Embodying Liminality: The Disruptive Potentialities of

Medically Unexplained and In/Visible Chronic Illness

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

This thesis explores how fluctuating, ambiguous, and medically unexplained illnesses might be quintessentially postmodern conditions that disrupt taken-for-granted medical and socio-cultural classifications. Drawing on qualitative interviews with people with the "contested" diagnosis of Fibromyalgia Syndrome (FMS), I offer the concept of *embodying liminality* to describe the disruptive possibilities of embodiment that resists containment and instead resides in the liminal space in-between health/illness, dis/ability, in/visibility, and absence/presence. Situating this analysis within a broader context of neoliberalism and disablism/ableism, I argue that the liminal embodied experiences of people with unexplained, contested, and in/visible illnesses might provide a critique of the increasing pressure we are all under to embody and enact narrow cultural ideals of healthiness, fitness, and competence. Ultimately, this thesis hopes to contribute to the deconstruction of damaging dichotomous categories and the harmful illusion of the invulnerable and perfect(able) body, and to reveal the liberating potentialities of embracing the fluid spectrum of embodiment.

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List of Abbreviations

ADHD – Attention Deficit Hyperactivity Disorder
AISH – Assured Income for the Severely Handicapped
AS – Autism Spectrum
CAT – Computerized Axial Tomography
CDA – Critical Discourse Analysis
CFS – Chronic Fatigue Syndrome
CPP-D – Canada Pension Plan – Disability
DID – Dissociative Identity Disorder
DLA – Disability Living Allowance
EI – Employment Insurance
FMS – Fibromyalgia Syndrome
GWS – Gulf War Syndrome
IB – Incapacity Benefit
IBS – Irritable Bowel Syndrome
JHS – Joint Hypermobility Syndrome
MCS – Multiple Chemical Sensitivity
ME – Myalgic Encephalomyelitis
MRI – Magnetic Resonance Imaging
MS – Multiple Sclerosis
MUPS – Medically Unexplained Physical Symptoms
MUS – Medically Unexplained Symptoms
NA – Narrative Analysis
OAP – Old Age Pension
PTSD – Post-Traumatic Stress Disorder
RA – Rheumatoid Arthritis
RSI – Repetitive Strain Injury
SLE – Systemic Lupus Erythematosus
SMA – Spinal Muscular Atrophy
SPD – Symphysis Pubis Dysfunction
TMJD – Temporomandibular Joint Disorder

Chapter 1 - Liminality and Contested Chronic Illness: Outlining the Research Questions

Introduction

This thesis explores how fluctuating, ambiguous, and medically unexplained illnesses might be quintessentially postmodern conditions that disrupt taken-for-granted biomedical and socio-cultural classifications. Drawing on qualitative interviews with women and men with the "contested" diagnosis of Fibromyalgia Syndrome (FMS) in Canada and the UK, I offer the concept of *embodying liminality* to describe the disruptive possibilities of bodies that resist containment, and instead reside in the liminal space "in-between" health/illness, dis/ability, in/visibility and absence/presence. Based on analysis of the participants' accounts of their social interactions and relationships, and their experiences within the spheres of biomedicine and public policy, this thesis hopes to reveal how embodying liminality is both painful and productive within a culture where intelligibility is often dependent on being able to "fit" within pre-determined categories. Situating this analysis within a broader context of neoliberalism and disablism/ableism, this thesis presents the argument that the embodied experiences of people with undefined and ambiguous illnesses provide a critique of the increasing pressure we are all under to embody and enact narrow cultural ideals of healthiness, fitness, and competence. Finally, this thesis hopes to provide further justification for the deconstruction of damaging dichotomous categories and the harmful illusion of the perfect(able) body, while also revealing the liberating potentialities of accepting the fluid spectrum of embodiment.

Background: Medically Unexplained and Contested Chronic Illnesses

Within the last 20 years there has been a steady increase in the number of people being diagnosed with medically unexplained chronic illnesses such as FMS (fibromyalgia syndrome), CFS (chronic fatigue syndrome), ME (myalgic encephalomyelitis), MCS (multiple chemical sensitivity), PTSD (post-traumatic stress disorder), GWS (Gulf war syndrome), and IBS (irritable bowel syndrome) (Bendelow, 2009, p. 25). The symptoms associated with these illnesses (i.e. pain, fatigue, dizziness, nausea) are "invisible" and cannot as yet be confirmed through medical technology or traditional diagnostic procedures (Bulow, 2008). This means that people with these conditions do not appear physically unwell despite experiencing a range

of debilitating and fluctuating chronic symptoms. The subjective and hidden nature of these illnesses makes them difficult for medical professionals, policy makers, employers, co-workers, family, friends, and others to comprehend (Armentor, 2015; Juuso et al., 2014; Nettleton, 2006; Rhodes et al., 2002). This uncertainty and lack of understanding can lead to stigma and scepticism, which in turn may result in allegations of laziness and faking illness (Asbring and Narvanen, 2002; Richardson, 2005).

Moss and Teghtsoonian (2008, p. 7) argue that these conditions are best understood as "contested" illnesses because they are often "dismissed as illegitimate – framed as 'difficult,' psychosomatic, or even non-existent – by researchers, health practitioners, and policy-makers operating within conventional paradigms of knowledge." The controversy and uncertainty surrounding these conditions means that they are not granted the same legitimacy as other chronic diseases and conditions, such as arthritis, asthma, diabetes, and heart disease. Contested diagnoses receive far less attention in terms of medical and scientific research and fall near the bottom of the illness hierarchy within medicine (Album and Westin, 2008; Harsh et al., 2015). In addition, these conditions tend to be diagnosed in women more than men and it has been argued that this contributes to their marginalization (Asbring and Narvanen, 2002; Barker, 2005; Katz et al., 2008). FMS, in particular, has been regarded as a "women's condition" (Asbring and Narvanen, 2002), and some researchers argue that doctors might actually "protect" men from this stigmatizing diagnosis (Katz et al., 2008).

Being diagnosed with a contested illness can also restrict one's access to support and services because people with medically unexplained conditions are deemed "not disabled enough" by policy-makers and gate-keepers of these services (Lightman et al., 2009). At the same time, people with contested conditions alongside allies (including some doctors, family and friends) are finding ways to "survive within the cracks of institutions arrayed against them" (Dumit, 2005, p. 588). Support groups and patient organizations have emerged to promote public understanding and awareness, advocate for services and public resources, and provide support and information (Barker, 2005; Dumit, 2006; Zavestoski et al., 2004).

The Research Questions

The section above provides a brief overview of a growing body of work on contested illnesses. The next chapter will discuss this set of literature in more detail, however, at this point it is important to note that this research has focused on a range of overlapping themes, including; living with debilitating and fluctuating chronic symptoms (Chow, 2008; Johansson et al., 1999; Raheim and Haland, 2006; Soderberg et al., 2002), the diagnostic process (Barker, 2011; Overend, 2014; Zavestoski et al., 2004), doctor-patient interactions and legitimacy (Asbring and Narvanen, 2004; Cooper, 2002; Nettleton et al., 2005; Skuladottir and Halldorsdottir, 2008), social interactions and experiences of stigma (Armentor, 2015; Asbring and Narvanen, 2002), institutional policies and practices (Lightman et al., 2009; Lippel, 2008; Teghtsoonian and Moss, 2008), and the gendered dynamics of medically unexplained illnesses (Barker, 2005; Werner et al., 2004; Werner and Malterud, 2003).

While these studies examine a wide variety of important aspects of living with contested conditions, very few address the broader importance of understanding and appreciating ambiguous, uncertain, and undefined illness experiences (Nettleton, 2006; Overend, 2014). In addition, research on chronic illness generally, and contested conditions specifically, has been largely neglected by researchers working in the field of disability studies (de Wolfe, 2002; de Wolfe, 2012; Scambler, 2012; Vick, 2013; Wendell, 2001). In turn, very little research from the sociology of health and illness has applied theories and concepts from disability studies to this topic, despite the clear applicability (Thomas, 2007). Finally, both fields have rarely focused on researching and theorizing the interstitial space between health and illness and disability and ability; however, it is in this liminal space that many disabled and chronically ill people reside (Reeve, 2002; Vick, 2013).

This thesis aims to fill in these gaps by taking a postmodern and feminist approach that draws on work from both the sociology of health and illness and disability studies to address the following broad research questions: First, based on the analysis of qualitative interviews with people who have been diagnosed with the contested illness, FMS, this thesis explores how individual experiences of undefined illness might be more generally applicable in a postmodern age of uncertainty and ambivalence (Nettleton, 2006). Second, drawing on the participants'

accounts of their social interactions, and their experiences within the spheres of biomedicine and public policy, this study examines how the liminal bodily experiences of people with ambiguous and unexplained illnesses might be disruptive of the modernist illusion of stable and secure biomedical and socio-cultural categories (Overend, 2014; Vick, 2013). Third, this thesis explores both the painfulness and the subversive potentialities of existing in the borderlands between the worlds of the healthy and the sick, the non-disabled and the disabled through the concept of *embodying liminality*.

Undefined Illness as Postmodern and Structurally Disruptive

This thesis examines how the ambiguous embodied experiences of people with contested, unexplained illnesses might be emblematic of postmodern life, and disruptive to modernist biomedical and socio-cultural classifications. In addition to being termed "contested conditions" (Armentor, 2015; Barker, 2011; Clarke and James, 2003; Moss and Teghtsoonian, 2008), illnesses like FMS are also referred to as "controversial" (Lippel, 2008), "uncertain" (Asbring and Narvanen, 2004; Dumit, 2006), "unexplained" (Nettleton, 2006; Zavestoski et al., 2004), "invisible" (Barker, 2005; Vickers, 1997; Wall, 2005), "emerging/emergent" (Fox and Kim, 2004), "episodic" (Vick, 2013), and "undefined" (Overend, 2014). Similarly, postmodernity (or late/high modernity) is characterized as fragmented and provisional (Price and Shildrick, 2002), uncertain (Giddens, 1990; Giddens, 1994), ambivalent (Bauman, 1991), unstable, and complex (Clarke, 2005; Corker and Shakespeare, 2002). Given this, Nettleton (2006, p. 1176) contends that the study of medically unexplained conditions has "broader conceptual applicability," because the extreme form of *embodied doubt* attached to having a contested, medically unexplained illness provides important insight into the "uncertainty and fluidity" that characterizes life in a postmodern context.

This thesis builds on Nettleton's assertions by exploring the uncertainty and ambiguity of living with a non-visible, fluctuating, and contested condition, and how this might provide a useful metaphor for the current social context in which we all live that is characterized by unpredictability, vulnerability, and precariousness (Shildrick, 2015). In addition, it examines how FMS, and similar conditions, might also be quintessentially postmodern because they are potentially "culture-bound syndromes" (Delaney and Bell, 2008, p. 33) that reflect the

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inevitable breakdown of bodies due to the increasing pressure to meet unrealistic standards of productivity within neoliberal capitalism (Goodley, 2014; King, 2012; Shildrick, 2015).

By exploring the idea of FMS as a postmodern condition, this thesis also examines how the uncertain and ambiguous embodied experiences of people with unexplained illnesses might disrupt seemingly stable and fixed biomedical and socio-cultural categories. In addition to being described as uncertain, undefined, and contested, these conditions are also termed "episodic," as the severity of the symptoms, as well as the type of symptoms, fluctuate from day-to-day, and often even within the same day (Lightman et al., 2009; Vick, 2013). Thus, people with hidden episodic illnesses are "sometimes healthy, sometimes ill, sometimes able, sometimes disabled" (Vick, 2013, p. 179). Furthermore, while bodily experiences of pain, fatigue, and other chronic symptoms are very present and visible in the lives of people who live with them, these symptoms are absent from view and are invisible to both lay people and medical professionals (Overend, 2014). The fluctuating nature of these absent/present, in/visible symptoms only serves to make them more difficult for others to comprehend as they do not "fit" with "conventional notions of what constitutes bodies as able, disabled, healthy and ill" (Vick, 2013, p. 182).

Drawing on postmodern theories that highlight the fluidity and leakiness of categories (Shildrick, 1997), this thesis questions how the embodied experiences of people with the specific contested illness, FMS, might be disruptive as they are both *invisible* (unseen, marginalized, denied, contested) and *visible* (experienced, accepted, validated, understood) in a variety of contexts. In addition, this thesis explores how people with undefined and episodic conditions are also situated in-between other apparently fixed and constant categories (such as, healthy/ill and disabled/non-disabled), and by employing Turner's (1967) work on liminality, this thesis offers the concept of *embodying liminality* to refer to the potentialities of existing "betwixt and between."

In his work, Turner (1967, p. 95-97) focuses on the liminal or transitory stage of rites of passage, arguing that the "subject of passage ritual is, in the liminal period, structurally if not physically, 'invisible'":

As members of society, most of us see only what we expect to see, and what we expect to see is what we are conditioned to see when we have learned the definitions and classifications of our culture…The structural "invisibility" of the liminal personae has a twofold character. They are at once no longer classified and not yet classified…Their condition is one of ambiguity and paradox, a confusion of all the customary categories (Turner, 1967, p. 95-97).

The notion of liminality lends itself to the analysis of this thesis, because contested chronic illnesses are in/visible, ambiguous, unexplained, and undefined (Overend, 2014). *Embodying liminality* is the concept that I offer in this thesis to refer to the painful and productive process of living in the unclear space in-between health/illness, dis/ability, in/visibility and absence/presence. This thesis explores how power operates through cultural dualisms by categorizing and privileging bodies that conform to standards of normality, healthiness, and ability while marginalizing those that do not. By questioning how one particular contested illness is made *in/visible* in a variety of contexts, this thesis has the potential to address broader inquiries into how certain conditions, bodies, and bodily experiences are made *visible* (privileged, validated, acknowledged, understood, and accepted) while others are rendered *invisible* (oppressed, marginalized, questioned, ignored, and denied). It is hoped that the notion of *in/visibility* and the concept of *liminality*, will allow for an examination of how people who are situated in-between health/illness and dis/ability negotiate dichotomous cultural categories and destabilize the illusion of the perfect(able) body by resisting containment within exclusionary predetermined categories.

Why Fibromyalgia Syndrome (FMS)?

FMS is an instructive case through which to explore these inquiries given the episodic and fluid physical aspects of the condition, the social framing of it as a contested illness, and the possibility that it is a "culture-bound syndrome" caused by cultural pressures that lead to overstressed and overworked lifestyles (Delaney and Bell, 2008, p. 33).[1] In order to demonstrate the usefulness of FMS as a case, the following section will give a very brief history of the

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[1] The other main reason FMS was chosen as a "case" is my personal understanding of, and interest in, this condition; my mother was diagnosed with FMS over 20 years ago. This will be discussed further in chapter four.

condition, discuss the symptoms associated with FMS, outline its contested status, and explain the incidence of the condition in both Canada and the UK.

The term "fibrositis" was first used by British neurologist Sir William Gowers in 1904 to refer to "muscular rheumatism" resulting in "inflammation of fibrous tissues of the muscles" (Wessely and Hotopf, 1999, p. 428). It was not until the 1980s, however, that "fibromyalgia" became the accepted medical term for this condition. As Wessely and Hotopf (1999, p. 429) argue, by the end of this decade "the fibromyalgia concept was well-established in the public imagination, and was endorsed by sufficiently large numbers of professionals to ensure its survival." In 1990, FMS was officially recognized when the American College of Rheumatology (ACR) published the "Criteria for the Classification of Fibromyalgia" (Wolfe et al., 1990).

The ACR classification, which narrowly defines FMS as chronic pain in multiple parts of the body and tenderness in at least 11 out of 18 specific points, has come to be accepted worldwide as the diagnostic criteria for FMS (Hauser et al., 2009; Wilke, 2009). Following the ACR classification, the World Health Organization acknowledged the existence of the condition in 1992 (Lippel, 2008). Presently, FMS remains formally under the jurisdiction of rheumatology, and is categorized as a sub-type of arthritis (Fitzcharles, 2010).

While the ACR diagnostic criteria is based on the presence of chronic pain and joint and muscle tenderness, people with FMS are also likely to experience many other symptoms, including, stiffness, fatigue, sleep disturbances, headaches, dizziness, numbness, lack of concentration, bladder irritation, and digestive problems (Keddy, 2007; Preece and Sandberg, 2005; Shaver et al., 2006). As such, it is not a medically classified "disease," rather it is understood to be a syndrome characterized by a grouping of symptoms (Barker, 2005; Keddy, 2007). Although the ACR criteria are still used for scientific research purposes, given the wide range of possible symptoms associated with FMS, the criteria are not strictly adhered to in clinical practice (Barker, 2005). In 1992 a panel of FMS experts put forth the recommendation that "an individual with fewer than the eleven required tender points may still have a diagnosis of FMS if he or she experiences several of the associated symptoms that cluster together as part of the wider syndrome" (Barker, 2005, p. 4). Similarly, a Canadian group of physicians recently

published guidelines on the diagnosis and treatment of FMS and stated that the "tender point examination is not required to confirm the diagnosis" (Fitzcharles et al., 2013, p. 3).

Diagnosing FMS is mainly accomplished through exclusion, and this process is further complicated by the overlapping symptoms between FMS and other conditions, such as CFS/ME and MCS, which all fall under the broad category of "medically unexplained physical symptoms" (MUPS) (Zavestoski et al., 2004). CFS/ME in particular is a diagnosis that overlaps considerably with FMS. The a label of CFS/ME is used to diagnose people with persistent and medically unexplained fatigue; however, people with CFS/ME also report experiencing symptoms such as muscle and joint pain, impaired memory and concentration, gastrointestinal problems, and headaches (Prins et al., 2006). Some physicians argue that chronic pain and fatigue conditions are really best understood as syndromes which are part of a more general group of "affective spectrum disorders" or "functional somatic syndromes" (Buskila and Sarzi-Puttini, 2006; Goldenberg et al., 2008). In contrast, some researchers have proposed that these conditions are really part of a natural continuum that expands from no muscle pain to severe pain with tender joint and muscle points (Wessely and Hotopf, 1999). The final possibility is "that there is no categorical condition called fibromyalgia, CFS or any other name" (Wessely and Hotopf, 1999, p. 432).

For all of these reasons, and due to the "feminization" of FMS (discussed below), there is a great deal of scepticism regarding the "reality" of this condition (Barker, 2011). Indeed, FMS has been described as a "paradigmatic contested illness" (Barker, 2011, p. 834). Due to the invisible, fluctuating symptoms associated with FMS and the continuous debates within the medical community regarding causes, diagnoses, and treatments of the condition (Barker, 2011; Edwards, 2013), it is an excellent "case" for investigating the research questions outlined above. People with this chronic illness have to deal with symptoms that can change from day-to-day and even sometimes within the same day. They also are likely to have periods of good health and experience periods of acute illness. Thus, living with FMS and similar episodic illnesses means living with a body that is constantly in a "state of flux" and occupying a space in "the muddled borders of health and illness" (Moss and Dyck, 2002, p. 126). This "in-

betweenness" can lead to uncertainty and doubt regarding the "reality" of the condition, as people with FMS often appear healthy to both medical professionals and lay people.

The contested, marginalized status of FMS also means there is additional suspicion relating to whether a person with FMS is legitimately "disabled." This is because it is widely accepted that in order for a person to fit into the category "disabled" they must have a stable, physical, and visible impairment (Rhodes et al., 2008). Thus, people with in/visible conditions, such as FMS, face suspicion because they "misfit" both sides of the cultural categories healthy/unhealthy and disabled/non-disabled.

FMS as a "Women's Condition"

Despite its contested status, FMS continues to be a fairly common diagnosis in primary care and rheumatology clinics. Various reports state that it affects anywhere from 2% to 6% of the general population (Barker, 2005; Fitzcharles, 2010; Wilke, 2009). Following osteoarthritis, FMS is the most common diagnosis in rheumatology clinics in Canada (Chow, 2008). FMS affects approximately 2% - 3% of Canadians (Fitzcharles, 2010; Fitzcharles et al., 2013) and according to Arthritis Research UK, FMS affects up to 4% of the population in the UK (Thompson, 2011). Gallagher and colleagues (2004, p. 574) state that there was a "remarkable growth" in the diagnosis of FMS between 1990 and 2001 in the UK and this resulted in FMS becoming a "more common diagnosis in primary care than CFS and ME combined."

FMS is much more likely to be diagnosed in women than in men (Barker, 2005; Gallagher et al., 2004; Keddy, 2007; Shaver et al., 2006). According to a recent Canadian report on FMS, women are 6 - 9 times more likely to be diagnosed with the condition than men (Fitzcharles et al., 2013). Given the much higher incidence of FMS among women, it is perhaps not surprising that FMS is described as a "women's condition" (Asbring and Narvanen, 2002). While children, teenagers, and elderly people are also diagnosed with the condition, the highest prevalence is among women aged 30-50 (Chow, 2008; Fitzcharles et al., 2013).

There are several possibilities as to why men are not diagnosed with FMS as often as women. Some research suggests that due to a combination of biological, socio-cultural, and psychological factors, women are more likely to experience chronic pain, fatigue, and other symptoms of FMS than men (Yunus, 2002). The argument has also been made that FMS and

other related syndromes might actually occur more often in women because they are "culture-bound syndromes," meaning that these conditions are caused by a culture that expects women to engage in "double-duty" by working around the clock in both the public and private spheres (Delaney and Bell, 2008, p. 33). Other research suggests that men might not be diagnosed as often with these types of conditions because they do not seek treatment for symptoms such as pain and fatigue as often as women due to masculine stereotypes that encourage men to be stoic (Bird and Rieker, 1999; Charles and Walters, 2008; Courtenay, 2000; Freund and McGuire, 1991; Hoffman and Tarzian, 2001). Even when men do report these symptoms to their doctors however, some research suggests that men are less likely to be diagnosed with FMS due to gender bias in the diagnostic process (Katz et al., 2010; Katz et al., 2008). Indeed, some research points to the possibility that when men do come to their doctors with symptoms of pain, fatigue, and other FMS- type symptoms that rather than assign these to the "feminized" label of FMS, doctors might actually seek to "save" men from this stigmatized diagnosis (Katz et al., 2008).

The labelling of FMS as a "women's condition," and the stigma this label carries with it, also makes it an excellent "case" for investigating the in/visibility, uncertainty, and ambiguity of medically unexplained illness. Research has revealed that "women's illnesses" such as FMS and CFS/ME are often situated in the "grey area" between biomedical approaches and psycho-social understandings of illness (Cooper, 2002; Richman and Jason, 2001). Wessely and Hotopf (1999, p. 428) argue that suspicions of "psychoneurosis" or "malingering" have been present throughout history in both professional and lay discussions of FMS, stating that "the historical literature confirms that there has never been a time when discussion about fibrositis, fibromyalgia, neurasthenia, or chronic fatigue was not concerned with organic verses psychogenic polemics." It has been argued that this association of FMS (and conditions like CFS/ME) with "psychoneurosis" and "malingering" occurs because the large majority of those diagnosed with these illnesses are women (Barker, 2011; Edwards, 2013; Werner et al., 2004; Werner and Malterud, 2003). Indeed, the stereotype of the "hysterical" woman is still very much at play in current medical, scientific, and lay discourses surrounding pain conditions like

FMS (Barker, 2011; Edwards, 2013; Hoffman and Tarzian, 2001; Showalter, 1998; Werner et al., 2004), and this also contributes to the contested status of these chronic illnesses.

Thus, to be a woman or a man with FMS is to be largely invisible (marginalized), and to uncomfortably fit, at times and in certain situations, into the cultural categories ill/disabled. At the same time, as was described above, women and men with this condition (at times and in certain situations) will also partially fit into the categories healthy/non-disabled. In addition, because FMS is understood to be a women's condition, and illness and disability are conflated with femaleness (Garland-Thomson, 2002; Shildrick, 1997), a woman with FMS fits with these cultural stereotypes and assumptions, and by extension, women with FMS comprise a relatively visible group compared to men with the condition.

Drawing from interviews with women and men with FMS, this thesis investigates how gender stereotypes and assumptions are brought in to social interactions in various contexts, particularly medical encounters, day-to-day interactions with family, friends, and others, and in relation to institutional policies and practices. When investigating these issues, this thesis draws on feminist disability theory (see chapter two) that understands sex and gender, and impairment and disability as "interactional" rather than "additive" components of one's sense of self and identity (Schriempf, 2001). This approach provides insight into the impact of "intertwining ideologies and oppressions" and reveals "how bodies—marked by gender and by disability, by impairment and sex, among other things – are formed in, created by and acted upon by society, and also act within and impact society" (Schriempf, 2001, p. 66-67).

FMS in Canada and the UK

To more fully understand the interaction of social context, gender, health/illness, and dis/ability this thesis draws on interviews with women and men in Canada and the UK. According to Raphael and Bryant (2006, p. 39), Canadian "public health communities are focused upon individualized approaches to risk management," whereas in the UK "public health scenes are more oriented toward broader approaches to health determinants." Similarly, other research has revealed that UK public health policy is much more concerned with how social factors (such as gender, ethnicity and income) shape health outcomes than is Canadian public policy (Bryant et al., 2011). In addition, a comparative study on public policy and income

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support for disabled people in Canada and the UK found that despite many similarities between the two systems, the UK does have a larger number of programs available, as well as more opportunities for support and advocacy than Canada (Malacrida, 2010). This research concluded that there appears to be a "stronger commitment to social inclusion" in UK policy than in Canadian income support policy (Malacrida, 2010, p. 684).

While historically the UK might have had better benefit programs, and an overall more socially inclusive model than Canada, recent research reveals that due to the current political-economic climate following the financial crisis of 2008/2009 the UK has since imposed austerity measures that have narrowed the category of those deemed "worthy" and "deserving" of disability-related entitlements (Briant et al., 2013; Goodley, 2014; Shildrick, 2015). This has been particularly harmful to people with invisible impairments, including people with non-visible chronic illnesses, who do not appear disabled (Briant et al., 2013). In addition, Canada and the UK might be more similar than different in other important ways; in line with other westernized countries, both States have adopted neoliberal philosophies that assume citizens are individually responsible for their health (Galvin, 2002). This means that at the same time crucial healthcare services and disability benefit programs have been cut, citizens are increasingly considered to be accountable for their health and well-being; in turn, individuals are considered blame-worthy and morally culpable for experiences of ill-health and unhappiness (Galvin, 2002; Shildrick, 2015).

This thesis draws on interview data from Canada and the UK to explore the challenges people living with ambiguous, fluctuating and non-visible illness encounter within two unique, yet similar contexts. In particular, it explores the participants' accounts of having a contested, medically unexplained diagnosis and the issues this poses in relation to workplace accommodations and disability benefits that are based on narrow and dichotomous categorizations. In addition, this thesis considers the participants' accounts of their social interactions in relation to neoliberal notions of individual responsibility that contribute to "victim-blaming" of people with chronic illnesses (Galvin, 2002), and a political-economic climate that encourages scepticism, surveillance, and hostility toward disabled people –

especially invisibly disabled people – receiving disability-related institutional accommodations and benefits (Briant et al., 2013; Shildrick, 2015).

Outline of the Thesis

In summary, this thesis draws on interviews with women and men with FMS in Canada and the UK to explore the challenges and possibilities posed by living with a body "in flux" (Moss and Dyck, 2002). Drawing on accounts from people whose bodies are situated in the liminal space in-between, this thesis examines their experiences within the spheres of biomedicine, public policy, and in relation to social relationships and day-to-day social interactions, in order to explore how contested conditions, such as FMS, might be experienced as personally and socially disruptive, because they are in/visible, uncertain, and episodic. It explores the challenges, difficulties, and painfulness of existing in the interstitial space between in/visibility, health/illness, and dis/ability, but also how the participants' accounts might offer an important perspective on living with uncertainty and ambiguity that is especially instructive within the current social context. In addition, this thesis seeks to understand how embodying liminality might offer a potentially liberating and subversive way of being in the world.

Before outlining the structure of the thesis, it is helpful to briefly introduce some of the significant theoretical ideas that will be further outlined in the following chapter. Campbell (2012, p. 212-213) states that while the concept of *disablism* "focuses on the negative treatment towards disabled people," *ableism* is more subtle and elusive as it something "we all live and breathe…our bodies and minds daily become aesthetic sculptures for the projection of how we wish to be known in our attempt to exercise competency, sexiness, wholeness and an atomistic existence." Furthermore, Campbell (2012, p. 215) explains that the "building blocks of ableism" are the "idea of *normal* (normative individual)" and a "*constitutional divide* – a division enforced between the 'normal' = human and the aberrant (sometimes pathological) = subhuman." Similarly, Siebers (2013, p. 279) argues that the "ideology of ability" is "the preference for able-bodiedness" and it "defines the baseline by which humanness is determined" (p. 279). These ideas also align with Davis's (2005, p. 158) argument regarding the "human paradigm" employed in western cultures:

A society's "human paradigm" both embodies and expresses its beliefs about what human beings are and what (in that particular society) people think they ought to be. The human paradigm that a society embraces thus shapes or defines the character of life in that society in salient respects…the way we view disability has been profoundly affected by the fact that *our society's human paradigm treats being able-bodied as both normal and normative and accords a primacy to being (and being seen to be) able-bodied*. To conform to our society's vision of what a human should be, one must be (thought to be) able-bodied (emphasis added).

When a society adopts a disablist/ableist human paradigm rooted in an "ideology of ability" it inevitably results in various attempts to distinguish and categorize bodies/people as normal or abnormal, healthy or sick, non-disabled or disabled, and in a de/valuing of bodies/people depending on the category they "fit."

Living in a society with an oppressive classification system that enforces "compulsory able-bodiedness" (McRuer, 2006) is highly problematic for all people, but especially for chronically ill and disabled people. In addition, as was previously discussed, dualistic thinking creates further problems or "misfits" for people with contested, non-visible health conditions, as they are in the liminal space in-between health/illness and dis/ability. Building on these insights, one of the central goals of this thesis is to trouble seemingly natural and inevitable cultural binaries. Through interviews with people with FMS this thesis explores the leakiness and fluidity of seemingly pure cultural categories.

Drawing on accounts from people whose bodies occupy that interstitial space in-between, this thesis has the broader potential to disrupt our taken-for-granted assumptions regarding all bodies, as these embodied and social experiences reveal "the relational component and the fragility of fitting" and how "any of us can fit here today and misfit here tomorrow" (Garland-Thomson, 2011, p. 597). According to Shildrick (2002, p. 79), this is the advantage of a postmodern approach: "where the convention insists that some bodies are or become vulnerable by default, the postmodernist understanding of discursive instability speaks to an intrinsic vulnerability of all bodies and indeed all embodied selves." The approach taken in this thesis acknowledges the fluidity, vulnerability, and uncertainty of humanity, and as Fox (1994, p. 21) explains, this "raises difficulties for a straightforward engagement with the world;" however, it also opens up possibilities for a "delight in difference."

The next chapter provides a detailed discussion of the theoretical framework adopted in this thesis. Chapter three is a review of relevant research and literature on chronic illness generally, and contested chronic illness specifically. This chapter explores previous theoretical approaches used in the study of this topic, further clarifies why this thesis adopts a different framework drawing from postmodern and feminist theories, and examines how this approach provides new possibilities, potentially opening up new areas of inquiry. Following the literature review, chapter four outlines the methodology employed, discusses the reasons for choosing in-depth interviews, presents information on the research participants, and highlights ethical considerations pertaining to the study. Chapters five, six, and seven present the central findings of the research (see below).

Rather than having a chapter specifically focused on findings relating to gender, all of the findings chapters examine in/visibility and liminality in relation to norms of masculinity and femininity. Instead of viewing gender as an "additive" part of one's identity, this thesis conceptualizes the relationship between gender, disability, and illness to be "interactional" (Schriempf, 2001). This thesis explores how dominant conceptions of femininity and masculinity, interacting with cultural discourses relating to dis/ability and health/illness, are adopted into institutional policies and practices, and are "taken up" during social interactions. In addition, where applicable, the thesis highlights how the national context interacts with other components of identity and social location. Chapter seven in particular explores these issues as it looks at the similarities and differences between Canada and the UK in terms of workplace and disability benefit policies, and the extent and types of accommodations and income support programmes available for people with FMS.

Chapter five examines the respondents' accounts of the onset of symptoms and the process of receiving the FMS diagnosis through the framework of in/visibility and in relation to recent theorizing on "haunting" and "estrangement" (Overend, 2014; Shildrick and Steinberg, 2015). Specifically, it explores how the onset of non-visible, medically unexplainable, fluctuating, and debilitating symptoms might be understood as a "haunting" and estranging embodied process. In addition, it investigates how medicine is also "haunted" by bodily experiences and symptoms that are in/visible, un/known, absent/present and situated in-between

health/illness and dis/ability. The notion of containment is used to examine the challenges that ambiguous and fluid embodiment poses to the biomedical imperative to contain, classify, and categorize bodies.

As part of the analysis, this chapter examines the usefulness of the concept of "diagnostic illusory" (Nettleton et al., 2014) with regard to FMS. This chapter explores how both individuals suffering from unexplained symptoms and medical professionals seek certainty by attempting to contain varied and fluid embodied experiences under the diagnostic label FMS. Rather than finding certainty through a stable and secure medical diagnosis, however; the "illusory" FMS diagnosis – represented as an overflowing or leaky container – actually contributes to uncertainty and estrangement. Chapter five concludes by considering the possibility that the "haunting" onset of symptoms and the process of estrangement might be "both painful and productive" (Diedrich, 2015, p. 72). Specifically, it explores how *embodying liminality*—occupying the space "in-between"—might mark a path to resistance and empowerment, because it is the "condition of moving on" and "of becoming otherwise" (Shildrick and Steinberg, 2015, p. 6). In addition, this chapter considers how embracing ambiguity and uncertainty might be beneficial for both patients and medical professionals (Einstein and Shildrick, 2009, p. 298).

Chapter six continues to investigate themes relating to in/visibility, disruption, and liminality through the participants' accounts of social interactions following the FMS diagnosis. This chapter explores how, when, why, and to whom people with FMS make their condition in/visible and/or identify as disabled. This chapter moves beyond previous research and theory on *stigma* and *passing* (Goffman, 1963), by drawing on concepts from disability studies, particularly the concepts of *internalized ableism/internalized oppression*, *ableist passing*, and *psycho-emotional disablism* (Campbell, 2008; Reeve, 2002).

Drawing on these theoretical concepts and accounts from people with FMS, chapter six explores the personal and political consequences of *passing*, as well as the difficulties and possibilities posed by verbally disclosing, or otherwise signalling to others, that one is chronically ill and/or disabled. As we will see, interviews from two different countries reveal the pervasiveness of the assumption that disability is always visible, and this compounded by

the scepticism surrounding the reality of FMS, means that identifying as a chronically ill person and/or as disabled is never straightforward. It is argued that reactions of scepticism, disbelief, and denial that people with FMS face in their day-to-day interactions with family, friends, and others constitute *psycho-emotional disablism* (Reeve, 2002; Thomas, 1999a). This results in people with non-visible conditions being treated as misfits and outcasts who are not given "permission to be ill" (Nettleton, 2006) and who are simultaneously regarded as dubiously disabled. The chapter concludes by exploring how making visible hidden suffering and difficulties, and/or identifying as a disabled person is painful, but also potentially subversive and liberating both personally and politically as it destabilizes taken-for-granted assumptions regarding the visibility and stability of health/illness and dis/ability.

Chapter seven builds on the insights from the previous chapters by examining how FMS is marginalized with regard to disability-related entitlements. Previous research shows that having a contested illness restricts one's access to support and services because people with these conditions are deemed "not disabled enough" by policy-makers and gate-keepers of these services (Lightman et al., 2009). Similarly, other research argues that people with visible (recognized/ legitimate/accepted) conditions can access disability benefits and other forms of support much easier than people with "invisible" and contested illnesses (Fox and Kim, 2004).

Chapter seven expands on this previous research by exploring how strict dichotomous definitions of disability and impairment are realised in institutional policies and practices, and how this creates issues for people with FMS who do not fit within these narrow predetermined categories. This chapter investigates how people with FMS have to either make their needs visible in order to receive disability benefits, workplace accommodations, and other forms of support, or remain invisible and try to get by without. It also examines the difficult process involved in making FMS fit within the exclusionary criteria for disability-related entitlements, especially in recent times of austerity. This chapter picks up some of the ideas presented in chapter six regarding identifying as chronically ill and disabled within a disablist/ableist context, by exploring the issues raised when having to identify as disabled in order to qualify for disability-related entitlements. Finally, it returns to the concept of *embodying liminality* to explore how being in the "grey area" of the criteria for disability-related entitlements

contributes to marginalization, discrimination, and exclusion. At the same time, this "liminal positioning" (Titchkosky, 2003, p. 537) might radically disturb these neoliberal policies, by revealing the damaging effects of policies that are based on fundamentally flawed and exclusionary categories of embodiment.

Chapter eight contains my "final thoughts" and provides a brief summary of the main findings, discusses the limitations of the study, and suggests possible areas for further research. Most importantly, this chapter brings all of the threads from the previous chapters together to discuss the concept of *embodying liminality* and to examine how the experiences of people living in the interstices of health/illness, dis/ability, and ab/normality might be more broadly applicable to all of our lives in postmodernity and within a neoliberal capitalist society, and how their accounts might shed light on the importance of recognizing the wide diversity of the full spectrum of human embodiment.

Chapter 2 – Theoretical Framework: A Postmodern Feminist Approach

Foucault, Power, and the Body

Before going any further, it is necessary to take a step back to outline the key theoretical ideas that informed this thesis. As was previously mentioned, this thesis is informed by postmodern theories, and it also draws on feminist theorizing, particularly feminist disability theory. Foucault is the theorist most clearly associated with postmodernist approaches to the body, because his theories reveal that the body is constituted through culturally and historically specific "relations of power" (Reeve, 2002, p. 496). As Foucault (1995, p. 25) explains it, the body is "directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs." *Biopower* is the Foucauldian concept that refers to these power relations that inscribe the body. The concept of *biopower* explains how bodies are governed and constituted as *docile bodies* both through "external surveillance" (the *gaze*) and through "internal regulation" (*self-policing/self-surveillance*) (Thomas, 2007, p. 37).

Foucault's concept of the *gaze* and the notion of *self-policing/self-surveillance* are based on his reading of the Panopticon – an architectural design for a prison put forward by Jeremy Bentham in the late eighteenth century. This design allows a prison officer to observe all of the inmates without the inmates being able to see their observer, or each other. As the inmates have no way of knowing exactly when they are being observed, this design encourages the inmates to police themselves (i.e. regulate their own behavior) in order to ensure that they are always acting according to the rules of the prison. In his book *Discipline and Punish*, Foucault (1995) uses the idea of the Panopticon as a metaphor for understanding modern methods of social control. It is through disciplinary regimes that social control operates to create *docile bodies* as "they are constantly and repeatedly inscribed with the normalizing power of a judgmental gaze" and "the state of always being seen imposes a self-surveillance on the disciplined subject" (Brush, 1998, pp. 37-38).

Feminist work on the body has usefully applied these ideas to argue that as objects of the patriarchal male *gaze*, women are induced to *police* their physical appearances in order to

approximate culturally and historically specific ideals of femininity (Bartky, 1988; Wolf, 1991). It is argued that through various disciplinary beauty practices (most obviously cosmetic surgery) the female body becomes a *docile body* and it "comes to serve as a site of inscription, a billboard for the dominant cultural meanings that the female body is to have in post-modernity" (Balsamo, 1996, p. 78).

Theorists and researchers working in the field of the sociology of health and illness have also been greatly influenced by Foucault's work and have shown how the body is inscribed by powerful authoritative discourses of biomedicine and science via the clinical *gaze* in the modern clinic which has become a dominant site of *biopower* (Foucault, 1994; Turner, 1997). As Lupton (1997, p. 99) explains:

> From the Foucauldian perspective, power as it operates in the medical encounter is a disciplinary power that provides guidelines about how patients should understand, regulate and experience bodies. The central strategies of disciplinary power are observation, examination, measurement and the comparison of individuals against an established norm, bringing them into a field of visibility.

Foucauldian inspired sociological theorizing within this vein suggests that bodies are shaped by dominant (particularly biomedical) discourses regarding illness and disability including assumptions regarding how the "healthy" and "normal" body should look, feel, and behave (Fox, 1994, p. 23). The clinical biomedical gaze establishes certain bodies as normal, healthy, and fit and others as abnormal, ill, and unfit; it externally regulates bodies by observing, examining, measuring, and categorizing bodies, and at the same time, it also provides us with the tools to discipline our own bodies in line with these normative standards.

It should be stressed at this point that employing Foucauldian inspired postmodern theories regarding the *discursive construction* and *corporeal inscription* of the body does not mean that the body has no material reality. As Shildrick and Price (1996, p. 98) argue, however, it does mean that there is "no *essential* matter upon which meaning is inscribed," instead "the body is materialized through discourse both as word and practice" (italics in original). According to Foucault, "nothing has meaning outside of discourse" (Foucault, 1972 in Hall, 2001, p. 73). Thus, for example, Foucault argues that knowledge and practices relating to various subjects, such as the "hysterical woman," the "homosexual," or the "madman" cannot "meaningfully exist outside specific discourses, i.e. outside the ways they were represented in

discourse, produced in knowledge and regulated by discursive practices and disciplinary techniques of a particular society and time" (Hall, 2001, p. 75).

Drawing on Foucault's theories it is possible according to Grosz (1994, pp. 141-142) to appreciate how the body is inscribed both violently and in more subtle ways by authoritative discourses and disciplinary techniques:

> [V]iolence is demonstrable in social institutions of correction and training, prisons, juvenile homes, hospitals, psychiatric institutions, keeping the body confined, constrained, supervised, and regimented…Less openly violent but no less coercive are the inscriptions of cultural and personal values, norms, and commitments according to the morphology and categorization of the body into socially significant groups…The various procedures for inscribing bodies, marking out different categories, types, norms, are not simply imposed on the individual from outside…They are commonly undertaken voluntarily and usually require the active compliance of the subject.

It is this more subtle and insidious form of corporeal inscription that is of greatest concern to this thesis. As is discussed below, Foucault's work has been usefully applied by theorists in disability studies to examine how the disciplinary regime of *compulsory able-bodiedness* (McRuer, 2006), contributes to the *internalization* of oppressive *ableist* norms and values (Campbell, 2008), and in turn, this compels individuals to act on themselves through techniques of *self-surveillance* (Reeve, 2002). Also related to these ideas, and discussed below, is how Foucault's conceptualization of power as both repressive and productive has been used by feminist, queer, and crip theorists to reveal how dominant discourses and cultural norms and values might be resisted through performative acts of embodied subversion (Butler, 2006).

We will return to these ideas later, however at this point it is important to further explain the significance of Foucault's work for challenging modernist binaries and for revealing how normative standards of embodiment that all bodies are judged against are historically, culturally, and socially specific (Davis, 1997). As was discussed above, biomedicine as a dominant discourse shapes our understandings of bodies as either healthy or ill, able or disabled, normal or abnormal. Both mainstream feminist theorists and feminist disability theorists (discussed further below) have highlighted how these hierarchical dichotomies provide justification for the oppression and marginalization of those whose bodies are deemed to be "non-normative" and "other." For example, Shildrick and Price (1996, pp. 98-99) argue that dominant discourses "take as their referent the healthy male body," and therefore, "it is against

that discursive ideal that all others – the female body, the sick body, the disabled body – are measured and valued, as inferior, as different, as threatening, as needing control." Similarly, Goodley's work (also discussed below) reveals how neoliberal and ableist (*neoliberal-ableist*) discourses work together to create the dominant understanding that the ideal neoliberal citizen is rational, autonomous, competent, economically productive, and above all else, able-bodied; thus Goodley (2014, p. 33) argues that: "disability is the quintessential Other of neoliberal-ableist society." These examples reveal how oppressive discourses are founded on modernist binary categories. As Goodley (2011, p. 104) explains, discourses only "work" in dichotomous terms – i.e. "in order to speak of the *I* (able), I must distinguish it from an *other* (disabled)" (italics in original). Throughout this thesis, dualistic concepts, such as health and illness, and disability and ability are written as health/illness and dis/ability in order to show how these concepts are inextricably linked. In addition, as will be elaborated further below, this thesis attempts to destabilize this binary thinking by focusing on the *liminal* space in-between these categories.

Foucault's work is significant, because it has been used by academics to deconstruct these dominant discourses. According to Tremain (2005, p. 1), it "has provoked scholars to question what had previously been considered self-evident, timeless, unchanging, and necessary." While encouraging the deconstruction of taken-for-granted "grand narratives" and dominant discourses, Foucault also encourages an emphasis on "subjugated knowledges":

> A whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naïve knowledges, located low down on the hierarchy…such as that of the psychiatric patient, of the ill person (Foucault, 1980, p. 82).

Similarly, speaking about postmodernism more generally, Fox (2016, p. 65) argues that this perspective is "typified by suspicion of meta-narratives" and "by its contrary effort to acknowledge the validity of multiple perspectives." This thesis is part of a growing body of sociological work that employs a postmodernist approach, because it recognizes the uncertainty, multiplicity, complexity, and ambiguity of the social world, bodies, and identities (Corker and Shakespeare, 2002). Even when not explicitly Foucauldian, postmodern approaches to health/illness, dis/ability and the body owe a great deal to Foucault's work.

In line with Foucault's scepticism toward Enlightenment "meta-narratives," a postmodernist perspective, recognizes that all knowledges are partial, biased, and "situated,"

including authoritative scientific and biomedical knowledges that are often taken to be objective, pure, and universal "truths" (Clarke, 2005, p. xxiv). The utility of this framework is evidenced by current sociological theory and research that examines the biomedical imperative to *categorize* (Lerum et al., 2015; Nettleton et al., 2014; Overend, 2014) and *pathologize* (Armstrong, 2014b, p. 801) in order to "promote and maintain a certain medical reality."

In a recent article, Armstrong (2014, p. 15) challenges the widely-accepted idea "that the emergence and dominance of chronic illness is due to the receding tide of infectious diseases and an ageing population." He argues that the commonly recognized idea of an "epidemiological transition" has been largely accepted and promoted even by sociologists prioritizing a "biological rather than a sociological account of illness." (Armstrong, 2014, p. 25). Reconsidering chronic illness as a construct that came into being, not as a result of the decline in acute infectious diseases, but due to a "relabelling of ageing and senility" is incredibly important according to Armstrong because "this at once makes visible the social and historical forces that have reconfigured medical reality" (Armstrong, 2014, p. 25). Rather than reflecting the objective "truth" about chronic illness, this construct has masked how biomedicine "established a pathological lens to transform the natural ageing process" opening up "all of life (and death) to intensive surveillance" (ibid). Armstrong's (2014) revisionist account of chronic illness thus highlights the usefulness of a postmodern approach for destabilizing unchallenged hegemonic claims.

Other current research similarly questions taken-for-granted biomedical "truths." In an article by Nettleton, Kitzinger, and Kitzinger (2014, p. 134) on differentiating between "vegetative" and "minimally conscious" states, the authors present the concept of "diagnostic illusory" to "capture the ambiguities and nuanced complexities associated with the biomedical imperative to name and classify." The authors argue that medical diagnoses often fail to provide certainty and in many cases might actually worsen "existential challenges" and "raise hopes and expectations of clarity which may be unfulfilled" (Nettleton et al., 2014, p. 140). Based on a related study on motor neurone disease, Lerum et al. (2015, p. 81) argue that due to improvements in health services and the advancement of medical technology "the distinction between chronicity and terminality has become more vague and ambiguous." Lerum and

colleagues (2015, p. 82) offer the term "unstable terminality" to reflect this "ambiguity." This article highlights that what are taken to be clear-cut medical categories are actually "fundamentally unstable" (Lerum et al., 2015, p. 93). Finally, in a similar article, Overend (2014, p. 77) applies the concept of "haunting" to the case of Candida – an undefined illness – to argue that ambiguous and unexplained illnesses haunt modernist biomedical ways of knowing, understanding, and treating illness. According to Overend (2014, p. 64) the "ghostly matters" of contested illnesses fall outside of conventional biomedical classifications, thus revealing the "limits of modern biomedicine."

Feminist Disability Theory: A Brief Overview

The sociological literature discussed above destabilizes the illusion of a firm biomedical reality by showing the "manufactured-ness" of seemingly "natural" categories and revealing how they are "made, unmade, and remade" (Diedrich, 2015). This work underscores the value in a postmodern perspective that "shakes up entrenched beliefs" and has at its core a "deep scepticism towards the idea that boundaries are naturally given rather than constructed" (Einstein and Shildrick, 2009, p. 298). This discussion brings us back again to the importance of a postmodern perspective for deconstructing taken-for-granted categories and to further explore this we now turn to feminist theory. According to Fox (1994, p. 91), feminism is central to any postmodern analysis of the body, health/illness, and dis/ability as it provides a strong critique of "modernist social theory" and "supplies important lessons for postmodern readings of health."

One of the crucial insights of mainstream feminist theory has been to expose the oppressiveness of cultural dualisms by pointing out that one side of every binary is clearly valued over the other: man is valued over woman, culture over nature, healthy over sick, ability over disability, and so on (Moss and Dyck, 2002, p. 13). This means that one side of the binary comes to represent the "norm" and its opposite is then understood to be "less than," "lacking," and "other." Thus, opposed to the valued "male standard" of embodiment, female bodies are constructed as "dependent, incomplete, vulnerable, and incompetent" (Garland-Thomson, 2002, p. 7). In addition, mainstream feminist theory highlights the problematic cultural associations between the valued and the devalued sides of these dualisms, and the material consequences of these associations. According to Grosz (1994, p. 14), the mind/body opposition is closely

aligned with the male/female opposition, and "patriarchal oppression...justifies itself, at least in part, by connecting women much more closely than men to the body."

While the mainstream feminist agenda has long been concerned with the social construction of women as "other," the association of women with the body, and how this alignment has been used to oppress women as a group, disabled women's voices were historically excluded (Be, 2012; Garland-Thomson, 2002; Morris, 1992; Wendell, 1989). It was not until the 1980s that feminist researchers and theorists really began to expose disabled women's experiences of oppression, exclusion, and disadvantage, and to highlight the importance of incorporating these experiences into feminist theory. In the seminal article "Toward a Feminist Theory of Disability," Wendell (1989, p. 105) makes the crucial connection that that many of the "same attitudes about the body which contribute to women's oppression generally also contribute to the social and psychological disablement of people with disabilities." Furthermore, Wendell (1989, p. 111) argues that cultural values and assumptions regarding "normal/healthy" and "other/deviant" bodies, results in the social world and the built environment being constructed for the able-bodied male standard:

> Feminists have shown that the world has been designed for men…Much of the world is also structured as though everyone is physically strong, as though all bodies are "ideally shaped," as though everyone can walk, hear and see well, as though everyone can work and play at a pace that is not compatible with any kind of illness or pain, as though no one is ever dizzy or incontinent or simply needs to lie down…[T]he entire physical and social organization of life, assumes that we are either strong and healthy and able to do what the average able-bodied person can do, or that we are completely disabled, unable to participate in life.

Drawing on many of the same insights, Garland-Thomson (2002) similarly argues for the need for *feminist disability theory*. She proposes that feminist theory can be transformed (and greatly enriched) by "integrating disability":

> Integrating disability does not obscure our critical focus on the registers of race, sexuality, ethnicity, or gender, nor is it additive…Integrating disability clarifies how this aggregate of systems operates together, yet distinctly, to support an imaginary norm and structure the relations that grant power, privilege, and status to that norm. Indeed, the cultural function of the disabled figure is to act as a synecdoche for all forms that culture deems non-normative (Garland-Thomson, 2002, p. 4).

She goes on to argue that "feminist disability theory" offers a "radical critique" of what she refers to as the *disability/ability system*:

The disability/ability system produces subjects by differentiating and marking bodies…[It] functions to preserve and validate such privileged designations as beautiful, healthy, normal, fit, competent, intelligent – all of which provide cultural capital to those who can claim such statuses, who can reside within these subject positions (Garland-Thomson, 2002, p. 5-6).

The emergence of feminist disability theory, exemplified by theorists such as Wendell and Garland-Thomson, constituted a "new way of thinking" that "exposed the ableist ideas and (mis)conceptions about 'being disabled' that are deeply engraved in our culture and way of being, as well as the difficulty in changing them" (Be, 2012, p. 364). Despite mainstream feminism not yet fully "integrating disability" into all feminist theory, feminism has been greatly enriched by these important insights, and similarly, disability studies as a discipline has been significantly influenced by feminist theory. In particular, the "old feminist maxim 'the personal is political' would profoundly influence the debate in Britain during the 1990s over the role of impairment in the social model of disability" (Be, 2002, p. 365).

In the 1970s disability activists in the UK began to seriously challenge the "common-sense meaning of disability and its individualizing essence and consequences" (Thomas, 2007, p. 13). This struggle to redefine disability resulted in the *social model* of disability. The social model reconceptualised disability as a form of social oppression, rather than a medical problem, and according to Oliver (2004, p. 19), this was revolutionary because it proposed "that it was not impairment that was the main cause of the social exclusion of disabled people but the way society responded to people with impairments." While the social model has been central to many of the successes of the disabled people's movement, the model's separation of impairment (the body) from disability (society) has been subject to significant critiques put forth by disabled feminists (Corker and French, 1999; Crow, 1996; Morris, 1996; Schriempf, 2001; Thomas, 1999a; Tremain, 2002; Wendell, 1996). These feminist critiques centre around the contention that the "impairment/disability distinction" dismisses the importance of the embodied experience of impairment. As Schriempf (2001), explains, the social model effectively "amputated disabled (especially women's) bodies from their impairments and their biological and social needs" (p. 60). It is further problematic, because it reflects "the classic patriarchal split that mainstream feminism had challenged – the split between the public and the private,

where the 'private' becomes a personal arena of no collective significance" (italics in original, Be, 2012, p. 366).

In addition, feminists with chronic illnesses, such as Wendell (1996; 2001), argue that the separation of impairment from disability is problematic, because it results in illness becoming "equated with impairment, even by disability activists and scholars, in ways that disability is not; hence there is anxiety to assure nondisabled people that disability is not illness" (Wendell, 1996, p. 22). In turn, this contributes to the marginalization of chronically ill people within the disabled people's movement, and the problematic assumption that illness falls under medical jurisdiction and therefore is not of primary concern to disability politics and research (de Wolfe, 2002).

Thomas (1999) similarly argues against the untenable and undesirable separation of the private/personal from the public/political. In line with the critiques outlined above, she criticizes the masculinist position in disability studies which holds that "'personal' issues to do with living with either disability or impairment effects are 'private' matters which should not be foregrounded by the disability movement" (Thomas, 1999, p. 74). Thomas (2004, p. 579) also points out, however, that many of the critiques of the social model of disability (including those made by disabled feminists) focus on a reductionist and "impoverished" version of the model thus setting it up as a "straw person." For Thomas it is the *social relational* understanding of disability that needs to be adopted because it takes into account both the social aspects of disability and the embodied aspects of being disabled (Thomas, 1999a; Thomas, 2004b; Thomas, 2007; Thomas, 2012). In addition, this approach includes a focus on the *psycho-emotional dimensions of disablism* which have tended to be ignored completely by both academics and activists, including disabled feminists (Thomas, 1999, p. 75). Thomas (1999, p. 46) argues that although it is important to attend to social barriers to "doing" (i.e. *disablism*), it is equally important to emphasize who disabled people are "prevented from being," and how disabled people "feel" and "think" about themselves (i.e. *psycho-emotional disablism*).

Along the same lines, Schriempf (2001, p. 70) argues that in order to further bridge disability and feminist theory it is necessary to adopt an "interactional" approach:

> I am suggesting that "impairment" and "disability" be understood as interactional. That is, there is no clear line between the two; neither one can be relegated to either the "biological" or the "social" realm…The interactionist model describes claims of "impairment" and "disability" as those which emerge from a historical and cultural tradition of classifying bodies, objects, behaviours and so on…Classification takes place in a social context that is governed by norms…If these norms depict certain bodies as "able-bodied," then other bodies are always already "impaired."

Schriempf's interactional framework sheds light on the mutual constitution and interaction of culturally constructed opposites such as able-bodied" and disabled, and proposes a way to move beyond the seemingly inevitable dichotomizing tendencies of previous theories and approaches to the study of disability and impairment. The conceptualization of an interactional framework leads us into the following discussion of current theories within disability studies that are central to the theoretical framework employed in this thesis.

Dis/Ability and Dis/Ablism

Theoretical insights from within the broad category of "feminist disability theory" helped to lay the groundwork for contemporary theorizing in disability studies in relation to concepts such as dis/ability and dis/ablism. According to Goodley (2014, p. xiii), we need to conceptualize disability and disablism using the split terms *dis/ability* and *dis/ablism* because this "acknowledges the ways in which disablism and ableism (and disability and ability) can only ever be understood simultaneously in relation to one another." The term *disablism* refers to the "social beliefs and actions that oppress/exclude/disadvantage people with impairments" (Thomas, 2007, p. 13). In contrast, Campbell (2001, p. 44) defines *ableism* as "a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect species-typical and therefore essential and fully human." The "chief feature of an ableist viewpoint is a belief that impairment or disability (irrespective of 'type') is inherently negative" (Campbell, 2001, p. 44). Similarly, McRuer (2006, p. 8) combines insights from queer theory and critical disability theory to create "crip theory," arguing that *compulsory able-bodiedness*, like *compulsory heterosexuality*, are disciplinary systems "seemingly emanating from everywhere and nowhere." Both *compulsory able-bodiedness* and *compulsory heterosexuality* are built on the "presumed naturalness of the norm, whether it be able-bodiedness, heterosexuality, or – since they are mutually constitutive – able-bodied heterosexuality" (McRuer, 2003, p. 97).

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As was previously pointed out, the importance of using split terms (such as, dis/ability and dis/ablism) is that they represent the "complex ways in which opposites bleed into one another" and it keeps "disablism and ableism, disability and ability in play with one another, to explore their co-construction and reliance upon one another" (Goodley, 2014, p. xiii). Similar to the feminist theorizing discussed above, it proposes that we cannot adequately theorize and understand disability and disablism if we do not take into account their opposites. This is because "disability is always haunted by the spectre of ability" and "ability needs disability to be by its side in order to speak of what it is not" (Goodley, 2014, p. 153). As Davis (1997, p. 9) explains:

> To understand the disabled body, one must return to the concept of the norm, the normal body…I would like to focus not so much on the construction of disability as on the construction of normalcy. I do this because the "problem" is not the person with disabilities; the problem is the way that normalcy is constructed to create the "problem" of the disabled person.

Focusing on both disability and ability produces new questions such as, "what do we mean by being able?" and "what is valued by being as able as possibly or ideally one could be?" (Goodley, 2014, p. xi). Similarly, it encourages us to question what we mean by "healthy," and in so doing, it reveals that what we assume to be stable categories are actually remarkably "moveable" (Fox, 1998, p. 11).

Embodied Liminality: Conceptualizing Undefined Illness

Building on the theoretical insights outlined above, this thesis provides a space for "rethinking" chronically ill and disabled bodies and by extension "reconsidering the way we think about *all* bodies and mentalities" (Campbell, 2012, p. 215). To this end, this thesis draws on in-depth interviews with 31 people (25 women and 6 men) with the contested chronic illness FMS in Canada and the UK. Similar to Nettleton's (2006, p. 1176) analysis of in-depth interviews with 18 people with medically unexplained symptoms (MUS), this thesis has "broader conceptual applicability" (p. 1176). It examines the fluidity and ambiguity of living with a fluctuating and contested condition, and how this might be widely applicable in a postmodern context characterized by uncertainty and instability. In addition, by exploring the possibility that FMS, and similar conditions are "culture-bound syndromes" (Delaney and Bell, 2008, p. 33) this thesis also provides a space to examine the social forces that induce all of us to

engage in damaging practices of in/visibility by *hiding* our needs, *ignoring* our bodies, and *denying* ourselves time for self-care and rest as we strive to embody neoliberal-able cultural imperatives to constantly (and visibly) be in-control, competent, productive, responsible, and autonomous citizens.

This study of one particular contested illness attempts to connect the individual experiences of people with FMS to broader cultural issues, such as the increasingly constraining and marginalizing ideals of normality in contemporary neoliberal societies. Utilizing the notions of *in/visibility* and *liminality*, this thesis explores how the embodied and social experiences of people with the specific contested illness FMS might provide a critique of dominant cultural categories that mask the variance of human embodiment, and obscure the pressure all of us are subject to in the current neoliberal context to embody and enact strict cultural ideals of healthiness, fitness, and competence. By highlighting the interstitial experiences – the *embodied liminality* – of people with FMS, this thesis exposes the illusion of pure cultural categories, makes visible the "messiness," fluidity, and vulnerability of all bodies, and points to the liberating potentialities of embracing the chaos, disarray, and disorder inherent in the full spectrum of embodiment.

Normative and Subversive Embodied Performances

To explore the subversive potentialities of *embodying liminality* this thesis draws on Garland-Thomson's (2011) notion of the *misfit*, and Shildrick's (2002) work on the *monstrous*. Garland-Thomson (2011, p. 593) argues that the term '*fit*' "suggests a generally positive way of being and positioning based on an absence of conflict and a state of correct synchronization with one's circumstances." In contrast, "*misfit*" describes "both the person who does not fit and the act of not fitting…to mis-fit renders one a *misfit*" (italics in original). According to Garland-Thomson (2011, p. 593) it is the "discrepancy between body and world, between that which is expected and that which is, that produces fits and misfits." Thus, chronically ill and disabled people are "misfits" due to disablist/ableist social norms and stereotypes, and because the world is designed so that only certain bodies (mainly able-bodied, white, heterosexual, male bodies) easily "fit."

These ideas are particularly useful in this thesis because people with contested chronic illnesses experience multiple forms of "misfitting." People (most often women) with contested illnesses "misfit" because social norms and discourses regarding "normal" bodies designate chronically ill people as abnormal, and "other," and the social world is not designed to "fit" the needs of people with pain, fatigue, and other chronic symptoms. At the same time, people who have been diagnosed with a medically unexplained and *contested* chronic illness do not unquestionably "fit" into the categories unhealthy or disabled. These conditions are invisible, the symptoms of illness fluctuate, and many people experience some periods of good health; their bodies are likely to appear, and in some cases they will also experience their bodies, as normal/healthy/able. A person with a contested illness really represents the ultimate "misfit," in that they do not "fit" comfortably into either side of the dualisms healthy/ill or non-disabled/disabled.

Similarly, Turner (1967, p 97) explains that "transitional beings" are "betwixt and between" in that they are "neither one thing nor another." This also aligns with Shildrick's (1996; 2002) work on the "monstrous," because as she explains liminal beings/monsters are "excessive to the binary, uncontained by any fixed category of exclusion" (Shildrick, 1996, p. 8). In addition, Turner (1967, p. 97) explains, to be "unclear is to be unclean." Thus, to embody liminality is also to be deemed potentially "polluting" and "dangerous," because misfits/monsters are constructed as "matter out of place" (Douglas, 1966). Oppression, discrimination, and marginalization are all experiences of people who are constructed as misfits and monsters. This thesis explores the difficulties, challenges, and painfulness of liminality within biomedicine, in day-to-day social interactions, and in relation to social policies. At the same time, by drawing on postmodern and feminist theories, this thesis also explores how misfits and monsters might be subversive, as those who embody liminality "signify other ways of being in the world" (Shildrick, 1996, p. 6).

To explore social exclusion, marginality and in/visibility, as well as the radical subversive possibilities of *embodying liminality* this thesis draws on work that understands identity as *performative*. These theories are inspired by Foucault's work (see above), as well as Goffman's work (1959; 1963) on *stigma*, identity management, and *passing*.

Butler's work on *performativity* "queers" Foucault's concepts of *self-surveillance* and the *docile body* (Corker and Shakespeare, 2002). In addition, Butler also draws on Goffman's dramaturgical analysis of social interactions and identity formation. In Goffman's (1959) work he conceptualizes social interactions as performances, and he does this with reference to "front stage" and "back stage" regions. According to Goffman (1959, p. 110), in the "front stage" our performances are governed by the audience and certain "rules" or standards, and thus we engage in impression management in order to ensure that our performances are properly received by the audience and that they embody and maintain these standards. In the "back stage" region, however, we are not subject to the same "front stage" rules. So, for example, Goffman explains that waiters and waitresses act differently in the restaurant when they are in front of customers than they do when they are hidden from view in the kitchen (i.e. in the "back stage").

Similar to Goffman, Lawler (2008, p. 104) explains that for Butler "identity is always something that is done: it is achieved rather than innate." In addition, both theorists use the idea of "performance" to understand how subjectivities are created through social interactions, and both are concerned with how identity is socially constructed in relation to dominant social and cultural norms, beliefs, and attitudes. While Goffman's work in particular has been critiqued for overemphasizing "freedom, agency and the 'micro' world of interaction," both Butler and Goffman clearly "see individual actions and responses as part of a wider social order that permits some actions and disallows others" (Lawler, 2008, p. 104).

In particular, Goffman's (1963) work on *stigma* and *passing* reveals how performances are severely constrained by social and cultural norms, values, and beliefs. Stigma, according to Goffman (1963, p. 13), is a culturally relative term which refers to "an attribute that is deeply discrediting," however, "an attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself." While some stigmatized individuals are *discredited* by the fact that their "differentness is known about already or is evident on the spot," others (such as people with invisible chronic illnesses) are *discreditable* as their "differentness" is "neither known about by those present nor immediately perceivable by them" (Goffman, 1963, p. 14). A *discreditable* person must constantly manage information in order to prevent becoming a *discredited* person:

> When in fact he is a discreditable, not a discredited, person…the issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where (Goffman, 1963, p. 57).

Some individuals may choose *not* to reveal their "differentness" to others, and instead will attempt to *pass* as "normal." The ability to *pass*, however, is often dependent on the "visibility" or "perceptibility" of the stigma. This means that people with non-visible disabilities, such as FMS, can choose to *pass* as healthy/able-bodied. Goffman (1963, p. 95) argues, however, that "[b]ecause of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent."

Similarly, Butler argues that we do not "freely" choose how to perform femininity and masculinity, rather these are disciplined performances that reflect dominant gender norms. Thus, clearly drawing on Foucault, as well as Goffman, Butler (2006, pp. xxiv-xxv) states that "to the extent that gender norms establish what will and will not be intelligibly human, what will and will not be considered to be 'real,' they establish the ontological field in which bodies may be given legitimate expression." Just as Goffman (1963, p. 95) argues there are "great rewards" to hiding "differentness," such as disability, Butler (2006, p. xxiv) argues that complying with gender norms permits a person to recognized as "intelligibly human." At the same time, drawing on Foucault's conceptualization of power as both repressive and productive, Butler offers the possibility of resistance. If, as Butler (2006, pp. vx-xvi) argues, gender is not an "internal feature of ourselves" but instead, "is one that we anticipate and produce through certain bodily acts" then alternative performances of gender are possible. Specifically, Butler argues that "drag," understood as a subversive performance of gender, "is an example that is meant to establish that 'reality' is not as fixed as we generally assume it to be" and thus it reveals "the tenuousness of gender 'reality' in order to counter the violence performed by gender norms" (ibid).

The theories directly above are not only useful for understanding how gender is materialized, but also other aspects of embodied identity. Campbell (2005, p. 109) argues that through the processes of ableism, disability comes to be understood as "inherently negative" and "ontologically intolerable." The hegemonic perspective that only bodies that are deemed able,

fit, and healthy are to be valued is only possible through binary thinking that privileges certain

forms of embodiment over others, creating hierarchical ontological divisions (Hughes, 2007). In

other words, the cultural understanding that disability is "inherently negative" is only possible,

because ability is constructed as "the corporeal standard" (Campbell, 2001, p. 44). Thus,

"instead of ontological embrace, the processes of ableism, like those of racism, induce an

internalization which devalues disablement" (Campbell, 2008, p. 154).

According to Campbell (2008, p. 151) living in an ableist culture results in all of us

"internalizing ableism," because "[w]e are all, regardless of our subject positions, shaped and

formed by the politics of ableism." In order for *internalized ableism* to happen "there needs to

be an existing *a priori* presumption of compulsory ableness" (Campbell, 2008, p. 156). McRuer

(2006, p. 9) argues that able-bodiedness is "compulsory" because we live in a culture that

"assumes in advance that we all agree: able-bodied identities, able-bodied perspectives are

preferable and what we all, collectively, are aiming for." The internalization of compulsory

able-bodied cultural norms induces disabled people to conform to standards of ability and hide

difference, through what Campbell (2008, p. 156) terms "ableist passing." While Campbell's

work clearly draws on Goffman's notion of passing, it also reflects a critical engagement with

Foucault's theories, particularly his ideas relating to *self-surveillance* and *disciplining/inscribing*

the body.

To further explore these ideas, we now turn to Reeve's (2002) influential work that

draws on Foucauldian concepts to elaborate Thomas' (1999) concept of *psycho-emotional*

disablism (see above). Reeve (2002) explains that internalized oppression is the process

whereby disabled people internalize dominant negative stereotypes regarding disability, and this

idea fits well with Foucault's concept of *biopower*. Internalizing oppression also relates to

psycho-emotional disablism, because internalizing negative stereotypes and prejudices about

disability impacts how disabled "think" and "feel" about themselves (Reeve, 2002, p. 495). In

turn, *psycho-emotional disablism* relates to *self-surveillance* as disabled people who feel "less

than" and think of disability as "tragic" might discipline their own bodies to conform to able-

bodied norms. This process also has detrimental effects on the psycho-emotional well-being of

disabled people, because "living a contradictory identity" – i.e. hiding disability and passing as non-disabled – is stressful and confusing (Reeve, 2002, p. 501).

Within a context where able-bodiedness is compulsory (McRuer, 2006), resistance to able-bodied norms is difficult. As Stone (1995, p. 421) explains:

> In a world in which people with disabilities are objectified as the alien 'other', it makes sense to work at passing for normal; to pretend that one has nothing in common with the 'disabled'; it makes sense to ignore the ways in which we can identify with living in a body that has impairments. It even makes sense for us to deny to ourselves that we are limited by disabilities. The benefits of passing are myriad.

While resistance is difficult, it is not impossible. Foucault offers a theory of power that understands power as not only oppressive, but also productive; and as Reeve (2002, p. 497) explains the "most important product to be created from power is resistance to that power." Drawing on Foucault, and similar to Butler's work on performativity, both Campbell (2008) and Reeve (2002) offer possibilities for resistance. Campbell, (2008, p. 160) argues that by "daring to speak otherwise about impairment" resistance against the understanding of disability as inherently negative is possible. Similarly, Reeve (2002) argues that "coming out" as disabled and claiming the label "in a positive manner through disability pride" is a form of resistance against the dominant understanding of disability as personal tragedy. Likewise, Patsavas (2014, p. 203) argues that by offering alternative de-individualized understandings about chronic pain, it is possible to challenge the dominant understanding of chronic pain as a "fate worse than death." Finally, forging an alliance between queer and crip theorists and activists, it is argued that resistance is possible through a "recognition that another world can exist in which an incredible variety of bodies and minds are valued and identities shaped" (McRuer and Wilkerson, 2003, p. 14).

Drawing on the theories above, this thesis explores the internalization of oppressive cultural norms, and how this relates to *passing* as healthy/non-disabled or *coming out* as chronically ill/disabled. In addition, it examines possibilities for resistance by exploring how people who are ambiguously un/healthy and dis/abled might disrupt the illusion of stable and secure biomedical and socio-cultural categories, as well as how they might offer embodied alternatives that challenge hegemonic neoliberal-ableist expectations regarding performances of un/healthiness and dis/ability. It explores both the painfulness of residing in the liminal space

in-between the worlds of health and illness, disability and ability, but also the potentialities of this liminality for "speaking otherwise" about chronic illness. Finally, through the concept of *embodying liminality*, the thesis explores how being "betwixt and between" health/illness and dis/ability might be a subversive way of being in the world that disrupts the dominant myth of bodily perfection (Stone, 1995), and encourages an acceptance of the uncertainty, fluidity, and vulnerability of all bodies and lives in postmodernity (Shildrick, 2002).

Chapter 3 – Contested Chronic Illness: A Review of Previous Research and Literature

Introduction

To position this thesis relative to previous research and theorizing on (contested) chronic illness it is helpful to engage in a more detailed discussion of the themes that have emerged from sociological research and literature in this area. The work discussed in this chapter originates mainly from the sociology of health and illness, and this is not surprising, as the study of chronic illness has been marginalized in mainstream disability studies (Scambler, 2012). According to Scambler (2012, p. 142) "whilst purporting to champion the cause of disabled people, disability studies…has sidelined the huge numbers of disabled people who are disabled through long-term, often degenerative, conditions." In part, the lack of research on chronic illness within disability studies is due to the social model and its separation of impairment (the body) from disability (the social) (de Wolfe, 2002; Wendell, 2001). As was discussed in the previous chapter, disabled feminists have been particularly critical of this distinction arguing that the *personal*, embodied experiences of impairment (including chronic illness) cannot (and should not) be separated from the *political* – disabling social beliefs, attitudes, behaviours, and environments (Corker and French, 1999; Crow, 1996; Morris, 1992; Thomas, 1999a; Tremain, 2002; Wendell, 1996). Despite these critiques, "impairment" remains a controversial issue within disability studies (Thomas, 2004a), and it has been argued that there is a reticence on the part of some researchers in disability studies to include experiences of certain impairments that cause bodily suffering (especially experiences of chronic illness), partly because these bodily experiences cannot be improved by social accommodation alone (de Wolfe, 2002; de Wolfe, 2012). As de Wolfe (2002, p. 261) explains: most chronically ill people do indeed "construe themselves as potential clients of curative medicine [and] no amount of social accommodation can totally compensate for lost quality of life," however, this does not mean that certain forms of social accommodation would not greatly improve the lives of chronically ill people.

Although disability studies has "sidelined" chronic illness (de Wolfe, 2002; Scambler, 2012; Wendell, 2001), this field nonetheless offers important theoretical tools, and different

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ways of examining this topic. This is because, while the sociology of health and illness (or medical sociology) has a long and rich history of studying chronic illness, this field has tended to individualize the experience of disability and illness and "rarely focuses on the wider issues of political oppression and discrimination faced by these groups" (S. Scrambler, 2012, p.136). In the literature review that follows it is argued that one of the main issues with the sociological work on this topic to date is that it is predominately embedded within a "social deviance paradigm" (Thomas, 2007; Thomas, 2012). Thomas (2012, p. 215) argues that in the same way that it is wrong to define women, queer people, or people of colour as deviant, it is also clearly unacceptable to employ the binary normal/deviant when engaging in research of chronically ill and disabled people. Yet, according to Thomas (2012, p. 216), the social deviance paradigm that has informed, and continues to inform, research from the sociology of health and illness does exactly that, because it is deep rooted in the "enlightenment inspired *normal/pathological* bifurcation" mirrored in biomedical conceptions of the body (italics in original).

In order to avoid this, Thomas argues that it is crucial that sociology look to disability studies and begin focusing not on chronically ill people as "deviant" individuals, but on how disablism (oppression and discrimination) impacts the lives of chronically ill people (Thomas, 1999a; Thomas, 2003; Thomas, 2004b; Thomas, 2012). Thomas (2012, p. 211) defines *disablism* as the "*social* imposition of *avoidable restrictions* on the life activities, aspirations and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal'" (italics in original). Thomas argues that disability studies has made important contributions to the study of *disablism*, but she admits that this field has largely ignored the importance of *impairment effects* – what she describes as the "direct and *unavoidable* impacts that 'impairments' (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world" (emphasis added, Thomas, 2012, p. 211).

Beyond Binaries and Deviance: Toward Fluidity and Potentialities

In line with Thomas' assertions, this thesis draws on work from both fields, and it attempts to move beyond the "social deviance paradigm" (Thomas, 2007). The literature review below highlights that the vast majority of work to date on chronic illness (including contested chronic illness) starts from the assumption that health and illness (like ability and disability) are

separate and opposing categories. This binary thinking upholds the dominant understanding that health (like ability) is the norm and the ideal, and thus illness (like disability) is deviant, inherently negative, and a personal tragedy (Campbell, 2005; Campbell, 2008; French and Swain, 2004; Thomas, 2007).

The postmodern approach taken in this thesis hopes to transcend this binary thinking by examining the liminal space in-between these categories. As Shildrick (1996, p. 6) explains, if we want to deconstruct oppressive dichotomies then "what happens at the boundaries, where the leaks and flows across categories signal not so much the breakdown of security as the impossibility of fixed definition, becomes of crucial importance." By exploring this topic from the perspective of people who are in the "borderlands" this thesis hopes to move outside of the deviance perspective and challenge hegemonic understandings of health/illness and dis/ability. Understanding illness in terms other than negativity, lack, and deviance does not imply, however, that people's experiences of chronic illness are wholly positive. The accounts presented in this thesis, like the majority of the research discussed below, reveal that chronic illness involves bodily suffering, chaos, and loss. As such, chronic illness is often understandably interpreted as being negative. At the same time, it is important not to individualize experiences of illness and disability by separating these embodied experiences from the social context, or to reaffirm binaries that devalue ill and impaired bodies. In keeping with a postmodern focus on complexity, this thesis explores how living with chronic illness is multidimensional: not wholly negative or completely positive. As Wendell (1996, p. 83) who has CFS/ME explains:

> I want to have more energy and less pain, and to have a more predictable body; about
> that there is no ambivalence…Yet I cannot wish that had never contracted [CFS] ME,
> because it has made me a different person, a person I am glad to be, would not have
> missed being, and could not imagine relinquishing, even if I were 'cured.'

Wendell's experience sheds light on some of the positive aspects of being chronically ill. By starting from the assumption that chronic illness is solely negative, the majority of research from the sociology of health and illness fails to acknowledge these and other important positive dimensions of being chronically ill and disabled (Scambler, 2012, p. 142).

This thesis hopes to avoid this by exploring both the negative and painful experiences, as well as the positive, potentially liberating, and transformative aspects of being chronically ill. It attempts to go beyond binary thinking to explore the complexity, difference, and fluidity of embodiment and examines how individual experiences of medically unexplained illness might be generally applicable and instructive in a postmodern age of uncertainty, ambivalence, and precariousness (Bauman, 1991; Nettleton, 2006; Shildrick, 2015). It also seeks to understand how ambiguous, uncertain, and unexplained chronic illness might be both personally and structurally disruptive, as these embodied experiences reveal the leakiness and fluidity of seemingly stable and secure medical and socio-cultural categories (Shildrick, 1997). Finally, this thesis explores the subversive potential of transgressing categories of embodiment within a "neoliberal-able" context (Goodley, 2014). By exploring these three broad research questions it is hoped that this thesis will provide an ontological reframing of chronic illness that does not represent illness as solely negative, but instead sheds light on the instructive, disruptive, and subversive dimensions of the chronically ill body.

Previous Research and Literature on (Contested) Chronic Illness

Having outlined the research questions and the approach taken in this thesis, as well as some of the major critiques of past research on chronic illness, the chapter will now turn to a discussion of this set of literature. This chapter discusses research on chronic illness more generally, however, it mainly focuses on work on contested illnesses specifically. As we will see, the subjective nature of FMS, and similar chronic contested illnesses, has led to an expanding body of research drawing on "chronically ill people's stories," and this is a reflection of the general "narrative turn" within the social sciences, and specifically the sociology of health and illness (Charmaz, 2000, p. 288). Research in this vein mainly investigates the embodied experiences of chronically ill people and the meanings individuals attach to their experiences of illness, and in so doing this method attempts to "restore the illness to the patient" (Bendelow, 2000, p. 27). Drawing from narratives on the "lived experience" of illness, the majority of previous research on chronic illnesses has been informed by phenomenological, narrative or interactionist approaches, and has focused on issues, such as, experiences of disruption and uncertainty following the onset of illness, doctor-patient interactions, the

diagnostic process, stigma related to having a contested illness, and decision-making around passing and disclosure. The disruptiveness of chronic illness, and especially contested chronic illness, is a particularly dominant theme in the research and literature discussed below. Previous research highlights how people with contested conditions have to deal with both the embodied disruption brought about by debilitating chronic symptoms, and the social disruption that comes from the stigma and uncertainty that surrounds these conditions.

In addition to the more traditional, micro-level approaches to the study of (contested) chronic illness, this chapter highlights research that explores the connections between embodied experiences of illness and socio-cultural structures. This includes research that draws on the combined insights of the lived body approach (discussed directly below) and Mol's (1999; 2002; Mol and Law, 2004) influential work to reveal how illness and disability are embodied and enacted, as well as literature that explores how the embodied experiences of people with chronic illnesses might provide a metaphor for all of our lives in postmodernity, and research from the subfield of sociology, known as the *sociology of diagnosis*. Finally, this chapter looks at research that examines the gendered experience of chronic illness and disability, particularly in relation to contested chronic illnesses, which tend to be diagnosed in women more than men.

Phenomenology, Bodily *Dys-Appearance*, and Chronic Illness

Previous research on chronic illness that employs a phenomenological framework explicitly or implicitly draws from Merleau-Ponty's theorizing of the "body-as-experiencer," or in other words, the body as the "medium whereby our world comes into being" (Leder, 1990, p. 5). According to Merleau-Ponty it is through our bodies that we experience the world, and this means that, contrary to Cartesian philosophies, the mind and body are necessarily interrelated:

> The perceiving mind is an incarnated body. I have tried, first of all, to re-establish the roots of the mind in its body and in its world, going against the doctrines which treat perception as a simple result of the action of external things on our body as well as against those which insist on the autonomy of consciousness. These philosophies commonly forget – in favour of a pure exteriority or of a pure interiority – the insertion of the mind in corporeality, the ambiguous relation which we entertain with our body and, correlatively, with perceived things. (Merleau-Ponty, 1964, pp. 3-4).

Drawing on Merleau-Ponty's understanding of the interrelatedness of the mind and body, Leder (1990) discusses the potential of theorizing from the point of view of the "lived body":

This notion of lived body provides a potential mode of escape from cognitive habits of dualism deeply entrenched in our culture. Insofar as the body is restricted to its causal-physicalistic description, those aspects of self involving cognition and intentionality are commonly relegated to a substance called "mind." This division of labor between res extensa and res cogitans, between the scientific and the humanistic domains, is the very basis of Cartesian ontology. Yet this is precisely what the concept of lived body subverts. If the body as lived structure is a locus of experience, then one need not ascribe this capability to a decorporealized mind. The self is viewed as an integrated being (Leder, 1990, p. 5).

Instead of viewing the body as purely an object or purely a subject, this phenomenological framing understands the body to be both; the "body is both object (for others) and a lived reality (for the subject), it is never simply object or simply subject" (Grosz, 1994, p. 87).

The notion of the lived body has proven useful for understanding embodied experiences of chronic illness. According to Leder (1990, p. 84), for many of us in our day-to-day lives the body is largely absent, but when we experience pain and other forms of "dys-ease" we become fully aware of our bodies. Leder describes this as the "principle of "*dys-appearance*" – the body appears as thematic focus, but precisely as in a dys state – dys is from the Greek prefix signifying 'bad,' 'hard,' or 'ill'" (Leder, 1990, p. 90, italics added). He further explains that when we are healthy, "the body is alien by virtue of its disappearance," but when we are ill, "this gives way to dys-appearance" (Leder, 1990, p. 91). When illness, and in particular pain, strikes, "the body is no longer alien-as-forgotten, but precisely as remembered, a sharp and searing presence threatening the self" (ibid).

The principle of *dys-appearance* has been taken up in empirical research on contested chronic illness. For example, the idea that the onset of chronic illness results in a struggle between the body and self is highlighted in an article by Raheim and Haland (2006) that draws on qualitative interviews to understand the embodied experience of FMS. Grounded in hermeneutic phenomenology, and drawing from 12 "life-form" (in-depth) interviews with women who have FMS, the authors probe the following research question: "How is the everyday world experienced from the perspective of a chronically painful body?" Three typologies emerge from the data: (1) at the will of the treacherous body (powerlessness); (2) struggling to escape the treacherous body (ambivalence); and, (3) caring for the treacherous body (coping). Overall, the authors argue that the women's narratives in all three typologies support the hypothesis that living with FMS "implies a never-ending struggle with an unwilling

body," and conclude by stating that "the women's stories point to a world experienced as fundamentally changed by a body in chronic pain, describing a struggle in which they feel that their existence is at stake" (Raheim and Haland, 2006, p. 758).

Similarly, Johansson and colleagues (1999, p. 1791) argue that interviews with women who have "biomedically undefined musculoskeletal pain" reveal that pain has negative consequences in their everyday lives and challenges their competence as women to carry-out tasks such as paid work, housework, and caring duties. The women in their study express pain as unpredictable, threatening, alien, and invasive. In addition, the women describe feeling as though they are powerless victims to the pain they experience and thus their identities as "capable women" are at risk (Johansson et al., 1999, p. 1794).

Other research reveals that the embodied experience of chronic symptoms leads to a heightened experience of the body that is described by Barker (2005, p. 87) as "body mindfulness." She argues that whereas a "lack of body awareness is the taken-for granted privilege of health," for people with FMS "constant body mindfulness is a central cognitive template" (Barker, 2005, p. 88). This is similar to the argument made by Soderberg et al. (2002, p. 253) who state that, in contrast to the experiences of healthy women, women with FMS describe how the "lived experience of the body becomes the focus of attention" and thus chronic symptoms "disrupts one's ongoing involvement in the world" (p. 253). Put simply, the lived body experience of FMS means that the "taken-for-grantedness of daily life is interrupted" (Soderberg et al., 1999, p. 582).

These empirical studies clearly highlight how "illness disrupts the usual phenomenological anatomy" (Pickard and Rogers, 2012, p. 106). As Leder (1990, p. 76) explains*:*

> The disruption and constriction of one's habitual world thus correlates with a new relation to one's body. In pain the body or a certain part of the body emerges as an *alien presence*. The sensory insistence of pain draws the corporeal out of self-concealment, rendering it thematic. No event more radically and inescapably reminds us of our bodily presence. Yet at the same time pain effects a certain alienation…The painful body is often experienced as something foreign to the self (italics added).

Thus, while rejecting Cartesian dualism, the notion of the lived body and the principle of *dys-appearance* also reveals why this understanding of the separateness of mind and body is so

compelling in our culture, especially when we experience pain or other bodily suffering. Leder (1990, p. 70) explains that "[i]nsofar as the body seizes our awareness particularly at times of disturbance, it can come to appear 'Other' and opposed to the self."

Embodying and Enacting Chronic Illness and Disability

According to Pickard and Rogers (2012, p. 104) research that employs the phenomenological notion of the lived body focuses on the "corporeal experience of illness and disability within the lifeworld, highlighting experiential aspects such as changes to embodied self-awareness, motility, spatiality and temporality." It is an approach that has proved fruitful not only in medical sociology, but also in disability studies. Hughes and Paterson (1997, p. 334) argue that the "value of a phenomenological sociology of the body…is that it embodies the addition of sentience and sensibility to notions of oppression and exclusion." In addition, they claim that phenomenology is useful for highlighting how "[d]isability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help constitute its meaning" (Hughes and Paterson, 1997, p. 335).

In contrast to the proponents of this approach, some critics have argued that a phenomenological, lived body perspective neglects to consider the "influence of socio-structural factors on embodied dispositions" (Pickard and Rogers, 2012, p. 104). In addition, some disability studies scholars have questioned the political motivation of research focused on the embodied experience of illness and impairment. For example, Thomas (2007, p. 169) argues that most sociological studies on the lived experience of chronic illness "focus on *being* in illness rather than *doing* in the face of disablism" (italics in original). The phenomenological research discussed up until this point is vulnerable to both of these criticisms; while research adopting this approach claims to move beyond the Cartesian mind/body split, by referring to chronic illness as a "struggle" between the self and an ill body that is described as "treacherous," "unpredictable," "threatening," "alien" and "foreign," this research implicitly reaffirms the opposition between the rational self/mind and the uncontrollable body. Furthermore, these descriptors of illness make it difficult to imagine how being chronically ill might be understood as anything other than a personal tragedy. Thus, in line with the critiques discussed at the beginning of this chapter, phenomenological studies like those outlined above

tend to individualize illness and to focus on "personal suffering in ways that mask structural forms of disablism" (Goodley, 2011, p. 55).

While these criticisms might be applied to some phenomenological research, it is also possible according to Crossley (2001, pp. 320-321) that critics fail to understand how "structure and the lived body are fundamentally intertwined" and that "individuals embody and enact social structures." Indeed, there are noteworthy examples of research that employs the lived body approach to examine *doing* (or *enacting*) illness and disability in order to make connections between individual embodied experiences and socio-cultural structures. One particularly excellent example is an article by Pickard and Rogers (2012) that explores the act of *doing* self-care with multiple chronic illnesses. These authors argue that adopting a lived body approach "redresses the emphasis given to cognitive processes and puts the body firmly back into the centre of the account" and it "suggests that our experience of everyday embodied practices is itself a *fact about the world*, compatible with genuine scientific enquiry" (italics in original, Pickard and Rogers, 2012, p. 104-105). Based on a case study comprised of longitudinal qualitative interviews, Pickard and Rogers (2012, p. 109) examine the "embodied self-awareness" and "bodily knowledge" of a patient with chronic multi-morbidities. The researchers then contextualise these embodied self-care practices by examining the "situated dimensions of [sic] chronic illness work" and by highlighting the "role played by health-care professionals and the place of biomedical regimens in supporting chronic illness work" (Pickard and Rogers, 2012, p. 109-110). Drawing on the assertion made by Mol and Law (2004, p. 58) that all medical procedures are "interventions into lived bodies, and thus into people's daily lives," this study highlights how illness is enacted through practices of self-care, and how these embodied practices are shaped by the complex interaction of bodies, healthcare professionals, social policies and healthcare systems.

Galis (2011, p. 825) advocates a similar framework to that employed by Pickard and Rogers (2012) to shift sociological analysis away from "what disability is" to "how disability is created." In this article, Galis draws on Mol's (1999) theory of "ontological politics." Mol (1999, p. 75) defines ontological politics as such:

> *Ontological politics* is a composite term. It talks of *ontology* – which in standard philosophical parlance defines what belongs to the real, the conditions of possibility we live with. If the term 'ontology' is combined with that of 'politics' then this suggests that the conditions of possibility are not given…So the term *politics* works to underline this active mode, this process of shaping, and the fact that its character is both open and contested (italics in original).

Galis (2011, p. 825) argues that applying this framework to the study of disability integrates bodily experience into the analysis through a "politics of reality" and has the potential to reveal "how disability is experienced and enacted in everyday practices, in policy-making, in the body, and in the built environment."

In addition, the concept of *enacting* has also proved useful in the field of sociology known as the *sociology of diagnosis*.[2] Gardner et al. (2011, p. 843) employ a "material-semiotics methodology" to examine the "link between diagnostic practices, patient awareness of the body, and biopolitical governance." The "material semiotics methodology" used in this research draws on Mol's (2002) important ethnographic study of atherosclerosis which highlights how the condition is made intelligible in a hospital through the "material and non-material entities" that serve to "enact the disease" (Gardner et al., 2011, p. 844). Mol's (2002, p. 84) study found that atherosclerosis took *multiple* forms within one hospital, depending on the health professional, specialty, test, or treatment defining it, however, she argues that while "atherosclerosis in the hospital comes in different versions, these somehow hang together...there is a manyfoldedness, but not pluralism." In other words, "these multiple forms hang together, not as a coherent whole, but as a 'patchwork singularity'" (Gardner et al., 2011, p. 844). Similarly, Gardner and colleagues (2011, p. 845) found that diagnostic practices both create multiplicity and coherence, producing a "patchwork patient." Furthermore, they argue that their analysis reveals that "drawing attention to the specific entities involved in the enactment of disease and the body" underscores the "relationship between diagnostic practices and wider social and political forces" (ibid).

These ideas were helpful for the development of the thesis research project, because this set of work "attempts to animate ontology, and to explain (rather than start with) binary opposites" (Cussins, 1996, p. 577). In contrast to some phenomenological research (above), or

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[2] Below is a further discussion of research from the field of the sociology of diagnosis.

studies adopting a narrative framework (discussed below), research that emphasizes ontology

does not reify the mind/body dualism (Pickard and Rogers, 2012), and it avoids the trap of

constructing illness and disability as inherently negative. Instead, it shifts the analysis from what

illness (or disability) is to a focus on how illness and disability are created and enacted through

embodied practices, and by the complex interaction of bodies with socio-political structures and

the built environment (Galis, 2011). With regard to this thesis, these ideas were useful for

developing research questions that explore how ambiguous illness is shaped, embodied, and

enacted in relation to biomedicine, social interactions, and policies.

Disruption, Chaos, and Uncertainty: Narrative Analyses of Chronic Illnesses

Unlike the research above on enacting health/illness and dis/ability, the studies

discussed in this next section employ a narrative framework tends to separate mind from body

by adopting a "predominately cognitive view of the self" (Pickard and Rogers, 2012, p. 104).

Similar to some phenomenological research, it understands embodiment as "symbolically

associated with disruption" (Shildrick, 1996, p. 3). In particular, the research below focuses on

how the onset of chronic symptoms disrupts one's sense of self and identity (Bury, 1982; Kelly

and Field, 1996; Richardson et al., 2006; Sanders et al., 2002). According to Bury (1982, p.

168), acquiring a chronic illness such as rheumatoid arthritis, is best understood as a form of

biographical disruption or a *critical situation*:

> My contention is that illness, and especially chronic illness, is precisely that kind of
> experience where the structures of everyday life and the forms of knowledge that
> underpin them are disrupted. Chronic illness involves a recognition of the worlds of
> pain and suffering, possibly even death, which are normally only seen as distant
> possibilities or the plight of others.

Research in this vein also highlights the "biographical consequences for the family"

(Richardson et al., 2007, p. 347) by revealing the disruption that chronic illness has within the

family context and the ways in which family members adapt and support the family member

with chronic illness (Preece and Sandberg, 2005; Richardson et al., 2007). Related literature

specifically examines the effect of chronic illness on partners of people with chronic illnesses

(Axtell, 1999; Paulson et al., 2003), including issues relating to how chronic symptoms, such as

pain and fatigue, may put a strain on sexual relationships (Schlesinger, 1996).

The notion of *narrative reconstruction* is closely aligned with the conceptualization of chronic illness as a form of *biographical disruption* (Williams, 1984). Whitehead (2006, p. 2236) states that "narrativised reconstruction is concerned with gaining meaning and import to the illness by placing it within the context of one's own life and reconstructing the narrative of the self." Research employing narrative reconstruction as an analytic tool assumes that the onset of chronic illness is disruptive and is interested in understanding the ways in which individuals with chronic illnesses rebuild and restore their identities and confer meaning to their illness. As Williams (1984, p. 197) argues, "narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society."

Research employing an illness narrative framework largely draws from Frank's (1995) seminal work, *The Wounded Storyteller*. In this book Frank outlines three types of narrative: the *restitution* narrative, the *chaos* narrative, and the *quest* narrative. Nettleton (2006, p. 1173) provides a concise summary of Frank's narrative typologies:

> The *restitution* narrative is typified by the Parsonian sick role; a person is ill, finds out what is wrong, seeks help, treats their condition or brings the symptoms under control. In the *quest* narrative the person gains something from the illness experience such as self-awareness. The *chaos* narrative is the antithesis of the restitution narrative, in that there is no clear beginning and no actual or imagined end. The narrative lacks structure; there is no clear 'plot' or 'route map' (italics in original).

Given the above definition of these three narratives, and the understanding that chronic illness is disruptive, it is not surprising that the *chaos* narrative has featured prominently within literature on chronic illness, particularly contested chronic illness. Indeed, research informed by a narrative framework reveals that contested chronic illnesses are often experienced as even more disruptive/chaotic than other non-contested and "legitimate" chronic illnesses (Nettleton, 2006; Nettleton et al., 2005; Stockl, 2007; Whitehead, 2006).

For example, based on interviews with 17 British people with CFS/ME, Whitehead (2006) argues all of the participants initially presented a restitution narrative; they saw their initial illness symptoms as temporary and thus assumed that they would enter into the sick role for a temporary period of time and then fully recover and return to their "normal" roles and

obligations. The chaos narrative began when the participants realized that their symptoms were not temporary. As Whitehead (2006, p. 2240-2241) explains:

> The use of an everyday framework to explain the existence of symptoms diminished. People could no longer attribute the symptoms to an acute illness. Symptoms became more severe yet remained non-specific in origin and no explanations were forthcoming. People remained in limbo in the medical system and at this point all moved into a chaos narrative.

The length of time the participants employed a chaos narrative to explain their experiences was dependent on a medical diagnosis. Following a diagnosis the majority of the participants moved back into a restitution narrative as they began to "seek recovery" through a search for treatments, including alternative therapies.

Similarly, Nettleton (2006) and Nettleton and colleagues (2005) found that within the overall illness narratives of people with medically unexplained symptoms (MUS), the chaos narrative was common. Uncertainty regarding onset and cause, numerous diagnostic tests, but no diagnosis (and thus no treatment options), were all present as part of the participants' chaos narratives. In addition, Nettleton (2006, p. 1173), states that a "defining feature of the chaos narratives is that 'other people' refuse to acknowledge the existence of illness, or alternatively, offer 'well meaning' suggestions." The respondents discussed how they were expected to either recover, or be constantly trying to find a cure, and this can constitute a further form of tyranny, leading one woman in the study to say, "I just want permission to be ill" (Nettleton, 2006, p. 1175). This study reveals that medically unexplained chronic illnesses might be experienced as especially chaotic, because the symptoms associated with these illnesses are "invisible" and therefore contestable.

The research above draws on the narratives of people with chronic illnesses to highlight the disruption and chaos brought about by the onset of illness. Proponents of the narrative framework have pointed to its humanitarian and ethical strengths, arguing that through the act of communicating illness narratives chronically ill people are able to reconstitute and realign body and self after illness (Charmaz, 2000; Frank, 1995). According to Frank (1995, p. 53) telling illness stories is a means to "*repair* the damage that illness has done to the ill person's sense of where she is in life, and where she may be going" (italics in original). In this way, illness narratives are a "way of redrawing maps and finding new directions" (ibid).

In contrast to advocates of narrative analysis, some have critiqued this work, because narrative approaches tend to assume a separation between body (chronic illness) and mind (identity), and then posit that stories about illness are unquestionably tied to one's sense of self and identity. As Brubaker and Cooper (2000, p. 12) state, "social life is indeed 'storied,' but it is not clear why this 'storiedness' should be axiomatically linked to identity."

In addition, critics have pointed to some of the potential issues raised by employing narratives as data and the perceived tendency to present these as "hyperauthentic," "special," "transformative," and/or "therapeutic" (Atkinson, 1997; Atkinson, 2009; Bury, 2001; Shapiro, 2011; Thomas, 2010; Woods, 2011). Atkinson (1997; 2009) has been particularly critical of what he describes as the "privileging" of narrative data in research on chronic illness, stating that this approach assumes that disabled and chronically ill people should "produce extended and elaborated accounts of personal experience" and likewise that "researchers 'ought' to generate extended narratives of a particular sort: heroic, resistant, sense-making and so on" (Atkinson, 2009, para. 2.16). In addition, he argues that this often leads to a "romantic view of the speaking subject" (Atkinson, 2009, para. 2.14) and in turn this "misplaced sentimentality and romantic vision" results in common dualisms where patients are portrayed as "heroes" and doctors as "villains" (Thomas, 2010, p. 649). Finally, Atkinson (2009, para. 2.14) states that this "stress on narrative frequently strips the inquiry of any sociological or anthropological thrust" as "individual narrators" are "portrayed as just that: they speak alone, about themselves, for themselves, in a social vacuum." Similarly, Thomas (2007, p. 169) argues that "there is little or no attempt to make an explanatory link between personal illness biographies and the social structures and mechanisms that serve to exclude or oppress."

Embodied Uncertainty: Connecting Embodied Experiences with Social Structures

Although some narrative research is guilty of these criticisms, there are important studies that draw on qualitative data (narratives and accounts) to highlight both the embodied and social disruptiveness of chronic illness, including experiences of social exclusion and oppression. One exceptional example is a study by Crooks (2007) that offers the notion of *altered geographies/ lifeworlds*. Based on a study of women with FMS, Crooks (2007) argues that the onset of pain and fatigue combined with the women's diminished financial means and

social network – due to the social barriers preventing them from continuing into paid work and/or engaging in social hobbies and recreation – results in *altered geographies/ lifeworlds*. Crooks (2007, p. 587) states: "It was not the women's changing bodies alone that altered their lifeworlds and daily geographies but also their changing locations in society and space." This research by Crooks (2007) is an excellent example of sociological research that looks at the interconnections between impairment effects (pain and fatigue) and disablism (barriers to paid employment and social isolation).

Returning to the research described before by Nettleton et al. (2005) and Nettleton (2006) that draws on the narratives of people with medically unexplained symptoms (MUS), it is also possible to see how narrative analysis can connect individual narratives to broader social structures and inform theory. As was discussed previously, Nettleton (2006, p. 1169) uses the term *embodied doubt* to describe current uncertainty regarding medicine, health, and our bodies; stating that *embodied doubt* is a "feature of contemporary life." Nettleton further argues that "the relatively marginalised and neglected set of people who live with MUS comprise an extreme example of the lives of the majority of people" (ibid). In this way the embodied experiences of people with MUS provide an extreme example of the uncertainty that is characteristic of contemporary society.

Similarly, drawing on qualitative interviews with 30 people (28 women and 2 men) diagnosed with systemic lupus erythematosus (SLE) Stockl (2007) argues that this diagnosis often results in feelings of ambivalence and *existential uncertainty*. To cope with *existential uncertainty* people with SLE may adopt strategies such as becoming "proto-professionals," resisting psychological explanations for their symptoms and demanding legitimacy for their experiences of illness. Stockl (2007, p. 1558), like Nettleton (2006), further argues that the *existential uncertainty* people with SLE experience might be "emblematic" of contemporary society and if this were to be "integrated into modern medical practice, a lot of the social pressure to be diagnosed with a clear-cut disorder might also be lessened."

The studies above by Crooks (2007), Nettleton (2006), and Stockl (2007) underscore the utility of examining the complex interaction between individual accounts/narratives of medically unexplained conditions and socio-cultural structures. Crooks' (2007) research

provides a more nuanced understanding of the complexity of living with ambiguous illness by looking at experiences of social exclusion and discrimination (disablism) *and* bodily symptoms of pain and fatigue (impairment effects). Similarly, instead of solely focusing on illness as disruptive to the self, Nettleton (2006) and Stockl (2007) highlight how embodied uncertainty/chaos/disruption is also broadly applicable and "emblematic" of the ambivalent postmodern context. This thesis draws on research in this vein and also attempts to avoid individualizing experiences of illness, by looking at disablism – including *psycho-emotional disablism* (Reeve, 2002; Thomas, 1999a) – and by situating the participants' accounts within the wider socio-cultural and political context. The literature discussed in the following section from the subfield of sociology known as the *sociology of diagnosis* also significantly informed this thesis, because this set of research is interested in how "diagnosis fits into the wider structures of society and how these wider structures implicate diagnostic categories, processes and consequences" (Jutel and Nettleton, 2011, p. 799).

Sociology of (Contested) Diagnosis

The sociology of diagnosis is a relatively new discipline, however, it could be argued that the centrality of diagnosis in the study of chronic illness has meant that it has long been an absent presence within medical sociology (Jutel and Nettleton, 2011). Put simply, diagnosis is both a category and a process (Blaxter, 1978; Jutel and Nettleton, 2011). As Nettleton et al. (2014, p. 135) argue, diagnosis is a noun as it acts as a label for a condition, but it is also a "verb that implies that the act of diagnosing is deeply embedded in our notions of medical work." Based on this understanding, the sociology of diagnosis treats "diagnosis as a kind of focal point where numerous interests, anxieties, values, knowledges, practices, and other factors merge and converge" (Jutel and Nettleton, 2011, p. 798).

Of particular importance to this thesis are those studies that focus on diagnosis in relation to contested illnesses. Previous research reveals that attaining a medical diagnosis is one way in which people suffering with invisible chronic symptoms hope to gain legitimacy (Asbring and Narvanen, 2004; Clarke and James, 2003; Cooper, 2002; Dumit, 2006; Lillrank, 2003; Rhodes et al., 2002; Skuladottir and Halldorsdottir, 2008; Zavestoski et al., 2004). Receiving a biomedical diagnosis, rather than a psychological one, is especially important to

many people suffering from invisible symptoms, because it proves that the illness has a "legitimate" organic cause and is therefore not psychosomatic (Asbring and Narvanen, 2002; Denny, 2009). In addition, it is only with a diagnostic label that people with invisible, medically unexplained symptoms might be granted access to the "sick role with all its associated rights and privileges" (Nettleton, 2006, p. 1170).

While a medical diagnosis is desired by patients, the process of getting a diagnosis is highly problematic for people with non-visible symptoms, and it can make doctor-patient interactions frustrating for both doctors and patients (Clarke and James, 2003; Cooper, 2002; Harsh et al., 2015; Rhodes et al., 2002). The desire for a diagnosis and the credibility it confers is argued to be why many people with chronic conditions endure countless tests, consult multiple health professionals, and engage in various strategies to influence control and power within the medical encounter (Asbring and Narvanen, 2004; Cooper, 2002; Denny, 2009; Sim and Madden, 2008; Werner and Malterud, 2003). The amount of resources expended in order to receive a diagnosis suggests that contested illnesses are "illnesses you have to fight to get" (Dumit, 2006, p. 578).

One of the main struggles in the diagnostic process is the value placed on "visible" medical results and findings. Overend's (2014) research (briefly discussed in the previous chapter) applies the concept of "haunting" to the case of Candida – an undefined illness – to explore how the "ghostly matters" of ambiguous illness symptoms unsettle positivist biomedical diagnostic procedures. According to Overend (2014, p. 70) uncertain and medically unexplained illnesses, like Candida, FMS, and CFS/ME, haunt modern biomedicine, because these illnesses are characterized by the absence of an objective, identifiable (i.e. visible) "sign of illness pathology." Ambiguous and unexplained illnesses are "ghostly" Overend (2014, p. 72) argues in that they do not have an "empirical trace" or an "ocular presence" and thus they "lurk, loom and haunt the diagnostic methods of biomedicine, and in doing so, also come to haunt those people all-too-familiar with its nebulous effects."

In a related article, based on 54 interviews with both men (20) and women (34) with chronic back pain, Rhodes and colleagues (2002) argue that visible results, such as those produced through X-ray, MRI, or CAT scans, are extremely important because this proves to

both doctors and patients that the pain is "real" rather than imagined. Testing is a double-edged sword, however, as patients who do not receive a visual confirmation of their pain through diagnostic tests "face a disjunction between their inner experience of the reality of a body that has become an ongoing negative and constraining influence in their lives and the 'normality' of their test results" (Rhodes et al., 2002, p. 39). This can result in feelings of alienation from individual physicians as well as the medical system in general.

Similarly, Cooper (2002) highlights the tension between the biomedical uncertainty surrounding illnesses, such as CFS/ME, and the cultural value placed on medicine to confer legitimacy. Drawing from ten life history interviews of people with CFS/ME, Cooper (2002, p. 187) states:

> Naming an illness with an authenticated biomedical disease label is the ticket for entry into the sick role. Thus the *name* becomes the symbol for this legitimation and exculpation. Respondents failed to receive a bona-fide disease label, and thus a full passage into the sick role. Consequently the majority were not allowed passage into a state of legitimate patienthood free from responsibility and blame for their illness state. Also more concretely, their social position was to some extent eroded, their social identity devalued and stigmatized, and they found it difficult to obtain legitimate absence from work or disability benefit (italics in original).

While receiving a medical diagnosis might be the "ticket" to legitimacy for people with CFS/ME, according to Cooper (2002, p. 180-187), the process of receiving the diagnosis is often rife with problems. Specifically, he argues that the interviews reveal how people with CFS/ME are not always seen as legitimately ill by doctors, and they face the risk of being labelled "malingerers," "school phobics," "depressed adolescents," and "bored housewives." This treatment by doctors places people with medically unexplained symptoms in a difficult position. Being labelled as "malingerers" and "lazy" is felt to be abusive and thus there is the clear desire to turn away from traditional medical professionals. At the same time, people rely on medical professions both for legitimation and treatment for their symptoms.

In a related study, Asbring and Narvanen (2004) examine the strategies women with FMS and CFS/ME employ during their interactions with health care providers (mainly doctors) in order to gain control and influence power within the medical context. According to the authors these strategies are aimed at gaining a diagnosis and/or specific treatments. The authors carried out semi-structured interviews with 25 women who have FMS (13) or CFS/ME (12) and

found that there are two general strategies employed by women during encounters with health care providers: gaining control through knowledge and gaining control through practicing patient power. These techniques to gain power in the medical encounter can be seen as individual acts of resistance, however, these strategies do not seriously question the authority of the medical profession, and can actually be counterproductive as they might jeopardize the women's chances of receiving a diagnosis and compassionate care.

The research discussed above focuses on diagnosis as process, but diagnosis also refers to the label a set of symptoms is given. Research from the sociology of diagnosis reveals that the inexact *process* of diagnosing certain conditions, means that these *labels* are also perceived to be imprecise. The perceived vague methods of diagnosing conditions, such as CFS/ME, FMS and GWS, means that these illness labels are often contested, augmenting uncertainty and doubt and increasing the likelihood of struggles between patients and health professionals. According to Zavestoski and colleagues (2004, p. 164), "[l]ay and professional worlds intersect even when diseases are not contested, but when a diagnosis is difficult to determine, the intersection is often highly charged with conflict."

In addition, research reveals that debates surrounding some diagnoses are further complicated by the involvement of multiple stakeholders outside of patients and health professionals (Barker, 2011; Brown et al., 2011; Dumit, 2006; Zavestoski et al., 2004). For example, Barker (2011) argues that disputes regarding the "reality" of the condition labelled as FMS have become even more complex since 2007 when the Food and Drug Administration (FDA) approved the drug "Lyrica" for the treatment of the condition. The approval of Lyrica, and then two other drugs, was seen by many patient advocates, including some clinicians and health researchers, to be an indication of the legitimacy of the condition. Barker suggests that the phenomenon of a pharmaceutical drug conferring authenticity to a medical condition should be understood as "pharmaceutical determinism" and it "represents an important new phase in the proliferation of contested illness diagnoses" (Barker, 2011, p. 834). While the "pharmaceutical determinism" of FMS might have some positive implications (including bestowing credibility to the diagnosis), it also has negative consequences. In particular, Barker (2011, p. 840) argues that the advertising of Lyrica constructs "an unrealistic public

expectation" and so when the majority of people (mostly women) with FMS are not "cured" after taking the drug it might be seen as confirmation "that their problem is all in their head, that they are hysterical, or that they do not want to get better." Rather than providing legitimacy and promoting greater public understanding, the introduction of drugs for contested conditions might actually increase uncertainty and contestation.

As we can see from the above discussion, literature from within the field of the sociology of diagnosis highlights the centrality of diagnosis; diagnosis is both a noun and a verb, it refers both to the categorization of illness and also the process of defining illness, and it "carries social, moral, economic, political as well as prognostic consequences" (Nettleton et al., 2014, p. 135). This body of literature also illuminates the differences between uncontested and contested diagnoses. Jutel (2011, p. 5) explains that unlike a contested diagnosis, an uncontested diagnosis has the "power to confirm status and allocate resources." A contested diagnosis does not automatically grant one acceptance into the sick role and the exemption from some societal responsibilities. In addition, having a contested diagnosis poses problems for people trying to access disability benefits and other forms of support and accommodations (de Wolfe, 2012; Fox and Kim, 2004; Lightman et al., 2009). Despite this, research highlights that people with medically unexplained symptoms are willing to struggle for a diagnosis, even if it is a contested one (Dumit, 2006), because "stigmatized diagnoses" are often preferred to having no label at all (Zavestoski et al., 2004, p. 170).

Stigma, Passing, and Disclosure

While a contested diagnosis might be preferential to the alternative of having no label, the literature discussed in this next section shows how the invisibility of symptoms and the stigma attached to certain diagnoses poses issues for people in their day-to-day social interactions. Goffman (1959, p. 1) describes the body as a "sign vehicle" that is "read" by others and coveys social information. He explains that our bodies, both intentionally and unintentionally, tell people many things about ourselves and that as soon as an "individual enters the presence of others, they commonly seek to acquire information about him" (Goffman, 1959, p. 1). For people with non-visible illnesses, such as FMS, their bodies unintentionally convey to others that they are healthy/non-disabled.

Although it might be assumed that stigma and discrimination are more likely to follow from visible impairments, this is not always the case. In fact, French (1994, pp. 24-25) argues that many researchers have found that people with less obvious impairments or invisible impairments experience "more social difficulties" than those with more obvious, or visible, impairments. Richardson (2005, pp. 35-36) explains that the subjective quality of symptoms, such as chronic pain, can "lead to doubts regarding its very existence" and consequently can result in allegations of "malingering" and "bludging." Not only are invisible chronic illnesses difficult for lay people to understand, but they are also often not easily comprehended by physicians and other health care specialists. To have one's experiences of illness questioned by friends, family members, co-workers, acquaintances and even some medical professionals can have profound negative emotional and psychological effects (Asbring and Narvanen, 2002; Kelley and Clifford, 1997; Nettleton, 2006; Wendell, 1996).

Research specifically addressing the challenge of deciding whether or not to reveal invisible illness to others often draws (explicitly or implicitly) from the theoretical work of Goffman (1963) and his conceptualization of *stigma* and *passing* (see previous chapter). For example, employing Goffman's analytic framework, Asbring and Narvanen (2002) examine the social dilemma of passing and the consequences of stigma in relation to the experiences of women diagnosed with FMS or CFS. The authors argue that FMS and CFS are stigmatizing conditions because they are "shrouded in great uncertainty" and they are among a group of "low status" conditions that primarily affect women (Asbring and Narvanen, 2002, p. 149). The women in their study employ several different strategies for dealing with this stigma, including "passing as healthy" by "avoiding people who had reacted negatively to them and their illness" and concealing their illness from others by "maintaining a façade and giving a self-presentation according to others' expectations" (Asbring and Narvanen, 2002, p. 155-156). In contrast, some of the women in the study discuss the importance of informing others to minimize stigma and promote awareness of FMS and CFS.

In a similar study, Armentor (2015) draws on in-depth qualitative interviews with 20 women with FMS to examine how the women manage stigma in their relationships. The findings from this research echo some of the findings from the study by Asbring and Narvanen

(2002); both studies highlight how stigmatization is related to the invisibility of symptoms and to the FMS diagnosis. Armentor's (2015, p. 10) study found that because many medical professionals do not recognize FMS as a "real illness" this diagnosis compounded the stigma attached to the invisibility of their symptoms, and "further reinforced others' scepticism of the women." In addition, both studies found that avoidance was one of the main strategies the participants' used to evade stigma (Armentor, 2015, p. 8). In Armentor's (2015) study the strategy of avoidance was found to be used primarily when the women believed that due to a particularly acute "flare-up" of their symptoms they would not have been able to "pass."

In another related study, Lonardi (2007) argues that the dilemma regarding whether or not to pass emerged as a common theme within the narratives of 31 men and women who experience chronic headaches. Lonardi examines the respondents' negotiation of the risks and benefits of passing as healthy and the specific strategies they employ to "manage" social perceptions. According to Lonardi it is the invisibility of chronic headaches that makes passing a viable strategy to avoid stigma. Passing also prevents others from knowing about the disease and offering support, however, and there is the constant risk of "failing" to pass "that would expose the person to discredited moral judgment" (Lonardi, 2007, p. 1629). Lonardi (2007, p. 1627) presents the possibility that the invisibility of certain chronic illnesses may mean that "a satisfying social representation of the disease has no chance of being produced" thus "making biographic disruption all the more heavy because of mechanisms of discredit."

Wall (2005, p. 12) provides a first-hand account of living with an "invisible illness," and describes the tensions between the possible benefits and harms of passing:

> Invisibility is luxury as well as burden. As long as I could carry on I could meet the world as teacher, mother, neighbour, not "that person who is ill," the label that can supplant all else. "Passing" as a well person can be an act of self-preservation, allowing dignity, control, and a chance to maintain a pre-illness identity, often vital to one's sense of self. It also increases the invisibility of this illness. And, depending on how ill you are, it can be folly, exacting a cruel price.

The benefits of passing described by Wall are similar to those discussed above, such as, gaining control over how one is perceived by others, maintaining a "pre-illness" identity, and preventing stigma. Conversely, hiding chronic illness precludes social support and can demand a "cruel price" (i.e. exacerbate ill health). Wall, like Lonardi (above), also illuminates a further, more

far-reaching, negative consequence of passing and that is how the individual act of passing contributes to scepticism regarding the very existence of invisible and contested illnesses.

Beyond Stigma?

The concepts of stigma and passing have proved useful for expanding our understanding of the intersubjective experiences of people with chronic and contested illnesses, however, this type of research has been subject to critiques (Saunders, 2014). As was discussed above, disability studies scholars have argued that research focusing on stigma starts from the problematic assumption that disabled and chronically ill people are "deviants," making this type of research inherently flawed (Thomas, 2007). According to Thomas (2007, p. 173), the majority of sociological research in this area adopts a "social deviance" or "personal tragedy" perspective and thus "chronic illness and disability continue to be characterised as socially stigmatised states of being that require individual management in the interactional order." Other researchers from disability studies have found these ideas useful, however, and have expanded on work in this area by looking at "coming out" (or not) as disabled (Davidson and Henderson, 2010; McRuer, 2006; Sherry, 2004; Swain and Cameron, 1999). Sherry (2004, p. 773) argues that although far more analysis has been done on the concept of the closet and "coming out" in queer literature, disability studies has focused a considerable amount of attention on the "visible/invisible dichotomy" and how people with non-visible impairments deal with issues of disclosure and passing. For example, Davidson and Henderson (2010, p. 155) argue that due to the lack of visible signs, people on the Autism Spectrum (AS) engage in "selective strategies of information and identity management," and describe the process of "coming out on the spectrum as analogous to the process of coming out for other marginalized groups."

Debates regarding the relevance of stigma for the study of chronic illness and disability have also come from within medical sociology. For example, Green (2009) has proposed that the notion of stigma is now outdated, while others argue that Goffman's theories still have utility, but need to be reformulated (Scambler, 2009). According to Scambler (2009, p. 453) research and theory drawing on Goffman's formulation of stigma should not be completely discarded, rather it needs to be "re-framed and deepened sociologically." He argues that this means understanding that "[s]tigma and deviance can be inscribed on persons as well as

embodied; but they are also – and this is where lessons can be learned from disability theorists and activists promoting an oppression paradigm – 'structured' social relations" (G. Scambler, 2009, p. 453). Currently, debates regarding the relevance of stigma as a concept are still playing out, as is evidenced by a recent article by Saunders (2014) in which he challenges arguments questioning the significance of the concept of stigma, arguing that his study of young adults' accounts of inflammatory bowel disease clearly demonstrates that stigma is central to the experiences of people with chronic illnesses, particularly non-visible conditions.

As was discussed, through the accounts of people with FMS this thesis examines when, where, how, why, and to whom the participants reveal/conceal illness and how this relates (in part) to FMS being a "stigmatized illness" (Armentor, 2015; Asbring and Narvanen, 2002). Drawing on work from disability studies, however, this thesis also attempts to move away from simply understanding passing in relation to stigma. In particular, it examines how passing as healthy and able-bodied, could also be rooted in *internalized ableism* (Campbell, 2008, p. 151). Put another way, this thesis examines how living in a world that "always and everywhere privileges very narrow (and ever-narrowing) conceptions of ability" (McRuer, 2006, p. 151) might induce chronically ill and disabled people to pass. It also explores the *psycho-emotional* dimensions of living in an ableist society, and how negative attitudes, ideas, and stereotypes about impairment and disability shape how chronically ill and disabled people feel about themselves (Thomas, 1999a, p. 46), potentially impacting their decisions to tell others about non-visible illness and/or to identify as disabled (Reeve, 2002).

Gender and (Contested) Chronic Illness

Until this point there has been little discussion of gender (or other aspects of identity) in relation to contested chronic illness. Studies on chronic illness have been critiqued for focusing on the similarities and failing to acknowledge the differences amongst chronically ill people in terms of age, gender, class, ethnicity, and sexuality and how all of these aspects of social location and identity interact with experiences of chronic illness and disability (Thomas, 2007, p. 169). Critiquing narrative research on chronic illness in particular, Woods (2011, p. 74) cautions that when employing illness narratives researchers must be mindful of intersectionality

and cultural context as "[t]oo often particular kinds of narrative are presented as transcultural, transhistorical truths of the human experience."

Similar to other critiques discussed above, the criticism that much literature on chronic illness fails to address intersectionality does by no means apply to all research on this topic. The following section addresses literature that examines the intersection of gender, chronic illness, and disability. It should be noted that there are other important elements of one's identity and social location that also intersect with chronic illness and disability in important ways, such as age, class, ethnicity, sexuality, nationality and the presence of other visible or non-visible impairments. The following section, however, specifically addresses literature on the gendered experience of chronic illness and disability, because of its direct relevance to the thesis.

As was previously mentioned, the general consensus within literature on chronic illness is that women are far more likely than men to suffer from all forms of chronic illness, including pain and fatigue syndromes (Barker, 2005; Bird and Rieker, 1999; Gallagher et al., 2004; Katz et al., 2008; Shaver et al., 2006). Consequently, while women can generally expect to live longer than men, they are also likely to spend more years of their lives with chronic illness or other impairments (Allsop, 1995; Bury, 2005; Morris, 1994; Sheldon, 2004). It has been argued that within Western cultures illness and disability are "gendered feminine" (Garland-Thomson, 2002, p. 10), and contested chronic illnesses, such as FMS, are particularly likely to be perceived as "feminine" (Asbring and Narvanen, 2002; Barker, 2005).

In addition, these "feminine" conditions have been described as new forms of "hysteria" (Katz et al., 2008; Showalter, 1998), and the assumption that women with these conditions are "neurotic" or "hysterical" is reflected in empirical studies. For example, Werner et al. (2004, p. 1035) argue that women with medically unexplained chronic muscular pain (some with the diagnosis of FMS) organize their narrative accounts of illness in line with normative biomedical conceptions of illness and in accordance with strict gender norms. The authors state that the women's narratives can be read as gendered stories of illness where the women attempt to present themselves as both credible women and legitimately ill, and that behind the women's narratives there are "whispered rejections of the stereotype medical account or cultural

perceptions of the crazy, lazy, illness-fixed or weak woman patient" (Werner et al., 2004, p. 1043).

In related articles, Grape et al. (2015), Skuladottir and Halldorsdottir (2008), and Werner and Malterud (2003) argue that women with medically unexplained symptoms (many with FMS) describe the "hard work" they do both to cope with the physical symptoms, and to be taken seriously during doctor-patient interactions. Werner and Malterud (2003, p. 1412) state that by engaging in "various strategies such as appropriate assertiveness, surrendering, and appearance, [the women in their study] attempted to fit in with normative, biomedical expectations of what was 'just right.'" The authors describe the women's "struggles" and "hard work to make the symptoms socially visible, real and physical when consulting a doctor" (Werner and Malterud, 2003, p. 1409). Despite this "hard work," the women felt that healthcare professionals "did not meet them with comprehension, respect, or acceptance" (Werner and Malterud, 2003, p. 1412). Similarly, Skuladottir and Halldorsdottir (2008, p. 891) found that many of the women in their study were "demoralized" during their interactions with health professionals, arguing that health professionals need to be aware that they are "powerful people in the lives of women with chronic pain."

Gender is not only an important factor in relation to medically unexplained and contested chronic illness, however, as Thomas (2001) argues that her research on disabled women's experiences of their interactions with doctors confirms that doctor-patient interactions are gendered encounters where women have to contend with disabling and sexist stereotypes. In particular, many women in the study "encountered hostility that manifested itself in classic gendered forms" and some of the women "found themselves characterized by male doctors as 'hysterical' or neurotic" (Thomas, 2001, p. 256).

The examples above are part of a larger body of work on women's experiences of the intersection of chronic illness and disability with sexist stereotypes. Space will not allow for a detailed discussion of this expansive set of literature; suffice it to say that this topic has received considerable attention, and in the past far less research has been devoted to understanding men's experiences (Bury, 2005; Thomas, 2006). Even currently, research on men's experiences of contested chronic illnesses is particularly lacking (Paulson et al., 2002). A search of social

science literature for research on men's experiences of medically unexplained conditions resulted in one article by Paulson, Danielson and Soderberg (2002). The researchers interviewed men with "fibromyalgia type pain," and argue that "the meaning of men's lived experience of chronic pain was experienced as a change in the body, self, and relationships" (Paulson et al., 2002, p. 238). In conclusion, Paulson and colleagues (2002, p. 247) state that "no studies to date have described the meaning of men's experiences of living with pain of FMS type from an insider's viewpoint," and thus research on this topic is needed in order to "illustrate the insidiousness and the limitations of contemporary masculinity."

Although research focusing specifically on men's experiences of contested chronic illness is sparse, there is an expanding body of literature on men's experiences of other medical conditions and impairments, including, arthritis (Gibbs, 2005), prostate cancer (Chample and Ziebland, 2002; Oliffe, 2009), depression (Johnson et al., 2012), diabetes (Broom and Lenagh-Maguire, 2010), and cardiovascular disease (Robertson et al., 2010). According to Kvigne et al. (2014, p. 197) this previous sociological research highlights how "chronic illness may threaten a man's taken-for-granted masculinity."

Similarly, research from disability studies has explored the complex intersection of masculinity, illness and disability. In contrast to chronically ill and disabled women who are likely to be perceived as fulfilling cultural expectations of femininity in terms of passivity and dependency, it has been argued that chronically ill and disabled men are socially constructed as emasculated, "impotent," "incomplete," and "vulnerable" (Morris, 1991, p. 96). The experience of oppressive masculine stereotypes in relation to disability and chronic illness are themes discussed in Tepper's (1999, p. 37) article based on his "personal story and professional perspectives." (p. 37). Tepper describes having Chron's disease since he was 12 and having to wear a colostomy bag from the age of 17; interestingly however, he states that he was not "disabled" until he broke his neck when he was 20. Tepper (1999, p. 45) concludes by arguing that dominant cultural myths regarding masculinity, impairment, and male sexuality must be deconstructed as they are oppressive and result in the equating of chronic illness and physical impairment with a loss of power, independence, success (specifically in terms of paid work), sexual prowess, and ultimately a loss of manhood.

In a similar article, Ostrander (2008) investigates the impact of spinal cord injury on the identities of eleven men. Drawing from qualitative interviews, Ostrander (2008, p. 595) concludes that all of the men "vigorously noted how the injury affected their masculinity." In line with Tepper's (1999) conclusions above, Ostrander (2008, p. 595) states that the men felt the spinal cord injury and "resulting disability violated social understandings of what it means to be a man in their environment."

Both of the above articles reflect that oppressive stereotypes associated with disabled people (e.g. dependency, weakness, vulnerability) are at odds with social and cultural constructions of ideal masculinity (e.g. independence, strength, virility). While this research provides important understanding regarding disabled men's experiences, there is still a gap in the research in relation to the experiences of men who are diagnosed with contested illnesses. It is hoped that this thesis will begin to fill this gap, by drawing on accounts from both women and men diagnosed with FMS.

A Postmodern Feminist Approach

This thesis, based on in-depth interviews with 31 people (25 women and 6 men) with FMS in Canada and the UK, draws from and thus shares many similarities with the approaches discussed above, which also utilize qualitative data (i.e. "narratives," "stories" or "accounts"). As was previously noted, research drawing on chronically ill people's stories has been charged with focusing on the body in pain, "romanticizing" individual suffering, and feeding into a "personal tragedy" understanding of illness and disability (Atkinson, 1997; Atkinson, 2009; Morris, 1992; Thomas, 2010). This thesis is rooted in a feminist perspective and there was an expectation from the outset that in the stories told by the respondents there would be accounts of disadvantage, exclusion, and "profound disempowerment" (Thomas, 2010, p. 657). In contrast to the usual theoretical approaches on this topic, however, which tend to be embedded in a "social deviance" paradigm, this thesis examines "experiential concerns" under the "social oppression paradigm" (Thomas, 2007, p. 176). It connects the personal with the political; attending to both the embodied experiences of illness and the social structures that shape, and are shaped by, these experiences. In line with this approach, there has been a conscious attempt to avoid focusing solely on the body in pain, and "romanticizing" or "sentimentalizing" the

interview participants' accounts. In addition, by including women and men in two different countries, this thesis attempts to avoid universalizing experiences of dis/ability and health/illness by paying attention to important similarities and differences in social location, particularly in relation to gender and national context.

Furthermore, unlike the majority of the research and literature outlined above, this thesis draws from both sociology and disability studies, and employs a postmodern framework (see previous chapters and below). While medical sociology has been charged with individualizing illness and disability, scholarship from disability studies has been critiqued for its lack of engagement with the embodied aspects of illness and disability (Crow, 1996; de Wolfe, 2002; Hughes and Paterson, 1997; Scambler, 2012; Shakespeare and Watson, 2002; Thomas, 1999a; Wendell, 1996; Wendell, 2001). As was discussed previously, chronic illnesses in particular have largely been ignored by researchers in disability studies (de Wolfe, 2002; Scambler, 2012; Wendell, 1996; Wendell, 2001). These critiques posit that disability studies scholars and activists are "reluctant to acknowledge the resistance of certain bodily problems to purely social solutions," and when they do acknowledge these problems they often "regard them as falling outside of their domain" (de Wolfe, 2002, p. 257).

Given the pitfalls of both perspectives, this thesis turns to Thomas' extensive body of work that convincingly argues in favour of connecting medical sociology and disability studies so that both *impairment effects* (the body) and *disablism* (the social) are addressed (Thomas, 1999a; Thomas, 2003; Thomas, 2004b; Thomas, 2012). This thesis is influenced by the sociological traditions discussed above that focus on impairment effects to highlight the pain and suffering that are often part of the embodied experience of illness. These insights underscore the significance of the materiality of the body, and warn against the body becoming an absent presence in research on chronic illness and disability (Shilling, 2003).

Whereas most previous research and theorizing on chronic illness does not "trouble the meaning of 'illness' and its required binary opposite 'healthy'" (Goodley, 2011, p. 55), however, this thesis specifically sets out to problematize dichotomous thinking that results in the in/visibility and de/valuing of certain forms of embodiment. Shildrick (1997, p. 9) argues that "a postmodernist approach uncovers both the *multiple* differences and distinctions that

mediate interactions, and paradoxically the way in which all boundaries are permeable and ultimately indistinct" (italics in original). Unsettling cultural binaries is not simple or straightforward, as Shildrick (2009, p. 52) admits, however it does underscore that what are often understood to be "pure" categories, such as normal/abnormal, non-disabled/disabled, healthy/ill are actually "never fixed nor stable" and that they "constantly contaminate one another." By drawing on accounts from people with FMS, a contested condition that is predictably unpredictable, and insistently un/certain, un/stable and in/visible, this thesis hopes to explore how *embodied liminality* disrupts dichotomous thinking and the harmful illusion of the predictable, invulnerable, and perfect(able) body.

Drawing on postmodern and feminist theories, alongside the participants' accounts, this thesis also explores possible resistance to unrealistic *neoliberal-able* (Goodley, 2014) norms and values that pressure all of us to be more able, more productive, more in-control, and increasingly more responsible for our own health (Galvin, 2002, Shildrick, 2015). These cultural standards impact all of us, but are especially oppressive in the lives of people who live with chronic pain, fatigue, and other impairments. The research on contested illness to date highlights the disruptiveness of these conditions in relation to the body, self, and identity. What is largely missing, and this thesis hopes to contribute to, is research that looks at how this disruptiveness might also be positive. As Goodley (2013, p. 636) explains "the non-normative body" or a "body that sticks out – that challenges conventions and standards – permits a moment of disruption and a chance to ask; what counts as a valued body?" The concept of *embodying liminality* is offered as a notion for understanding the often difficult and painful experience of ambiguous and disruptive embodiment, but also the subversive and liberating possibilities of liminality for unsettling taken-for-granted assumptions regarding the stability of dichotomous medical and socio-cultural categories of embodiment.

Chapter 4 – Methodology

The Method: In-depth, Qualitative Interviews

Following a review of relevant previous research and theory, a research design was developed that would allow for a comprehensive examination of the embodied and social experiences of people diagnosed with FMS. Given the research goals and the postmodern feminist approach adopted in this thesis (see previous chapters), in-depth qualitative interviewing was chosen as the method for obtaining data, as it would allow for important connections to be made between the respondents' personal accounts of health/illness and dis/ability, and dominant socio-cultural structures that shape these accounts. In addition, through in-depth, semi-structured qualitative interviews with women and men diagnosed with this condition in Canada and the UK this project contributes to the tradition of doing qualitative research as a way to emphasize disabled and chronically ill people's own accounts of their lives.

Qualitative Interviewing and Postmodern Theory: Opportunities and Challenges

Before discussing the research design in more detail, it is useful to further consider why qualitative interviewing was chosen as the best method for this particular project. When choosing a method, it is crucial that researchers understand their own ontological and epistemological assumptions regarding the world. According to King and Horrocks (2010, p. 23), "qualitative interviewing, requires a great deal of effort, with researchers having to explore how they conceive of the world." The approach adopted in this project starts from the assumption that "our understandings and experiences are relative to our specific cultural and social frames of reference, being open to a range of interpretations" (King and Horrocks, 2010, p. 9). This might be described as a postmodern and "relativist" position, and in contrast, a modernist "realist" perspective is one that assumes that the "real world is out there and exists independently from us" (ibid).

As was discussed previously, postmodern perspectives are anti-foundationalist and critical of Enlightenment assumptions regarding "truth" and "reality" (Corker and Shakespeare, 2002, p. 4). One of the main goals of a postmodern perspective is the deconstruction of problematic "grand narratives," and "either/or formulations that are replete in scientific and

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other culturally dominant discourses: individual/society, society/nature, mind/body, normal/abnormal, diseased/healthy" (Thomas, 2007, p. 65). Postmodernism is sceptical of "meta-narratives," and highlights the importance of acknowledging the multiplicity of perspectives (Fox, 2016, p. 65).

This thesis emphasizes the validity of multiple viewpoints, but also acknowledges the partiality and "situatedness" of *all* knowledge and remains critical of the positivist assumption that there is a "reality out there" waiting to be discovered. This does create some tensions and challenges for researchers, because a postmodern approach does not permit an unproblematic, straightforward, and "clean" interpretation of the respondents' accounts. As Clarke (2005, p. xxviii) explains:

> The methodological implications of the postmodern primarily require taking situatedness, variations, differences of all kinds, and positionality/relationality very seriously in all their complexities, multiplicities, instabilities, and contradictions. The postmodern has too often been greeted with disdain by some/many sociologists and other social scientists precisely because of the deep, and at least century-long commitments of the discipline to the erasure of context/situatedness, variation, and complexity through the bulk of empirical research (both quantitative *and* qualitative) (italics in original).

In addition, this approach requires researchers to be reflexive about their role in producing the research (the importance of reflexivity is discussed further below). Fully taking on board postmodernism is often challenging then, because it involves being reflexive and avoiding the impetus to oversimply. Again turning to Clarke (2005, p. 15), she explains that this often means "doing even more analysis," because as researchers we must "address head-on the inconsistencies, irregularities, and downright messiness of the empirical world – not scrub it clean and dress it up for the special occasion of a presentation or a publication." The "pay off" of this extra work, however, is a much more rich and nuanced analysis. It is also politically and ethically significant, because as Clarke (2005, p. 21) argues, acknowledging the "messiness" and "heterogeneity of perspectives remains a radical act" within a social context where modernist binary thinking dominates.

In addition, it is clear that a postmodern framework is well suited to this particular topic. As was discussed in the previous chapters, medically unexplained, contested conditions are described as uncertain, ambiguous, and undefined, and these are the same ideas emphasized

by postmodern researchers and theorists (Price and Shildrick, 2002). FMS is a particularly ambiguous and heterogeneous illness as not everyone diagnosed with this condition experiences the same set of symptoms, and although all people who are diagnosed with FMS have chronic pain, this varies considerably in terms of the location of the pain and the intensity, and even for the same person the pain may change over time, or even within the same day (Barker, 2005). In addition, there is no known "cause" of FMS, and while many consider it a life-long chronic condition, others argue that it is possible to be "cured" (Grape et al., 2015).

Qualitative interviewing as a method to explore the possibilities and challenges posed by a body "in-flux" as well as the issues tied to having a contested diagnosis permits a "deep level of knowledge and understanding" of a complex, multi-dimensional topic (Johnson, 2002, p. 106). The research questions and goals of this project could not be adequately understood through quantitative survey based methods. It is necessary to actually speak with people who have been diagnosed with FMS in order to gain a more thorough understanding of this multifaceted topic. As Kvigne et al. (2014, p. 200) explain, interviews "provide an 'inside perspective' or describe experiences through the eyes of the experienced, and they bring with them the richness of personal and social history." In addition, interviews offer access to personal experiences which shed light on socio-cultural structures, because as Thomas (1999, p. 75) argues "experiential accounts can act as windows on the social."

Furthermore, the fluidity, flexibility, and openness of this method aligns well with a postmodern theoretical approach; semi-structured, in-depth qualitative interviews allow the respondents to share their experiences in their own words, rather than having to choose a response based on pre-determined, closed categories. The fluid, flexible, and open nature of qualitative interviewing permitted rich insights into the embodied and social experiences attached to living with a non-visible, physically debilitating, and socially contested condition that does not "fit" with cultural understandings of health/illness and dis/ability.

Feminist Research: Connecting the Personal and the Political

In addition, the idea that research should begin from the perspective of the research respondents draws from feminist theory and research methods (Hartsock, 1998; Oakley, 1981; Reinharz, 1992). According to Thomas (1999a, p. 68) feminist research is significant for

"bringing in the personal.," and "starting out from personal experience challenges conventional distinctions between the 'private' and the 'public/social'" thus disturbing "malestream epistemes" (Thomas, 1999, p. 80). Similarly, Letherby (2003, p. 44) explains that at the core of a feminist epistemology is the belief that "experience should be the starting point for any knowledge production" and the insistence on the importance of examining and theorizing from the perspectives of the socially disadvantaged. Thus, a feminist perspective advocates connecting the personal with the political, and this approach to research and theory aims to improve the lives of socially disadvantaged groups (particularly women) by making connections between individual experiences and larger social structures that oppress and marginalize certain groups of people.

My mother was diagnosed with FMS over twenty years ago. It is important to acknowledge my personal connection to the research project. While I have this personal attachment to the project, it is also important that I make it known that I am not chronically ill/disabled. When non-disabled researchers do research on disability it is extremely important according to Morris (1992) not to reproduce oppressive perspectives of disability, and in part, this can be avoided by not simply focusing on the physical aspects of disability, and instead highlighting experiences of disablism (i.e. oppression, exclusion, prejudice). As was previously discussed, this research project was designed with this in mind, and seeks to do more than simply acknowledge the physical suffering caused by chronic illness. By drawing on the experiences of women and men with FMS to examine the embodied and social experiences of people with the condition, as well as the discourses and structures at play that marginalize, oppress, and exclude, this project hopes to make the participants' largely invisible/marginalized experiences visible/acknowledged, and to open up a space for awareness and social change.

This awareness includes not only an acknowledgment of the physical suffering caused by chronic illness, but also the social issues related to living with a contested condition. This is ethically and politically significant, because it was clear in the interviews that the participants wanted their experiences of illness to be recognized, not simply because they desired people to understand their hidden struggles, but also to make the condition visible within academic research and in other public spaces. Furthermore, by drawing solely upon on the accounts of

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people with FMS this research recognizes the participants as experts of their own experiences, and it promotes social change by turning "disadvantaged social positions into powerful intellectual and political resources" (Harding and Norberg, 2005, p. 2012).

Interview Research as Intersubjective: Issues of Power and Reflexivity

In addition, drawing from feminist and postmodern approaches to interview research, the method of in-depth qualitative interviewing attempts to be non-hierarchal and non-exploitive, and allows the participants the opportunity to discuss their often marginalized experiences with an understanding researcher. While a completely egalitarian relationship between the researcher and the participants is the ideal, in reality it is impossible to completely eliminate the power relations inherent in the "interviewer – interviewee" relationship (Harding and Norberg, 2005; Oakley, 1981). As Letherby (2003, p. 125) explains it is important for researchers to appreciate that we often occupy a "privileged position" compared to research participants due to our ties with the respected academic world.

During the interviews it was clear that the respondents often understood me to be "the expert," despite attempts to acknowledge their expertise, and it was obvious in many instances that I did occupy a relatively privileged position compared to many of the participants. Instead of attempting the impossible task of trying to completely ameliorate the power differentials at play in the interview, the focus was on being ethically accountable to the research participants and employing the "distinctive powers" of a researcher to "advance social justice" (Harding and Norberg, 2005, p. 2012).

Furthermore, feminist research, like postmodern approaches more generally (see above), acknowledges that "all knowledge is *situated*, that knowledge is a social product bearing the marks of time, place and social positionings" (italics in original, Thomas, 1999, p. 68). Due to the intersubjective quality of interview research the participants were active subjects in the interview process and integral in the mutual construction of knowledge. According to Lupton (1998, p. 90):

> The data derived from empirical research such as one-to-one interviews are treated as simultaneously a means by which the participants articulate and convey some of their understandings and experiences in relation to the issues in question, but also as themselves a social product, produced together by the interviewer and the interviewee in a particular context.

The understanding that the interview is an intersubjective experience necessitates a discussion of reflexivity in the interview process. As was mentioned above, reflexivity takes into account the position of the researcher as an actor in the production of the interview data. According to Doucet and Mauthner (2002, p. 125) "reflexivity holds together methodology, epistemology and ethics." The ethical significance of reflexivity relates to issues of "honesty, transparency, and overall accountability in research."

Given that this thesis draws on in-depth interviews, wherein both the interviewer and the respondents are engaged in a mutual construction of knowledge, it is crucial to highlight that the researcher is a co-producer of the knowledge that is created during the interviews (Kohler Riessman, 1993). According to Gubrium and Holstein (2012, p. 32):

> Treating interviewing as a social encounter in which knowledge is actively formed and shaped implies that the interview is not so much a neutral conduit or source of distortion as an occasion for constructing accounts.

In this thesis, the data from the interviews are mainly described as "accounts," as this acknowledges the process of creating mutual knowledge during the unique social interaction of the interview. This also acknowledges that by producing a text (the thesis) based on these accounts, the researcher is implicated in the "constructive effects of discourse" (Phillips and Hardy, 2002, p. 2).

Sampling and Recruitment

Following approval from the ethical review board at the University of Leeds, recruitment of adults with a diagnosis of FMS in the UK and Canada began in August 2010 and finished in March 2011. Interviewees were invited to participate through individual conversations, referrals from other interviewees (snowball sampling), and through contacts made through "advertisements" circulated among FMS support groups and placed on public notice boards (see appendix II). The "advertisement" to recruit potential participants was written in clear and accessible language, allowing the participants to gain a sense of what their participation in the research would entail. These advertisements contained my contact information so that the participants could reach me with any questions regarding the study.

After the process of informed consent (see section below), the participants were given the opportunity to set up a time and place for an interview. As the participants were mainly invited to participate either by people they know and trust (including friends, family members, and support group members) or through the use of "advertisements" there was little risk of coercion. The main risk involved with snowball sampling is the possibility that some of the participants might know each other, however, all of the participants' identities have been protected and no potentially identifying information is included in the thesis. In addition, pseudonyms are used throughout the thesis, and all illustrative examples are presented in such a way that no identifying feature of the individuals are included.

Description of Participants[3]

Ultimately, 31 individuals (25 women and 6 men) in Canada and the UK were recruited to participate in the study. The greater proportion of women included in the sample reflects statistics on the prevalence of the condition in the general population (Barker, 2005; Fitzcharles et al., 2013; Gallagher et al., 2004; Keddy, 2007; Shaver et al., 2006). As was previously discussed, the inclusion of both women and men sets this thesis apart as most previous research on FMS, and similar conditions, has focused on women only. Including both women and men allowed for an investigation into how dominant gender norms and stereotypes interact with the national context, and embodied and social aspects of health/illness and dis/ability.

To explore differences and similarities in the experiences of people with the condition in different national contexts, the sample included 17 people (14 women and 3 men) from the UK and 14 people (11 women and 3 men) from Canada. The majority of the UK respondents were living in Northern England at the time of the interview, and the majority of Canadian respondents were living in Southern Alberta at the time of the interview. Although it would have been ideal to interview people with FMS throughout the UK and Canada, this was not feasible given the limited resources available and the short time frame. Despite the relatively focused geographical sampling, there were many common themes across all of the interviews,

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[3] Please refer to appendix I for detailed demographic information.

thus it is very plausible that other women and men with FMS in different parts of the UK and Canada would have similar experiences to those of the respondents in this study.

At the time of the interviews, the respondents ranged in age from 21 to 69, with a mean age of 43. While the sample includes people from a variety of racial and ethnic backgrounds, the large majority are White British and White Canadian. This is not surprising, however, as other research has found that FMS tends to be diagnosed in white people much more often than any other ethnic or racial group (see for example, Barker, 2005, p. 167-168).

The majority (20) of the participants were in partnerships at the time of the interview. Eighteen of the participants were married or in common-law partnerships and two of the participants were in relationships, but were not living in the same household. Eleven of the participants were single when interviewed. Five of the respondents had been divorced, and were now either single or in another partnership. Including women and men in partnerships, as well as single and divorced women and men, was important as it allowed for an examination of social support, and issues around experiences of in/visibility with regard to personal relationships. In addition, just over half (17) of the participants have children, while the remaining fourteen had no children at the time of the interview. Including some women and men who were parents was important as well, because it permitted insight into issues around parenting with an in/visible chronic illness.

The participants' educational backgrounds ranged from partial completion of secondary school to post-graduate degrees. Just less than half (14) of the participants were working in paid employment when interviewed, and as is discussed in chapter seven, many of these participants voiced concerns about being unable to work in the future due to their health. Of the fourteen participants who were working, five were living in the UK and their jobs included University lecturer, academic assistant, teacher, manager and banker. The nine Canadian participants who were working when interviewed were also employed in a variety of jobs that included, homecare nurse, newspaper delivery, accountant, realtor, newspaper editor, College instructor/education assistant, church minister and receptionist. In addition, two of the participants from the UK and one from Canada were in University or College at the time of the interviews. Having participants from a range of socio-economic backgrounds and different

working situations allowed for interesting examinations into issues around in/visibility in the work setting and in relation to disability-related entitlements and workplace accommodations.

Interviewing 31 people in two countries allowed for clear data "saturation," meaning that enough interviews were conducted so that I felt that no new information would be obtained by doing any further interviews (Johnson and Rowlands, 2012, p. 108). In addition, it was not feasible to conduct additional interviews, as transcribing and analysing in-depth qualitative interviews requires a high level of attention to detail and is extremely time-consuming. All of this had to be taken into account when recruiting for this project. As Kohler Riessman (1993, p. 69) explains: "The methods are slow and painstaking. They require attention to subtlety: nuances of speech, organization of response, local contexts of production, social discourses that shape what is said, and what cannot be spoken."

Ethical Considerations: Informed Consent and Confidentiality

All participants were given full informed consent before agreeing to participate in the research project. Participants were briefly informed of the research requirements at the time of first contact. At this time, voluntarism was discussed, and potential interviewees were invited to commit to participate. Before each interview, a printed copy of the consent letter and signature form, written in clear and accessible language, was provided for the participants to read (see appendices iii and iv). Those participants who were interviewed over the phone were emailed a copy of the consent letter and form that was signed and sent back via email, or if this was not possible, they gave verbal consent over the phone prior to the interview. All of the participants were given a brief verbal overview of the consent form contents, and were assured that they were not obliged to continue with the interview if they no longer wished to participate. All of the participants were provided with a copy for their records, and my contact details were on this form along with a statement inviting the participants to contact me at any time if they had any questions or concerns.

At the beginning of the interviews, the participants were reminded that they were not required to answer any question(s) that they were uncomfortable with. During the consent process of the interview it was also explained that the information provided would remain completely confidential. The participants were also informed that following the interview, and

any time prior to the conclusion of the project, they could withdraw their consent for any portion of the interview, or their participation in entirety.

Ethics of Interviewing: Potential Risks and Benefits

It is often very difficult (if not impossible) for researchers to gauge how research participants might be negatively affected by the research and what strategies should be employed in order to minimize these risks (Guillemin and Gillam, 2004, p. 272). It was evident, however, that the women and men interviewed for the research project actually benefited from the opportunity to speak openly about their experiences (see below). At the same time, it was anticipated that they might have difficulty talking about certain experiences or find some of the interview questions uncomfortable. The written consent form highlighted this potential risk and, as was discussed above, the participants were told that they did not have to answer any question(s) that they were not comfortable with, and that they could pause or end the interview at any time. Although none of the participants requested any resources, I did make myself aware of a range of support services that they could access following the interview if necessary.

Face-to-Face and Phone Interviews in the UK and Canada

Following informed consent, the interviews were undertaken in a mutually agreed upon place. The possible meeting places for the face-to-face interviews included the participants' homes and public spaces (such as community centres and coffee shops) as well as on the premises of the University of Leeds (UK), and the University of Lethbridge (Alberta, Canada). Phone interviews were arranged for the few instances when travel to meet the participants in a place convenient for them was not possible, or in cases where the participants preferred to be interviewed over the phone.

The large majority (26) of the interviews were face-to-face, and five of the interviews were done over the phone. The face-to-face interviews and the telephone interviews were similar in relation to the central findings of the research, however the telephone interviews on average were slightly shorter in length. The telephone interviews were likely shorter only because they tended to contain less discussion of topics unrelated to the research. Offering both face-to-face interviews and telephone interviews allowed for the inclusion of a wider sample of

people from various geographical locations in the UK and Canada. In addition, having the option of doing a telephone interview was appreciated by some of the participants as this required less effort and potential stress on their part. As Clarke and James (2003, p. 1389) argue, for people with chronic illnesses, telephone interviews have the "distinct advantage" of allowing "participants to rest in bed." This was voiced as an advantage by a few of the respondents in this study, who stated that the telephone interview was preferable to a face-to-face interview, precisely because they could do the interview while in bed.

On average the interviews were very in-depth and lengthy ranging from one and a half hours to three hours in length. During the interviews an interview guide (see appendix v) was used simply to provide some structure to the interviews and to ensure that the general research questions were addressed in all of the interviews. The interview guide began with a question asking the interviewees to think back to when they were diagnosed with FMS, and to describe the events leading up to the diagnosis. The interviews were designed to explore this particular question first, because as Wagner and Wodak (2006, p. 392) explain the "main idea is to stimulate a person to tell stories – significant episodes in her life that illustrate why and how certain events are significant in her biography, and the role of relevant others in these events." This was an excellent starting place as most of the participants told long and complicated stories about the events leading to a diagnosis. Inevitably they discussed other important experiences while describing their illness trajectories and these were discussed in more detail later in the interview. The interviews covered a variety of topics; in particular, the respondents were asked to discuss their experiences in relation to the following: identity, and particularly, self-identifying as a person with FMS and/or as disabled; relationships with family and friends; paid and unpaid work; interactions with health professionals; and, access to disability related entitlements and workplace accommodations. In addition to these substantive themes, general demographic information was collected (i.e. age, ethnicity, occupation, education level, relationship status, and number of children).

Qualitative interviewing requires time and effort on the part of the participants, and some researchers provide incentives in order to entice people to participate. This research project did not offer an incentive to participate, but this did not prove to be an obstacle in this

research. All of the participants were very willing to take time to share their experiences. It was clear that because FMS is a socially marginalized condition, the participants were genuinely pleased to be interviewed in order to discuss their largely ignored experiences, and to advance knowledge of this topic. All of the participants thanked me for choosing this topic to study and for taking the time to interview them. None of the participants voiced any regret about doing the interview, and not one of the respondents chose to withdraw from the study. Finally, included in the consent form was a section where participants could notify me of their interest in receiving a brief research summary once the project was completed. All of the participants requested a summary of the findings, further reflecting that the interviews were experienced positively by the respondents.

Transcription

The interviews were tape recorded to allow for a detailed transcription of the interviews. According to Lapadat and Lindsay (1999, p. 80), detailed transcription is important as it "preserves the data in a more permanent, retrievable, examinable, and flexible manner." The interviews were transcribed in detail, however it was not a form of "naturalized transcription" where every utterance is transcribed, as this type of transcription style is most often used in conversation analysis and thus does not fit with the objectives of the research project (Oliver et al., 2005, p. 1276). Instead, a "denaturalized" style of transcription was employed, as this form of transcription focuses on the informational content of the data rather than the technical linguistic nature of the data. The main focus during transcription was on the "substance of the interview, that is, the meanings and perceptions created and shared" during the interviews (Oliver et al., 2005, p. 1277).

Deductive versus Inductive Approaches to Data Analysis

The project draws from existing literature and theory on chronic illness, disability and gender. In this sense, the project is deductive as this literature and theory informed both the development of research questions and data analysis. In particular, a feminist postmodern framework helped to frame the research questions and was used to interpret and analyse the participants' accounts. The use of a theoretical framework has implications for all stages of the

research and analysis, and it means that the project was not completely grounded in the data. According to Maynard (1994, p. 23), however, "*all* feminist work is theoretically grounded" and this is to be encouraged (italics in original). She goes on to explain that:

> [W]hatever perspective is adopted, feminism provides a theoretical framework concerned with gender divisions, women's oppression or patriarchal control which informs our understanding of the social world. It is disingenuous to imply otherwise. No feminist study can be politically neutral, completely inductive or solely based in grounded theory. This is a contradiction in terms (ibid).

This reflexive positioning is rooted in the understanding that critical social research should do more than simply let the participants' words "speak for themselves." As a feminist researcher, I believe that it is important to connect the participants' individual experiences of chronic illness to larger cultural and structural factors that shape, and are shaped by, these experiences.

This is not to say that the analytic approach to the research project is completely deductive, however; some components of grounded theory (Corbin, 1990; Strauss and Corbin, 1998) informed the research analysis. Strauss and Corbin (1998) argue that grounded theory provides researchers with a "set of tools" for conducting research, and this project employs certain tools from grounded theory while departing from others that are not in harmony with the project's research objectives. One of the main tenets of grounded theory is that data collection and analysis are interrelated, so that "analysis begins as soon as the first bit of data is collected" (Corbin, 1990, p. 419). In this project, note-taking, data collection, and transcription occurred simultaneously, allowing for the incorporation and analysis of emerging themes.

Thus, the research project was both partially "data driven" and informed by theory, and as such, it combines an inductive and deductive approach. It was a fluid and continuous approach that involved a careful "back-and-forth" dialogue between the literature, theory, and the data. It is an approach that Blaikie (2009, p. 156) refers to as "abductive," where "data and theoretical ideas are played off against one another in a developmental and creative process":

> *Research becomes a dialogue between data and theory mediated by the researcher.* Data are interpreted and reinterpreted in the light of an emerging theory, and, as a result, change in the process. The emerging theory is tested and refined as the research proceeds (italics in original, Blaikie, 2009, p. 156).

Finally, the analysis process did not end once all of the interviews had been read and "coded" either; it continued through the "writing-up" stage as interview extracts that best reflected

particular themes were chosen and the theory and literature was "interwoven with the research findings" (Oliffe, 2009, p. 351).

Critical Narrative Analysis

The interview transcripts were analysed using "tools" from both critical discourse analysis and narrative analysis (see below). Phillips and Hardy (2002, p. 3) define discourse as "an interrelated set of texts, and the practices of their production, dissemination, and reception that brings an object into being." It is through texts (written texts, spoken words, pictures, symbols) that discourses are "embodied and enacted" (Phillips and Hardy, 2002, p. 4). In discourse analysis, texts are not individually significant; rather, they are made significant through their interconnection with other texts (Bloor and Bloor, 2007; Phillips and Hardy, 2002). Bloor and Bloor (2007, p. 52) explain that it is crucial that researchers examine "how the cultural settings (in terms of historical time, domain and social practice) interrelate with text in the creation of meaning." Similarly, Johnson and colleagues (2012, p. 4) state that "discourses are shaped by broader social structures and social relations thereby defining, constructing and governing topics and subjects." Thus, researchers applying discourse analysis to qualitative data must "consider how texts (that is, the interview transcripts) are constructed in terms of social, cultural, political and historical situatedness" (ibid).

There are multiple types of discourse analysis. The differences between the various forms can be categorized according to two key dimensions: "the degree to which the emphasis is on individual texts or on the surrounding context, and the degree to which the research focuses on power and ideology as opposed to process of social construction" (Phillips and Hardy, 2002, p.18). As was stated above, this research project utilizes tools from both critical discourse analysis (CDA) and narrative analysis (NA). Combining these two types of discourse analysis meant that dominant (macro-level) discourses that were present in all of the interviews were identified, as well as micro-level "discursive strategies of positive self-representation" (Wagner and Wodak, 2006, p. 393). Utilizing tools from both CDA and NA this thesis attends simultaneously to macro and micro levels of discourse; and as such, it is an approach that draws on both Foucauldian and Goffmanesque traditions. According to Hacking (2004, p. 278), "Foucault's research was 'top-down', directed at entire systems of thought" whereas "Goffman's

research was 'bottom-up' – always concerned with individuals in specific locations entering into or declining social relations with other people." He further explains that both Foucault and Goffman were concerned with discourse:

> One of [Goffman's] projects was to understand how people were constituted, defined themselves and were understood by others...I call this 'bottom-up' because we start with individual face-to-face exchanges, and develop an account of how such exchanges constitute lives. I call Foucault 'top-down' because he starts with a mass of sentences at a time and place, dissociated from the human beings who spoke them, and uses them as the data upon which to characterize a system of thought, or rather, its verbal incarnation, a discursive formation (ibid).

Hacking (2004, p. 300) argues that Foucault's work permits an understanding of "what is said, can be said, what is possible, what is meaningful - as well as how it lies apart from the unthinkable and indecipherable." The "critical" method of discourse analysis is most often associated with Foucault and is concerned with the disciplinary aspects of discourse and the relationships between discourse, power and knowledge (McHoul and Grace, 1993; Phillips and Hardy, 2002). According to Bloor and Bloor (2007, p. 4) CDA is based on the understanding that "discourse is an integral aspect of power and control." In particular, Foucauldian approaches to discourse analysis "recognize the pervasive, complex, and contradictory nature of power relations" (Wall, 2001, p. 595). Wall (2001) explains that this involves examining both what is said and what is not said, and "that which goes unchallenged in the presentation of issues and in debates over these issues" (p. 595). Many researchers adopting a "critical" perspective examine how social processes and practices contribute to a "social reality that is taken for granted and that advantages some participants at the expense of others" (Phillips and Hardy, 2002, p. 15).

This thesis is "critical" then in the sense that the analysis of the interviews focused on the social context of the interviews and how certain discourses – or ways of representing the social world –dominate others, and are then taken for granted to be reflections of "truth" and "reality." In addition to employing methods from CDA, the research is also focused on some of the elements more closely associated with a narrative approach to data analysis. When analysing the interviews attention was paid to how the participants constructed accounts of their experiences. This approach allows for insight into the identity management strategies of the

respondents, because as Radtke and Van Mens-Verhulst (2001, p. 382) explain, "identity is an accomplishment, something that we create and recreate discursively as we move from one social interaction to another."

According to Hacking (2004, p. 278) Foucault's work is missing "an understanding of how the forms of discourse become part of the lives of ordinary people, or even how they become institutionalized and made part of the structure of institutions at work." Hacking therefore concludes that we need to turn to Goffman to "fill out" these gaps in Foucault's work. The understanding that qualitative interviews are opportunities for respondents to tell a specific narrative, and offer a particular "portrayal" or "performance" is clearly rooted in Goffman's (1959) *dramaturgical* analysis, as well as more recent theories of *performativity* (Butler, 2006). To be clear, this does not imply that these performances are false, inauthentic, or somehow "made up." As Lawler (2008, p. 114) explains, "[t]here is no person behind the mask: the mask (the performance) constitutes the person." Similarly, Kohler Riessman (2003, p. 7) argues:

> To emphasise the performative element is not to suggest that identities are inauthentic (although this reading is suggested by the dramaturgical perspective), but only that identities are situated and accomplished with audience in mind. To put it simply, one can't be a 'self' by oneself, identities must be accomplished in 'shows' that persuade. Concepts of self do not come into being only in discourse situations, of course, but it is primarily through discourse that 'selves' are represented, and consequently, enter the social world.

She further explains that interview respondents "negotiate how they want to be known in the stories they develop collaboratively" with the interviewer and this means that the "narratives do no reveal an essential self so much as the preferred one" (Kohler Riessman, 2003, p. 8).

While traditional forms of qualitative research provide important insight into *social meaning*, discourse and narrative analysis provide methods for understanding *social construction* (Philips and Hardy, 2002, p. 82). A great deal of research and literature on contested illnesses has sought to understand *meaning* in relation to illness. Some research has examined the meaning of chronic pain and fatigue in the lives of people with chronic illnesses (Johansson et al., 1999; Raheim and Haland, 2006; Soderberg et al., 2002). Other research has explored how chronically ill people give meaning to their illness in order to "remake" their identity (Richardson et al., 2006). Still other research has looked at the meaning of a contested diagnosis (Clarke and James, 2003; Madden and Sim, 2006). By employing an approach that

focuses on the interaction between macro level discourse and the specific discourse produced during the interview, the current project shifts the focus; in particular, it examines how FMS is made *invisible* (marginalized, denied, contested) and *visible* (accepted, validated, understood) by different actors in a variety of contexts. In addition to examining the *in/visibility* of FMS, this thesis explores how people with contested conditions fall "in-between" other apparently fixed and constant categories such as health/illness and dis/ability. Through a critical analytic approach it is possible to investigate how FMS is socially *produced* or *constructed* as a contested illness, and how people with FMS misfit (and become misfits) due to particular social configurations and dominant conceptualizations of health/illness and dis/ability.

In addition, as Thomas (1999, p. 78) argues, "the micro is constitutive of the macro," meaning that "narratives offer a route in to understanding the socio-structural." Through a focused analysis on how people with FMS present themselves in the interviews it is possible to see how they also serve to make the condition in/visible, and how their particular accounts of disruption, uncertainty, and misfitting relate to broader biomedical and socio-cultural discourses. It also allows for a more nuanced analysis that takes into account gender, national context, and other important aspects of one's identity and social location that all interact to produce a particular presentation of self in the interview and a situated account.

Coding the Data

Drawing from CDA and NA, and with the aid of Atlas-ti (a qualitative data analysis software program) coding of the interviews began first with a reading of all of the transcripts, and then more focused coding followed. The focused coding involved several "levels" or "layers" of analysis. The process of data analysis began by analysing the *structure* of the accounts, or in other words, how the accounts are organized. At this stage it was important to examine the ways in which the various accounts are organized in order to make an argument and "counter alternatives" (Potter, 2004, p. 207). In addition to paying attention to structure, the initial stages of analysis examined the *content*; or in other words, what is said (or not said) in the accounts. During this stage of the analysis it was crucial to look for taken for granted assumptions underlying the language used (Kohler Riessman, 1993). As the analysis progressed it moved from the "inside" and "expanded outward" from the individual texts in order to

analyse the interconnections between the accounts and to examine common themes, categories or concepts. The final level of analysis "expanded outward" further in order to connect how the individual accounts are "situated in particular interactions, but also in social, cultural, and institutional discourses, which must be brought to bear to interpret them" (Kohler Riessman, 1993, p. 61). This approach to data analysis recognizes that "stories are always personal but at the same time connected to the flow of cultural stories" (Grape et al., 2015, p. 680)

Finally, it is important to acknowledge that the interview itself was an opportunity for the participants to make FMS a visible (acknowledged) medical condition, and to offer a particular portrayal of themselves as a person diagnosed with this condition. This presentation of the self in the interview formed another "layer" of analysis. In addition to analysing the content and structure of the interviews, the interview itself (which is an intersubjective interaction between interviewer and interviewee) was analysed as it forms another type of account. This idea of multiple "layers" of analysis is rooted in the understanding that it is important to analyse interview data from "various perspectives – from the content of the story told, from the way this story is told, and from a here-and-now perspective in which the interaction between the interviewee as a storyteller and the researcher as a listener becomes central" (Bulow, 2008, p. 139).

Revisiting Reflexivity: Executive Authorship and Representation

> Researchers interpret the meaning of, and provide some sense and order to, the material studied; develop their own story as they construct others' voices and realities; narrate results in ways that are both enabled and constrained by the social resources and circumstances embedded in their disciplines, cultures and historical moments and write or perform their work for particular audiences, resulting in a range of complex issues about voice, representation and interpretive authority (Kvigne et al., 2014, p. 200).

This quote highlights many of the issues previously discussed, and in particular, the importance of being reflexive. The interview is an intersubjective exchange between the interviewer and the interviewee that results in the production of a particular historically and culturally situated text (the interview transcript). According to Grape and colleagues (2015, p. 686) interview texts (understood as narratives or accounts) do not represent "how something actually is or was," but they offer a "portrayal" that when carefully analysed can give us a "broader understanding" of the topic being studied. This means that the accounts offered in this thesis are "constructed,

creatively authored, rhetorical, replete with assumptions, and interpretive" (Kohler Riessman, 1993, p. 5).

It also means that I am implicated in the accounts that were constructed during the interviews, and that I made executive decisions regarding the final text that was produced. Although not always considered, the "writing-up" of research findings is another stage of the research process where ethical challenges come to the fore; in particular, it involves issues regarding accountability and how best to represent the respondents and present their accounts (Finlay, 2012, p. 328).

Thomas (2010, p. 657) argues that while she is "predisposed to *emphatic witnessing*, and to *identifying* with many stories told by patients and carers" she does "not indulge in making things up, in selective reading, or in *sentimentality* or *romanticism*" (italics in original). She states that "*sentimentality* does not sit comfortably, for [her], alongside storylines about the brute reality of advancing disease or strained relationships" (italics in original, ibid). Similarly, in this thesis I made a conscious attempt to balance the necessity of representing embodied and social suffering, while also refusing to romanticize this suffering, or gloss over important accounts of resistance, or make simplistic generalizations that portray patients as "good" and doctors and other experts as "bad." The perspective adopted in this thesis acknowledges that living with contested chronic illness involves both social and physical suffering, but it also recognizes that this does not preclude positive experiences or mean that all narratives of illness and disability are tragedies.

Chapter 5 - Disruptive Bodies: Haunting Biomedical (Un)Certainty

Introduction

This chapter follows the participants' accounts from symptom onset, through the diagnostic process, and up to receiving the FMS diagnosis. Drawing on the notions of "haunting" and "estrangement" (Overend, 2014; Shildrick and Steinberg, 2015), the chapter begins by examining how the onset of multiple, fluctuating and imperceptible symptoms unsettles comforting illusions of certainty, control, and the invulnerable body. Following this, the chapter turns to an examination of how biomedicine is also haunted by bodily sensations and symptoms that are liminal, as they are in/visible, un/knowable, and both absent/present. The notion of "containment" is used to understand the ambiguousness and fluidity of liminal embodiment, and the challenges this poses to the biomedical imperative to classify and categorize. As is discussed, the diagnostic label FMS is arrived at primarily by a process of exclusion, where conditions are "ruled out" through the use of medical tests and scans that rely on the visual confirmation of pathology. In the absence of a knowable/visible presence of pathology what remains is an almost exhaustive list of possible symptoms that are then all included under the FMS label. It is argued that the simultaneous process of exclusion and inclusion is an attempt to place medically unexplained, ambiguous symptoms in a fixed container, but instead of the certainty of a stable and secure diagnostic category, the FMS diagnosis – represented as an overflowing or leaky container – actually contributes to uncertainty and estrangement. Thus, the disruptive bodies of people with medically undefined and unexplained illness refuse to be contained in stable and fixed categories, and instead reside in the liminal space in-between health/illness, in/visibility, dis/ability, and absence/presence. The chapter concludes by exploring how the participants' accounts provide a critique of the supposed infallibility of biomedicine, and point to the potentialities of *embodying liminality*.

The Haunting and Estranging Onset of FMS

The collection of symptoms that are grouped together under the FMS label include, but are not limited to, chronic pain, fatigue, headaches, sleep disturbances, irritable bladder, difficulty concentrating or brain fog (also known as "fibro-fog"), mood and anxiety disorders,

dry eyes and mouth, sensitivity to cold, dizziness, and coordination problems (Barker, 2005; Janssens et al., 2015). The symptoms of FMS overlap with other conditions, and thus many people with FMS have been diagnosed with, or experience symptoms related to chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), irritable bowel syndrome (IBS) and multiple chemical sensitivity (MCS) (Brown and Jason, 2007; Yang et al., 2015). As has been previously pointed out, the majority of people with FMS are women and there have been links made between the condition and other women's health issues, including premenstrual syndrome (PMS), dysmenorrhea and endometriosis (Barker, 2005; Pasoto et al., 2002).

Thus, FMS overlaps with many other conditions, and the diagnostic category includes an expansive composite of ambiguous, subjective symptoms, many of which are considered "normal" to some degree. Intermittent and brief experiences of most of the symptoms above are considered an "ordinary" part of life, and in many cases would not elicit concern or the need for medical attention (Barker, 2005). Indeed, many of the respondents in the current study allude to the blurriness between "normal" bodily experiences and the onset of their FMS symptoms, and some of the participants explain that they likely first started having symptoms many years before they considered them to be signs of illness. A few of these participants state that the onset could be traced back to early childhood.

The participants who had symptoms long before they were diagnosed as FMS describe the condition as being a *looming presence* in their lives. The symptoms were present in one form or another, but the ambiguousness of the symptoms meant that they were a "haunting" presence (Overend, 2014) rather than clear indicators of illness. Based on her research on candida (a medically unexplained, yeast-related condition), Overend (2014, p. 64-65) describes the symptoms of this condition (many of which overlap with the symptoms of FMS) as vague and "ghostly" in that they are present/absent, visible/invisible and known/unknown. Similarly, it is argued that the onset of FMS is experienced as "haunting," because the symptoms are liminal; ambiguously extra/ordinary and episodic. The respondents' accounts reflect that the symptoms fluctuate; they are present, but then they are absent. In addition, the symptoms are known and visible as felt embodied sensations, but as is discussed later in the chapter, the cause of the symptoms is medically unknown and invisible.

When asked about the onset of her symptoms, Carolyn (Canada) replied:

I've had fibromyalgia before they even had a diagnosis for it…I got it quite early. My mom said that I couldn't walk until I was about three because they called it poor coordination. And I'd always had pain in my legs and stuff. I remember thinking, oh they're growing pains.

Samantha (UK) also describes having FMS related symptoms as a child:

I've always kind of been a bit more kind of like a weakling, kind of like a runt. And I was always really tired. I was always kind of like the one that was slower and complained more. And every time I did any sports it really hurt, and everyone else seemed to be fine, so I just kind of thought it was me, like all the way growing up. And I'd had problems sleeping. And I'd have like random pains, and you know fainting and all wierdnesses. And again, I just thought it was me, because everybody else was fine.

What some of the participants initially considered ordinary and temporary bodily experiences, were later deemed to be the first signs of the onset of chronic illness. Due to the indistinctiveness of the symptoms, however, they were easily dismissed and left largely unacknowledged for many years, even by the participants themselves. Their symptoms thus represent both a *looming presence* in their lives, and a haunting *absence* of certainty as to whether these bodily experiences are extra/ordinary.

In contrast, some of the participants describe a gradual onset where the symptoms seemed to worsen and expand eventually fully possessing the body. Again, the metaphor of "haunting" is clearly useful here; these participants describe the onset of illness as a sort of *creeping presence* that became more noticeable/present in their lives. Lillian (UK) provides a detailed description of how her symptoms have "grown" over the years:

It started off with a spinal cord problem and I was in a lot of pain. And then I started having dizzy spells, migraines, black outs and problems with my eye sight, not remember things, lack of concentration, severe depression. And then I started to get pain spreading throughout my body rather than just localized in my spine.

Summarizing her experience Lillian explains that: "It's like you get the same certain symptoms and then those symptoms seem to expand and you gather even more." Shannon (UK) and Gordon (Canada) also similarly describe the onset of their symptoms as being a gradual process:

I started getting symptoms when I was 19 in my first year at Uni. I got a really bad virus and then after I got the virus every time I would drink alcohol my body would feel like I was bruised all over. And that went on for about two years. I didn't really think that anything was wrong with me, I just thought I was a bit sensitive to alcohol… And then gradually it became not just when I drink alcohol but just when I was really tired and run down I started getting pain, and then eventually maybe 18 months ago I started getting pain every day and it wouldn't go away (Shannon, UK).

> I remember it started when I was 17 or 18. That's when the pain started. It was just like a general stiffness and then it got worse and worse. Then after my first daughter was born was when it started to get really bad. I was doing some physical labour type jobs at that time and I noticed successively it just consistently got worse and worse and worse (Gordon, Canada).

These participants refer to their experiences of pain as a gradual "spreading/creeping" that eventually became a daily presence in their lives. Along the same lines, Michael (Canada) describes his pain as "sneaky" in that it started out as manageable, and he initially understood it as being related to the strenuous work he was doing, but then it eventually became "obvious" and "unbearable." In his words: "The interesting part about it is it just sneaks up on you to the point where you don't realize how much pain you're in."

The excerpts above reflect the "ghostly" fluidity of bodily sensations and symptoms that refuse to be clearly defined in rigid biomedical terms. The uncertainty as to whether symptoms are indicators of ill health or are "normal" temporary bodily experiences – as they are "growing pains" or the result of particularly strenuous work – destabilizes the dominant cultural understanding that health and illness are distinct and stable categories (Vick, 2013). I do not intend to imply that the participants were simply being overly sensitive to ordinary pain, fatigue, or other symptoms. In the interviews the respondents clearly convey suffering, and as Barker (2005, p. 76) explains it is the "additive, intense and persistent character of otherwise commonplace symptoms that distinguishes FMS." The important point is that these examples disrupt the taken-for-granted assumption that health, as well as illness, are always clearly defined and obvious categories.

Unlike the participants who describe symptoms that haunted them for months or many years, some of the participants describe a "sudden" onset. For example, Katelyn (UK) explains: "About two years ago all of the sudden I just noticed that I was extremely tired and couldn't get out of bed." Similarly Jessica (Canada) states: "For me it came really suddenly. My bones and pain and everything just started like boom I woke up sore one day. It was really sudden." Other participants, like Julie (Canada), describe becoming suddenly ill with a virus and then never recovering:

> I woke up one day and I felt like I had a really bad flu. I was sick for 10 days, but a really strange kind of sick. I was like a sickly person. I could barely lift my arms up to take my clothes off…And I ended up in emergency. I was throwing up on the way to

the hospital, and I had a headache like I'd never experienced before. And you know what? My life has changed since that moment.

The unexpectedness of the onset of their symptoms meant that these participants had a particularly disconcerting understanding of bodily vulnerability and uncertainty. The use of words like "boom" insinuates that the onset of symptoms was "bomb-like," revealing the disturbing experience of bodies/lives changed in a moment. While these participants were not haunted in the same way as those who had the presence of symptoms for months or years, their experiences of abrupt bodily changes are just as deeply unsettling in a culture that is "highly invested in fantasies of an invulnerable body" (Shildrick and Steinberg, 2015, p. 7).

Although the specific circumstances surrounding the onset of their symptoms varied, all of the participants' accounts lend themselves to an analysis that draws on the notions of "haunting" and "estrangement." For some the onset of symptoms was like a "ghostly" looming presence, others endured a "sneaky" possession, and still others experienced an unsettling abrupt occupation. In all instances the participants' accounts reflect the haunting uncertainty connected to shifting embodiment, and how bodily disruptions are inextricably linked to estrangement from the self. Emma (UK) summarizes this well by explaining that "it's a disease that messes up your foundation of everything. You're sort of peace and serenity totally gets messed up." Following the onset of illness, one's "foundation" is no longer stable, and the "peace and serenity" that comes from the once taken-for-granted and comforting illusion of bodily invulnerability, control, and certainty is shattered. The onset of illness thus marks the beginning of changes to body and self, and it is a process of estrangement that as Diedrich (2015, p. 72) explains is "both painful and productive." The painfulness of this process is evident in Emma's reference to her now unstable foundation, and the peace and serenity that has been replaced by chaos and disarray. The process of estrangement and "becoming something new or someone else" (Diedrich, 2015, p. 72) is not only painful, however, and the liberating possibilities of *becoming/shifting/changing* are discussed in greater detail at the end of the chapter.

Unsettling the Diagnostic Process: In/Visible and Un/Identified Symptoms

Following the onset of various symptoms all of the participants turned to medicine for answers. To extend the "haunting" metaphor, it was evident in the participants' accounts that they expected medicine to exorcize them of both their uncertainty and their suffering by finding a cause and offering a cure. The participants' expectations of medicine are understandable, because as Shildrick and Steinberg (2015, p. 7) explain we are all extremely invested in the illusion that "our fragile, disordered and possibly diseased bodies can be returned to an originary wholeness by the intercession of highly skilled and trusted [biomedical] experts." The next section examines how the "high stakes" of maintaining this illusion means that medicine is haunted by the "messiness" and the "disorder" of bodily experiences and symptoms that are in-between health/illness, dis/ability and are both in/visible, absent/present and un/knowable. In addition, it explores how trying to explain, define, and ultimately contain fluctuating and ambiguous symptoms under one medical label actually contributes to uncertainty and estrangement.

For a few of the participants the diagnostic process took less than a year, but the majority described a long and painful struggle for legitimation and recognition in the form of a biomedical label. One of the reasons the process often takes several months, if not years, is that a diagnosis of FMS is made by excluding the presence of other conditions. Julie (Canada) summarizes this process:

> This is how the diagnose fibromyalgia: they rule out other things. They rule out obvious things like a stroke and then they rule out MS [Multiple Sclerosis] and Lupus and different things like that. And when they can't find something wrong with you, 99.9% of the time somebody will be diagnosed with fibromyalgia, because they don't know what else it is.

A diagnosis of exclusion is, as Julie explains, the process of "ruling out" or excluding the presence of "obvious" conditions. Through a diagnosis of exclusion that involves medical tests, blood work, and/or scans a range of medically unexplained and seemingly unrelated symptoms are then labelled as FMS. It is only after the visible/knowable conditions are found to be absent, that FMS is diagnosed; thus, it is a diagnosis based on the absence of certainty.

Uncertainty then haunts the FMS diagnostic process from the beginning, and in large part, this is due to the in/visibility of the condition. While all too visible a presence in the lives

of those suffering with a range of painful and debilitating symptoms, the existence of an underlying cause remains invisible to medical experts. This in/visibility is highly problematic in a cultural context where "seeing" and "knowing" are entwined so that only that which can be seen is known/certain. According to Draper (2002, p. 775):

> On the one hand, vision is the "lion" of the senses, gathering information which is regarded as autonomous, pure and objective. On the other hand, however, vision can also be regarded as mundane, unseen, embedded, taken for granted and unquestionable. Vision both observes and constructs our social world and therefore incorporates elements of both seeing and knowing.

Common phrases such as, "Seeing is believing," and "See what I mean?" further reflect the connection between seeing and knowing (Draper, 2002; Jenks, 1995).

With regard to biomedicine, Draper (2002, p. 1) argues that because it is "firmly rooted in the paradigm of positivism, [it] privileges vision so that only that which can be seen can be believed." The privileging of the visual within modern medicine can be traced back to the Renaissance when interest regarding the internal workings of the body led to the designing of tools and techniques of dissection (Sawday, 1995). Modern medicine's use of dissection brought into light areas of the body previously unseen, generating a "reorientation between the visible and the invisible, creating new classes of phenomena previously imperceptible and thus indescribable" (Petersen, 2012, p. 14). Today, visual confirmation of pathology is central to the diagnosis and treatment of illness and disease, however, "corporeal dissection" is no longer the primary means by which medicine gains access to the interior body. Instead, medicine relies on "technological dissection" through CAT and MRI scans, and ultrasound technology, all of which create a "new interior map of the body" (Draper, 2002, p. 777).

Drawing on Foucault, Mol and Law (2004, p. 45) explain that biomedical scans and tests, along with a specific configuration of other biomedical processes, practices, and treatments have combined so that "pathology [has] the last word." All of the participants in this study describe undergoing some form of "technological dissection" in order to confirm the absence/presence of pathology. Connie (UK) and Gordon (Canada) provide two such examples:

> I kept going back to the GP over and over again with the pain and he sent me for various tests, but couldn't find anything wrong. At first they thought it might be osteoarthritis. And then I was tested for rheumatoid arthritis. But they found no problems at all with any of the blood tests. And then finally I was diagnosed with fibromyalgia (Connie, UK).

> And I went for test after test after test. I went for x-rays, and blood tests, and scans. And went to see all kinds of specialists, and they all thought it was arthritis. And then my doctor sent me to a different specialist. And this rheumatologist she did another series of tests, and then she diagnosed it as fibromyalgia (Gordon, Canada).

Pain, which is the main symptom associated with FMS, is also a sign of many other conditions. According to Jutel (2011, p. 81) beginning in the nineteenth century, the "symptom took on a new role" and "transformed the doctor's role into one of detective: unscrambling the messages of the symptom to discover the link between signifier and pathology." The blood tests, x-rays, and scans the participants underwent were done to search for an identifiable cause for the pain and other symptoms they were experiencing. It is only after their doctors were unable to detect a "link" between their symptoms and pathology that the participants were diagnosed with FMS.

Even in the cases where FMS was considered a possibility before any tests were done, the "doctor as detective" model requires a search for, and visual confirmation of, the absence/presence of pathology. For example:

> I told the doctor my symptoms and he just immediately said it sounds like fibromyalgia but it could also be these other things so we'll test for everything else and if you don't have anything we can find then its fibromyalgia. So I had quite a few tests, like blood tests and scans and things like that, and there was nothing. They couldn't find anything wrong. So then he said, "Right well you've got fibromyalgia" (Shannon, UK).

Patricia (Canada) similarly explains that her GP discussed the possibility of FMS over two decades before she was officially diagnosed:

> But she said that we would need to run a whole bunch of tests to make sure it's not something else first. So as I got older it's got progressively more painful and literally to the point where I wanted the official diagnosis. So about a year ago I went to see the rheumatologist and he explained that with all of the blood tests and scans nothing came up showing anything else, so officially it is fibromyalgia…And really it's a kind of disease that is often diagnosed because it is the last thing left. It is awful disconcerting that there isn't a way of testing for it, without having to go through 50 million other things first.

As the excerpts above reflect, a patient's description of symptoms is not enough to confirm an FMS diagnosis. Biomedicine relies on visual confirmation to connect the patient's symptoms with an organic cause and provide a diagnostic label. Overend (2014, p. 72) describes how medically unexplainable conditions thus "haunt the diagnostic methods of biomedicine," because these are illnesses with no known pathology. When there is an absence of a visual confirmation of pathology, it is then absence that confirms (and haunts) the diagnosis of FMS.

Tyler (Canada) summarizes the exclusionary diagnostic process well: "they said it's fibro, because they couldn't figure out anything else that I might have."

It is not only the diagnostic process that is haunted by the absence of visual confirmation, however; people diagnosed with medically unexplained conditions are also haunted by a diagnosis of exclusion. The accounts reflect the clear disappointment and frustration the participants felt when their doctors were unable to locate the cause of their symptoms. Phrases such as, "they couldn't find anything wrong," and "they couldn't figure out anything else," as well as Patricia's statement that a diagnosis of exclusion is "disconcerting" all reflect the participants' feelings of estrangement when the invisible presence of their pain, fatigue, and other symptoms were not confirmed by the visible presence of pathology.

In addition, Patricia states that there "isn't a way to test for it [FMS]," but there actually is a test for FMS called the "tender point test," and Patricia as well as all of the other participants underwent this physical exam as part of the diagnostic process. The tender point test involves a physician pressing down on eighteen tender points on the patient's body, and FMS is confirmed if at least eleven of these eighteen tender points elicits a patient response of "mild or greater tenderness" (Barker, 2005, p. 113). Whether it was done by a primary care physician, a doctor working at a pain clinic, or a rheumatologist, all of the participants describe having this exam following the exclusion of other conditions, and they all had positive results for most, if not all, of the tender points. That Patricia states there is "no test" for FMS, however, reflects that the "tender point test" is not a "real" test like a blood test, scan or x-ray that produces an "objective" (i.e. visible/known/certain) result. The understanding that the tender point test is vague and inexact is further reflected by the recommendation by medical experts that the FMS diagnosis can be confirmed without the physical exam (Fitzcharles et al., 2013, p. 3). The tender point test then is just another example of how the FMS diagnostic process is haunted by the absence of a "real" (i.e. visual) validation of illness.

The desire for the unambiguous confirmation of pathology might initially seem illogical. As both Overend's (2014) research on candida and Ware's (1992) research on CFS/ME highlights, however, the yearning for certainty is so strong that people long for it even if this certainty comes at the cost of the presence of disease. Similarly, I argue that the

respondents in the present study express a strong desire for certainty through the visible confirmation of illness. For example, Lillian (UK) explains, "I feel sometimes that you wish they could find something specific that started all of this." Similarly, Karen (Canada) states, "it's not to say people with cancer have it easy, but when you have a tumour in your body they know what it is. But when you have something like fibromyalgia, it is way harder, because it is not tangible."

For people with chronic pain, fatigue and other non-visible symptoms, the practice of "technological dissection" is a dubious one. The cause of these symptoms are rarely revealed through medical scans or tests, and this lack of visible evidence can lead to questions regarding the reality of illness. The respondents' accounts reflect that the absence of a "tangible" organic cause for their symptoms was unsettling, and in part, this was because it left open the possibility that their symptoms might be dismissed as being "all in their head."

Indeed, some of the participants (mainly women) describe how the absence of an organic pathology led to their symptoms being psychologized. Tracy (UK) provides a clear example of this:

> And before I got diagnosed with fibromyalgia I had every test under the sun from lumbar punctures to CTs. And one minute they thought I had a brain tumor, then I had Parkinson's and then something else and so on. Then after three and a half months they decided that because they couldn't find anything on their tests, no abnormalities, they said that it was all in my head and sent me off to the psychiatric ward.

Tracy's experience might seem extreme, but Courtney (Canada) similarly describes being sent to a psychiatric facility:

> They sent me to a mental hospital and I had to prove that there was nothing mentally wrong with me. I mean how barbaric is that? To be in that amount of pain with no help. I don't think doctors believed how painful it was, because I just can't believe that a doctor would leave you in that amount of pain and not give you some pain relief.

Looking back on her experience, Courtney speculates that her doctor was "irritated" with her, because she "was going back all the time" for appointments, but after numerous medical tests "they couldn't find anything wrong":

> And because I was sick I felt like I couldn't cope. I think the word "cope" in hindsight to them it was like, "Oh she's not coping and she is a new mother, she must be having post-natal depression or something," you know? So they totally disregarded that I was in this terrible pain.

The dismissal of pain that does not have a known organic cause, combined with what Courtney felt were unfair and sexist assumptions about her inability to "cope" with her role as a new mother resulted in physicians psychologizing her symptoms. In this way, Courtney's account suggests that she felt she was not only treated as a "bad" patient, but that her competency as a mother was also called into question. Accounts like Courtney's reflect that the failure of biomedicine to explain in/visible and ambiguous illnesses results in the shaming of people with these conditions; especially women whose bodily experiences are often disbelieved and who are then constructed as being frustrating and difficult patients (Caron, 2008, p. 20).

Like Courtney, the excerpt from Carolyn (Canada) below reveals how sexist assumptions might enter into doctor-patient interactions:

> I even had a rheumatologist tell my husband that he should take me out to dinner more often. So like I'm a frustrated housewife. They would never have said that to a man. If a man got up there and was complaining of the same things you know they never would have said to him "oh you should go out to dinner more often." But then you do start doubting yourself, you know. Am I crazy? Is this psychosomatic?

The implication that Carolyn is a "frustrated" or "bored" housewife who has the "blues," understandably made her angry. It also made her question her own bodily experiences, as she began to wonder if she was "crazy" and thus not "legitimately" ill. Similar to other research, the women's accounts above seem to suggest that underlying the doctor's psychologizing of their symptoms are sexist notions of women as "irrational" and "weak," and "hysterical," resulting in the dismissal of their embodied experiences (Asbring and Narvanen, 2002; Barker, 2005; Caron, 2008; Denny, 2009; Werner et al., 2004; Werner and Malterud, 2003).

In addition to the above examples, several other women in the current study explain that their doctors implied or explicitly stated that their symptoms might be "psychosomatic." For example, Diana (UK) explains the distressing encounter she had with a medical consultant who implied that her symptoms were "all in her head":

> I had one consultant who was a musculoskeletal chap and he referred me for a scan and an x-ray and stuff and I was feeling really low, because I just felt so terrible. And when I went back to see him this particular time he was so rude to me. He said, "What are you expecting us to do for you? There is nothing we can do for you. We can't see anything on the x-rays. There is nothing we can do for you. You just have to get on with your life." And he was just so rude and implied that it was all in my head. I came out of there crying and you just think, am I making it up? Am I exaggerating? You know am I feeling a tiny pain and thinking it is huge? You know you start to think is there something wrong with me that I'm too sensitive to pain?

Similarly, Beverly and Patricia explain how they have had encounters with doctors who do not recognize FMS as a legitimate diagnostic category, and have implied that their symptoms are not indicators of a chronic illness, but are psychosomatic:

> My old GP didn't believe in it. He didn't believe in the [FMS] diagnosis at all. Like he doesn't feel that that's a firm medical diagnosis. And he more or less implied that you know it could be psychosomatic (Beverly, Canada).

> I've had doctors who don't believe in it. They don't believe it is a legitimate illness. And, trust me there is nothing more demoralizing than to be told by the medical profession that it is all in your head (Patricia, Canada).

Having the reality of their symptoms questioned by medical professionals and/or being told that the illness they have been diagnosed with is not medically legitimate is demoralizing, and as other research has confirmed this is experienced as an attack on their morality and integrity as patients and women (Skuladottir and Halldorsdottir, 2008; Werner and Malterud, 2003).

While most of the women interviewed for this research had the experience of their symptoms being psychologized, only two of the men had similar experiences. Despite also having medically unexplained symptoms, the majority of the male respondents had their bodily experiences taken seriously, and not one of them had a doctor imply that their symptoms might be caused by their inability to cope as fathers or husbands. In addition, unlike the men interviewed, many of the women describe being offered anti-depressants before pain medication, confirming previous research findings regarding the psychologizing of women's pain (Hoffman and Tarzian, 2001). The findings from this research thus support Barker's (2005, p. 99) assertion that the invalidation of medically unexplained symptoms is "structurally gendered."

Finally, the participants' accounts reflect that attributing psychological factors is often understood as a way to "pass on" the diagnosis and treatment of their symptoms, and the participants interpreted this as a negation of the reality of their embodied experiences. According to Wendell (1996, p. 100) medically unexplained symptoms are often labelled as "psychosomatic," because this labelling "transfers responsibility" and bolsters the illusion of biomedical control and certainty. Defining unsolved pain, fatigue, and other symptoms as "psychosomatic" or dismissing them as being "all in your head," is a way to try to control the

body and contain the ambiguous and "messy" embodied experiences that are in/visible, absent/present and do not clearly fit into the categories healthy or ill, normal or abnormal. As Meredith (UK) put it, "medicine needs to fit everything in neat little boxes," and similarly Tracy (UK) said, "They have only got two boxes: physical or mental." That the participants' liminal bodily symptoms refuse to be clearly defined and resist classification as either physical or psychological, further reflects how ambiguous and episodic illness experiences haunt biomedicine and the diagnostic process.

A Diagnosis of Inclusion: FMS as a "Best Fit"

The interviews reveal that the first step to an FMS diagnosis is the "ruling out" of the presence of organic pathology through medical tests and scans. This step often also involves the never fully complete process of excluding psychological causes, and the possibility that their symptoms might be due to psychological factors constitutes another haunting aspect of diagnosing illness without an obvious organic cause (Nettleton et al., 2005). Following the process of exclusion the tender point test is done, although as was already discussed, this is not necessary to confirm the FMS diagnosis. The following section explores the next step in this process which I term a *diagnosis of inclusion*. Without "conclusive pathogenic and etiological explanations" diagnosing physicians are in the difficult position of trying to fit patients' illness symptoms into an "explanatory model" that is both "credible" and "understandable" (Swoboda, 2008). The inclusion phase in the diagnostic process might thus be understood as an attempt to contain all of the in/visible, absent/present, and un/explainable symptoms under a label that is not "perfect," but is a "best fit" explanatory model. Instead of resulting in a stable diagnostic category, however, the FMS label is like a "leaky" or "overflowing" container, representing the resistance of ambiguous and fluctuating bodily experiences to be contained within narrow biomedical terms.

As was discussed above, the list of FMS related symptoms is extensive. It has even been termed the "irritable everything syndrome" (Barker, 2005, p. 3). The severity, fluctuation, and the combination of specific symptoms, as well as the absence/presence of overlapping symptoms/conditions/diagnoses means there is no "typical" FMS illness experience. Although the presence of chronic pain is necessary for an FMS diagnosis, the respondents' specific

experience of pain varied. Some experience "all over" pain, while others have localized pain, and still others experience "moving pain." While some have a degree of pain every day, others have pain that fluctuates greatly in intensity, and some have pain free days. The descriptions of pain range from "unbearable" pain that feels like "stabbing" or "burning" to more manageable pain described as "stiffness" and "aches and pains."

In addition to different experiences of pain, Emma (UK) describes other variations in the illness experience of people diagnosed with FMS:

> It's not a disease where everybody has the same symptoms or equally has mental, physical and neurological symptoms. People have totally different symptoms and severity. There are people who have completely been in bed for 20 years. And then there are others who have energy to do stuff but still can't live a normal life. Or there are some people who virtually never get better, but they can live a relatively normal life as long as they don't exhaust themselves.

In line with Emma's comments, Barker (2005, p. 66) argues that there are "nearly as many FMS symptom composites as there are those who suffer from FMS" (p. 66). Similar to Barker's (2005) findings, this research project reveals that the participants' symptom sets were strikingly different. Here are six examples from the data that reflect the variance: Michael (Canada) describes having severe chronic fatigue and fluctuating levels of pain. Unlike some of the other participants he has been diagnosed with CFS/ME in addition to FMS. Michael is also very sensitive to cold and suffers from "fibro-fog." Maria (Canada) has pain, fatigue, sensitivity to cold, and "fibro-fog," as well as irritable bowel syndrome (IBS), trouble with balance and dizziness, blurry and dry eyes, and chronic headaches. Diana (UK) also has IBS symptoms, as well as "flu-like" symptoms, including "aches and pains," and she suffers from depression, insomnia and endometriosis (which has been linked to FMS). In addition, Diana developed symphysis pubis dysfunction during her pregnancies and has residual pain from this, as well as a chronic coccyx pain condition. Mark (UK) has "soreness and stiffness" in his neck and shoulders, and has been diagnosed with Joint Hypermobility Syndrome (JHS), but has none of the other FMS symptoms. Katelyn (UK) has similarly been diagnosed with JHS, and she experiences chronic fatigue, localized back pain and endometriosis. Veronica (Canada) describes pain that "moves" to different locations of her body and fluctuates in intensity, as well

as fatigue that "comes and go." She has also been diagnosed with colitis and rheumatoid arthritis which both overlap with her FMS symptoms.[4]

This is just six examples, but they reflect how the inclusiveness of the FMS label allows for very different symptom sets amongst people diagnosed with the same condition, as well as the presence of in/separable and overlapping symptoms/conditions/diagnoses. In the excerpt below, Shannon (UK) highlights how the inclusiveness of the FMS diagnosis means that it is possible for "everything" to fit under the label:

> You go online and everything is a symptom of fibromyalgia. I was thinking the other day my hair is thinning and then I look online and it's a symptom. Everything is basically a symptom. Everything I get now, every little twinge, everything I'm just like, oh its fibromyalgia. And then I have to like really tell myself it might just be normal. I think that sort of perpetuates the collection of symptoms. Because I don't think all of my symptoms are fibromyalgia. I don't think my headaches are, because I've had those for a long time. I don't think my sleep disturbances are, because I think that's just related to stress. So it's easy when you've been given this word fibromyalgia to just put everything into it… And that's why the boundaries between things have been sort of muddied, because everything could actually be fibromyalgia. But maybe hair loss is fibromyalgia. Maybe everything is fibromyalgia.

As Shannon explains, because "everything" might fit the FMS diagnosis this creates "muddiness" and uncertainty. The permissiveness of the label means that many of the symptoms that are considered to be FMS related are also "normal" or "ordinary" bodily experiences.

In addition, symptoms such as pain, headaches, and sleep disturbances are both possibly connected and separate; these bodily experiences fit under the FMS label, but they might also be signs of distinct conditions. As Lillian (UK) explains:

> And in a way when they finally diagnosed me with fibromyalgia I thought, "Well at least it's got a name." Unfortunately the down side to that is with fibromyalgia everything gets all lumped into that one condition. And what has happened over the years now is that the spinal problems have got worse and I've also now got shoulder problems for a year and a half now and those are not strictly to do with the fibromyalgia.

Other participants similarly expressed that the inclusiveness of the FMS label means that it is difficult to distinguish if any bodily experiences are *not* FMS related:

> I have some other health issues that have kind of overlapped in some ways in terms of pain. So it's been very difficult to say, okay this is fibro and this is related to whatever, you know? (Patricia, Canada)

> So I've spent the last nine months going to doctors and specialists trying to figure out what's going on, because the pain has been significantly worse than the last 28 years or

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[4] Please refer to appendix I for the complete list of all of the participants' medical conditions.

whatever…But they don't know if that is just the fibromyalgia and it has just stepped up to a new level (Nancy, UK).

The participants' accounts reflect that the uncertainty attached to this inclusiveness also made for some difficult doctor-patient interactions, as they felt that at times all of their health issues were dismissed as being FMS related. Lillian (UK), Patricia (Canada), and Nancy (UK) specifically voiced concerns that FMS had become a sort of "master" diagnosis that was obscuring other possible causes for their pain, and preventing them from receiving compassionate medical treatment and care.

According to Barker (2005, p. 156) the FMS diagnosis is a "vast collection of ubiquitous and vague symptoms [that are] not restricted to a specific beginning (etiology or onset), intensity (severity), or trajectory (symptom course)." The participants' accounts reflect the shared understanding that this inclusiveness results in a diagnosis that almost everything and everyone fits, but this does not result in greater certainty, and indeed, this inclusiveness often has the opposite effect:

I don't have it very bad at all and that is if I've even got at all. You know an expert on fibromyalgia told me I've got fibromyalgia, but I'm actually not convinced, even though the symptoms do sort of make sense (Mark, UK).

While FMS might be the "best fitting" diagnosis available, the participants' accounts reflect the shared understanding that a diagnosis should engender certainty; instead, the permissiveness of the FMS label contributes to disconcerting uncertainty.

The muddied complexity and ambiguity of the all-encompassing FMS diagnosis is further reflected by the presence of in/separable and overlapping conditions and diagnostic labels. For example, a shared overlapping diagnosis amongst four of the UK participants was Joint Hypermobility Syndrome (JHS).[5] This condition overlaps with FMS, as it is also a medically unexplained chronic pain condition that is characterised by "non-inflammatory" chronic pain, especially joint pain, as well as other symptoms, such as dizziness or faintness and gastrointestinal disorders (Ross and Grahame, 2011). Depression is another example of overlapping and in/separable symptoms; while some of the participants were officially

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[5] Interestingly, JHS is not a common diagnosis in Canada, and this is reflected by the data as none of the Canadian respondents were given this diagnostic label.

diagnosed with depression – and thus understood it to be separate from, but related to FMS – other participants explained that they were not officially diagnosed, yet they experienced depression as part of their FMS symptom composite.

The presence of overlapping and in/separable symptoms meant that in some cases the same symptoms had been given several different diagnostic labels. As Tracy (UK) explains, "It's kind of complicated, because I haven't just got one diagnosis, but they're all tied together." Similarly, Emma (UK) and Nancy (UK) describe having several different diagnoses:

> And I went through fibromyalgia, CFS, glandular fever, ME and all of these different labels, because my symptoms were all of those things. It's like different combinations of all of these similar symptoms at different times (Emma, UK).

> First I was diagnosed with RSI [repetitive strain injury]. And then they said I had carpal tunnel syndrome, and then tendinitis. And to a certain extent it got better, or I got better at managing it. But then the pain started again and I just wanted somebody to tell me what was going on. And I saw this neurologist who actually diagnosed me with chronic muscular skeletal pain condition. So that was like we're just going to give you something that's got to do with it being chronic, muscular and it's skeletal. (Laughs.) Which really is the same as a fibromyalgia diagnosis (Nancy, UK).

Thus, the FMS diagnosis is haunted by uncertainty through inclusion as well as through exclusion. The inclusiveness of the FMS label is an attempt to remove uncertainty by containing all of the bodily experiences that were rendered unexplainable following a diagnosis of exclusion. The permissive/inclusive FMS label, however, is like an overflowing and leaky container, making for an even murkier and more undefined diagnostic category.

"The word fibromyalgia seems so completely obsolete": FMS as a "Diagnostic Illusory"

According to Nettleton et al. (2014, p. 134), "diagnosis is something of a modernist notion, rooted in the idea that we can have bounded, stable and more precise diagnostic categories identified by increasingly sophisticated technologies." The analysis above reveals that despite, and indeed because of, the biomedical imperative for precision and stability, the FMS diagnosis is haunted by uncertainty and ambiguity. Through a diagnosis that involves both exclusion and inclusion, this diagnostic category is a complex configuration of tensions. The FMS diagnosis is both "deficient" and "excessive." It is a diagnostic category based on the absence of pathology and the medically unexplained. At the same time, the presence of an

almost exhaustive list of possible symptoms means this diagnosis also tries to explain too much. As Nettleton, Kitzinger and Kitzinger (2014, p. 139) argue:

> [T]he more we try to name and classify the more confused we become; the more confused we are the more we try to classify…The attempt to firm up diagnostic categories, to place and to name, may be a *diagnostic illusory*. The apparent stability of diagnosis not only belies its inherent instability, but a diagnosis may also fail to attend to meanings inherent in illness, life and death (emphasis added).

FMS is an excellent example of a "diagnostic illusory." The "illusory" FMS diagnosis fails to bring meaning, comfort, and certainty to those given the label, and it does not provide – and perhaps in some cases even discourages – more understanding and compassionate medical care. Other research has revealed that medically unexplained diagnoses, such as FMS, are frustrating for both patients and medical professionals (Harsh et al., 2015; Nettleton, 2006; Zavestoski et al., 2004). Based on the participants' accounts in the current study, it is argued that this frustration is related in part to having an "illusory" diagnosis that only adds to their uncertainty and fails to provide desired significance to their illness experiences.

In the excerpt below, Mark (UK) highlights the unsettling uncertainties attached to the illusory FMS diagnosis:

> I'm actually not sure whether I've got fibromyalgia at all, right? I was diagnosed with it. It is the best diagnosis that anyone can come up with. I'm taking a fibromyalgia drug which definitely helps the pain symptoms that I have. But in the back of my mind I'm actually not convinced that this is necessarily what I've got, although nobody seems to know what it is that I do have.

Many of the participants' accounts reveal that it is disconcerting that the FMS diagnosis gives rise to more questions than answers, and similar to Mark, some of the respondents voiced concerns regarding whether FMS was the correct diagnosis.

Shannon (UK), similar to the other participants in the study, explains that she was initially "relieved" to have all of her disparate symptoms brought together under a single diagnosis. This sense of relief, however, was short-lived:

> Then I did feel quite, almost cheated, because I didn't feel like it was necessarily the right diagnosis. And like to this day I still don't really think that I have fibromyalgia. They were just like, "right, that doesn't really fit anything but it fits fibromyalgia, so you've got fibromyalgia"…And I think that the word fibromyalgia seems so completely *obsolete*. It just means, "you're ill and we don't know what's wrong with you and we can't fix you," that's all it means to me basically. I really feel isolated with this diagnosis.

Shannon's description of FMS as "obsolete," and how this has left her feeling "cheated" and "isolated," clearly reflects the estranging consequences of a diagnosis that is nothing more than a "mirage of certainty" (Nettleton et al., 2014, p. 140). As was discussed above, the participants (like all of us) are highly invested in an illusion of biomedical certainty and control (Shildrick and Steinberg, 2015). This illusion is bolstered by the understanding that diagnostic categories are rooted in objective reality that has been brought to light through a configuration of highly specialized professionals, medical expertise, and advanced technology. When a diagnosis like FMS disturbs this comforting illusion, it is understandable the participants experienced this as distressing and alienating, and why in some cases they preferred to believe that it was a misdiagnosis, rather than accept the uncertainty attached to having a diagnosis unconfirmed by the presence of pathology.

It is important to note that not all of the participants express the idea that the FMS diagnosis is meaningless. The participants' accounts reflect that some of them feel any diagnosis is preferable to no diagnosis, while others are quite content with the FMS diagnosis, because they believe it is the "best fit" for their symptoms. At the same time, these participants also express feelings of uncertainty, because, as was discussed above, FMS is a diagnosis based on exclusion and it has no identifiable cause. The participants' accounts reflect that it is the liminal ghostliness of the un/known, absent/present, and in/visible symptoms of FMS that continues to haunt them even after a diagnosis.

Conclusion: *Embodying Liminality* as Painful and Productive

At the start of each interview the respondents were asked to describe the onset of their symptoms and the process of receiving a diagnosis. Their accounts included a description of the beginning of a range of episodic, non-visible, and seemingly unrelated symptoms, appointments with primary care doctors and specialists, multiple medical tests and scans, the eventual exclusion of other conditions, a "tender point test" and a final diagnosis of FMS. While all of the participants' accounts included these major "plot points," there was a great deal of variation in terms of the circumstances surrounding the onset of their symptoms, the severity of their symptoms, the type of symptoms and symptom sets, the order and timing of events, as well as the type of medical professionals involved and the specific tests and scans performed. Put

simply, all of the participants provided unique, complex, and convoluted accounts of the events that began with the onset of symptoms and led eventually to a FMS diagnosis.

Despite differences in their accounts, all of the participants – both the female and male respondents in both Canada and the UK – describe the haunting onset of fluctuating absent/present and in/visible symptoms, an unsettling diagnostic practice of exclusion/inclusion, and the uncertainty of receiving a medically unexplained diagnosis. The alienation and isolation felt by many of the respondents when they were given the FMS diagnosis reflects the painfulness of known/visibly felt embodied experiences that are unconfirmed and unexplained by biomedical expertise and technology. At the same time, the process of *becoming in/visible—* occupying the liminal space in-between —might mark a path to resistance and empowerment, because it is the "condition of moving on" and "of becoming otherwise" (Shildrick and Steinberg, 2015, p. 6).

The process of *embodying liminality* by existing in the "liminal spaces that evade classification" (Shildrick, 2002, p. 5) offers the disruptive potential of the "monstrous":

> It is, above all, the corporeal ambiguity and fluidity, the troublesome lack of fixed definition, that marks the monstrous as a site of disruption…What makes the other monstrous is not so much its morphological difference and *un*familiarity, as the disturbing threat of its return. It is in the failure to fully occupy the category of other, in its incomplete abjection, that the monster marks the impossibility of the modernist self. Monsters haunt us, not because they represent an external threat – and indeed some are benign – but because they stir recognition within, a sense of our openness and vulnerability that western discourse insists on covering over (Shildrick, 2002, p. 80-81).

Echoing Nettleton (2006), it is important to explain that by using Shildrick's (2002) theory of the monstrous I am not suggesting that the participants in this study are "monsters," rather that their embodied experiences might be understood as "monstrous" as they "defy classification, categorisation and, worst of all, they cannot be controlled" (Nettleton, 2006, p. 1175). As the analysis above reflects, the fluid and ambiguous embodied experiences of the participants, and the "leaky" diagnosis of FMS haunt our taken-for-granted notions of the whole and invulnerable body, and unsettle the illusion of biomedical control and certainty.

Listening to the accounts of people with in/visible, unexplained illnesses and appreciating their *embodied liminality* thus offers important lessons for all of us. As Overend (2014, p. 79) explains:

> In an illness culture that heavily weights empirical modes of knowing (even when those modes of knowing continue to fray), we must learn to attend to, acknowledge, listen and care for, that which exists in the interstices of biomedical ways of knowing. To give credence to the ghostly matters of undefined illness is to respect (and perhaps even trust) that which we do not know…[this is] vital if we want to move beyond the empirical frames of bodily knowing that were so limiting to begin with.

Respecting and trusting the "monstrous" and "ghostly" embodied experiences of people with medically unexplained illness is important, because this allows us to "be open to the other within," (Shildrick, 2002, p. 132); to accept uncertainty and acknowledge the vulnerability of the human condition.

In turn, this offers possibilities for new beginnings, transformations, and breakthroughs. King (2012, p. 68) argues that "letting go of control over things we can't control, such as incurable illness, may enact a transformative process." "Letting go" of the illusion of certainty, resisting the imperative to constantly appear in-control, and to always be working on perfecting our bodies, opens up possibilities for embodying alternatives, and the opportunity to reshape/reprioritise our lives for the better. The transformative possibilities of "letting go" and embracing ambiguity and uncertainty was reflected in some of the participants' accounts:

> And I think the most difficult part for me was that I was determined that I was going to get to the bottom of this. But there are no clear-cut answers and I'm realizing now that there is no cure and that I have to learn to live with it, which I never thought that I would say that…I'm just learning to be thankful for the good days and to live life to the fullest (Julie, Canada).

Embodying liminality has allowed Julie to realize that there are "no clear-cut answers." Rather than remain haunted, this excerpt suggest she is "letting go" in order to "live life to the fullest."

Similarly, Gordon (Canada) explains the relief in accepting uncertainty, even though this means allowing for the possibility that he might always be un/well:

> When I said, "What is the best that I can expect? Can I expect to be pain-free ever?" The specialist said, "Probably not. The best you can probably expect is to manage and make it liveable." And that was difficult to hear, but not having the expectation that there is a miracle cure is a huge help. And I'm learning to live with it…I want to exist with it, rather than constantly fighting against it.

It is significant that Gordon's physician is involved in this process of acceptance. This excerpt suggests that having a trusted medical professional honestly explain that there is no cure, but it is possible to have "liveable" pain, greatly assists Gordon to learn to exist with the pain. Although it was difficult to hear there is no "miracle cure," this has given him permission to

stop constantly fighting against his body, and in this way, Gordon is embodying an alternative. He refuses to be defined as a sick person who is fighting to get better. Instead he embraces being in the liminal space between healthy/sick, and accepts a liveable life with pain.

While Julie and Gordon reveal the possibilities of "letting go," it is important to emphasize, as King (2012, 67) does, that "this is not a happier-ever-after fairytale." Instead, it should be understood as a long and difficult process without an end. In addition, according to King (ibid), for people with chronic illnesses, "letting go" is not a "free choice," rather learning "what to let go and when to let go" is "the only way to stay alive." Similar to Julie and Gordon, some of the other participants' accounts reflect that one way they are surviving is "letting go" of the search for a cure. All of the participants describe the harmful effects of stress on their bodies, and while the participants describe typical stresses that other people experience (i.e. stress related to finances, work, relationships, family responsibilities) they also describe the stress attached to being chronically ill within a neoliberal and consumerist culture that expects all of us to continually work on perfecting our bodies (Galvin, 2002; Shildrick, 2015). Nancy (UK), for example, explains that she initially "tried everything" to cure her symptoms, but now she has "let go" of the search for a solution:

> When I was first diagnosed I was always reading and researching and I tried everything thinking it might work to get rid of the pain. And then it was like other people too were like, "Oh have you done this? What about this?" And I used to try it all, but now I'm just like, "Oh just go away. I don't care." (Laughs.) I'm done with trying new things. I just do not want to engage with it anymore and try something else. There is no cure. The best I can do is manage it with pain medication so that's what I do.

Echoing the findings from Nettleton's (2006) study, the respondents' accounts – exemplified by Nancy (above) – reflect the "tyranny" of "searching for solutions and closure." Thus, it might be both a liberating relief and a means of survival to learn to "let go" of the stressful obligation to search for answers and certainty.

The difficulty – but again also the liberating potential – of "letting go" and just trying to exist in the liminal space in-between illness/health is that all of us are expected to be active agents and take responsibility for perfecting our bodies within the current neoliberal context (Armstrong, 2014a; Galvin, 2002). As Shildrick and Steinberg (2015, p. 9) explain, neoliberalism with its insistence that we all engage in acts of self-governance becomes entwined

with biomedicine resulting in the "promotion of an active subject who appears to manage her own health status and priorities." Managing one's health supposes actions/doing, and in relation to illness, this means putting on a "brave face" and going to battle against illness (Steinberg, 2015). In comparison, to exist with illness is seen to be passive and this passivity makes one a "bad patient" (Armstrong, 2014a; Steinberg, 2015). Neoliberal healthcare regimes also contribute to the negative perception of chronically ill people as blame-worthy and morally suspect (Galvin, 2002). The "paradox" of being held accountable for the active management of our health, however, is that we are "enmeshed in forms of governance that regulate the status of which lives count as healthy" (Shildrick and Steinberg, 2015, p. 10). Within this context, embodying an alternative is extremely difficult, but there is also the liberating potential of being able to resist harmful and constraining biomedical and "neoliberal-able" norms (Goodley, 2014). The process of "letting" go of the search for solutions and certainty, and instead learning to be un/well and to stop fighting against the body, are all important acts of resistance.

Finally, embracing uncertainty might also improve healthcare practices and benefit medical professionals as well as patients. Allowing for biomedical uncertainty might be the beginning of more compassionate and understanding care not only for people who live with ambiguous and undefined illnesses, but for all of us as "all corporeality is constantly changing and ultimately uncontainable" (Einstein and Shildrick, 2009, p. 294). Accepting the haunting cracks in biomedical knowledge, and letting go of the expectation for biomedical certainty would also likely relieve some pressure on medical professionals. As Michael's account above reveals, when doctors are perceived to be willing to acknowledge uncertainty and the limits of biomedicine, both patients and doctors might find they are then free to work together on finding liveable ways to manage chronic illness. Similar to previous research, the findings in this chapter thus suggest that a more "patient-centred" approach would be beneficial, particularly one that focuses on the whole experience of illness (Nettleton et al., 2005).

Chapter 6 - Unsettling Social Interactions and Transgressing Boundaries

Introduction

The previous chapter argued that the symptoms associated with FMS are "ghostly" in that they are both absent/present and in/visible, and that liminal bodily experiences haunt the biomedical imperative to classify and categorize (Overend, 2014). Building on these ideas, the current chapter explores how this liminality also unsettles socio-cultural classifications concerning health/illness and disability/ability by examining how FMS is made visible (revealed, recognized, and acknowledged) and invisible (concealed, discredited, and ignored) during day-to-day social interactions. The cultural assumption that disability and illness are self-evident means that people with non-visible chronic illnesses, like FMS, are inevitably assumed to be healthy and non-disabled (Vick, 2013). It is therefore mainly through verbal disclosure that people with non-visible conditions make their hidden impairments visible and known to others. Disclosure is often unsettling, however, because just as biomedicine is haunted by the uncertainty of medically undefinable illnesses, so too are social relationships and interactions. Rather than receiving understanding and compassion, the participants' accounts reflect that in many situations disclosing having a contested in/visible chronic illness is socially disruptive and often results in dismissal, scepticism, invasive questioning, and outright denial of their embodied experiences.

These negative reactions impact how people with FMS feel about themselves, and in turn this influences their decisions regarding whether or not to *pass* as healthy and non-disabled. This chapter argues that passing when done intentionally is not simply a form of stigma management; it is also deeply rooted in the internalization of cultural norms and values relating to gender, health/illness, and dis/ability. While the participants' accounts reflect that there are benefits to intentionally passing as healthy and non-disabled, it is also an untenable practice for many people with debilitating chronic illness, because of the emotional and physical toll required to conceal impairments. The chapter concludes with a further discussion of the concept of *embodying liminality* through an examination of both the painfulness and the potential

productiveness of unsettling social interactions by looking well and being ill, and appearing

non-disabled, but identifying as disabled.

Haunting Social Interactions: The Disruptiveness of Disclosure

In this thesis, chronic illness is conceptualized as a "category of impairment," and as

such, it is argued that chronically ill people experience various forms of social oppression and

exclusion, similar to people with other forms of impairments, even if they do not self-identify as

disabled (Thomas, 2007, p. 50). At the same time, it is important to acknowledge that people

with non-visible chronic illnesses, and other hidden impairments, exist in the "borderlands

between the disabled and non-disabled worlds" (Thomas, 1999b, p. 55). In addition, as Wendell

(2001, p. 19-20) explains there are crucial differences between people who are *healthy disabled*

and *unhealthy disabled* people. She states that *healthy disabled* people "regard themselves as

"healthy, not sick" and have "physical conditions and functional limitations that are relatively

stable and predictable for the foreseeable future." In contrast, *unhealthy disabled* people,

including people diagnosed with FMS, do often think of themselves as sick and do experience

different degrees of chronic physical suffering. The fluctuating and unpredictable nature of their

bodily experiences, however, means that their hidden impairments are persistently

unpredictable, and thus people with FMS and similar episodic conditions also live between the

worlds of health and illness (Lightman et al., 2009; Vick, 2013). Existing in this liminal space,

people who are *un/healthy dis/abled* fluctuate between health and illness, and may identify as

disabled and/or non-disabled.

Yet, the dominant cultural assumption that there are visibly obvious differences

between these categories means that individuals with hidden impairments, including people with

non-visible chronic illnesses, are automatically assumed to be healthy and non-disabled (Davis,

2005; Rhodes et al., 2008; Stone, 2005; Vick, 2013). People with non-visible impairments

therefore have to rely on verbal disclosure during most social interactions if they wish to make

others aware of their bodily experiences and limitations. While verbal disclosure is necessary to

make hidden suffering and unapparent difficulties visible to others, it is very uncomfortable and

at times quite distressing:

It is awkward to tell people and explain what it is really. And I'm quite choosy about who I tell, because I'm aware that I look healthy so people don't really understand (Katelyn, UK).

When you tell people you know they are looking at you and thinking there is nothing wrong with you, "oh she is perfectly fine." It is hard to explain that I've got an illness and I've got all of these symptoms and stuff that they don't see. It really frustrates me that you can't see it, because basically you can't explain it to people so that they will understand (Jane, UK).

The participants explain that even being open and candid with close family and friends is frequently problematic, because it is difficult for others to understand imperceptible illness:

I tried to explain it to my family, but nobody got it. I don't think my ex-husband really, truly got it. He just didn't understand, because physically you look fine. And I know the kids didn't get it. Because you look well, people just don't understand (Beverly, Canada).

I just think it is so hard to get people to understand, even your family and friends have a hard time understanding, because you can't see it. And not to say people with cancer have it easy, but with cancer you get a lot more compassion out of your family, and out of your support group. But when you have something like fibromyalgia, it is way harder, because it is not tangible. You know your hair doesn't all fall out. Like if I walked around with a scarf on my head and was bald, you know people would be a lot more understanding, and probably a lot more sympathetic (Karen, Canada).

The interviews highlight that it is difficult to tell others about illness and receive understanding when you "look well." Although not all people with cancer look ill, Karen makes the important point that telling others (even family and friends) about physical suffering results in very different (re)actions than visibly signalling this to others through non-verbal cues.

According to Vick (2013, p. 183), trying to explain that you are chronically ill/disabled while appearing healthy/able-bodied, "flusters cultural logic about what plausibly and performatively counts as health, illness, ability, and disability." The previous chapter discussed how the in/visible and absent/present symptoms of FMS and similarly undefined conditions are "haunting" in that they fail to be easily classified and contained within biomedicine (Overend, 2014). Similarly, liminal and "ghostly" (in/visible, episodic, and medically unverifiable) bodily experiences come to haunt social relationships and interactions, because they disrupt dominant taken-for-granted assumptions regarding the stability of the categories healthy/sick, disabled/non-disabled, and cultural notions of the physical verifiability of health/illness and dis/ability (Vick, 2013).

Gordon (Canada) explains that disclosure is difficult, because people often seem doubtful and tend to minimize his embodied experiences:

> It is hard because when you have it you don't look like you're sick and so people don't understand. And it isn't just the pain, there is the severe fatigue. And it is not just being tired, it is this insane fatigue. It is all you can do to just breathe sometimes. It is hard for people to understand. People just go, "Oh yeah right."

Other participants discuss how they feel their chronic symptoms are dismissed by others as simply being an overreaction to "ordinary" bodily experiences. Emma (UK) states:

> One thing you get with most people is, "oh you're just tired." That nice patronizing thing. And it just gets on your nerves, because it's not just tiredness, it's beyond tired.

Patricia (Canada) and Jane (UK) also explain that when they try to describe their experiences of pain, they sense that people tend to disbelieve them, or assume they are being hyperbolic:

> When you tell somebody that you've been in pain for years without a break they kind of look at you like, "Yeah right. Like how can you always be in pain?" (Patricia, Canada).

> When you say you have pain, they're thinking, "Oh well I have pain as well." But it is just so different. It is so different (Jane, UK)

These quotes all demonstrate how the participants use the interview as an opportunity to confirm that their experiences of pain and fatigue are outside "ordinary" bodily experiences. In the excerpts above, Gordon describes how he has "severe" and "insane fatigue," and Emma explains that "it is not just tiredness, but beyond tired." Similarly, Patricia and Jane both highlight how the pain they experience is "so different" from normal and temporary experiences of pain. In line with previous research, the interviews reveal how accounts of hidden and contested conditions are constructed to counter scepticism by emphasizing the "extraordinary" (Richardson, 2005).

At the same time, the accounts highlight how difficult the participants feel it is to make others comprehend their bodily suffering when pain and fatigue are both normal and ordinary (as we all experience them to some degree) and abnormal and extraordinary (as they are indicative of illness). Bodily experiences that are extra/ordinary, in/visible, absent/present and un/known haunt biomedical classifications, and in turn, disturb socio-cultural categories that define who is entitled to identify as healthy/ill and disabled/non-disabled. As such, the participants' accounts of scepticism or denial might be read as a way to reject the unsettling

possibility that dichotomous categories are illusory, while simultaneously reinforcing the boundaries of health/illness and dis/ability.

"Why can't you do it?": Disclosure as Forced Justification

Liminal embodiment transgresses boundaries that are heavily policed, and it means that people who embody liminality are often treated as suspect and potentially as "misfits." To review, Garland-Thomson (2011, p. 593) explains that the term "*misfit*" describes "both the person who does not fit and the act of not fitting…to mis-fit renders one a *misfit*" (italics in original). In addition, she explains that it is the "discrepancy between body and world, between that which is expected and that which is, that produces fits and misfits" (Garland-Thomson, 2011, p. 593). It is assumed that those who appear healthy and non-disabled do not have any limitations or difficulties and thus they should be judged "according to conventional standards about what constitutes acceptable behaviour" (Stone, 2005, p. 294). The participants' accounts reflect the understanding that there is a discrepancy (a "misfit") between how people perceive them (i.e. as healthy and able-bodied) and their actual unseen and unknown limitations.

The participants describe how this misfitting means that they feel forced to disclose having a chronic illness in certain situations in order to justify their hidden struggles. Meredith (UK), for example, explains that she feels obliged to tell people about having FMS when she is questioned about why she is unable to perform certain tasks: "There's things you can't do and they'll say like, "Well why can't you do it?" Similarly, Jane (UK) states that having a non-visible illness that is also episodic means that she feels as though she has to tell people she has FMS in order to justify her changing dis/ability:

> People think why can't you do that today when you could do it yesterday. I don't blame them for not understanding. It is a disease that sometimes I can't even explain myself.

Jane admits that even she has difficulty comprehending her own bodily inconstancy, however, she feels as though because people do not understand her fluctuating ill/health, they question why she is episodically (in)capable.

At times then the participants' accounts suggest that verbal disclosure feels more like a *forced confession*, because people with non-visible and fluctuating conditions feel compelled to tell others about their hidden impairments in certain contexts in order to explain episodic limited

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function or their occasional inability to perform certain tasks, or to provide a reason for being unable to regularly participate in social and recreational activities.[6] Gordon (Canada), for example, explains that because FMS "isn't something people can see" he is concerned that people assume he is "just being lazy," and thus he feels compelled to disclose having a chronic illness in order to counter this negative perception. Similarly, another quote from Jane (UK) reflects how being unable to take part in certain social activities results in her feeling like she must justify her behaviour:

> For instance if you go out on a date, and then they want to go on a date the next week, you can't say for sure that you can go, because you don't know what you are going to be like next week. And so it is hard to sort of have a social life. Because it's like well she went out last week so what is wrong with her this week that she can't go out? It is hard to say to people well these are my symptoms and I don't know what I'm going to be like on a day to day basis.

This quote also points to how people with ambiguous and misunderstood conditions might be doubly burdened in that they have to manage negative social reactions (particularly scepticism) while simultaneously dealing with the physical effects of fluctuating chronic illness, thus highlighting the complex interaction between what Thomas (1999; 2012) terms *(psycho-emotional) disablism* and *impairment effects* (discussed later in the chapter).

It is also important to note that disclosure might be intended to justify behaviour, but without "proof" it can be interpreted as a "made up" excuse. For example, Shannon (UK) states:

> If one day I cancel with one of my friends for instance, because I'm feeling really tired and I have a headache, I do kind of worry that they might think, "Oh she's not really ill any way." That I'm just making it up.

Along the same lines, Meredith (UK) describes sensing that people think she is lazy and not really ill:

> You get the impression that people think you're being lazy almost. They don't understand that it is because of the pain and exhaustion you can't do it. It's not that you're being lazy. But you get the idea from people, you feel like that's what they are thinking, that you're just using it as an excuse.

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[6] The workplace in particular is a setting where it might be necessary to disclose hidden impairments in order to provide justification for missing work due to medical appointments, "sick days" and/or to explain difficulties performing certain work-related tasks. It is also necessary to identify as chronically ill or disabled in order to receive workplace accommodations and disability benefits. The following chapter examines these themes.

Similarly, Jessica (Canada) explains: "My fiancé's friends think it is like a lazy thing, you know, that I'm using it to try to get out of doing stuff."

Writing about her own experience of trying to explain to others her hidden struggles with CFS/ME, Wendell (1996, p. 27) highlights many of the same issues as the participants:

> The problem was that when I had recovered enough to return to work part-time I no longer *looked* very ill although I still fought a daily battle with exhaustion, pain, nausea, and dizziness…I was struggling and since people could not see that I was struggling, I was constantly explaining to them that I was struggling, that I could no longer do things I had done before, and that I did not know when or even if I would ever be able to do them again. I simply wanted my friends and the people I worked with to recognize my limitations and to accept, as I had, that they might be permanent, but it is hard to describe the invisible reality of disability to others without feeling that you are constantly complaining and asking for sympathy.

In addition to disclosure being misinterpreted as an excuse, Wendell and the participants explain that telling people about pain, fatigue or other hidden impairments might be misconstrued as moaning and complaining and/or a plea for sympathy and pity.

Katelyn (UK) states that she is often anxious about telling others she is chronically ill as she assumes they might either think she is lying or that she is "moaning":

> If you tell them you think that people are going to think that you're moaning. "Oh she's a moaner. She's ill and she's just moaning about it all the time." You have that in your head that they're going to be thinking I'm blagging them, or that I'm a moaner or a whiner or whatever.

Similarly, Beverly (Canada) describes how she finds it difficult to be honest with her family:

> You feel like you are just complaining. So I found that hard, because I don't want to whine. And I think the family was sick of me, frankly, because they said, "Mom that's all you ever say is that you are in pain."

Other participants discuss how telling people they are chronically ill and/or disabled is also difficult, because they sense that it is often misinterpreted as pity-seeking. As Julie (Canada) states, "I don't like to tell people, because I just don't want people pitying me."

Similarly, Jane (UK) explains:

> When you tell them that you're not well or you're disabled and you see people's reactions, sometimes it is pity and I hate pity. I hate people feeling sorry for me. That is the worst. I don't need people crying on my behalf.

Researchers in disability studies have argued that the dominant cultural assumption that disability and chronic illness are personal tragedies results in the belief that chronically ill and disabled people are to be pitied (de Wolfe, 2002; French and Swain, 2004; Morris, 1991). The

participants' accounts reflect that they feel as though when they try to tell people about their hidden struggles that people assume they are complaining or asking for pity, rather than simply trying to gain acceptance and understanding for their limitations and difficulties.

"Does fibro really exist?": Disclosing a Marginalised and Contested Diagnosis

In addition to the issues outlined above, there are difficulties attached to disclosing a socially marginalized and contested diagnosis. Some of the participants explain that it is awkward to tell people they have been diagnosed with FMS, because it is not well-known:

> And you try to explain to people how it affects your joints and when you tell them that it's called fibromyalgia, well they've never heard of it (Harold, UK).

> It seems to be that the general public knows nothing about it…I think at the end of the day fibromyalgia is quite a meaningless term to most people. So it would make life just a lot easier for people who have fibromyalgia if people actually knew what it was (Shannon, UK).

> When you tell people you have fibromyalgia they just look at you blankly as if to say, "What's that?" It is not a recognized illness that people understand (Meredith, UK).

Researchers like Barker (2005) and Asbring and Narvanen (2002) have pointed out that FMS and similar conditions are low-status and marginalized illnesses. The participants' accounts reflect that during some interactions having a low-status condition that is not widely known results in a feeling of being dismissed by others. Although it is not necessarily a matter of people intentionally dismissing FMS, the participants explain that they sense there is the implication that the diagnosis is "meaningless" and thus not important enough to be recognized or understood.

While the participants' accounts reflect that FMS is not widely recognized, at the same time, the participants also describe that FMS is known as a contested and medically unexplained illness. In turn, the participants felt that the contested status of FMS contributed to perceived negative assumptions that FMS is a "made up" condition that is "all in your head," or just another label for hypochondria. Even the participants themselves discuss holding these negative perceptions about FMS. For example, Jessica (Canada) explains that she was shocked when she was diagnosed, because she did not consider FMS to be a legitimate illness:

> When I was reading up on rheumatoid arthritis [FMS] came up a couple of times and I started looking at it and I thought, oh that just sounds like a hypochondriac or something, right? And I just went poopoo that's obviously not me, right? I had real pain.

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Being diagnosed with FMS was unsettling for Jessica, because the diagnostic label (and the meanings attached to it) did not fit with her perception of herself as a credible woman with genuine ("real") pain.

Jessica further explains: "[FMS] seems to be the worst thing in the world to have. You know like it's not like acknowledged and even some doctors don't think it's real." People (particularly women) with contested diagnoses sense scepticism regarding the reality of their embodied experiences, and feel subjected to the psychologizing of their symptoms by both medical professionals and lay people (Asbring and Narvanen, 2002; Werner and Malterud, 2003). The previous chapter examined how many of the women interviewed for this project experienced their symptoms as being psychologized by medical professionals, and this left them feeling demoralized. The women describe interactions with medical professionals where they implicitly or explicitly implied that the women's symptoms were "all in their head," and/or that FMS was not a "legitimate" illness.

In addition to feeling discredited during doctor-patient interactions, some of the participants describe emotional encounters with lay people (including family and friends) who they felt questioned, or even outright denied, the existence of their symptoms and the validity of the FMS diagnosis. For example, both Michael (Canada) and Amber (Canada) describe feeling that they are not believed, and that people assume FMS is a "bogus" illness:

> You talk to people about fibromyalgia and there's the body language that they don't believe you. There's the stigma that oh it's just slacking or it's not real (Michael, Canada).

> You try to explain it and you say, "I've got fibromyalgia" and there is a real stigma still against it. People just look at you as if to say, "Oh yeah right. That's not real" (Amber, Canada).

Along the same lines, Monica (Canada) describes being subjected to suspicion and intrusive questions regarding the reality of her pain, and the legitimacy of the FMS diagnosis:

> I would say that I had it and some people would say, "Well are you sure?" Like I've had people say, "Are you sure it's not just in your head?" Like "Does fibro really exist?" Like one time in particular this woman kept asking me questions, and she said, "Are you sure it is not in your head?" And I said, "Well yeah I'm sure it's not in my head." And so then I just kind of figure well there are other people here I can talk to. I don't need to sit and get into any controversy with you.

"I don't want people labelling and stigmatizing": Concealing FMS

The interviews highlight how disclosing a medically unexplained and contested illness is difficult in some social situations because of fears, or previous experiences of, being met with suspicion, invasive questioning, and implications that they might be "faking" illness. I argue that the participants' accounts of past and anticipated responses of scepticism, as well as potential allegations of malingering or pity-seeking, all contribute to a desire to conceal illness and disability from others, and instead *pass* as healthy and non-disabled. As was previously discussed, Goffman (1963, p. 14) differentiates between the *discredited* (those whose "differentness" is visibly evident) and the *discreditable* (people whose "differentness" is hidden). *Passing* is only an option for *discreditable* people who can intentionally manage information to avoid stigma and to prevent becoming *discredited* (Goffman, 1963). There have been multiple studies and autobiographical accounts of the social difficulties experienced by people with non-visible and contested illnesses (Asbring and Narvanen, 2002; Lonardi, 2007; Vickers, 1997; Wall, 2005; Wendell, 1996). Drawing on Goffman's (1963) concepts of stigma and passing, this research reveals that non-visible, medically unexplained, and contested illnesses are experienced by affected individuals as stigmatizing, and thus passing allows people with these conditions to manage how others perceive them.

Supporting the conclusions of previous research, the findings from this project highlight how people feel FMS is a stigmatized condition, and that this might induce people to intentionally hide it from others. Courtney (Canada) explains that because FMS is a medically unexplained illness she conceals the diagnosis from others for fear of being disbelieved:

> I would love to know what causes it. I think anybody who is ill wants to know the cause of it. It gives it validity and I think that is extremely important not only for yourself but for other people. You know because I've hidden it for years, because you don't know who is going to believe you and who is not going to believe you.

Julie (Canada) also explains that regardless of the pain and suffering she experiences she does not tell people she has FMS:

> I don't want people labelling and stigmatizing, because of this fibromyalgia bit, so I have a tendency when I'm in a lot of pain and I'm in social situations I never let anybody know that I'm in absolute misery almost all the time. I feel like people really do not understand, and people tend to think it is all psychological.

Again, the assumption that FMS is a psychological disorder is seen as potentially discrediting and thus something to be hidden from others in order to not become fully discredited. Although this might seem extreme, as the analysis thus far has served to elucidate, and has been highlighted by other research, disclosing having medically unexplained and contested conditions in order to account for limitations and difficulties does in some cases actually lead to increased scepticism and even outright disbelief (Armentor, 2015).

A sense of the stigma attached to medically unexplained and uncertain illnesses is further reflected by those participants who describe telling people they have recognized and legitimate illnesses and diseases, such as MS, cancer, migraines and arthritis, instead of disclosing having FMS. Harold (UK) states, "I often tell people I have cancer." Similarly, Shannon (UK) explains that she sometimes tells people that she has an "obvious illness that people know," or that she has a migraine, and Nancy (UK) regularly tells people that she has MS. Thus, rather than risk the potential stigma associated with having a contested diagnosis, some of the participants describe passing not as healthy, but as legitimately ill. By concealing FMS and claiming to have a medically explained and uncontested illness, the participants were able to provide acceptable justification for why they look healthy, but behave as though they are ill (i.e. have difficulty walking long distances, need to rest for long periods, being unable to work etc.).

"I don't want to be a burden": Disablism and Intentionally Passing

The participants' accounts clearly reflect that their sense of the stigma associated with having a medically unexplained and contested condition leads them to conceal FMS and instead pass has healthy/non-disabled, or in some cases, to pass as legitimately ill. It is argued in the following section, however, this sense of stigma is only part of the underlying reason for passing. As was previously mentioned, sociological research on stigma and passing has been critiqued for framing chronic illness and disability as deviance (Goodley, 2011; Thomas, 2007). This thesis moves beyond previous research and theorizing by examining systemic social oppression by incorporating the concepts of *compulsory able-bodiedness* (McRuer, 2006) and *internalized ableism* (Campbell, 2008). McRuer (2006) argues that able-bodiedness is "compulsory" because we live in a culture that assumes ablebodiedness is both the ideal and the

norm that we all are striving to embody. *Compulsory able-bodiedness* like "compulsory heterosexuality…functions by covering over, with the appearance of choice, a system in which there is actually no choice" (McRuer, 2006, p. 8). Campbell (2008) similarly argues that from the moment we are born we begin to internalize ableist cultural norms and values and we quickly come to believe that to be disabled is to be "less than." Thus, disabled people "internalize" ableism in the same way that it has been argued that "people of colour absorb and internalize aspects of racism" (Campbell, 2008, p. 154), and how women internalize sexist standards of idealized femininity (Bartky, 1988). Campbell (2008, p. 156) further argues that internalized ableism can lead to *ableist passing*: "keeping the colonizer happy by not disturbing the peace, containing matter that is potentially out of place."

The notion that internalized ableism contributes to disabled people passing so as to not "disturb the peace" is reflected in the interviews. Specifically, the respondents' accounts reveal that answering the seemingly innocuous question, "how are you?" is challenging, not only due to the stigma and scepticism attached to having an in/visible and medically unexplained illness, but also because they want to protect other people, especially family and friends, from what is perceived to be the burdensome reality of chronic illness/disability. For example, Curtis (UK) explains that he feels "trapped" into concealing his pain, because of the responsibility he feels to not burden his family and due to the obligation to not worry or upset anyone:

> I don't want to be a burden to my family. They don't hear about how dad's in pain. You know, you try and keep it from them. And the same thing when people ask "how are you?" I say, "Oh I'm not too bad today." But I'm not, it's just that I'm trapped. I just say I'm fine and I smile.

Similarly, Patricia (Canada) states:

> I feel bad for people who ask, "So how are you feeling today?" It's like I want to give them something encouraging. I don't want to moan and whine about it. And I don't want them to feel like they have to worry or anything.

Maria who was originally from Mexico, but is now a Canadian citizen, also discusses how she feels forced to tell people she is "fine":

> When I moved here in the beginning I thought that everyone was so nice and that they really cared how I was doing. So you know if some people would say, "How are you?" I'd say, "Well I'm not feeling too good," or "Oh today is not a good day." And then my husband said, "Just tell them you're fine." I still don't know why they ask that, because they don't actually care how you are at all. You would only ask that in Spanish if you

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really cared to know. But even friends or family here do not want to know. I guess somehow it puts you down if you know that somebody is suffering so much.

Coming from another culture with a different language, Maria offers acute insight into how passing is related to cultural norms and values that instruct us that only affirmative responses, such as, "I'm fine/okay/better" are acceptable (or "speakable") answers to the question, "how are you?" In contrast, it is "unspeakable" and "wrong" to tell others about the reality of living with pain, fatigue and other impairments, as this is assumed to be burdensome. As is discussed further below, it also might be that self-policing and passing are rooted in the knowledge that the act of telling others about suffering, pain, or simply the need for more rest, is seen as transgressive within a neoliberal-able and capitalist context where we are all expected to carry on and "push through," even if this means we become (further) debilitated in the process (Goodley, 2014; King, 2012; Shildrick, 2015). The participants' accounts thus suggest that an awareness of cultural expectations leads to self-policing to conform through *ableist passing*, which is ultimately about being non-disruptive and compliant (Campbell, 2008, p. 156). In line with Siebers' (2013, p. 289) argument regarding passing, the participants' accounts reflect that "[d]isabled people who pass for able-bodied are neither cowards, cheats, nor con artists but skillful interpreters of the world."

Even when they are not explicitly asked about their health, most of the participants explain that they often feel compelled to smile and silently suffer, rather than upset, worry or distress others by telling them about their bodily experiences. Nora (UK), for example, describes how she feels as though she cannot be honest with her son, because it causes "friction":

> Sometimes I can't tell my son that's wrong with me or that's wrong with me, 'cause he doesn't understand. He finds it difficult and then it causes friction between us as well.

Similarly, Robyn (UK) discusses how she has become "really reluctant" to tell anyone about her hidden impairments, because it upsets people and then she ends up comforting them:

> I don't tell new people that I meet. And even when the pain is really bad I'm really reluctant to mention it to anyone. When I'm at work or in meetings I can barely sit, but I'm really reluctant to say anything and I think it is because it is just much easier not to mention it. I end up trying to comfort other people for me being in pain, and I don't have the energy for that when it is bad. So it is easier not to mention it.

Disclosing having a chronic pain condition would likely allow for accommodations to be made that would make her pain more manageable, yet Robyn often chooses to pass, in part, because it is "easier" than performing the emotional labour involved with disclosure.

Being a Good Woman and a Strong Man: Gender Stereotypes and Passing

The participants' accounts also referenced gender norms and expectations in relation to hiding illness/disability. Specifically, the social expectation that women will care for, and protect, others can be "internalized as an ethic of responsibility" and this makes women "particularly vulnerable to guilt and to a concern with 'not upsetting people' or ever acting so as to fracture a relationship" (O'Grady, 2004, p. 95). The women's accounts in this study reveal that the guilt and shame attached to telling family, friends and others about pain, fatigue and other bodily suffering, combined with the cultural pressure for women to make sacrifices and prioritize caring for others above self-care constrained their decisions regarding whether or not to reveal/conceal being ill. Jane (UK), for example, explains how she conceals how she truly feels, because she does not want to "hurt" her family:

> I know like for me with relationships you feel like a liability. And I know my family find it really difficult seeing me like this. And that's why I always say, "I'm fine." And I try and stay positive and upbeat and motivated and smile a lot. It's like you have to lie so you don't hurt them.

Similarly, Courtney (Canada) explains how she hid being ill to protect her children:

> I always hid it from children. I didn't want them growing up with a sick mother so I did everything that I could do so they didn't know. And you know the kids never, ever knew until probably recently that I have this. And I still don't really talk about it in front of them, you know?

The impetus to pass is thus related to identity-management and morality; specifically the desire to be seen as a "good woman" and "good mother," who sacrifices her emotional needs and physical health for the benefit of family, friends, and others.

Finally, the quotes below from Lindsay (UK), Lillian (UK) and Robyn (UK) reveal how relationships are strained when women are not seen to be measuring up to gender expectations, and particularly when there is a "role reversal" (i.e. mothers needing care from children, and wives and female partners needing care from husbands and male partners):

> My son and daughter-in-law don't get it at all. They get angry with me when I forget things, and they think I'm being difficult. I'm not the kind of sparky, you know, uplifting, person I was, and I think they resent it, really (Lindsay, UK).

> Because it wasn't going away and it was going to continue and it could get worse I suppose it's scary. I'm not saying he left me because he didn't want to look after me. I think it just got too much for him and he thought he couldn't help me (Lillian, UK).

> I have had two major relationships and I think with both of them their quality of life has suffered quite a lot from being with me and my pain. Yes, definitely it has put a strain on relationships (Robyn, UK).

Although Curtis describes feeling "trapped" into passing, because he does not want burden his family or upset anyone, overall the accounts suggests that women (more than men) pass due to feminine gender norms that require women to care for others and protect relationships. In our culture, women are valued for their ability to take care of others, and are "trained to shield" family, friends, and acquaintances from the reality of living with chronic illness (Stone, 1995). The interviews reflect that women with non-visible illnesses might "shield" others by "downplaying" their need for rest, or concealing their pain and suffering. In contrast, the accounts reflect that women who reveal that they are ill (or perhaps more accurately, are unable to hide it) reported feelings of shame and guilt about needing, rather than providing, care to others. Additionally, being unable to meet these gendered expectations can lead to resentment and damage relationships, which results in further shame and guilt.

In contrast, the accounts from the male respondents suggest that their motivation to pass might be rooted in the perceived stigma attached to having a "feminized" illness. FMS (like all illness) is "gendered feminine" (Garland-Thomson, 2002, p. 10), but FMS in particular is diagnosed in women far more than men and is often described as a "women's condition" (Asbring and Narvanen, 2002), and it tends to be framed as a "women's issue" (Barker, 2005). The male respondents express the understanding that men with FMS are a marginalized and socially in/visible group. All of the men interviewed describe how they tend not to talk to people about having FMS, and instead "suffer in silence," due to the assumption that it is a women's condition. Harold (UK), for example, explains:

> I wish there were more men coming forward to say they've got his. I found fibromyalgia UK, and joined the magazine like I say. So there's information on it, but I find there's not enough information in that magazine as well. It's basically all women writing for women. It's just like as men we don't want to say anything to anybody we just suffer in silence. And that needs to be conquered.

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Similarly, Gordon (Canada) states:

> It would be nice to know other men who are going through it. You really feel marginalized, because you feel like very few people have this and out of them very few are men.

Passing by concealing illness, particularly an illness that is gendered feminine, might also be the result of hegemonic masculine stereotypes that encourage men to be stoic and not to speak about how they are feeling (Bird and Rieker, 1999; Charles and Walters, 2008; Courtenay, 2000), as well as the imperative to not ever appear "feminine" (i.e. frail, dependent, vulnerable). As Courtenay (2000, p. 1389) explains:

> Rejecting what is constructed as feminine is essential for demonstrating hegemonic masculinity in a sexist and gender-dichotomous society. Men and boys who attempt to engage in social action that demonstrates feminine norms of gender risk being relegated to the subordinated masculinity of "wimp" or "sissy."

Michael (Canada) clearly describes the understanding that disclosing having chronic pain and fatigue would somehow make him appear less masculine:

> I don't like talking about it. I mean guys don't complain. You know real men don't cry. It's that mentality. It is just you know suck it up and keep going.

Another particularly telling example of not wanting to be considered "weak" or somehow "less than" is given by Gordon:

> There is a huge pressure that to be male you have to be physically strong right? Amongst other guys we don't want to admit that we're in pain. I remember days when I would be getting ready to go to work and I could barely stand up and I was in tears it hurt so bad and I would think, "How could I tell this to my buddy?"

The accounts reflect that concealing physical suffering, difficulties and limitations is related to the pressure, especially for men, to appear "strong" and physically capable. In addition, masculine stereotypes align with *neoliberal-ableist* discourses that pressure all of us to always appear independent, able, fit, and competent (Goodley, 2014). To identify as disabled, and suffer with illness, to show any weakness or dependency, to be seen as a burden or a "liability," sits in opposition to internalized neoliberal-ableist ideals of selfhood and embodiment.

"I wish I could have a badge": Unintentionally Passing

Within our culture passing as healthy and non-disabled holds significant privileges, whereas there are "profound disincentives" and few benefits to identifying as "sick" or

"disabled" (Garland-Thomson, 2002, p. 22). While passing intentionally is rooted in internalized cultural norms and values, and a unique understanding of the benefits of being perceived to be healthy and able-bodied, it is also important to acknowledge that passing is not always done deliberately. The respondents' accounts reveal that in many day-to-day interactions they pass unintentionally, rather than by intentionally concealing that they are ill or by actively choosing not to identify as disabled.

Samuels (2003, p. 240) argues that passing is most often assumed to be a deliberate act, but this fails to acknowledge situations where people pass "by default." Speaking about her own experience as a queer and "invisibly" disabled woman, Samuels explains:

> I certainly do not make an effort to appear "heterosexual" or "nondisabled" when I leave the house in the morning; those are simply the identities usually derived from my appearance by onlookers. While there are a number of queer accoutrements, such as buttons, stickers, jewelry, and T-shirts, that I could (and often do) choose to wear to signal my lesbian identity, a very different cultural weight is placed on any attempt to signal a disabled identity, as suspicions of fraud attach to any visible sign of disability that is not functionally essential (Samuels, 2003, p. 240-241).

Samuels makes two important points; first, that passing unintentionally ("passing by default") describes the experience of most people whose appearances signal to others that they are healthy and non-disabled. Second, Samuels argues that there are few ways to make oneself "look" disabled that will not be deemed suspicious or fraudulent.

The respondents' accounts reflect that they feel as though they do not "fit" with dominant conceptions of how ill and disabled people are expected to look, and in many social situations it is easier not to challenge or disrupt assumptions that are being made based on their physical appearances. For example, Shannon (UK) explains:

> Sometimes it's difficult if I just really need to sit down on the tube or something and I just feel like if there is older people there then I feel really bad. I just wish there was a way to let everyone know I've got a condition and I need to sit down. Because you feel like they just look at you and assume that you're healthy and fine. So that can be quite difficult I guess. I used to joke that I wish I could have a badge for when I'm on the tube just saying "I'm disabled."

There is no straightforward way for Shannon to signal to others that she has hidden pain and fatigue that makes it difficult for her to stand for long periods of time. Given her physical appearance she passes unintentionally as it is assumed that she is a young, fit, healthy and non-disabled woman, and therefore she does not require any accommodation. In order for her to

receive the accommodation she needs – seating on public transport – she must publically

disclose this information to complete strangers. Not only would this be socially awkward, but

there is the possibility that people could become hostile and openly question whether she

actually does have a chronic illness, because as was discussed above, chronically ill people are

often perceived to be questionably disabled, and possible "imposters." This is confirmed by

Davis (2005, p. 208) who argues that disabled people with non-visible impairments are put on

trial and treated as suspect in their daily lives, and are often unable to "meet the burden of

proof," due to the absence of physical evidence. Faced with these possible negative reactions, it

is hardly surprising that Shannon desires a "badge" to indicate that she is chronically

ill/disabled.

Yet, some of the participants actually had disability "badges" in the form of disabled

bus and parking passes, and they still experienced scepticism and hostility. Given that the

"paradigmatic" disabled person is represented by a *healthy* individual in a wheelchair, *unhealthy*

disabled (chronically ill) people "do not fit most people's picture of disability" (Wendell, 2001,

p. 21). As such, having a disabled pass was not always taken to be confirmation of the

participants' status as disabled. Nora (UK), for example, explains:

> I've got a disability bus pass and the majority of drivers give me the most filthy look,
> because they see my disabled pass and look at me and it's like who are you conning?
> Or when I use my blue badge to park you can see people's faces when I drive in to the
> disabled spaces at the front, they look at me like why does she need a blue badge?
> What's wrong with her?

This excerpt reflects how passing unintentionally becomes socially disruptive when people with

non-visible impairments attempt to identify as disabled. Even in cases where there is visible

"proof" (i.e. a disabled bus or parking pass) there is still the persistent understanding that

appearance alone establishes whether one is disabled or non-disabled, and destabilizing this

taken-for-granted illusion is highly problematic.

According to Stone (2005, p. 294), people with "invisible disabilities" often experience

difficulties in day-to-day social interactions because:

> With regard to the body, we learn to take it for granted that, among other things,
> everyone may be placed into the category either of those who are disabled, or the
> category of those who are abled. Moreover, we are taught to believe that, by attending
> to the visual and/or auditory cues, it is easy to tell who belongs to which category...The
> hegemony of dualistic thinking means that there is the assumption of an unproblematic

divide between disabled/abled. Coupled with the belief that decisions about who belongs in which category can be determined with empirical evidence, there is no room for recognizing that those who appear to be abled may nevertheless have unseen difficulties. This dualistic thinking creates a problem for those with invisible disabilities, because they do not fit into neatly pre-defined categories.

Another account from one of the participants further reveals the disruptiveness of transgressing categories that are seemingly obvious and stable. Tracy (UK) explains how she uses a wheelchair in certain situations, because she can only walk short distances. Her account reveals that the widely held notion that disability is physically evident, combined with the dominant understanding that all disabled people have permanent and unchanging impairments (Rhodes et al., 2008), results in distressing social interactions:

> With fibromyalgia you can't see it, and people tend to judge a book by its cover don't they? People have got it in their head that if you're in a wheelchair you're either supposed to be old or really disabled, and if you're not either of those, they don't know how to categorize you. And sometimes I have to get out of my chair to stretch my legs because I'm getting stiff, and I'll just get up for a second and sit right down again and all of the sudden you'll hear people are like, "[gasp] she just got out of the chair she can't be disabled, what is she doing?" And I said one of these times I'm gonna stand up and go, "halleluiah, praise the Lord, I can use my legs," because you've got to just laugh about these things or you'll go crazy.

While Tracy explains that she tries to find the humour in this situation, she also discusses later in the interview how she feels people assume that she is using the wheelchair because she is "lazy" or "faking," or trying to gain sympathy or pity, and this results in her not using it very often, even though it helps with her pain.

The idea of *misfitting* is helpful for understanding the consequences of passing unintentionally; rather than accept that things are not always what we expect, or as they appear, the unfortunate reaction to this misfitting is scepticism and denial and the treatment of people who disrupt these expectations as outcasts/misfits. Further, as the next chapter discusses, it is important to take into account the wider social context to understand these reactions; following the financial crises of 2007/2008, and the resulting "reigning in" of benefits, there has been greater scepticism and surveillance of disabled people claiming disability-related entitlements (Briant et al., 2013). Implicit or explicit charges of non-visibly disabled people "conning" the system or "faking" being disabled, must be considered in relation to neoliberal-ableist discourses that create the understanding that many (if not most) recipients of disability-related entitlements are actually con-artists and benefit scroungers (Goodley, 2014, p. 9-10).

At the same time, Nora and Tracy offer subversive performances of dis/ability and un/wellness. People who appear healthy/non-disabled and verbally disclose, or otherwise identify themselves as ill and/or disabled, disrupt the illusion of distinct and stable dichotomous categories. In this way, Nora and Tracy disrupt dominant cultural understandings of disability and illness, but they also unsettle cultural assumptions regarding what constitutes ability and health. The concept of misfitting is helpful here as well, because it sheds light on these multiple layers of misfitting and liminality. Garland-Thomson (2011, p. 595) argues that an "iconic disability access scene of misfitting" is a person in a wheelchair who cannot enter a building, because the building has not been built with a ramp. With regard to Nora's and Tracy's accounts above, this misfitting occurs on more than one level. They are likely to encounter many of the same issues as disabled people with regard to accessibility, but due to their liminal embodiment they are also seen as transgressive and are cast as misfits when they use disability-related equipment or access services as disabled people, because they do not appear to be obviously disabled or legitimately chronically ill. This misfitting and liminality can be difficult, as the accounts above reveal; however, transgressing boundaries holds the potential for meaningful resistance against restrictive cultural categories that obscure the full range of bodily difference. Unexpected performances, such as Tracy getting up from her wheelchair to stretch her legs, are subversive as they reveal "that which exceeds the norm" (Shildrick and Price, 1996, p. 107) and in this way, "performativity may evade normalization and move instead into transgressive resistance" (ibid). The potentialities of embodying liminality for subversion and resistance will be discussed further below.

"Feeling like an Imposter": Psycho-emotional Disablism

The concept of *psycho-emotional disablism* (Reeve, 2002; Thomas, 1999a) is helpful for understanding the treatment of people with non-visible chronic illnesses as questionably ill and dubiously disabled. As was previously discussed, *disablism* is the "*social* imposition of *avoidable restrictions* on life activities" (italics in original, Thomas, 2012, p. 211). Thomas differentiates between disablism that is related to external social barriers and *psycho-emotional disablism* that places restrictions on inner wellbeing, such as, "feeling 'hurt' by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, unattractive,

hopeless, stressed or insecure" (Thomas, 1999, p. 47). The participants' accounts reflect they are often subject to *psycho-emotional disablism* in the form of dismissal, scepticism, hostile questioning, and the suggestion that their embodied experiences are not worthy of being recognized or understood.

In addition, the effects of disablism interact with *impairment effects*. Thomas describes *impairment effects* as the "direct and *unavoidable* impacts that 'impairments' (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world" (italics in original, Thomas, 2012, p. 211). The interaction between *impairment effects* and *psycho-emotional disablism* is also reflected in the participants' accounts. For example, Tracy describes encountering scepticism when she uses her wheelchair, and she feels as though people think she is "faking" being disabled for attention. The psycho-emotional disablism she is subjected to results in her rarely using her wheelchair, and in turn this exacerbates her pain and fatigue. Furthermore, given that people with FMS, and similar conditions, often experience a combination of bio-psycho-emotional symptoms, disablism resulting in depression, stress and feelings of insecurity, can lead to "flare-ups" resulting in more severe experiences of pain, fatigue, and other symptoms (Barker, 2005, p. 79).

While *psycho-emotional disablism* is most often associated with the attitudes, behaviours, and discourses that construct disabled people as "less than," and unworthy, it is also paradoxically the reason why people with chronic illnesses might feel they are simultaneously "less than" able and "less than" disabled; unworthy of love, understanding, and compassion for their illness experiences, and also unworthy of claiming to be disabled and thus undeserving of social accommodations and disability-related entitlements. It is through *psycho-emotional disablism* that people with contested, non-visible conditions come to be quintessential misfits, because they do not clearly "fit" either side of the oppositional categories healthy/ill or non-disabled/disabled. This understanding is supported by one of the participants who explains that she would feel like an "imposter" if she were to attend a disability support group:

> I mean if I was to go to a support group and everybody there is quite obviously disabled, maybe in wheelchairs or something like that then you'd feel a bit like you shouldn't really be there I think. I would feel like an imposter. Because I guess it [FMS] is an invisible disability…I just feel like I wouldn't fit in the usual support groups,

because I don't really know if I'm like ill enough to be considered disabled (Shannon, UK).

This quote highlights how *psycho-emotional disablism* contributes to the internalized belief that chronically ill people are not worthy of claiming to be disabled; because it is taken-for-granted that people with visible, stable impairments are unquestionably disabled, while those with non-visible impairments are potential "imposters."

Furthermore, *psycho-emotional disablism* is connected to *neoliberal-ableist* discourses that construct and differentiate between the "genuinely" disabled person and the disabled "imposter" and this has both political and personal implications (Goodley, 2014). As the next chapter argues, these harmful discourses justify the denial of entitlements to groups of disabled people who are deemed unworthy, because they are "not disabled enough" (Lightman et al., 2009), and they also shape how people who are in/visibly disabled feel about themselves and their own worthiness to receive entitlements. Here too, Shannon clearly feels undeserving of being in a group with other disabled people, because FMS is an "invisible disability," and thus not a "true" disability. Thus, Shannon's experience reflects how *psycho-emotional disablism* that results in her feeling unworthy and like a potential imposter, also leads her to "modify her behaviour via *self-surveillance*" (emphasis added, Reeve, 2002, p. 500). This has both personal consequences in terms of her feeling socially isolated, and political implications, because the self-exclusion of people with non-visible impairments from disabled groups and spaces contributes to the notion that they are not legitimately disabled. It also upholds the dominant conception of illness as an individual problem to be suffered with privately (Patsavas, 2014), obscuring how public recognition and social accommodations would greatly improve the lives of people with chronic illnesses (de Wolfe, 2002).

Conclusion: Misfitting, Isolation, and Subversion

Verbal disclosure of non-visible impairments has been compared to the process of "coming out of the closet" (Davidson and Henderson, 2010; McRuer, 2006; Sherry, 2004; Swain and Cameron, 1999). Samuels (2003, p. 241) argues, however, that this analogy is flawed in part, because there are a variety of ways to signal queer identity, but the "assumed visibility" of disability means that there is an "absence of nonverbal signs and a distrust of spoken claims

to those identities." Indeed, as the respondents' accounts above highlight, in a cultural context where "seeing is believing" people with hidden impairments who make spoken claims to being ill or disabled explain that they encounter scepticism. The participants also express the understanding that having a medically unexplained and contested condition seems to make people more sceptical of the reality of their illness. In addition, the participants explain that they feel as though when they try to tell others about their illness experiences that this is misinterpreted as complaining, seeking pity, or that they are making excuses.

Furthermore, the participants' accounts reflect that they pass unintentionally in many social situations, and this can lead to difficulties when they try to signal that they are chronically ill/disabled (e.g. when they use a disabled bus or parking pass). The accounts also reveal that at times the participants pass intentionally, and that this is a strategy to avoid anticipated negative reactions, and to manage perceived stigma. The analysis of the accounts also suggests that passing is related to the internalization of ableist and sexist norms, and the desire to present one's self in a favourable light. For women this might mean concealing illness in order to be a "good woman" and a "good mother" who puts care for others above self-care and protects relationships by shielding family, friends and others from the burden of her illness. Men, in contrast, might be more likely to pass due to masculine stereotypes that pressure men to be stoic and not show any sign of weakness or vulnerability. In addition, passing is related to the internalized ableist mandate that pressures all of us to constantly prove ourselves to be "as able as possibly or ideally one could be" (Goodley, 2014, p. xi).

While passing offers people with hidden impairments the possibility of "fitting" and belonging, it requires emotional and physical resources that most chronically ill people do not have in abundance. Respondents reported occasions when the painful, exhausted body with its attendant limitations and difficulties will make it impossible to present one's self as able-bodied and healthy. The participants' accounts reflect that when trying to "fit" in the world of the healthy and the non-disabled is not possible, but they are not given "permission to be ill" (Nettleton, 2006), the unfortunate result is far too often loneliness and social isolation. Julie states, "I have felt so alone, because it is an invisible disability that people just don't understand." Similarly, Emma (UK) explains:

I feel quite isolated. On days when you don't feel well you have to say I don't really feel like doing stuff. And after a while a lot of people just get disinterested. So now I only have acquaintances. I don't have what you would call proper friends.

Michael (Canada) also describes how he has become isolated, because he is not able to take part in the social activities that he feels expected to participate in as a man:

Being a guy our social outlets are based around sports, so you know for me it was based around golf, curling, squash and hockey. That's what we'd do and then we'd go out for drinks at the bar. And with this I can no longer play those sports. And as far as going out to the bars, forget about it. I'm just way too exhausted to go out for drinks and the brain fog means I can't really carry on a conversation. And they just really don't understand that I can't do what I used to do.

Referring again to Thomas' (1999a) and Reeve's (2002) work on *psycho-emotional disablism* we can see how the perceptions and experiences of the attitudes, behaviours, and (re)actions of family, friends and others can result in chronically ill and disabled people feeling lonely and excluded. Although the participants explain that being ill does prevent them from taking part in certain social activities; it is not just being ill, but also their worries about the dismissive and insensitive treatment they might receive from others that contributes to their sense of isolation.

Meredith (UK) explains that she no longer attends church, because of the judgemental reactions she received from the community when she was unable to regularly attend meetings and events:

I used to go to church and I was very judged because of the fibromyalgia. They wanted me to do all these things, and go to these meetings and when I didn't do it, they got quite frustrated with me, and they had the attitude that I wasn't bothering. And it was almost like, "Why didn't you bother coming?" It was very upsetting, because I felt really rejected. So in the end I just stopped going. And I want to go to church, but I'm too scared that they will have the same attitude so I stay away. Because I don't people to say, "Oh come to this meeting," and not realize that you literally can't. So I don't go. So I mean I isolate myself, I know I do, but I don't think I have a choice. People just don't understand it. They don't understand that you can't do several things, you just can't.

At another point in the interview, Meredith states that she thought the church members did not actually believe that she was truly ill, and that they thought she was simply making excuses. Meredith implies that if she were obviously ill and disabled she would not have received the same treatment, because then her limitations would have been self-evident. This is confirmed by other research on "invisible disabilities" that concludes that because we live in a culture where it is assumed that "what you see is what you get," chronically ill people and others with hidden

impairments, are assumed to be able-bodied (and healthy), and are expected not to have any limitations or difficulties (Stone, 2005, p. 295).

Therefore, people with medically unexplained and non-visible illnesses express a strong sense that they are not permitted to be sick, nor are they accepted as disabled. This leaves them in a liminal space where their experiences are not fully recognized, and they become quintessential misfits. Maria (Canada) speaks poignantly about how being treated as an outcast causes her psycho-emotional distress, and results in her isolating herself even more:

> And now I feel in my heart it's like they don't care so I don't tell them how I feel. Sometimes I close the blinds, and I don't answer the phone. You want somebody to understand. You need the love, and everybody with this is just more vulnerable. You really need love. And maybe because you know you can't find it, because they can't understand you, you just close off.

Similar to other participants, Maria feels as though she does not fit in the world of the healthy, but she is not afforded the understanding and compassion of people who are permitted to be ill. She also does not identify as disabled and thus does not feel she belongs in that category either.

The participants' accounts reflect that feeling isolated is a potential consequence of liminality and being a "misfit" living between the worlds of the disabled and the non-disabled and the healthy and the sick. The painfulness of misfitting, however, is not the end of the story. I argue that underlying the marginalization of people who exist in the liminal space in-between, is a fear and anxiety of the "monstrous," which leads to attempts to understand and control that which cannot be classified and contained, or visibly identified. As the previous chapter revealed, the symptoms associated with FMS and the diagnosis itself are "haunting" and "monstrous" in that they disrupt comforting illusions regarding bodily control and biomedical certainty. The haunting uncertainty of medically unexplained illnesses is also clearly reflected by the participants' accounts of unsettling social interactions. Looking well and appearing non-disabled, while claiming or otherwise signalling to others that one is ill and disabled disturbs the widely held assumption that "seeing is believing." While this can result in painful social interactions, embodying liminality is also powerfully subversive.

Within the participants' accounts we can find transgressive acts of resistance, and "embodied alternatives" (Goodley, 2011, p. 160). As was discussed, Butler (2006, p. xxiv-xxv) explains that "drag" is a subversive performance of gender, because it shows us "the

tenuousness of gender 'reality'" In the same way, transgressing the boundaries of health/illness and dis/ability is subversive, because it reveals "that which exceeds the norm" (Shildrick and Price, 1996, p. 107), and offers us all insight into the fluidity of bodily difference. Tracy getting up from her wheelchair to stretch her legs, and Nora who looks non-disabled using her disabled bus pass are clearly subversive performances of disability. Not all subversive performances are this obvious, but they are nonetheless important acts of "transgressive resistance" (Shildrick and Price, 1996, p. 107). For example, simply discussing hidden illness with a close family member, or telling a trusted person about invisible difficulties are significant acts, as they provide instruction about living with uncertainty and suffering, give insight into the wide spectrum of bodily difference, and reveal that not all struggles and limitations are obvious. These are important lessons that I distinctly remember learning from my mother who has FMS. It is also possible that speaking about hidden pain, and telling others about the need for rest are transgressive acts, because they subvert the cultural mandate to keep bodily experiences of illness and disability as private matters (de Wolfe, 2002; Patsavas, 2014). The participants' accounts of disclosure, therefore, might be examples of resistance through exposure and the simultaneous refusal to hide their experiences, ignore their bodies, and be socially invisible due to the cultural imperative to silently suffer and "push through" (Patsavas, 2014). Finally, individual transgressive acts are also potentially politically significant, because by unsettling harmful norms and deconstructing damaging illusions of the perfect(able) and invulnerable body these acts can instigate larger social change, such as, "a wide-ranging and radical challenge to the organization and values of a society increasingly obsessed with bodily perfection" (de Wolfe, 2002, p. 266).

Chapter 7 - Disturbing Policies:

Disability-Related Entitlements and Bodies in the "Grey Area"

Introduction

This chapter examines how dominant dichotomous understandings of health/illness and disability/ability structure disability-related entitlement policies and how this might create issues for people with undefined illnesses when they make claims for entitlements, particularly institutional accommodations and disability benefits. With regard to institutional accommodations, the participants' accounts reveal numerous problems around disclosure. As was discussed in the previous chapter, the participants' accounts reflect the shared perception that disclosure of a non-visible, fluctuating, and contested condition is met with scepticism, judgement, and hostility. In order for people with non-visible conditions to receive formal institutional accommodations, however, disclosure is necessary. While very few of the participants fully disclosed having FMS and formally requested accommodations, those who did discuss how this facilitates them to continue working or studying while managing their chronic illness. At the same time, the participants explain that they felt that because they look well, and are not obviously disabled, that they are seen to be questionably entitled to accommodations. In the workplace specifically, the participants explain feeling that they must engage in a "balancing act" to prove that they are "disabled enough" to deserve workplace accommodations, but not "too disabled" to continue working.

In addition, the analysis in this chapter reveals issues related to claiming disability benefits as a person with a non-visible, fluctuating, and medically unexplained condition. The disability benefit policies in both the UK and Canada are based on the medical model of disability that understands disability in terms of bodily abnormality, medically verified pathology, lack of ability, and loss of "normal functioning" (Titchkosky, 2003, p. 532). As Lightman and colleagues (2009) explain, within these policies disability is constructed as stable, permanent, total, and complete; the policies do not allow for fluidity or fluctuation. Due, in part, to the strict and oppositional criteria, the participants explain that when applying for entitlements they feel that in order to increase their chances of having a successful claim they

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must downplay their fluctuating symptoms and emphasize the stability and severity of FMS. The participants also discuss how having and highlighting a "better legitimated condition" (de Wolfe, 2012, p. 621) on the application might increase a person's chances of having a successful claim. Overall, the accounts reflect the shared understanding that the process of claiming entitlements requires a considerable amount of time, as well as personal and outside resources, including expert advice. This hard-work still did not guarantee a successful claim, however, and many of the participants were in fact denied necessary entitlements, because as one of the respondents explains, people with FMS fall in the *grey area* where they might be too ill to work, but are not considered "disabled enough" to claim disability-related income support.

The participants who did manage to successfully claim disability benefits describe feeling as though this subjected them to scepticism, surveillance, and policing. In addition, neoliberal restructuring of welfare programs, particularly in the UK, meant that many of the UK participants expressed concerns regarding their financial security, and felt that they needed to continually defend their rights to entitlements by proving they are genuinely disabled. While all disabled people are in a similar disadvantaged position within neoliberal capitalist societies, the research suggests that people with non-visible, fluctuating, and contested conditions believe that they are likely to find it especially difficult to prove they are worthy of disability-related entitlements due to cuts to the welfare system and an "acute narrowing of definitions of impairment diagnoses that will elicit state benefits" (Goodley, 2014, p. 52).

This chapter also examines the accounts of those participants who are not receiving disability-related entitlements. The interviews reflect that the decision not to apply for entitlements is partly due to the perceived difficulties of securing and maintaining accommodations and benefits, combined with the sense that as a person with a non-visible and fluctuating illness they might be viewed as undeserving and thus could be met with scepticism and judgment as claimants. In line with the findings from the previous chapter, it is also argued that the analysis of the interviews reveals how the internalization of ableist cultural norms and assumptions regarding disability as inherently negative (Campbell, 2008) might impact decision-making around identifying as disabled in order to claim accommodations and benefits.

The chapter concludes by returning again to the concept of *embodying liminality* to explore how having an ambiguous and episodic condition, and being in the "grey area" of entitlement policies contributes to marginalization, discrimination, and exclusion. It also examines how this "liminal positioning" (Titchkosky, 2003, p. 537) might serve to radically disturb these policies, by illuminating the inherently flawed and exclusionary definitions on which they are built.

Balancing Act: Institutional Accommodations and Unseen Disability

Less than half (14) of the participants were working in paid employment when interviewed, and many of these participants voiced concerns about being unable to work in the future due to their ill/health. Of the fourteen participants who were working, five (Nancy, Lillian, Katelyn, Lindsay and Mark) were living in the UK, and nine were living in Canada (Amber, Tyler, Maria, Beverly, Karen, Julie, Veronica, Gordon and Courtney). Three of the participants – Robyn and Jane (UK) and Jessica (Canada) – were attending University or College at the time of the interviews.[7]

Both Canada and the UK have official government policies that are meant to enable disabled people to work or study by providing necessary accommodations (Canadian Human Rights Commission, 2013; Government of the United Kingdom, 2014b). The policies in both countries make it the obligation of the worker (or student) to notify the institution of their disability in order to request accommodations and these requests must be deemed reasonable and justifiable (ibid). Thus, to qualify for any disability-related entitlements the first step is to make it "known" that one is disabled (Jung, 2002); or to put it another way, to "signal" disability institutionally (Teghtsoonian and Moss, 2008). As was previously highlighted, choosing to disclose being chronically ill and identifying as disabled is experienced as highly problematic by people with FMS (as it is contested, non-visible, and fluctuating), and as the findings below reveal, when a person with an invisible and ambiguous chronic illness identifies as ill/disabled in order to request institutional accommodations this might result in a "plethora

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[7] Please refer to appendix I for a list of the participants' occupations and information regarding which participants were receiving disability benefits.

of other problems" (Teghtsoonian and Moss, 2008, p. 201). The following section discusses the problems (and the benefits) the participants describe experiencing after identifying as chronically ill/disabled and requesting institutional accommodations. With regard to the workplace, specifically, the participants' accounts reflect how they feel that they must negotiate a difficult "balancing act"; that is, they feel as though they must continually prove they are "disabled enough" to require (and have the right to) accommodations, but not "too disabled" to meet institutional standards of productivity.

Although the participants who chose to make themselves known/visible as chronically ill/disabled within the workplace or education setting reported being aware of the potential costs of disclosure – including, an awareness that they might be stigmatized and discriminated against (Jung, 2002; Teghtsoonian and Moss, 2008; Vickers, 1997) – for this group of participants this did not outweigh the possible benefits attached to having institutional accommodations. In line with previous research, the participants describe disclosure as necessary in order to receive practical adjustments and social support that would facilitate them to continue working or studying while managing chronic illness symptoms, particularly pain and fatigue (Munir et al., 2005, p. 1404). In other words, the main reason they chose to disclose having FMS, was because they felt that they would have faced serious difficulties working or attending school without accommodations, and disclosure is obligatory in order for this to happen. These participants describe how identifying as chronically ill/disabled permitted changes that made their workspaces and education settings more accessible and comfortable, allowed for them to work or study from home, provided them with paid sick leave, and time off for healthcare appointments. For example, Katelyn (UK) explains:

> Work has been great actually. They sent me for a work assessment to go and see a chap to discuss how my fibro was affecting my work and what they could do for me. They bought me a special chair that is for people with back problems, and it is brilliant and my pain is a lot better since I've got that chair. And they let me go for treatments and appointments - they give me time off for that.

Jane (UK) likewise discusses the accommodations she receives at University:

> They've given me some equipment – like I've got my own chair that's got memory foam on it to make it more comfortable for me and it's got a laptop stand. And I've an assistant to help me find books and carry books from the library. Just little things that make life a bit easier. And with my [practicum] they let me take extra breaks. I can sit

down and rest if I need to. And if I can't do the long hours I can go home and they are fine with that.

Similarly, after disclosing being diagnosed with FMS, adjustments were made to help Lillian (UK) continue to work, including altering her work hours, and providing her with a more comfortable desk chair. While her employer was willing to make these important accommodations, because FMS is a fluctuating condition that includes both good (or manageable) days and particularly bad days – in some cases "flare-ups" in symptoms might be severe enough that a person is completely bed-ridden and unable to engage in any work-related activities (Barker, 2005, p. 65) – Lillian felt that she came up against issues in relation to workplace policies around sick leave:

> A lot of problems I've had recently is we have these forms we have to fill in when we're off sick and sometimes I'll write it is the same as last time. Because obviously it all has to do with the same condition so it is all the same. But sometimes I think I'm sick of writing this. Every time I'm off sick I have to write this. If I'm off for like a day I have to fill a form in. I think this is where we need to differentiate between somebody who has a long term condition and somebody who has just been off sick and is normally not off sick.

The standard forms that Lillian must fill out every time she is unable to come into work cause her a great deal of frustration and stress, because they do not differentiate between someone who is off work due to an acute illness and a person with a chronic condition. Policies like this do not take into account the experiences of people with unapparent and unpredictable illnesses who might be considered "unhealthy disabled" (Wendell, 2001). For "unhealthy disabled" people their embodied reality is one of fluctuation and uncertainty – shifting between manageable days and periods of debilitating illness – and Lillian feels that the forms she has to fill in are not designed to accommodate this bodily ambiguity.

In addition, Lillian believes that these mandatory forms pose problematic questions regarding her capability to continue working. As she explains:

> One of the questions on the form is, "Is she capable of doing her job?" Well that is a really wrong wording for that. I am capable it's just that sometimes I'm not well enough. I kept reading the question and thinking, "Am I capable? Am I capable?" Does that mean they are going to sack me if I say, "No I'm not capable"?

Later in the interview, Lillian expresses further ambivalence about the compulsory documentation of her sick days:

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> Because that's obviously documented and everything, you being off…. Some people say in a way they're collecting information that they could say, "well based on this you can no longer work." But yeah the other side is they are aware of this condition and they are trying to put the support in to make sure that I can continue to work.

There is the possibility, as Lillian points out, that this record-keeping is a way to collect information on the capability and productivity of employees, and it is concerning that this documentation might be used to justify the termination of her employment if she is deemed to be no longer capable of continuing to work. Indeed, previous research has found that people with chronic illnesses have been made redundant, because they were perceived to have "over-used" or "abused" the workplace policy of sick leave (Vickers, 1997).

At the same time, Lillian explains that it is important to have this documentation, because it provides evidence of her condition and the need for adjustments to the workplace. Nancy (UK) similarly stresses the importance of having written documentation proving that she is disabled and requires accommodations:

> Despite thinking that I had disclosed that I have a disability it wasn't formalized. I went to my line manager and said, "I have a disability. This is what I need." And a health and safety officer came in, assessed me and got all of these things in place. And so I thought that was a formal notice, but no it's not. So for the last 18 months all of these unofficial agreements have been in place. And now we're coming to crunch time and the assumption is you must do 25% more. And I said, "Well sorry I can't do 25% more, because I told you from day one that I have a disability." And they said they had no record of it.

Although Nancy thought that she had gone through the proper bureaucratic channels, she has since found out that her status as disabled was not formalized, and now to prove that she is unable to work longer hours (i.e. do "25% more") she must have an official assessment done and provide medical proof of disability. As she explains later in the interview, without this documentation she worries that her job might be in jeopardy, because she feels that it could be argued that she is not achieving the new institutional standards of productivity.

Mark (UK), who has made arrangements with his employer to work from home one day a week, also describes issues attached to having unofficial accommodations put in place:

> I'm going to try and keep sticking with my work arrangements, because it is possible my job could change this year and if it does I've got to have an interesting conversation with a new manager which is you know, "Right, we've got you this new job and you want to work a day a week from home?" I'm just imagining that conversation taking place and that could be you know quite awkward.

As Mark, Lillian, and Nancy explain, official written evidence of disability is important for people with non-visible, fluctuating conditions who appear healthy/non-disabled. In the absence of visible signs of illness or disability, this documentation might justify the continued need for disability-related accommodations. Without official records indicating disability status and formally agreed upon accommodations, the participants explain how it is likely to become the responsibility of the non-obviously and unpredictably disabled worker/student to repeatedly make it known that they are disabled and then to negotiate arrangements on an ongoing basis.

In addition, similar to the findings presented in the previous chapter, for people with non-visible, fluctuating, and contested illnesses "signalling disability" within the workplace is considered by the participants to be problematic, because it is felt to elicit negative reactions, particularly scepticism regarding the severity and reality of illness (Teghtsoonian and Moss, 2008, p. 201). For example, Samantha (UK) explains that she told her work colleagues and line manager that she has FMS, because she felt that she needed to justify why she is not able to work consistently. Samantha had hoped that disclosing this would result in support and understanding, but instead, she feels that disclosure contributed to a hostile work environment:

> People at work didn't understand and some openly made fun of me, saying that it's "fake" and "all in my head." They implied that if I had a day off it's because I'm lazy. It was also very stressful when they'd ask if I was feeling better because "I look ok" to them. When I'd try to explain what the pain is like they'd say that I must be exaggerating, because they wouldn't even get out of bed if they felt like that. So I would usually just say, "I'm fine." But then when I'd be in too much pain to go to work they'd say, "But you said you were fine yesterday."

Samantha's account suggests that the perceived suspicion from her work colleagues is related to the fact that she does not look ill, and also because her health fluctuates on a day-to-day basis; in other words, she feels that because she does not "fit" dominant conceptions of how an unhealthy disabled person should look and behave (Stone, 2005) she is met with scepticism. In addition, at the time of the interview, Samantha had just recently lost her job. Although she was told that she was made redundant due to "cuts" at her office, she explains that because her employment was terminated not long after she disclosed having FMS she feels certain that this is the actual reason she was made redundant. Other participants had similar experiences and these are discussed further below.

The participants' accounts also reflect their sense that reactions of doubt and resentment (and potentially loss of employment) might be linked to the perceived notion that people who do not appear disabled are not deserving claimants of accommodations, and are instead simply asking for sympathy, trying to get special treatment, and/or are really just being lazy and attempting to take advantage of disability-related policies (Jung, 2002; Vickers, 1997; Vickers, 2003). In particular, the participants explain that they felt that others might view accommodations as unwarranted and unfair. Like Samantha, Mark (UK) discusses how he feels that he is mocked by work colleagues, because he does not appear ill/disabled:

> I work from home one day a week and obviously I work in a very male-oriented environment and so I still get the piss-taking, you know, "Oh how was your day off?" I deal with that on a regular basis. Of course the problem with fibromyalgia is that you look fine.

Both Samantha and Mark imply that if they appeared visibly ill and were seen to be unquestionably disabled then their work colleagues would be far less likely to outright question or mock their right to have workplace accommodations.

Lillian (UK) also describes a difficult working environment, and explains that she feels guilty about receiving workplace accommodations:

> You feel guilty because generally you don't look ill. That's one of the things that everybody said, "Well you don't look like there is anything wrong with you. You look well." And you can't sort of make them understand what you see is not what is going on inside. I've had so called colleagues that when I started my hours from 7:45 to 3:00 that refused to take over my phone calls at 3:00. They just said, "You don't look ill. You look perfectly well to us."

Lillian feeling guilty for receiving workplace accommodations – rather than feeling it is her right to have these accommodations – is another example of how *psycho-emotional disablism* can impact how disabled people feel about themselves (Reeve, 2002; Thomas, 1999a; Thomas, 2012). As Lillian explains, she feels guilty for receiving workplace accommodations, because she does not look ill. She implies that if she were obviously ill then she would feel deserving, and in turn, perhaps her work colleagues would be less likely to question why she requires an adjusted work schedule. In addition, it is important to place her account in relation to the wider social context, as this reveals how Lillian's feelings of guilt (as well as her sense that her colleagues are sceptical of her need for accommodations) might also be linked to negative cultural portrayals of recipients of disability-related entitlements (Briant et al., 2013), and the

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construction of the oppositional, but mutually constitutive, categories of the "genuine" disabled and the "bogus" disabled (Ahmed, 2004). These ideas will be taken up again further below.

The participants' accounts reflect that the perceived negative reactions they received from co-workers and employers also contributed to them having concerns about their job security. In particular, some of the participants worried that their co-workers might make complaints about their capability and productivity. Connie (UK), for example, describes how she was made redundant and that feels as though this was due in part to criticisms from work colleagues regarding her ability to carry out work-related tasks:

> There were some colleagues that would help me and would carry things for me and ask if I needed help. But then I found out that one particular person had gone and complained about me for asking them for help. So you sort of thought they were being helpful, but maybe they weren't.

The participants' accounts reflect the shared understanding that it is important that if non-visibly disabled people request accommodations that these are seen to be reasonable and justified; in other words, the participants explain that it is important that they appear disabled enough to deserve accommodations. At the same time, the participants accounts reflect the sense that it is also imperative that people who are documented as disabled workers/students are not deemed "too disabled" (i.e. incapable) to meet institutional/organizational standards.

Another quote from Connie reflects how she feels that she was made redundant due to the perception that even with accommodations she was too disabled to work:

> I was made redundant because of the fact that I was struggling… I did have a special chair to help with the pain and the arthritis side of things. And it was because I requested it myself. I took a leaflet on fibromyalgia and gave it to my boss and I just go the attitude of, "Why have you given me this?" And I said, "Just so you could try and understand the difficulties I have." I felt that I was a hindrance. And then prior to redundancy I had to sign an agreement and the solicitor did say I would have a case for disability discrimination in the workplace. Because if it was a straightforward case of redundancy why was I being asked to sign this form, you know? They knew that there were disability problems there. And even my boss said to me, "Well you're disabled now, why are you working?" But I didn't bother with the discrimination case, because it was such a stressful time anyway.

Similarly, Harold (UK) discusses how he feels that he was forced to go on medical leave and eventually quit his job after his employer refused to make accommodations that would allow him to continue working:

> I worked at a factory where they build cars and I was coming home and I couldn't move my fingers. My feet and legs were so swollen I had to wear two shoe sizes bigger. But I

just carried on and until it got so bad I couldn't work. So I went and asked work to give me some lighter duties. And they said no, if you're too disabled that you need lighter duties, then you need to be off work. So I got nothing from work. In the end I went off sick and I haven't worked since.

The participants' accounts align with previous research findings that report that many of the difficulties people with non-visible and fluctuating conditions face is related to them being "betwixt and between" and "organizational imperatives requiring employees either to be unequivocally well or manifestly ill" (Pinder, 1995, p. 625). In both accounts directly above, the employers are perceived to be operating under the assumption that if you are disabled enough to require accommodations, then perhaps you are "too disabled" to continue working. According to Connie, her employer said as much when he asked, "If you are disabled, why are you working?" The respondents' accounts reflect the sense that instead of being perceived as deserving, the request for accommodations might be perceived as an unreasonable demand for "special treatment," and in some cases, might be used to justify dismissal/redundancy (Devaney, 2008, p. 128).

In addition, Harold's account points to the possibility that it might be even more difficult for disabled people who are working in manual labour jobs (i.e. male-dominated, blue collar jobs) to make claims for workplace accommodations, because of the commonly accepted ageist and ableist assumption that only young, healthy, non-disabled (mostly male) bodies are fit to work these type of jobs (Connell, 2002). As Harold explains, his boss did not offer any suggestions for workplace accommodations, and it is plausible that this is because it is assumed that the job requires a certain type of body; thus, it is Harold's body that needs to be changed, not the job.

In the "Grey Area": Liminal Embodiment and Rigid Disability Benefits Policies

The participants unable to work explain a further issue that people with non-visible, fluctuating, and medically unexplained conditions are likely to face with regard to disability-related entitlements; that is, while they might be "too disabled" to continue working, they might not be considered "disabled enough" to be entitled to disability benefits. The analysis below reveals that this is partly because disability benefits policies do not recognize the fluidity and ambiguity of disabilities that do not fit neatly into either/or categories (Lightman et al., 2009). It

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is also difficult for people with FMS and similar undefined illnesses to secure disability benefits, because these conditions are medically unexplained and contested (de Wolfe, 2012). While over half of the participants are current or past recipients of benefits, all but one describe encountering barriers that hindered them from securing and maintaining an income, including, having to apply multiple times before having a successful claim, having their benefits reduced or revoked, and having to go through the arduous appeal process to have their benefits either increased or reinstated.[8]

To contextualize the interview participants' accounts it is helpful to first provide a brief overview of the disability-related income support policies in the UK and Canada that are most pertinent to the analysis below.[9] The majority of the UK participants on disability benefits were recipients of Disability Living Allowance (DLA). The DLA program provides income support to adults who require personal care and/or mobility assistance due to a "disability or health condition" (Government of the United Kingdom, 2014a). In addition to DLA, a few of the UK participants describe receiving Incapacity Benefit (IB). According to the IB policy, a person might qualify if they are unable to work due to "illness or disability" and they have made National Insurance Contributions (Malacrida, 2010, p. 676). In Canada, the federal government disability-related benefits program is the Canada Pension Plan - Disability Benefit (CPP-D). CPP-D is available to people under 65 who have a "severe and prolonged disability" and have made contributions to the Canadian Pension Plan (Government of Canada, 2013). In addition to the federal plan, there are provincial disability benefits. In the province of Alberta, where all but two of the Canadian participants were living when interviewed, the primary disability benefits program is AISH (Assured Income for the Severely Handicapped). To qualify for AISH a person must be means-tested and have a "severe and permanent disability" that prevents them

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[8] This includes three participants in Canada who receive non-disability related income support, including Employment Insurance (EI) and Income Support (welfare).
[9] This information is based on the policies that were in place when the interviews took place (2010-2011). The UK system is currently changing and adults who were previously on Disability Living Allowance (DLA) now have to apply for Personal Independence Payment (PIP) (please refer to https://www.gov.uk/dla-disability-living-allowance-benefit/overview for further information). In addition, the Incapacity Benefit (IB) program is being replaced by the Employment and Support Allowance (ESA) scheme (please refer to https://www.gov.uk/incapacity-benefit for more information).

from working (Government of Alberta, 2014).

Although there are some differences between the policies above, overall they are very similar, particularly in relation to how they frame disability (Malacrida, 2010). The policies in both countries define eligible disabilities as stable and permanent, with the implication being that in order to be considered deserving of benefits a person must have a predictable body/illness/disability that completely prevents them from working (de Wolfe, 2012; Lightman et al., 2009; Shildrick and Price, 1996). The interviews reflect that due to rigid policy criteria it is very difficult for people with shifting bodily function and fluctuating periods of health and illness to qualify for disability benefits in either Canada or the UK:

> I'd love to move out on my own but I got turned down for DLA because of the criteria. The only ones that seem to get it are the ones that are wheelchair-bound or totally bedbound. I'm kind of in the **grey area** where I'm not fit enough to work but not entitled to benefits (Emma, UK).

Emma's description of being in the "grey area" astutely describes the position of being in the liminal space in-between health/illness and dis/ability. She implies that people with FMS who have few (or no) "good days," and are instead consistently ill, are fortunate in a sense, because they might be more likely to be recognized as disabled and thus worthy of disability benefits. In contrast, Emma (like many other people with fluctuating conditions) feels that she is in the "grey area" as her illness/health shifts over the course of the day, from day-to-day, and from month-to-month. In other words, she feels as though she is too ill to work, but she is not predictably ill enough to qualify for benefits.

Other participants describe similar experiences. For example, Michael (Canada) believes that his claim was denied, because his illness was not deemed to be severe or permanent, stating that: "I was denied because they said that my health is 'indeterminate,' you know that I might get better." Harold (UK) likewise describes having his application rejected due to his uncertain and fluctuating symptoms:

> I applied for benefits, but I got turned down. They wrote back saying that if I can walk a little bit one day then I'm okay. I'm saying yeah I might have a good day and I can walk a little bit, but the next day might be the total opposite where every step I take hurts.

Diana (UK) also highlights issues she has had filling in benefit assessment forms that are based on the understanding that a person must have a stable disability to qualify for benefits. When

asked why she thought her last two applications had been rejected Diana explains:

> It is because of the way they assess you. The questions they ask are around daily care, so washing, bathing, cooking for yourself. I mean yes, you might be able to cook for yourself, but that doesn't mean you're not disabled. I could heat something up on the cooker, but then I would have to lie down on the sofa. And on a bad day I might struggle to get in the kitchen to cook at all. And some of the criteria are about being mobile. One of the questions is, "how far can you walk?" Well I can walk, but I'm in severe pain every time I walk, so how do you quantify that?

The benefit policies Diana and Harold are referring to require the applicant to prove that they need assistance on a daily basis (for personal care, cooking etc.) and/or that they cannot walk or have great difficulties walking (Government of the United Kingdom, 2014a). These forms do not allow for shifts in needs or bodily functioning. As Diana and Harold explain this means that an application can be rejected if the applicant indicates that s/he has even occasional days where s/he does not need assistance, and/or s/he is able to walk with minimal (or no) difficulty. Echoing findings by Lightman and colleagues (2009, p. np), the participants' accounts thus reflect that because people with "episodic disabilities" (i.e. fluctuating conditions, such as FMS) are neither completely unhealthy/disabled, nor totally healthy/able-bodied "they fit no standardized categories as they attempt to qualify for benefits."

In addition, the participants' accounts reveal that it is not only their fluctuating ill/health that is problematic with regard to securing disability benefits; it is also because FMS is medically unexplained and contested. Diana explains that, "they don't count fibromyalgia as an automatic right to getting [benefits], whereas other illnesses are." Other participants similarly express that FMS is not "considered" to be, or "recognized" as, a legitimate disability. In line with other research, the participants' accounts suggest that due to the contested status of FMS, people with multiple conditions might be more likely to have a successful claim if they are able to report a "better-legitimated condition" (de Wolfe, 2012, p. 621). Harold describes how he was awarded benefits only after he was diagnosed with depression:

> We finally went to get help with benefits, but we were told fibromyalgia is not even considered at all. And I was rejected at first, but I just got awarded disability allowance [DLA], but it was for my mental state, because I have depression, rather than for my physical state. They don't regard my fibromyalgia as an illness as such.

Likewise, Curtis (UK) explains that his initial application was denied, but when he changed his

listed disability from "fibromyalgia" to "chronic pain" the claim was accepted:

> I had to fight for my benefits, because they didn't want to recognize fibromyalgia. I didn't get it at first but as soon as I changed the word from fibromyalgia to chronic pain it was granted straight away. Within weeks it was granted. And I thought that is because you don't want that on your books for people with fibromyalgia to have benefits.

Similar to the respondents in de Wolfe's (2012) study, Harold and Curtis describe having to highlight other impairments, or use a different label in order to qualify for benefits. Ironically, their actions (while necessary) inadvertently serve to make FMS a further invisible/marginalized condition. As Curtis explains, "on the books" it states that he was entitled to benefits due to "chronic pain," not because he has FMS.

Other participants who were working, and had yet to apply for benefits, also shared the understanding that FMS is not "recognized" as a disability within benefits policies. Julie (Canada) explains that she has been struggling at work, even finding it difficult to walk some days, but that she does not feel she can stop working, because she needs the income and she does not believe that she would qualify for benefits:

> I wonder if I'm going to be able to continue working and that causes me a lot of stress, because going for disability benefits with fibromyalgia is the most stressful thing you can undertake in [Canada] ever. Some people have done it, but very few have. And they had to get lawyers, because it is not recognized. I've been told by many people that they've been fighting for years. I know somebody who was able to get it, but she could afford good lawyers. So I will not have an income should I leave my job and that is stressful. It is very stressful because I have a mortgage and bills.

Similarly, Lillian (UK) states that she experiences anxiety just thinking about not being able to work and having to apply for benefits, because she thinks FMS is not "recognized" as a disability:

> What do I do if I'm not working? Would I get disability living allowance? Would I get incapacity [IB]? Will they recognize my condition as a disability? And that is another fear for me in the next few years, is where do I go if I'm out of work? Will I be able to support myself? These are all the things that are going through my mind. And we don't really get information about that, because it is not recognized in regards to benefits.

These excerpts reveal the stress and anxiety some of the participants express regarding the possibility of having to apply for disability benefits as a person with a medically ambiguous condition. As is discussed below, feeling stressed and anxious are understandable given that one's income is on the line, and these feelings are obviously even more pronounced for actual applicants and claimants (de Wolfe, 2012).

Finally, two of the men interviewed suggest that the interaction of sexist, ageist, and ableist assumptions might make it even more difficult for young men with non-visible impairments to prove they are deserving of disability benefits. Tyler (Canada) explains that he was refused AISH, and when asked why he thought that his application was dismissed, he states:

> It's because they think I'm still young and capable enough to work. And yet 90% of the jobs I'm qualified to do, I can't do them anymore. And they still expect me to do them. Like I said I went out for that landscaping job and after two days on the job my hands hurt so bad I couldn't even hold a book.

Similarly, Michael (Canada) explains that he feels as though he was denied benefits partially because he is a young male and it is expected that he should be capable of doing a wide variety of jobs:

> I get $500 a month now, but its welfare. I applied for disability benefits [CPP-D] and got turned down. And I applied for AISH, and was turned down and I appealed, and was turned down again. There is just the expectation that he is 40, he is a guy, he can move around and you look at him and he seems to be able to do okay. I'm going to try applying for it again, because I really can't work, but I don't want to get my hopes up, because I don't think my odds are very good, even though I need it.

The assumption that young, able-bodied males are model labourers creates distinct benefits for men who can embody this ideal (Connell, 2002). For young men with non-visible health conditions, such as Tyler and Michael, these assumptions might work against them when they try to apply for disability-related entitlements, because as both men explain, they feel that it is difficult to prove they are not "able enough" to work when they are both young males who appear healthy/non-disabled.

To increase the likelihood of having a successful claim, the participants discuss doing their own extensive research and/or enlisting experts and advocates to help them with their applications. Amber (Canada) explains that after being turned down twice for benefits she asked her doctor to write a detailed letter justifying her claim. Amber believes that the expert testimony of her doctor worked as her third application was accepted. Meredith (UK) similarly explains how making a successful claim "wasn't straightforward at all," and that she eventually hired a solicitor to help here with the application process:

> I was turned down the first time and finally I got a benefit solicitor to help me appeal. And [the solicitor] explained that they just don't understand [FMS]. You can't say that you get bad days and good days. The disability benefits can kind of dismiss that.

Diana (UK) also describes applying (for the third time) to have her disability benefits reinstated. Despite two failed attempts, she is optimistic as she did some research to improve her chances:

> This time I got some hints and tips off the internet. And now I know that you've got to fill out the forms in the right way. So you never say you have a good day. You have to say you have worse days and slightly better days, but never a good day. Which is so ridiculous because obviously you do have good days. And you know some weeks you might need help every day and another week you might not need any.

The participants' accounts reveal the hard work involved with having a successful claim. While disability benefit policies within neoliberal states are designed to be exclusionary, requiring a great deal of all claimants regardless of the type of disability (Chouinard and Crooks, 2005), the participants accounts reflect that application forms with their firm either/or distinctions present even greater challenges for applicants whose bodies fall in the grey area and are essentially deemed unintelligible according to policy stipulations (Lightman et al., 2009).

In addition to the hard work related to applying, the interviews also reveal the large amount of time and resources expended as a claimant of disability benefits. As previous research has found, the participants feel that people with fluctuating and disputed conditions "must continually defend the contested credibility of their volatile bodies and situations" (Lightman et al., 2009, p. np). For example, Jane (UK) explains that like Amber (Canada) she managed to successfully claim disability benefits only because her doctor supported her application:

> I get disability living allowance now, but it was meant to take 6 weeks for me to get it, but it took 8 months. And that's only because my doctor wrote a damn good letter saying this is what she is taking, this is how she is getting through the day.

Despite a successful claim, however, Jane describes feeling as though she is constantly subjected to medical tests and assessments, and that she must continually prove she is deserving of disability-related entitlements:

> And there's just so many tests. It's test after test after test. I had to go for a medical last week for my benefits and I had to tell them again what I was doing, that I'm a student and these are my symptoms.

Similar to Jane, Tracy (UK) explains that she feels as if she repeatedly must prove that she is disabled and worthy of the benefits she receives. In part, this is because, like many of the other participants, Tracy was not awarded "indefinite" benefits, and thus she must reapply in order to

continue to receive an income. At the time of the interview she was currently going through the process of reapplying, and was worried that she might lose her benefits:

> I'm fighting to keep my benefits at the moment. And I've got a few friends that have got similar illnesses to me and they go through the same thing as me, having to jump through all the hoops and constantly having to prove yourself all the time. And it's exhausting obviously being ill, without having to constantly trying to explain yourself all the time and do all the forms. I feel like I've really had to fight for it. I recently had to do the forms again and there's so many questions it's just ridiculous.

Tracy sums up the work involved as a recipient, stating that: "Even if I could, I'm not sure I'd have time to go to work, because I'm too busy being ill and filling in them bloody forms."

The participants report that completing the assessment process, like the initial application process, requires a great deal of effort, and can cause stress and anxiety, because their "income is at stake" (de Wolfe, 2012, p. 622). The participants' accounts further reveal that the psycho-emotional strain of applying (and reapplying) might in turn have a negative effect on impairments. Michael (Canada), for example, explains:

> I had a doctor say I need to go on AISH. And I did all the forms and those forms are tough to fill out. They're lengthy and you have to go and find documents. And then it makes you stressed, and you're in the brain fog, and so you're not very functional, and then you have to fill out form after form. And at that time I was in really rough shape and it only made my pain and fatigue worse.

In addition, the participants' accounts suggest that when claims are denied this might be especially stressful, not only because of the financial loss, but also because of the psycho-emotional consequences. As Diana (UK) explains, she feels that a rejected claim implies that the applicant is not legitimately disabled and worthy of benefits, and instead is "lying" to take advantage of the system:

> I was turned down after my last two appeals and they said it's because "You do not need." Basically they are calling me a liar. At the time I was ill and quite depressed and to get this letter basically saying, "You're lying," I was just so upset. It was pretty awful. It really made me more depressed and my health got much worse after that. You know that can't be right to treat people who are ill that way.

Diana feels mistreated, unworthy, and depressed due to the perceived implication that she lied in order to claim disability benefits, and this has negative consequences for her physical health. Her experience reveals how *psycho-emotional disablism* impacts how chronically ill and disabled people think and feel about themselves and how this can exacerbate *impairment effects* (Thomas, 1999a, p. 46). The psycho-emotional effects related to claiming benefits as

evidenced by Michael and Diana might be particularly problematic for people with FMS and similar illnesses, because stress, anxiety, and depression tend to cause chronic pain, fatigue, and other physical symptoms to "flare-up" (Barker, 2005; de Wolfe, 2012).

Neoliberal Welfare Reform and the "Bogus" Disabled

Reeve (2002, p. 501) argues that claimants of disability benefits have to engage in self-surveillance and force themselves to "adopt the negative identity of the disabled person, someone who is abnormal and incapable." This exacts a high emotional cost, she argues, and might discourage disabled people from claiming entitlements (ibid). The participants' accounts presented in this thesis, however, reflect that in addition to the emotional strain of trying to conform to negative disabled stereotypes, they also experience *psycho-emotional disablism* due to these same stereotypes that they believe construct them as dubiously disabled, and possibly fraudulent claimants of disability benefits.

As was briefly discussed previously, based on the respondents' accounts, I argue that *psycho-emotional disablism* (Reeve, 2002; Thomas, 1999a; Thomas, 2012) resulting in people with unobvious and unstable disabilities feeling as though they are not rightfully disabled is also connected to *neoliberal-ableist* (Goodley, 2014) discourses that construct, and differentiate between, the genuine disabled, who are recognized as worthy of entitlements, and the "bogus" disabled, who are portrayed as con-artists trying to take advantage of the welfare system (Briant et al., 2013). In particular, I argue that the participants' accounts suggest that concerns regarding their perceived (un)worthiness of applying for, or being a recipient of, disability-related entitlements might be connected to welfare reform initiatives and the increasingly negative perceptions of disability benefits claimants (Briant et al., 2013; Chouinard and Crooks, 2005; de Wolfe, 2012; Morris, 2013).

In a recent study, Briant, Watson and Philo (2013) found that the mass media plays a major role in constructing widely accepted negative stereotypes regarding disabled welfare recipients. During the period of 2010/2011 (the same time period as the interviews) newspaper articles in the UK put a greater focus on "benefit fraud and entitlement benefits and words such as cheat, scrounger or fraud" were used frequently (Briant et al., 2013, p. 874). This focus on benefit fraud and the repetitive use of words, such as, "cheat," "scrounger," and "workshy" is

significant because this "creates new forms of word association, in the same way as 'bogus' has become associated with 'asylum seekers'" (Briant et al., 2013, p. 887).

Ahmed (2004) argues that certain figures such as the asylum seeker and the international terrorist become "stuck" together through "binding" emotions, particularly fear and hatred. She further argues that through the social construction of the "bogus" asylum seeker (who sits in opposition to the "genuine" asylum seeker) fear and uncertainty are increased as it is not possible to tell the difference between those who are bogus and those who are genuine, and this means that any incoming asylum seeker is potentially "bogus insofar as they could be the very agents of terror and persecution" (Ahmed, 2004, p. 136). Thus, it comes to be understood that "the asylum seeker is 'like' the terrorist, an agent of fear, who may destroy 'our home'" (ibid). Along the same lines, it is argued here that the disabled benefits claimant and the welfare "scrounger," and the "workshy" are also problematically associated and "stuck" together. In addition, attempts to differentiate between the "genuine" disabled claimant and the "bogus" claimant increase suspicion that any disabled person might potentially be an imposter.

As if responding to allegations of being a "bogus" recipient, Jane (UK) defends her right to disability-related entitlements:

> You want your own life. I don't want hand-outs from the government. If I could do stuff I would. But yeah I think people think, "Oh yeah you're just faking it." And I think they wonder why I would need cheques from the government.

Nora specifically describes the increasing media attention in the UK regarding welfare fraud and how she feels that this likely contributes to feelings of resentment, scepticism, and judgement of recipients, particularly those who do not appear to be "disabled":

> You know nearly every day, practically every minute with what's going on there's stuff in the media about people and disability benefits who were defrauding the government and therefore costing you taxes. I sort of take that personally because I don't like having to be on benefits. And it feels like people are making a judgement given my age and the fact that I look okay.

Nora quite understandably takes the portrayal of benefits claimants as frauds personally. Although operating at the abstract level of language, the "sticking" together of benefit recipients with words like "fraud," "cheat," "scrounger," and "workshy" can have real personal consequences as the stereotypes attached to benefits claimants contributes to negative social attitudes, and in turn this might contribute to oppressive social interactions and exclusion

(Briant et al., 2013; Morris, 2013). The participants' accounts reflect the plausible perception that these stereotypes fuel discrimination against people with invisible impairments in particular, as they do not have any visible markers to indicate they are obviously disabled and unquestionably entitled to benefits. Indeed, Briant and colleagues (2013, p. 883-884) found that newspaper articles have increasingly presented the argument that genuinely disabled people who are in "real need" are not at risk of being disqualified for benefits despite stricter tests and assessments, while simultaneously constructing people with non-visible impairments (such as chronic pain) as being "unworthy," "undeserving," and likely to "fake" illness in order to take advantage of the system.

Like Nora and Jane, other participants similarly express how they believe that the changing and hidden symptoms associated with FMS could result in accusations of fraud. For example, Shannon (UK) states:

> I read on the forums there are people that are on [DLA] and then their neighbour will see them fine one day walking down the street and they will report them and then it can get to be loads of trouble for them. But that's what happens with fibromyalgia, you might be fine one day but then the next you just can't really do much…It must be difficult to prove to the disability allowance people, because they probably wouldn't be able to understand that one day you'll be fine and then the next you'll be really bad.

Similarly, Karen (Canada) explains that she has considered applying for disability benefits, but she believes that if she became a benefits recipient she would be subject to criticism and possibly allegations of "faking" illness:

> People criticize people with fibromyalgia for being on AISH. But it is just so hard, because it is so subjective, right? You're paralyzed and you're in a wheelchair nobody is going to argue, right? But when you have something that is a chronic condition where one day I can do something and the next day I can't. So somebody looking at me would be like, "Oh my gosh like I saw you yesterday and you were fine."

The accounts reflect the sense that disability benefits claimants with fluctuating and non-visible chronic illnesses might be perceived as "bogus," because, there is no visible evidence to prove they are disabled, and in fact, if they are seen on a "good day" this could actually be seen as proof that they are not truly disabled, and are "faking" illness to claim benefits.

Overcoming Disability: The Neoliberal-Able Disabled

Within this context, it is hardly surprising that some of the participants did not make claims for disability-related entitlements. Chouinard and Crooks (2005, p. 30) argue that

punitive neoliberal restructuring of welfare programs discourages "individuals from requesting any form of assistance from the state." In part, neoliberal welfare policies discourage applicants, because (as was highlighted above) it requires a great deal of hard work to make a successful claim. Michael (Canada) summarizes this quite nicely when he states: "It's like they set it up going, okay well let's make this as hard as possible until they get so frustrated that they go back to work."

Furthermore, as was also discussed above, during the period of time that the interviews were conducted an "overhauling" of the UK disability benefits system was set to begin. The UK participants' accounts reflect the shared sense that this would make it even more difficult to qualify for benefits. Lindsay (UK), who was working as a manager at a disability agency when interviewed, states:

> There are sometimes I feel like, god how do I keep going? How do I keep working? But then the thought of trying to claim benefits – well I wouldn't pass the new test, you know? You have to be sort of blind, deaf, dumb, and quadriplegic to pass the new disability assessment test. So I do fear the future. You know I fear what might happen if I found myself really, absolutely, genuinely unable to work. Yeah that's quite scary.

As Lindsay is employed at a disability agency, it is plausible that she has "insider information" regarding changes to the policy criteria. Indeed, in support of Lindsay's comments, research suggests that due to the "narrowing" of criteria, it has become more difficult for certain groups of disabled people to qualify for benefits (Goodley, 2014, p. 52), such as, chronically ill people with medically unexplained and contested diagnoses (de Wolfe, 2012).

Thus, the research findings suggest that neoliberal restructuring to welfare programs might discourages applicants by making it difficult to obtain and retain disability benefits. In addition, according to Chouinard and Crooks (2005, p. 30), neoliberal welfare policies and practices are designed to limit applicants by constructing claimants as "abject others." Previous research suggests that welfare recipients in neoliberal societies are positioned as the antithesis of the *neoliberal-able* citizen – economically productive and personally responsible for all aspects of one's life/health/welfare (Chouinard and Crooks, 2005; Goodley, 2014; Titchkosky, 2003). Titchkosky (2003, p. 525), for example, argues that neoliberal notions of individual responsibility infuse government policies that "constitute disability as some people's individualized problem that those individuals should manage, and, ideally, *overcome*" (italics in

original). She argues that constituting disability in this way discourages individuals from accessing disability-related entitlements, because it is understood to be an individual problem requiring individual solutions; rather than a social issue necessitating social change and accommodations (Titchkosky, 2003).

The interviews reflect that some of the participants feel that illness and disability are individual problems that they are responsible for overcoming on their own. Responding to the question of whether or not she considers herself to be disabled, Maria (Canada) states:

> That's a tricky one. Like I said you need to fight it, not to accept it. It is not bigger than you. So if you say you are disabled and you get disability benefits and you're not going to work then you can't fight it. Before I thought I need to go on disability [benefits] and I can't work, but my mentality has changed a lot from then to now. I thought I needed disability benefits, but now I know I can fight it. So if I don't have disability [benefits], maybe it is good. It forces me to go to work. Pain or no pain I can do it.

Maria's account suggests that by continuing to work she is "fighting" to overcome disability and resisting the "mentality" of needing welfare. Her words might also reveal the unconscious internalized values of the "good" neoliberal-able citizen who fully accepts responsibility for her health and economic fate (Chouinard and Crooks, 2005; Galvin, 2002).

Although not as explicitly, some of the other participants' accounts similarly reflect that decisions not to identify as disabled – or to pass as non-disabled – and not to make claims for disability-related entitlements, might be partly related to dominant conceptions of disability and illness as inherently negative, because these stereotypes "get under our skin" as we internalize neoliberal-able norms and values (Goodley, 2014, p. 32). As was previously discussed, *internalized ableism*, Campbell (2008) argues, is an inevitable consequence of living in a society where able-bodiedness is compulsory (McRuer, 2006). According to this theoretical framework, all disabled people (regardless of whether they self-identify as disabled or not) experience internalized disablism/ableism, or "internalized oppression," to some degree, and when disabled people internalize the negative stereotypes and assumptions regarding disabled people this can contribute to *self-surveillance* (Reeve, 2002, p. 501). For example, Reeve (ibid) argues that disabled people might engage in *self-surveillance* "by conforming to the behaviour expected by non-disabled people" (ibid). Or, as Titchkosky (2003) argues, this might mean that disabled people attempt to "overcome" disability by embodying the *abled-disabled* ideal.

According to Titchkosky (2003, p. 530) the "abled-disabled are those people who can exclude attending to disability by attending fully to their ability to participate in society."

Some of the participants' accounts reflect the physical, emotional, and relational consequences of working with chronic illness without workplace accommodations. Despite these high costs, the participants describe concealing being ill and resisting the impetus to request disability-related entitlements. The excerpts below, according to my analysis, reflect how the participants engaged in self-surveillance and conformed to expectations of the *abled-disabled*, by overcoming – or, perhaps more appropriately erasing – disability (Titchkosky, 2003). Julie (Canada) explains that although she has told her boss that she has FMS, she does not consider herself to be disabled, and has not requested any workplace accommodations:

> I don't say that I'm disabled, because I'm really stubborn about this. I'm a go getter, let me tell you. I'm the type of person who will push through and if I die doing the job then so be it. My boss knows I have fibromyalgia, but I said to my boss, "I don't want any special privileges." So I still do as much as anybody else.

In this excerpt Julie resists identifying as disabled, because this does not fit with her self-conception as a person determined to *overcome* (i.e. a "go getter"). Echoing findings from a study by Crooks et al. (2008, p. 1843), Julie's account (as well as Maria's above) reflects that "coming to understand oneself as disabled is seen as defeat."

Instead of identifying as disabled, and requesting accommodations that might improve her work/life, Julie claims she would rather "push through" and potentially "die doing the job." Although this seems extreme, other participants made similar statements. Beverly (Canada) describes how she would rather be "out of commission" when she gets home from work than disclose that she is chronically ill:

> I don't go there. I don't discuss it. I just carry on. I guess it is just my personality. I just you know get the job done. Keep working at it, you know. And then I come home at the end of the day and crash and I'm in tears, and I'm pretty much out of commission.

Similarly, Karen (Canada) explains:

> I don't say anything. I just do what I gotta do and I don't use it as an excuse for anything. I know that I've just got to make it to Saturday and then I can go home and crash Sunday. And sometimes it takes all I've got just to put one foot in front of the other and get the work done, get my job done, and then I go home and I'm going to crash.

The participants' accounts of hiding pain and fatigue, and working so hard that their bodies "crash" are moral tales that position them as "good" and "hardworking" people. They embody the *abled disabled*; that is, "they are able to fit in and take up an appearance which shows that their conduct is undoubtedly oriented to an unquestioned normalcy" (Titchkosky, 2003). This is reflected by them not asking for "special privileges," or using disability as an "excuse," and by going to work and "getting the job done" regardless of the costs.

These accounts also clearly point to how the desire to pass as non-disabled, "push through," and to continue working regardless of the costs might be understood as the unconscious internalization of a particularly neoliberal capitalist ableism that prioritizes ability, healthiness, fitness and productivity. As King (2012, p. 62) argues:

> There are many reasons why [people] with invisible chronic illness may want to hide their difficulties, including a desire to privacy or resistance to being labelled or judged and just wanting to be treated like everyone else. But I wonder if for some of us there might also be at work, in our competitive, achievement oriented, advertising-driven, capitalist culture an unspoken yet internalized mandate that says we are never good enough and must always prove our worth. Ever-accelerating, unreasonable cultural standards push not only [people] with chronic illness but all of us to ignore or hide our pain and need for rest.

Like King states, there is reason to believe that acts of self-surveillance (passing as non-disabled and overcoming disability) are rooted in "internalized mandates" that tell all of us our worth is tied to being productive, and in particular, to the neoliberal capitalist notion that to be recognized as a citizen is dependent on ability – particularly one's ability to engage in paid labour (Chouinard and Crooks, 2005; Goodley, 2014; Titchkosky, 2003). The importance of being recognized as a citizen, being included, deemed worthy, and valuable should not be underestimated, but the costs of attempting to fit the *neoliberal-abled disabled* ideal are high. As Goodley (2014, p. 65) explains, "[w]e are quite literally working ourselves to wreck and ruin – under the fantasy that labour will save us and allow us to be recognized – under the inequities of capitalism."

Conclusion: Liminality and Disturbing Polices

Based on the analysis of the participants' accounts, I argue that the widely-accepted negative cultural stereotypes of disabled people as "invalid" "deficient," and "tragic," (French and Swain, 2004; Hughes, 1999); the understanding that being chronically ill is a "moral

failure," (Galvin, 2002); as well as, the prejudices against welfare claimants who are constructed as "scroungers," "work shy," and "frauds," (Briant et al., 2013) might combine to discourage some chronically ill people from identifying as disabled and making claims for disability-related entitlements even if these would improve the quality of their lives. At the same time, the participants' accounts suggest that people with fluctuating, non-visible illnesses do not always feel that they fit the picture of the stereotypical disabled person, nor do they feel as though they conform to the conventional image of an ill person (Wendell, 2001). Occupying this liminal space between health/illness and dis/ability means that people with non-visible, non-traditional disabilities/illnesses might feel as though they are treated as questionably ill and dubiously disabled. The participants' sense that people with non-visible illnesses/disabilities are not really disabled and worthy of disability-related entitlements might also explain the reticence on the part of some of the participants to identify as disabled and make claims for entitlements. Thus, based on the findings from the analysis, I argue that *internalized ableism* (Campbell, 2008) combined with the legitimate fear of being discriminated against, stigmatized, and treated with scepticism and hostility (*psycho-emotional disablism*) might result in self-surveillance (Reeve, 2002) barring some chronically ill people from identifying as disabled and claiming disability-related entitlements.

Given that the first step to claiming institutional accommodations and disability benefits is identifying as disabled, those participants who did not perceive of themselves, or want others to see them, as disabled meant that they were unable to receive entitlements. The participants' accounts reflect that identifying as disabled, however, is just the first obstacle to obtaining institutional accommodations or disability benefits. Within the workplace, the participants felt they had to engage in a "balancing act" whereby they appeared "disabled enough" to be deemed worthy of workplace accommodations, but not "too disabled" to be incapable of continuing to work. The precariousness of this situation is reflected by the accounts of those participants who disclosed their condition in order to receive accommodations, but feel they were made redundant because they were then perceived to be "too disabled." In addition, the interviews reveal the sense that FMS might not be recognized within disability benefit policies because it "misfits" the definitional criteria of what constitutes

a legitimate disability; namely that it should be medically verified, stable, and permanent. The participants who made claims for disability benefits describe highlighting a "better legitimated condition" (de Wolfe, 2012, p. 621), or focusing on the debilitating symptoms of FMS while hiding the fluctuating nature of these symptoms. The accounts reflect the shared understanding that obtaining and retaining disability benefits requires a great deal of time and effort, is very stressful, and in some cases can be detrimental to one's health.

The recipients of disability-related entitlements explain that they feel that others perceive them as unworthy of these entitlements, and some of the participants describe reactions of scepticism, hostility, and judgement. The interviews also reflect the perception that severe cuts to the neoliberal welfare state, particularly in the UK, alongside increasingly negative portrayals of welfare recipients (Briant et al., 2013), contributes to the understanding that non-visibly disabled people claiming benefits are "bogus" and simply trying to take advantage of the system. It is understandable that within this context of budget cuts and austerity measures that the UK participants especially voice concerns about having their benefits reduced or revoked. In addition, in both countries the participants currently working express feeling stress and anxiety about the possibility of being unable to work in the future, because they believe that it is becoming more and more difficult to obtain disability-benefits, especially as a person with a medically unexplained, contested, and fluctuating illness.

The concept of *embodying liminality* has been a continuous thread throughout this thesis. With regard to the findings in this chapter it is clear from the respondents' accounts how being in the "grey area" can lead to painful exclusion. **External barriers** – such as, cuts to social programs, tightening job markets, and narrowing policy criteria – are likely going to make it more and more difficult for chronically ill and disabled people to be included and recognized as valued citizens (Goodley, 2014). At the same time, the analysis in this chapter highlights that *internalized disablism/ableism* creates **internal barriers** (*psycho-emotional disablism*) that leads to *self-surveillance* and *passing* barring people who reside in the liminal space between disability/ability, illness/health from making it known that they are chronically ill/disabled, further contributing to marginalization.

Exclusion and marginalization are not the only effects of this "liminal positioning," however, as (Titchkosky, 2003, p. 537) explains; it also offers the possibility for a "radical space for the critical inquiry of culture." Overall, this thesis has hoped to highlight that people who are ambiguously un/healthy and dis/abled *haunt* (Overend, 2014) the illusion of stable and secure medical and socio-cultural categories, and thus are *monstrous* (Shildrick, 2002) as they refuse to be contained and classified as either healthy or ill, non-disabled or disabled. The findings presented here reveal that this places people with ambiguous and undefined illness experiences in a unique position to critique these policies. Specifically, the participants' accounts highlight the need for policies that are more fluid, conceptualizing disability "beyond the fixity of absolute categories…[and instead] as a shifting set of experiences or circumstances over an individual's life course" (Lightman et al., 2009, p. np).

Chapter 8 - Final Thoughts

This thesis project is based on accounts from people living with FMS; a contested, fluctuating, and medically unexplained illness. As the first two chapters outlined, there is a growing body of research on the experiences of people diagnosed with contested chronic illnesses, but very few of these studies have addressed the broader significance of understanding and appreciating ambiguous, uncertain, and undefined illness experiences (Nettleton, 2006; Overend, 2014). In addition, researchers in the field of disability studies have largely ignored the topic of chronic illness generally, and contested illness specifically (de Wolfe, 2002; de Wolfe, 2012; Scambler, 2012; Vick, 2013; Wendell, 2001). In turn, it is rare for researchers and theorists from the field of the sociology of health and illness to apply useful theories and concepts from disability studies to this topic (Thomas, 2007). Finally, the interstitial space between health and illness and disability and ability is the focus of very little research and theory on chronic illness and disability; however, many chronically ill and disabled people reside in this liminal space (Reeve, 2002; Vick, 2013).

Therefore, the main objectives of this thesis project were to fill in these gaps by adopting a postmodern and feminist perspective drawing on work from both the sociology of health and illness and disability studies in order to examine the following broad areas of interest: First, based on the analysis of qualitative interviews with people who have been diagnosed with FMS, this thesis aimed to examine how individual experiences of undefined illness might be more broadly applicable (Nettleton, 2006). Second, drawing on the participants' accounts of their social interactions, and their experiences within the spheres of biomedicine and public policy, this study examined how the liminal bodily experiences of people with ambiguous and unexplained illnesses might be disruptive of the modernist illusion of stable and secure biomedical and socio-cultural categories (Overend, 2014; Vick, 2013). Third, by offering the unique concept of *embodying liminality* I hoped to explore both the painfulness and the subversive potentialities of being "betwixt and between" the worlds of the healthy and the sick, the non-disabled and the disabled. The following will summarize the main research findings in

relation to these three broad areas of inquiry, and will discuss the study's limitations, as well as opportunities for future research.

Uncertain Chronic Illness as Reflective of Neoliberal Capitalist Postmodernity

Postmodernity is characterized by uncertainty, ambivalence, complexity, fluidity, and ambiguity (Bauman, 1991; Clarke, 2005; Corker and Shakespeare, 2002; Giddens, 1994). In line with Nettleton's (2006) research on people with medically unexplained symptoms (MUS), my analysis of the participants' accounts reveals that uncertainty, instability, ambiguity, and fluidity are central themes in the lives of people with FMS, and thus might be more widely conceptually useful to understanding life in postmodernity. In addition, I argue that the participants' accounts of living with profound stress and debility might offer an extreme representation of all of our lives within a neoliberal capitalist context.

The participants describe how their chronic illness symptoms are complex, fluid, fluctuating, and unpredictable. In addition to ambiguous and uncertain bodily experiences, the participants' accounts highlight uncertainty in relation to biomedicine and the diagnostic process. Specifically, the respondents' sense of uncertainty is related to FMS being a medically unexplained illness that is mainly diagnosed through exclusion. In other words, it is a diagnosis based on the absence of certainty in the form of an identifiable pathology. Without a confirmed link between the cause and their bodily experiences, the participants' accounts reflect that they are haunted with uncertainty regarding the aetiology of their symptoms and by the possibility that the cause might be psychological. It is also a complex and variable illness, and as the participants' accounts reflect, no two people diagnosed with the condition have the exact same illness experience in terms of the type of symptoms they have, or in terms of the degree to which their symptoms fluctuate and change in severity. In addition, some of the participants explain that without visible evidence to prove they have FMS, and because the symptoms overlap with many other conditions, they are uncertain if they have been given the correct diagnosis. Chapter five presented the argument that FMS might be best understood as a *diagnostic illusory* that is nothing more than a "mirage of certainty," (Nettleton, et al., 2014, p. 140) as some of the participants feel this diagnosis fails to provide closure, and does not make sense of, or impart meaning to, their illness experiences.

Uncertainty also enters into other aspects of the participants' experiences. The findings reveal that deciding whether or not to disclose having FMS is a difficult decision, especially given that the participants' accounts reflect the understanding that many people (including some doctors) doubt the validity of the diagnosis of FMS and the accompanying non-visible symptoms. The participants describe how they believe that perceived and experienced reactions of scepticism and doubt are related to the absence of visible proof of illness/disability, and the ambiguity of being episodically un/healthy and dis/abled. Finally, the participants' accounts reveal feelings of uncertainty and a sense of precariousness with regard to work and their financial security. In particular, the respondents describe job insecurities and questions about their ability to continuing working, and financial instabilities relating to claiming and retaining disability benefits as a person with a contested and episodic illness, especially given the current austere economic context and neoliberal welfare reform.

The participants' accounts thus reflect as Bauman (1991, 237) explains, a "postmodern awareness of no certain exit from uncertainty." In addition, I argue that FMS, and similar conditions, might also be quintessentially postmodern because they could be termed *culture-bound syndromes*. According to Delaney and Bell (2008, p. 33), *culture-bound syndromes* "capture the contradictions of a historical period." The participants' accounts in the thesis study reflect not only an "extreme" form of uncertainty that characterizes all lives in postmodernity, but also a pronounced sense of stress and anxiety that is emblematic of our culture. As Bendelow (2009, p. 28) argues, within our culture in "late modernity" stress is an ubiquitous term, and has a "profound impact" on everyone's life. The participants' accounts reveal that psycho-emotional stress and anxiety is very prominent in their lives, and that their psycho-emotional well-being impacts their embodied experiences of pain, fatigue, and other bodily symptoms. In addition, based on the analysis of the participants' accounts, I argue that this might be related to the emotionally stressful and anxiety-provoking work of embodying and performing health/illness and dis/ability in ways that are recognized as legitimate and acceptable. In other words, for people with FMS, and similar non-visible, fluctuating and contested illnesses, these psycho-emotional aspects might be related to the *dramaturgical stress*

(Bendelow, 2009, p. 45) of having a non-visible illness/disability and deciding whether to disclose this, or to pass as healthy/able-bodied.

Throughout this thesis the performative aspects of identity have been examined in relation to how people with non-visible illness reveal/conceal being ill and identify (or not) as disabled. My analysis of the participants' accounts reveals the emotional work of *passing* and trying to embody the able-bodied norm/ideal. In line with Reeve's (2002, p. 501) work on *psycho-emotional disablism*, I argue that the participants' accounts suggest that engaging in *self-surveillance* and *passing* is potentially harmful psycho-emotionally. This is because, as Reeve (ibid) argues, it is stressful to live a "contradictory identity," and also, as Goffman (1969) argues, there is the anxiety attached to possibly becoming discredited if it is revealed that one is passing. Conversely, the participants' accounts also reflect the emotional work of trying to act in ways that others might consider to be legitimate performances of illness/disability. The participants' experiences reveal that when they tell others they have FMS (or that they are chronically ill), or when they identify as disabled, they feel as though people react with scepticism and in some cases denial. This is an additional form of stress and it is argued that this is related to experiences of *psycho-emotional disablism* that result in people with contested, non-visible chronic illnesses feeling as though others do not believe they are worthy of compassion and understanding, because they are not perceived to be legitimately ill, and that they are undeserving of institutional accommodations and disability benefits, because they are not considered by others to be genuinely disabled.

To be clear, I am not arguing that FMS, or other similar illnesses, are caused by stress and anxiety (or other psycho-emotional factors). The argument I am making, however, is that FMS, and similar illnesses, are conditions that might be emblematic of the larger society and culture. I argue that these examples of psycho-emotional stress and anxiety that people with FMS experience might be more broadly applicable of many people, because as was stated above, postmodernity (or late modernity) is characterized by the ubiquity of stress and the sense that all of our lives are becoming increasingly stressful in at least some respects (Bendelow, 2009, p.28).

Furthermore, the participants' experiences in relation to work, specifically, might also be more representative of the increasing pressure and stress we are all under to meet unrealistic standards of productivity, ability, and fitness within neoliberal capitalism (Goodley, 2014; King, 2012; Shildrick, 2015). Returning to the concept of *culture-bound syndromes*, Delaney and Bell (2008, p. 33) argue that these syndromes are "exaggerations of behaviours that are normally held in high esteem." The authors go on to explain that chronic fatigue is exacerbated by the pressure to overwork, yet "working around the clock" is also understood to be model behaviour of the ideal worker (ibid). Similarly, the participants' accounts from the thesis study reveal that working until their bodies "crash" from pain and exhaustion might be preferable to identifying as chronically ill/disabled and making claims for disability-related entitlements. The analysis of the participants' accounts suggests that they are willing to pay a high price by performing the behaviours of the model *able-disabled* – that is, a disabled person who "pushes through," who does not ask for help or "make excuses," and overall, makes disability invisible by "overcoming" (Titchkosky, 2003). These are not just the expected behaviours of the ideal *able-disabled* person, however, these are behaviours that are more generally highly regarded within our culture. Full participation in the workforce, "especially in the form of 'normal' economic contribution, is a measure of one's full citizenship" (Titchkosky, 2003, p. 536). As was discussed in chapter seven, the strong desire to be recognized as neoliberal-able citizens pressures all of us to "work ourselves to wreck and ruin" (Goodley, 2014, p. 65). In addition, as Shildrick (2015, p. 13) argues, neoliberal capitalism has made *debility* "an inherent facet of the sociality in general", and thus we are all in a sense aiming to be the *able-disabled* as we strive to overcome *debility* and the "challenge of difference" in order to "become able to function within society, such as it is" (Titchkosky, 2003, p. 538).

The analysis of the participants' accounts is thus more generally applicable to life within neoliberal capitalism, and it offers a broad critique of cultural norms and values related to productivity, (hyper)normalcy, able-bodiedness, and the ideal of the "invulnerable body" (Shildrick and Steinberg, 2015, p. 7). In particular, it provides a significant critique of the damaging effects of our neoliberal capitalist work-centric, fast-paced, high-stress culture that

pressures all of us to become increasingly debilitated in order to be recognized as full and complete economically productive citizens.

Disruptive, Unsettling, and Disturbing: Bodies that Resist Containment

This brings us to the second major area of inquiry that was examined in this thesis; that is, how FMS and similar in/visible, ambiguous, and fluctuating conditions might disrupt/unsettle/disturb modernist notions of stability, control, and certainty. As was stated previously, research and theory on chronic illness and disability has rarely addressed the liminal space in-between binary categories (Reeve, 2002, Vick, 2013). This thesis expands on work that argues for a consideration of the liminal space as a topic worthy of research and theorizing (see for example Lightman et al., 2009; Vick, 2013), and it is hoped that this thesis has revealed the value in prising open dichotomous cultural categories by highlighting the experiences of people who live in the interstices between these binaries.

According to Bauman (1991, p. 255), while we are living in a postmodern society, "this has not displaced the modern lust for uniformity and certainty." This desire is reflected by the modernist impetus to "classify," which Bauman (1991, pp. 2-3) argues actually creates further uncertainty and ambivalence:

> Classifying consists in the acts of inclusion and exclusion…Ambivalence is the side-product of the labour of classification; and it calls for yet more classifying effort. Though born of the naming/classifying urge, ambivalence may be fought only with a naming that is yet more exact, and classes that are yet more precisely defined…and thus give yet more occasion for ambiguity.

As discussed, the participants' accounts reflect the personal difficulties of *embodying liminality* (taken up again further below), and the painfulness of living with embodied difference and uncertainty. Considering the participants' accounts in relation to Bauman's work on the modernist imperative to classify, it is possible to appreciate how their liminal experiences might be the "side-product" of modernist classifications, because ambiguous bodily experiences refuse to be contained within either side of the dichotomous categories healthy or sick, disabled or able-bodied, normal or abnormal. According to Nettleton (2006, p. 1175), people with medically unexplained illnesses or symptoms "are analogous to the *unruly bodies* depicted in contemporary horror movies; they are indecipherable, they are not subject to medical restoration and they are socially out of place and threatening." Similarly, based on the analysis of the

participants' accounts, I argue that people who are ambiguously un/healthy and dis/abled *haunt* (Overend, 2014) the illusion of stable and secure biomedical and socio-cultural categories, and thus are *monstrous* (Shildrick, 2002) as they refuse to be clearly classified.

To repeat the important point made earlier in the thesis, by using the terms *monsters* and *monstrous* I am not intending, as Shildrick (2002, p. 3) explains, to "reiterate the negative charge of that ascription" rather, the point "is to contest the binary that opposes the monstrous to the normal." Liminal monsters are potentially the most threatening, because they "evade classification"; they are "neither wholly self nor wholly other" (Shildrick, 2002, pp. 2-3). It is the monsters who do not "fit" clearly into the "oppositional category" of the "absolute other" who are the most "deeply disturbing," according to Shildrick (2002, p. 45), because, "what lies beyond the unproblematic horror of the absolute other is the far more risky perception that the monstrous may not be recognized as such, for it is not so different after all."

This is why it is theoretically, ethically, and practically important according to Overend (2014, p. 79) to "learn to attend to, acknowledge, listen and care for, that which exists in the interstices"; to acknowledge the embodied experiences of people who reside in the liminal space in-between biomedical and socio-cultural categories of recognition. People who *embody liminality* are, to use Bauman's (1991, p. 56) term, the *undecidables* and "they brutally expose the artifice, the fragility, the sham of the most vital of separations." According to Bauman (1991, p. 58-59), the *undecidables* are:

> The true hybrids, the monsters – not just *unclassified*, but *unclassifiable*. They do not question just this one opposition here and now: they question oppositions as such, the very principle of the opposition, the plausibility of dichotomy it suggests and the feasibility of separation it demands. They unmask the brittle artificiality of division (italics in original).

Based on the analysis of the participants' accounts, I argue that the *undecidable*, *monstrous*, and *hauntingly* ambiguous bodies of people with the episodic and in/visible illness FMS *disrupt*, *unsettle*, and *disturb* biomedical classifications, social interactions, and policy criteria founded on modernist dichotomous categories of bodies as either healthy or sick, able-bodied or disabled, normal or abnormal.

Before moving on to discuss the significance of *undecidables* and *monsters* for uncovering "the brittle artificiality of division" (Bauman, 1991, p. 59) as well as the

potentialities of *embodying liminality*, it is necessary to briefly consider again the painfulness and difficulties of existing "betwixt and between." As Morgan (2005, p. 312) argues "in general border crossers, challengers, and violators do not fare well in societies whose dominant apparatuses depend on nonpermeable binaries." Specifically, based on the participants' accounts, I argue that their experiences reflect the painfulness of being cast as misfits who do not fit into either/or categorizations, and instead reside in the interstices of in/visibility and recognition. As was discussed, the participants' accounts reflect that they live with disruptive bodies that haunt notions of biomedical certainty and control; and that they experience unsettling social interactions where their embodied experiences are treated as threatening, because they are not easily understood; and that they engage with disturbing policies that tend to construct their embodied realities as questionable at best and unintelligible at worst.

Recognizing the experiences of people who confound modernist notions of what constitutes ab/normal, un/healthy, and dis/abled embodiment is significant, then, because while these binaries are abstract, they have real consequences; not just for people who reside in the liminal space in-between, but for all of us. For example, the illusion of the invulnerable and perfect(able) body justifies the oppression of people who are deemed "other," "less than," "weak," and "flawed," and as Stone (1995, p. 416) argues it "keeps all of us alienated from our bodies" and "prevents us from acknowledging and accepting that all of us have limits to our abilities." Thus, as Garland-Thomson (2011, p. 603) argues, it is important to acknowledge the *misfits* – or the *monsters* – because they can be "agents of recognition":

> Although modernity presses us relentlessly toward corporeal and other forms of standardization, the human body in fact varies greatly in its forms and functions. Our experience of living eventually contradicts our collective fantasy that the body is stable, predictable, or controllable, creating misfits for all of us…The misfits that constitute the lived experience of disability in its broadest sense is perhaps then, the essential characteristic of being human.

Embodying Liminality: Possibilities Beyond Binaries

This chapter has served to show how this study based on the accounts of people who are in/visibly and episodically un/healthy and dis/abled is broadly instructive and more generally applicable to all of our lives. In addition, echoing Vick (2013, p. 186), this thesis is significant for "expanding an awareness of disability as grounded in the unfamiliar, evolving, raw moments

of lived experience." It draws on, and contributes to, both the field of the sociology of health and illness and the field of disability studies by adopting a postmodern and feminist perspective that seeks to bring to light "the silenced, 'borderline' or unfamiliar stories" of illness and disability (Corker and French, 1999, p. 11). I believe that there is much more to be gained by combining insights from these two fields, and by theorizing and researching from the perspective of the "borderline," and "unfamiliar" stories of people who reside in the liminal space in-between. Future research should continue to explore the monstrous and haunting liminality of people with non-visible, ambiguous, and medically unexplained illnesses. It might also begin to consider the *embodied liminality* of other disrupters, monsters, misfits, and border crossers who haunt dichotomous categories, such as sickness/health, ab/normality, and dis/ability, as well as other binary hierarchical cultural conceptions, such as, the classification of bodies as un/desirable, de/valued, in/competent, and un/worthy.

While this chapter has served to show the benefits of a broad approach that addresses how social structures impact embodied experiences, it is also has its limitations. Given the wide scope of the research, space and resources did not permit a detailed analysis of some of the important differences amongst the participants, and although gender and national context were addressed to some extent, these two factors were not the focus. Future research on contested illnesses specifically, therefore, might engage in a more detailed comparative approach looking at different national contexts, and it might also highlight gendered dynamics, as well as other aspects of identity, including age, social class, ethnicity, and other important dimensions of one's social location. It would also be useful to have complementary studies that address the "other side" of the interactions that the participants' accounts highlight, particularly, the perspectives of doctors, as well as the views of partners, family, friends, and other intimate, and more remote, individuals in the lives of people with contested chronic illnesses.

Another possible limitation is that by adopting a postmodern, feminist approach that focused predominately on the social aspects of health/illness and dis/ability, that the embodied suffering of living with a chronically ill body was made an absent present in the research. While this is a potential cost of the approach taken, I feel that there are many benefits to employing this theoretical framework. As was discussed, the research project was designed to move

beyond the limitations of other research predominately from the sociology of health and illness that tends to take a "social deviance paradigm" which operates under the assumption that health (and ability) are the norm and that illness (and disability) are deviant (Thomas, 2007). This paradigm has also been deemed the "personal tragedy" or "medical model" perspective as it upholds, rather than challenges, the dominant cultural understanding of disability (and illness) as "inherently negative," (Campbell, 2008) and the portrayal of chronically ill and disabled people as tragic sufferers (French and Swain, 2004). By adopting the "social oppression paradigm" that has dominated disability studies, and by drawing on postmodern and feminist theories, it was hoped that this thesis might offer a more complex picture of living with chronic illness that acknowledges the positive aspects of being ill/disabled, as well as the negative experiences of *disablism*, including *psycho-emotional disablism* (Thomas, 1999; Reeve, 2002). It was hoped that this thesis might therefore provide an ontological reframing of chronic illness that allows for a recognition of the complexity of chronically ill people's lives, and resists oversimplifying the topic by representing illness and disability as solely negative (or wholly positive), but instead, reveals the instructive, disruptive, and subversive aspects of *embodying liminality* (i.e. being un/healthy and dis/abled).

Having outlined how the participants' experiences might be more broadly instructive, and having discussed the disruptiveness of bodies that are uncontainable within either/or categories, the final section of this chapter will address the subversive potentialities of *embodying liminality*. According to Turner (1967, p. 97):

> Liminality may perhaps be regarded as the Nay to all positive structural assertions, but as in some sense the source of them all, and, more than that, as a ***realm of pure possibility*** whence novel configurations of ideas and relations may arise (emphasis added).

Similarly, Shildrick (2002, p. 4) argues that liminal beings/monsters are "transgressive and transformative." Based on the analysis of the participants' accounts I argue that the concept of *embodying liminality* offers important insight into the transformative, transgressive, and the pure possibilities of residing in the borderlands. As was discussed in chapter three, previous research and literature on contested illness has highlighted the disruptiveness of these conditions in relation to the body, self, and identity. This work has revealed the negative aspects of lives

disrupted by illness, by looking at experiences of suffering, loss, and chaos. What has been largely missed, and this thesis has attempted to contribute to, is research that examines the positive dimensions of this disruptiveness. I argue that *liminality* is a useful for concept for revealing the painfulness of liminality, as well as the "pure possibilities" of existing in-between health/illness and dis/ability for transgressing seemingly stable and secure boundaries, resisting neoliberal-ableist cultural norms, and subverting dominant cultural understandings of what constitutes recognisable embodied performances of health and illness, disability and ability.

In chapter five, it was argued that the participants' accounts reflect the transformative possibilities of "letting go" (King, 2012) of the search for answers and closure, and "giving in" to bodily needs, rather than "fighting" against the body. The findings in chapter six point to the possibility that people who exist in the liminal space in-between might resist and challenge negative perceptions of illness and disability by "daring to speak otherwise" (Campbell, 2008, p. 160) and thus disturbing dominant cultural assumptions regarding what it means to be un/healthy and dis/abled. In addition, I argue that the analysis of the participants' accounts also reflects how unexpected and subversive performances of health/illness and dis/ability might be transgressive in that they reveal the "tenuousness" of seemingly stable and harmful dichotomous categories (Butler, 2006). Finally, in chapter seven, the participants' accounts reflect how they are surviving in the "grey area" as they might be too ill/disabled to work, but are not considered ill/disabled enough to be entitled to disability benefits. The findings from chapter seven reveal the importance of challenging rigid and exclusionary policies, by considering how liminality might offer a "realm of possibility whence novel configurations of ideas might arise" (Turner, 1967, p. 97). These novel ideas might include a "conceptual shift" of "thinking towards porous interpretations" (Vick, 2013, p. 186), rather than either/or categorizations that fail to reflect the "real messiness of lived bodies" (Einstein and Shildrick, 2009, p. 293).

Indeed, the participants' accounts overall reflect that a conceptual shift rooted in the postmodern recognition that all bodies are "fluid and unstable, never given or fixed" (Shildrick, 2002, p. 10) might improve their lives as their liminal embodied experiences would then be recognized as legitimate. Challenging and reconceptualising dominant cultural understandings of health/illness, dis/ability and ab/normality is obviously not a simple or straightforward task,

and it would involve giving up comforting modernist illusions of stability, certainty, and control. Although it might be both "risky" and "scary" to let go of modernist notions and the "comfort of familiarity," it is also imperative that we do so, because as Shildrick (2002, p. 132) cautions, "though the constructs of modernity might seem to promise a limited security, they do so only at the cost of a violent and exclusionary ethic." Thus, an ideological transformation is necessary to stop the real violence done by abstract binaries, and it must come from embracing the complexity, fluidity, and difference inherent in the full continuum of human embodiment.

Appendices

Appendix I

UK Participants

Pseudo-nym	Sex	Age	Ethnicity	Other medical conditions	Education Occupation	Disability Benefits	Relationship status and family information
Emma	F	24	White British	CFS/ME	Partial completion of under-graduate degree. Unemployed	IB	Single, no children
Shannon	F	23	White British	Migraines	Master's degree. Unemployed.	N/A	In a relationship, no children
Nancy	F	44	White Australian	RSI, Carpal Tunnel Syndrome, Tendonitis	Doctoral degree. University Lecturer	N/A	Common-law, no children
Meredith	F	42	White British	ADHD, DID, RA	Partial completion of under-graduate degree. Unemployed.	DLA	Single (divorced), no children
Samantha	F	25	White British	Migraines	Partial completion of under-graduate degree. Unemployed.	N/A	Common-law (engaged), no children
Robyn	F	28	White Australian	PTSD, Spinal Injury, Asthma	Postgraduate (M.A.) Student	N/A	Single, no children
Lillian	F	48	White British	Localized spinal and shoulder pain (different than the FMS related pain)	Under-graduate degree. Academic Quality Assistant	N/A	Divorced. In a relationship. No children.
Diana	F	44	White British	SPD, Chronic coccyx pain, Endo-metriosis, Depression, IBS	Under-graduate degree. Full time mother.	Past recipient of DLA	Married, 3 young children

Connie	F	52	White British	Osteo-arthritis	Finished A Levels. Unemployed.	DLA	Married, no children
Katelyn	F	33	White British	JHS, Chronic back pain, Endo-metriosis	Master's degree. Teacher.	N/A	Single, no children
Lindsay	F	56	White British	Chronic pain from neck injury, Optic Neuritis	Master's degree Disability Charity Manager.	N/A	Single, 1 adult child
Mark	M	37	White British	JHS	Under-graduate degree Banker	N/A	Married, 2 young children
Jane	F	21	Black Caribbean British	JHS, Endo-metriosis, Depression	1st year University student.	DLA	Single, no children
Tracy	F	34	White British	CFS/ME, TMJD, DID, RA, JHS	Finished A levels. Unemployed.	DLA	Married, no children
Nora	F	43	White British	Depression, RA	Finished A levels. Unemployed.	DLA	Common-law, no children
Harold	M	52	Indian British	Depression, RA	Partial completion of under-graduate degree. Retired early for medical reasons	DLA	Single (divorced), 2 adult children
Curtis	M	55	White British	SMA	Under-graduate degree. Retired early for medical reasons.	IB	Married, 2 young children

Canadian Participants

Pseudo-nym	Sex	Age	Ethnicity	Other medical conditions	Education/ Occupation	Disability Benefits	Relationship Status and Family Information
Carolyn	F	52	White Canadian	MCS, ADHD	High school diploma. Housewife/ homemaker	AISH	Married, 3 adult children
Patricia	F	48	White Canadian	Localized hip and pelvic pain (different than FMS related pain)	College diploma. Manager; on disability leave.	Private workplace disability plan	Married, 2 adult children
Amber	F	63	White Canadian	RA, Spinal Injury, CFS/ME	College diploma. Part-time homecare nurse.	AISH	Single (divorced), 2 adult children
Tyler	M	36	White Canadian	ADHD, Bipolar Disorder	Partial completion of under-Graduate degree. Delivers newspapers.	Past recipient of Income Support	Married, 1 young child
Monica	F	69	White Canadian	IBS, Migraines	Completed Grade 11. Retired.	Past recipient of CPP-D, now she receives OAP.	Married, 2 adult children
Maria	F	47	Mexican Canadian	IBS	College diploma, Works from home as an accountant for her husband's business	N/A	Married, 1 adult child
Jessica	F	42	White Canadian	Carpal Tunnel Syndrome, ADHD	University student (social work)	EI	Common-law (engaged), 3 adult children
Michael	M	39	White Canadian	Depression, CFS/ME	Partial completion of under-graduate degree. Unemployed.	Income support	Single, no children

Beverly	F	48	White Canadian	Thyroid condition, Tendonitis, IBS	Under-graduate degree. Realtor	N/A	Single (divorced), 2 adult children
Karen	F	44	White Canadian	Carpal Tunnel Syndrome	College diploma. Newspaper Editor	N/A	Single, no children
Julie	F	52	White Canadian	Poly-myalgia rheumatica (initial diagnosis, before being diagnosed with FMS)	Master's degree. College instructor and Education Assistant	N/A	Married, one adult child
Veronica	F	57	White Canadian	Colitis, RA	College diploma, Homecare Nurse	N/A	Married, 2 adult children
Gordon	M	38	White Canadian	Chronic pain from sport related injury, Tendonitis	College diploma, Church Minister.	Past recipient of AISH	Married, 3 young children
Courtney	F	51	White Scottish Canadian	CFS/ME	High school diploma, Receptionist	N/A	Married, 2 adult children

Appendix II - Participants Needed for Research on Fibromyalgia

Research Title: Understanding "Contested" Chronic Illness: A Case Study of the In/Visibility of Fibromyalgia Syndrome (FMS) in the UK and Canada

Principal Researcher: Tiffany Boulton, MA
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http://www.sociology.leeds.ac.uk/research/students/boulton.php

I am a PhD student at the University of Leeds and I am currently recruiting participants for a research project that examines the experiences of women and men living with fibromyalgia in Canada and the UK. If you think that you might be interested in participating in this research project, please take a moment to read the following. I would like to thank you in advance for taking the time to read this information and for your interest in the research project.

Your involvement in this research project, if you choose to participate, will require approximately 1 - 2 hours of your time. During this time you will be asked to share your experiences of living with fibromyalgia. There will be questions on the following topics: receiving a diagnosis; identity; relationships with family and friends; paid and unpaid work; interactions with health and service providers; access to formal and informal support. In addition, during the interviews I will collect general demographic information (i.e. age, ethnicity, occupation, education level, relationship status, and number of children).

The interview will take place in a location that is most convenient for you, such as your home or a local coffee shop or community centre.

The information gathered during the interview is not meant to identify you in any way. Your identity will remain anonymous and the information you provide during the interview process will be kept strictly confidential.

The results from this research project will be presented in my PhD thesis. In addition, the results may be presented at academic conferences, public lectures, and in writing in academic journals. At no time, however, will your name be used or any identifying information revealed.

If you are interested in participating in this research project, or if you have any questions about this research, please feel free to contact me, **Tiffany Boulton**, at
fmsresearch.leeds@gmail.com or sstnb@leeds.ac.uk

I look forward to hearing from you!

Appendix III - Consent Form

Title of Research Project: Understanding "Contested" Chronic Illness: A Case Study of the In/Visibility of Fibromyalgia Syndrome (FMS) in the UK and Canada

Name of Researcher: Tiffany Boulton

Please initial box

1. I confirm that I have read and understand the consent letter explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

3. I understand that my responses will be kept strictly confidential.

4. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

5. I agree for the data collected from me to be safely stored for three years for research purposes.

6. I agree to take part in the above research project.

_____   _____   _____

Name of Participant   Date   Signature
(*or legal representative*)

_____   _____   _____

 Lead Researcher   Date   Signature
To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Appendix IV - Information for Potential Participants

Research Title: Understanding "Contested" Chronic Illness: A Case Study of the In/Visibility of Fibromyalgia Syndrome (FMS) in the UK and Canada

Principal Researcher: Tiffany Boulton, MA
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University of Leeds
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You are being invited to participate in a research project. This letter, a copy of which has been given to you, should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information. Thank-you for taking the time to read this information and for your interest in the research project.

Your involvement in this research project will require approximately 1 hour of your time. During the interview I will ask you questions on the following topics: receiving a diagnosis, experiences with the healthcare system and interactions with healthcare professionals, accessing disability support services and benefits, interactions in the workplace and the community and your relationships with family and friends. During the interview I will also ask you for some general demographic information (i.e. age, ethnicity, impairments other than FMS, occupation, education level, relationship status, and number of children).The interview is designed to be flexible and I encourage you to discuss other aspects of living with FMS that might not be covered in the topics listed above. It may also be necessary for me to do some follow-up work after the interview in order to clarify certain points, or to make sure I have understood you correctly. This follow-up work would simply involve either a phone conversation, e-mail correspondence or a face-to-face interview in a meeting place most convenient for you.

The information gathered during the interview is not meant to identify you in any way and several steps will be taken to ensure your identity remains anonymous and that the information you provide during the interview process is kept strictly confidential. Your involvement in this research project is completely voluntary. You are not obliged to answer any of the questions asked during the interview, and you may terminate the interview at any time. If you choose to withdraw from the study prior to its completion, copies of the interview (recorded and/or written) will be destroyed upon your request and will not be used in the study.

The results from this research project will be presented in my PhD thesis. In addition, the findings will be presented at academic conferences, community presentations and in writing in academic journals. It is my hope that this research will promote further awareness of the issues faced by people with FMS and that the knowledge gained through this project might be used to improve the lives of people with this chronic illness.

Your signature on the attached consent form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Tiffany Boulton, 07771433250, or sstnb@leeds.ac.uk or fmsresearch.leeds@gmail.com

Diagnosis
I'd like to start off by asking you how old you are
And, how old were you when you were diagnosed with fibromyalgia?
Please share with me your experiences leading up to your diagnosis
When you were diagnosed with fibromyalgia what do you think/feel? What sort of information were you given? Did you find this information helpful? What did the diagnosis mean to you? Does it have the same meaning for you now? Who did you tell about your diagnosis?

Relationships – Partner/Family/Friends
Please tell me a bit about your family. Are you in a relationship? Do you have any children? In what ways, if any, has living with fibromyalgia affected your personal relationships (including your relationships with friends)? What kinds of support (if any) do you receive from your partner/family/friends? What kinds of support (if any) would you like to receive from your partner/family/friends?

Work – Paid and Unpaid
What is your occupation at the moment?
Has the onset of FMS affected your ability to engage in paid work? If yes – please explain, and if possible, provide specific examples. How, if at all, did the onset of FMS affect your relationships and interactions with your employer and/or your co-workers/colleagues? Can you recall any particular instances where you felt that problems/issues with your employer and/or your co-workers/colleagues were related to your illness? In what ways, if any, has the onset of FMS affected your ability to carry out household tasks? In what ways, if any, has your illness affected your parenting?

Healthcare
Please share with me your experiences of the healthcare system.
Can you recall any specific examples (positive and/or negative) of your experiences with various healthcare professionals (i.e. GP's, rheumatologists, psychologists, nurses)? Can you share your experiences regarding the types of treatment you have received? (i.e. various medicines, cognitive therapy, physical therapy…) Have you tried any forms of complementary or alternative medicine/therapy? If so, can you please share your experiences? Or, why have you chosen not to try CAM? Did you seek out CAM or was it suggested to you?

Disability Benefits, Homecare, Support Services
Please tell me about your experiences with disability support services/government agencies. Do you receive any disability benefits/homecare services/social support? Can you explain the process you went through to receive this? Did you have any issues applying for these benefits/services?

Fibromyalgia and Disability Support Groups
Please share with me your experiences with FMS support groups and/or other disability related support groups (including online groups). Do you find them helpful? Why/why not?

Final thoughts
What do you think needs to happen in order to improve the lives of people with fibromyalgia? Do you have anything else you would like to add?

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