennett, K. M. (2015). Measurement of masculinity ideologies: A (critical) review. *Psychology of Men & Masculinity*, *16*(2), 115. https://doi.org/10.1037/a0038609

Valentine, G. (2005). What it means to be a man - The body, masculinities, and disability. In R. Butler, and H. Parr (Eds.), *Mind and Body Spaces.* Routledge. https://doi.org/10.4324/9780203979662

Van Hoven, B., & Hörschelmann, K. (Eds.). (2005). *Spaces of masculinities*. Routledge. https://doi.org/10.4324/9780203507254

Van den Hoonaard, D. K. (2007). Aging and masculinity: A topic whose time has come. https://doi.org/10.1016/j.jaging.2007.06.001

Waitt, G. R. (2006). Boundaries of desire: becoming sexual through the spaces of Sydney's 2002 Gay Games. *Annals of the Association of American Geographers*, *96*(4), 773–787. https://doi.org/10.1111/j.1467-8306.2006.00811.x

Waitt, G., and Stanes, E. (2015) Sweating bodies: men, masculinities, affect, emotion. *Geoforum 59*: 30–38. https://doi.org/10.1016/j.geoforum.2014.12.001

Walsh, K. (2011). Migrant masculinities and domestic space: British home-making practices in Dubai. *Transactions of the Institute of British Geographers*, *36*(4). 516–529. https://www.jstor.org/stable/23020826

Warren, A., & Gibson, C. (2011). Blue-collar creativity: re-framing custom car culture in the imperilled industrial city. *Environment and Planning A: Economy and Space*, *43*(11), 2705–2722.https://doi.org/10.1068/a44122

Werny, R. (2024). Cared for masculinities in nursing homes - A material perspective on the intersectionality of institutional, spatial, gendered and corporal materiality. *Journal of Aging Studies*, *68*, 101206. https://doi.org/10.1016/j.jaging.2024.101206

West, C., & Zimmerman, D. H. (1987). Doing gender. *Gender & society*, *1*(2), 125-151.

Whitehead, S. (2002). *Men and masculinities: key themes and new directions*. Polity.

Wilson, J., & Chu, E. (2020). The embodied politics of climate change: analysing the gendered division of environmental labour in the UK. *Environmental politics*, *29*(6), 1075-1104. https://doi.org/10.1080/09644016.2019.1629170

Wilton, R., DeVerteuil, G., and Evans, J. (2014). 'No more of this macho bullshit': drug treatment, place and the reworking of masculinity. *Transactions of the Institute of British Geographers, 39*(2), 291-303. https://www.jstor.org/stable/24582894

Wilton, R., & Fudge Schormans, A. (2020). "I think they're treating me like a kid": intellectual disability, masculinity and place in Toronto, Canada. *Gender, Place and Culture : A Journal of Feminist Geography*, *27*(3), 429–451. https://doi.org/10.1080/0966369X.2019.1596882

Wilton, R., & Fudge Schormans, A. (2025). "Asking for Help was Really Helpful, but Definitely Hard to Say": A Comparative Analysis of the Intersection of Disability and Masculinity. *Men and Masculinities*, *0*(0). https://doi.org/10.1177/1097184X251350276

Wilton, R., Fudge Schormans, A., & Marquis, N. (2018). Shopping, social inclusion and the urban geographies of people with intellectual disability. *Social & Cultural Geography*, *19*(2), 230–252. https://doi.org/10.1080/14649365.2016.1274773

Appendix

Appendix A. LETTER OF INFORMATION

Appendix Ai. LETTER OF INFORMATION - MS

A STUDY ABOUT THE LIVES OF MEN WITH MULTIPLE SCLEROSIS

The study:
We are looking for men with lived experience of MS to take part in a research project. The objective of the research is to learn more about the diverse experiences of men with MS and the extent to which these experiences are accurately reflected in prevailing norms of masculinity in Canadian society. In particular, we want to understand more about the activities, roles and relationships that are important in your daily lives, and how these activities, roles and relationships inform your sense of what it means to be a man.

Who are you?
My name is Rob Wilton. I am a professor at the School of Geography and Earth Sciences at McMaster University. You can learn more about my research here: https://www.science.mcmaster.ca/geo/component/comprofiler/userprofile/wiltonr.html

I am working on this project with Ann Fudge Schormans and Tommy Tan.

Ann Fudge Schormans is a professor at the School of Social Work at McMaster University. You can learn more about her work here: https://socialsciences.mcmaster.ca/people/schormans-ann-fudge

Tommy Tan is a graduate student in the School of Geography & Earth Sciences at McMaster University.

What do people do as part of this study?
There are 3 steps to this study. In step 1, you will take part in an interview over the telephone with a member of the research team. We will ask some questions about your life and about what you think it means to be a man. Here are some examples of questions we will ask:

- What do you think it means to be a man?
- How would you describe yourself as a man?
- What are some of the activities that help to define what it means to be a man?

- Has your experience of MS influenced how you think about your own masculinity? In what ways?
- Do you think your experience of MS influences how others see you as a man?

With your consent, we will record what you tell us using a digital audio recorder. After the interview, we will transcribe what was said during the interview and send it to you.

In step 2 we may ask you to meet again for a shorter interview so we can ask some follow-up questions. You can also elaborate on or clarify what you said during the first interview if you wish. If needed, this interview will also take place over the telephone.

In step 3, we will ask you to take part in an arts activity. In practical terms this means that we will ask you to create a picture that helps to illustrate what it means to be a man living with MS from your perspective. There is no pressure to be 'good' at drawing in this activity. We had originally planned to complete the arts activity in small groups but COVID-19 has meant some revisions to our plans. Instead, we will ask you to create a picture at home on your own time. We can provide you with arts supplies if you'd like.

We also have an arts facilitator working with us on this project. She is available to provide ideas and suggestions over the phone or online if you would like. If you don't feel comfortable creating a picture yourself, you can describe an image and the arts facilitator can draw it for you.

Once you've completed your picture, we'll ask you to take part in an interview with a member of the research team where we'll ask you to describe your picture and what it suggests about masculinity and MS. The interview will take place using the Zoom videoconferencing platform so you can show us your art. Alternatively, you can send us a digital picture of your art and we can discuss it over the telephone. With your consent, we will audio record the discussion and transcribe it for analysis.

There will be other activities later in the project that you might want to be involved in. These may include things like displaying your pictures and talking about your experiences to service agencies, other researchers, and other people. If you're interested, we can let you know when these things will be happening.

Where will the study take place?
You can choose the time and date of your interviews to suit your schedule. The first and second interviews take place over the telephone. The third interview will take place using the Zoom platform or the telephone if you prefer.

How long does it take to participate in this study?
Step 1 (the interview) will take about 90 minutes to complete. Step 2 (a follow-up meeting if required) will take about 30 minutes. Step 3 (the arts project) will vary depending on how long you spend creating your picture. The online/telephone discussion of your picture will take about 30 minutes to complete.

Will I be paid for taking part in this study?

You will be paid a maximum of $160.00 for participating in the study. You will be paid $30 for completing Step 1 (the interview), and another $30 for the follow-up meeting if needed (step 2). You will be paid $100 for taking part in the arts activity (step 3). If you do not complete a step, you will be paid for how much of the project you complete. For example, if you only complete the first interview but not the follow up interview or the workshop you will receive $30. If you complete the interview and the follow-up meeting but not the workshop you will receive $60. If you choose to withdraw during an interview or a workshop you will still be paid for your participation in that step of the study.

What are the risks of taking part in the research?
The risks involved in this research are minimal. You might feel uncomfortable answering some questions that are asked. You don't have to answer any questions if you don't want to, and you don't have to share any personal information that you don't want to share. The research is confidential but there is chance that people who know you might be able to identify you from the stories you tell

What good things could happen if I participate?
Participating in this study will not change your life or change the services you receive but it will give you an opportunity to tell other people about your opinions and experiences as a man with MS, and the kinds of opportunities and barriers that you face. This will help other people (service providers, family members, members of the public) to understand more about the diverse ways of being a man in today's society.

What do you do with all of the information I share with you?
We will use the transcripts from your interviews and the arts discussions as the basis for written reports about the views and experiences of men living with MS. We also intend to make presentations to agencies, researchers, and other people interested in the project. Remember that the research is confidential. This means that none of your personal information will be attached to these reports and presentations unless you want it to be. We hope that by sharing what you told us in these ways, other people will have a better understanding of the issues that are important to men living with MS.

Will my information be kept private?
The research is confidential which means that we know your identity but we will not reveal this to anyone. We will use pseudonyms when referring to people's experiences unless you explicitly ask us to use our own name. In addition, we will remove/edit potentially identifying details of men's lives before we publish reports and/or make presentations.

For the interview about your picture, we will ask if you are comfortable using the Zoom video-conferencing platform. It is important to note that Zoom is an externally hosted cloud-based service. A link to their privacy policy is available here (https://zoom.us/privacy). Whilst this service is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, we can conduct the arts interview over the telephone. Please let us know if you have any concerns.

During the arts interview on Zoom, we will only record audio data using a digital voice recorder. The audio recordings from all interviews will be saved to a password-protected local computer and then stored on a secure university server. They will not be stored on an external cloud-based service. Only myself, Ann and Tommy will be able to access this information. Once the study is finished, your name and contact details will be destroyed. Anonymized audio files and transcripts will be destroyed two years after study completion as a requirement of the funding agency.

What happens next if I want to participate?
If you would like to participate or if you have more questions, you can contact me at the e-mail address or phone number below. We will then arrange a time and date for an interview. Before the interview we will review the information provided here and you can ask additional questions. Then I will ask you to sign a consent form indicating that you are willing to take part in the research.

What happens if I don't want to participate or if I change my mind later?
It is important for you to know that it is your choice to be part of the study or not. If you decide to participate, you can decide to stop at any time - even if you already signed the consent form, and even if you are partway through the study and have already received payment for part of the research. You can also refuse to answer any questions during an interview or online discussion. If you stop participating, the information you have shared up to that point will be destroyed unless you say otherwise. However, we will not be able to remove information you have provided if we have already used the information in a final report or a presentation. For this reason, the last day to withdraw from the study is October 31st, 2020.

What happens when I am finished participating in the study?
After you have finished participating in the project, we will write our report. You and other participants will be invited to review the content of the report before it is finalized. We will also prepare a summary of the project and the things we learned from you and other participants. If you wish, we will send a copy of the longer report and/or the summary to you.

Can I contact you if I have more questions?
You can contact me in a few different ways. You can email me at wiltonr@mcmaster.ca or you can call me at (416) 432-5044.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster University Research Ethics Board
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

Appendix Ai. LETTER OF INFORMATION - FM

A STUDY ABOUT THE LIVES OF MEN WITH FIBROMYALGIA/M.E./CHRONIC FATIGUE SYNDROME

The study:
We are looking for men with lived experience of Fibromyalgia/M.E./Chronic Fatigue Syndrome to take part in a research project. The objective of the research is to learn more about the diverse experiences of men with Fibromyalgia/M.E./C.F.S and the extent to which these experiences are accurately reflected in prevailing norms of masculinity in Canadian society. In particular, we want to understand more about the activities, roles and relationships that are important in your daily lives, and how these activities, roles and relationships inform your sense of what it means to be a man.

Who are you?
My name is Rob Wilton. I am a professor at the School of Geography and Earth Sciences at McMaster University. You can learn more about my research here: https://www.science.mcmaster.ca/geo/component/comprofiler/userprofile/wiltonr.html

I am working on this project with Ann Fudge Schormans and Tommy Tan.

Ann Fudge Schormans is a professor at the School of Social Work at McMaster University. You can learn more about her work here: https://socialsciences.mcmaster.ca/people/schormans-ann-fudge

Tommy Tan is a graduate student in the School of Geography & Earth Sciences at McMaster University.

What do people do as part of this study?
There are 3 steps to this study. In step 1, you will take part in an interview over the telephone with a member of the research team. We will ask some questions about your life and about what you think it means to be a man. Here are some examples of questions we will ask:

- What do you think it means to be a man?
- How would you describe yourself as a man?
- What are some of the activities that help to define what it means to be a man?
- Has your experience of chronic illness influenced how you think about your own masculinity? In what ways?

- Do you think your experience of chronic illness influences how others see you as a man?

With your consent, we will record what you tell us using a digital audio recorder. After the interview, we will transcribe what was said during the interview and send it to you.

In step 2 we may ask you to meet again for a shorter interview so we can ask some follow-up questions. You can also elaborate on or clarify what you said during the first interview if you wish. If needed, this interview will also take place over the telephone.

In step 3, we will ask you to take part in an arts activity. In practical terms this means that we will ask you to create a picture that helps to illustrate what it means to be a man living with chronic illness from your perspective. There is no pressure to be 'good' at drawing in this activity. We had originally planned to complete the arts activity in small groups but COVID-19 has meant some revisions to our plans. Instead, we will ask you to create a picture at home on your own time. We can provide you with arts supplies if you'd like.

We also have an arts facilitator working with us on this project. She is available to provide ideas and suggestions over the phone or online if you would like. If you don't feel comfortable creating a picture yourself, you can describe an image and the arts facilitator can draw it for you.

Once you've completed your picture, we'll ask you to take part in an interview with a member of the research team where we'll ask you to describe your picture and what it suggests about masculinity and chronic illness. The interview will take place using the Zoom videoconferencing platform so you can show us your art. Alternatively, you can send us a digital picture of your art and we can discuss it over the telephone. With your consent, we will audio record the discussion and transcribe it for analysis.

There will be other activities later in the project that you might want to be involved in. These may include things like displaying your pictures and talking about your experiences to service agencies, other researchers, and other people. If you're interested, we can let you know when these things will be happening.

Where will the study take place?
You can choose the time and date of your interviews to suit your schedule. The first and second interviews take place over the telephone. The third interview will take place using the Zoom platform or the telephone if you prefer.

How long does it take to participate in this study?
Step 1 (the interview) will take about 90 minutes to complete. Step 2 (a follow-up meeting if required) will take about 30 minutes. Step 3 (the arts project) will vary depending on how long you spend creating your picture. The online/telephone discussion of your picture will take about 30 minutes to complete.

Will I be paid for taking part in this study?
You will be paid a maximum of $160.00 for participating in the study. You will be paid $30 for completing Step 1 (the interview), and another $30 for the follow-up meeting if needed (step 2).

You will be paid $100 for taking part in the arts activity (step 3). If you do not complete a step, you will be paid for how much of the project you complete. For example, if you only complete the first interview but not the follow up interview or the workshop you will receive $30. If you complete the interview and the follow-up meeting but not the workshop you will receive $60. If you choose to withdraw during an interview or a workshop you will still be paid for your participation in that step of the study.

What are the risks of taking part in the research?
The risks involved in this research are minimal. You might feel uncomfortable answering some questions that are asked. You don't have to answer any questions if you don't want to, and you don't have to share any personal information that you don't want to share. The research is confidential but there is chance that people who know you might be able to identify you from the stories you tell

What good things could happen if I participate?
Participating in this study will not change your life or change the services you receive but it will give you an opportunity to tell other people about your opinions and experiences as a man with chronic illness, and the kinds of opportunities and barriers that you face. This will help other people (service providers, family members, members of the public) to understand more about the diverse ways of being a man in today's society.

What do you do with all of the information I share with you?
We will use the transcripts from your interviews and the arts discussions as the basis for written reports about the views and experiences of men living with chronic illness. We also intend to make presentations to agencies, researchers, and other people interested in the project. Remember that the research is confidential. This means that none of your personal information will be attached to these reports and presentations unless you want it to be. We hope that by sharing what you told us in these ways, other people will have a better understanding of the issues that are important to men living with chronic illness.

Will my information be kept private?
The research is confidential which means that we know your identity but we will not reveal this to anyone. We will use pseudonyms when referring to people's experiences unless you explicitly ask us to use our own name. In addition, we will remove/edit potentially identifying details of men's lives before we publish reports and/or make presentations.

For the interview about your picture, we will ask if you are comfortable using the Zoom video-conferencing platform. It is important to note that Zoom is an externally hosted cloud-based service. A link to their privacy policy is available here (https://zoom.us/privacy). Whilst this service is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, we can conduct the arts interview over the telephone. Please let us know if you have any concerns.

During the arts interview on Zoom, we will only record audio data using a digital voice recorder. The audio recordings from all interviews will be saved to a password-protected local computer

and then stored on a secure university server. They will not be stored on an external cloud-based service. Only myself, Ann and Tommy will be able to access this information. Once the study is finished, your name and contact details will be destroyed. Anonymized audio files and transcripts will be destroyed two years after study completion as a requirement of the funding agency.

What happens next if I want to participate?
If you would like to participate or if you have more questions, you can contact me at the e-mail address or phone number below. We will then arrange a time and date for an interview. Before the interview we will review the information provided here and you can ask additional questions. Then I will ask you to sign a consent form indicating that you are willing to take part in the research.

What happens if I don't want to participate or if I change my mind later?
It is important for you to know that it is your choice to be part of the study or not. If you decide to participate, you can decide to stop at any time - even if you already signed the consent form, and even if you are partway through the study and have already received payment for part of the research. You can also refuse to answer any questions during an interview or online discussion. If you stop participating, the information you have shared up to that point will be destroyed unless you say otherwise. However, we will not be able to remove information you have provided if we have already used the information in a final report or a presentation. For this reason, the last day to withdraw from the study is October 31st, 2020.

What happens when I am finished participating in the study?
After you have finished participating in the project, we will write our report. You and other participants will be invited to review the content of the report before it is finalized. We will also prepare a summary of the project and the things we learned from you and other participants. If you wish, we will send a copy of the longer report and/or the summary to you.

Can I contact you if I have more questions?
You can contact me in a few different ways. You can email me at wiltonr@mcmaster.ca or you can call me at (416) 432-5044.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster University Research Ethics Board
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

Appendix B. INTERVIEW GUIDE

This study is about masculinity and chronic illness

The goal is to open the floor for you to tell your story, your experience. You're the expert, I'm here to listen and absorb what you have to say.

No right or wrong answers, say as little or as much as you like

Originally face-to-face, but the project has to adapt. There are 3 parts to the research project, you don't need to participate in all of them, but it would be greatly appreciated if you do.

First is this interview (1 hour); second is a shorter conversation to ask follow-up questions and/or to clarify points; and third, an arts component where you create a picture then discuss/describe how it captures your experience of living with chronic illness.

Regarding the interview…

You don't need to answer any questions you don't feel comfortable answering, or share any personal or general information that you don't feel comfortable sharing

Research is confidential, pseudonyms may be used

You can also choose to withdraw from the study at any time before Aug31, with no consequence. All records will be deleted

On that note, audio recordings will be used to make transcriptions of the interview, these will be kept securely and will not be shared with external individuals

Lastly, honorariums will be provided, regardless of whether or not the interview completes. And if you choose to participate in the other components of the research, their respective honorariums will be provided as well.

Do you have any questions? [turn on recorder]

Consent questions:

Do you agree to participate in this study knowing that you can withdraw at any point up until August 31st 2020 with no consequences to you?

Do you agree to have the interview audio-recorded?

Do you agree to be contacted about a follow-up interview and an arts activity/interview, understanding that you can always decline the request?

Would you like to receive a summary of the study's results

Unique: Would you like a pseudonym to be used?

Interview Guide

1. Can you tell me a bit about yourself?

2. Can you tell me a bit about your experience with chronic illness?

3. What do you think it means to be a man in today's society?

4. How would you describe yourself as a man?

5. Has your chronic illness influenced your experience of being a man? Can you explain?

6. Has that changed over time? Can you explain?

7. In some ways, we're defined by the things that we do in our lives. What are some of the things you do (or don't do) that help to define you as a man?

Topics to probe: "What about…":

a. Having a job/working for pay

b. Opportunities to be independent

c. Going out with friends

d. Having someone to love/having sex

e. Getting married

f. Being a dad

g. Being involved in sports and other activities

8. How do the things you've told me about fit with the way society expects men to behave? Why do you think that?

9. How do you think other people (those who know you; other people you encounter) see you as a man?

10. When you think about the future, what are the some of the things you hope will happen in your life?

11. What do you need in order for these things to happen (help, resources, etc)

12. Is there anything else you'd like to tell me?

Thank you very much for your time.

Honorarium

Do you know of others who may be interested in participating in this study?

Appendix C. ORAL CONSENT SCRIPT

Consent questions:

- Do you have any questions or would like any additional details? *[Answer questions.]*

- Do you agree to participate in this study knowing that you can withdraw at any point up until August 31st 2020 with no consequences to you?

  [If yes, continue.]

  [If no, thank the participant for his/her time.]

- Do you agree to have the interview audio-recorded?

- Do you agree to be contacted about a follow-up interview and an arts activity/interview, understanding that you can always decline the request?

- Would you like to receive a summary of the study's results?

Appendix D. ART ACTIVITY OUTLINE

Appendix Di. ART ACTIVITY OUTLINE - MS

Masculinity & MS

Arts Activity Outline

1. Arts Activity

As we explained in the letter of information, the purpose of this stage of the research is to create a picture or visual image that captures what you think it means to be a man living with MS. You can pick on one or more of the topics we talked about during your interview if you'd like. This image can be of anything or anyone you like related to this topic. There is no right or wrong approach to this, and the image doesn't have to be a work of art. It should show how you think and feel about this idea.

You can take as long as you like on this activity, and you can use whatever materials you like (pencils, paints, markers, images cut from magazines, or some combination of all of these). As we mentioned before, we can arrange to have materials delivered to you if you'd like.

Also, we are fortunate to have April, an arts facilitator, working with on this project. She is available to meet one-on-one over the telephone or on Zoom if you'd like some suggestions about how to create an image. If you're having trouble or you don't want to create an image, April can draw something that captures what your ideas.

2. Individual Reflection

Once your image is complete, we'd like to schedule a time when I can ask you some questions about your image and what it means to you.

Again, there are no right or wrong answers here. You can say as much or as little as you like about the image as you'd like.

We can do this over the Zoom videoconferencing platform, or we can do this over the telephone, depending on your preference. If we do it over the telephone, we'd ask that you take a picture of your image and send it to us ahead of time.

Appendix Dii. ART ACTIVITY OUTLINE - FM

Masculinity & Fibromyalgia/CFS

Arts Activity Outline

1. Arts Activity

As I explained in the letter of information, the purpose of this stage of the research is to create a picture or visual image that captures what you think it means to be a man living with Fibromyalgia/CFS. You can pick on one or more of the topics we talked about during your interview if you'd like. **This image can be of anything or anyone you like related to this topic. There is no right or wrong approach to this, and the image doesn't have to be a work of art. It should show how you think and feel about this idea.**

You can take as long as you like on this activity, and you can use whatever materials you like (pencils, paints, markers, images cut from magazines, computer graphics programs, or some combination of all of these).

Also, we are fortunate to have April, an arts facilitator, as part of the project team. She is available to meet one-on-one over the telephone or on Zoom if you'd like some suggestions about how to create an image. If you're having trouble or you don't want to create an image, April can draw something that captures what your ideas.

2. Individual Reflection

Once your image is complete, we'd like to schedule a time when I can ask you some questions about your image and what it means to you.

Again, there are no right or wrong answers here. You can say as much or as little as you like about the image as you'd like.

We can do this over the Zoom videoconferencing platform, or we can do this over the telephone, depending on your preference. If we do it over the telephone, we'd ask that you take a picture of your image and send it to us ahead of time.