

**FRAMING CHRONIC ILLNESS:
FATIGUE SYNDROMES, METAPHOR AND MEANING**

A Thesis Submitted to the College of
Graduate Studies and Research
in Partial Fulfillment of the Requirements
for the Degree Master of Arts
in the Department of Women's and Gender Studies
University of Saskatchewan
Saskatoon

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ABSTRACT

Fibromyalgia Syndrome (FMS) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) are primarily women's syndromes. Both syndromes are highly contested within the biomedical and scientific communities and within the general population. Because there is no apparent cause for the syndromes and no available treatment, women living with FMS and/or CFIDS must live with difficult and disabling symptoms.

This research also analyzes the metaphors used in the scientific and biomedical literature to describe the same symptoms as listed above. A comparison is drawn between this analysis and that focused on the women's use of metaphors. It is found that although many of the metaphors are the same, they differ in discursive employment. Environmental metaphors, along with metaphors of fracture, harm and productivity are used by the research participants with a very different intent than how the same metaphors are used in the biomedical literature. The women used the metaphors to reveal the ways in which their symptoms are influenced by the social and cultural forces in their everyday lives. The biomedical and scientific use of metaphors reinforced the highly contested view that the symptoms are influenced more by individual psychological and emotional deficiencies than by broader structural forces.

ACKNOWLEDGMENTS

I sincerely thank the guidance and support of my advisor, Dr. Pamela Downe.

I also wish to thank my Advisory Committee, Lesley Biggs and Kathleen James-Cavan,
for their support and advice during my research.

DEDICATION

In honour of my late Mother and Father, I dedicate this research. Their unconditional love helped me to believe in myself. I felt that love even in their absence.

To Lynn, thank you for your love and unwavering support.

There are so many others who supported me during my research. Thank you to my chosen family, Kell, Brittany and Kelsi.

To my daughter, Erin, my best friend, my child. You have been there through the good and the bad. I sincerely thank you.

Mozart. You have been beside me from the very beginning. Thanks, buddy.

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CHAPTER 1

FRAMING CHRONIC ILLNESS

1.1 Introduction

How do I tell someone I am physically unwell when I look so healthy? Many women with Fibromyalgia Syndrome (FMS) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) ask this question when they are speaking of the experience of living with one or both of these chronic diseases. For those who live with daily symptoms of pain and fatigue, FMS and CFIDS reframe their lives and ultimately change their self-concept and identity. FMS and CFIDS are debilitating and invisible diseases that often strike women in the most productive times of their lives and remain with them for the rest of their lives. Both FMS and CFIDS are mysterious illnesses without known cause and without effective treatment.

This study focuses on the language of pain, fatigue and other bodily irregularities used by a sample of women living with and FMS /or CFIDS. I cannot know precisely what occurs within their biological bodies. However, the women's perceptions of the external forces strongly suggests that such forces affect symptoms of FMS/CFIDS. The external factors may be aspects of daily life: work, social interaction or environmental factors. The experience of living with FMS/CFIDS becomes more meaningful when examining the metaphors of pain, fatigue, and cognitive dysfunction. It is difficult to see or feel the pain of others. We only know pain from the words spoken and the metaphors and descriptions used to express feelings and emotions.

Focus will also be given to a textual analysis of the relevant biomedical language that is used to describe these symptoms. The subjective expressions used by women living with FMS/CFIDS (WLWCs) appear to be directly opposed to the discourses of biomedicine, where

metaphors are more aptly described as scientifically removed from the subjective and tied more to political economy and mechanistic models of factories and machines or war (Birke, 2000; Martin, 1992; 1994; Kirmayer, 1988).

This study is about the struggles of women living with FMS/CFIDS and their concepts of their changing selves and their bodies. It is about the struggle, and the significant gains, people who live with chronic pain and fatigue make in their daily lives. This, too, is a study that came to me several years ago when I became ill with what I believed to be a simple virus. However, the virus was not simple and a diagnosis of FMS/CFIDS became part of how I know myself, a label that is misunderstood and carries a great deal of stigma. My journey is similar to the women in this study; however, their journey is their story, different in situation and in the individualistic nature of the disease. The research came to me through illness and I have gone to the women included in this study to understand more fully their experiences. Each woman who lives with FMS/CFIDS becomes an expert of her own bodily experiences. For the women participants in this research, I am the messenger. At times, the words of those who participated in this research describe my experience while, at other times, there is great divergence.

1.2 Study Objectives

The purpose of this study is to examine the metaphors and descriptive language the participants use to make sense of their pain, fatigue and the varied symptoms of the diseases. This analysis necessitates that attention also be given to how the women participating in this study perceive themselves and how they have reshaped their concepts of self as they relate to invisible chronic disability. Lakoff and Johnson (1980) suggest, “our conceptual system is largely metaphorical[;] . . . what we experience and what we do every day is very much a matter of metaphor” (p. 3). Using a theoretical approach that analyzes the metaphorical statements of

the participants will give greater scope to their concepts of chronic illness in their everyday lives. Metaphor is part of communicating that puts conceptual thinking into language. How one acts and responds is not always thought about; however, the language that is used to express thoughts and acts is most commonly communicated through metaphor (Lakoff & Johnson, 1980).

Metaphor and descriptive language also shape the discourse of science and medicine. Lakoff and Johnson's (1980) analysis of metaphors of war and structure, for example, is applicable to the biomedical discourses of disease and the body. At times, processes and ideas are not easily understood. Metaphors are linguistic expressions that are part of individual experience. Concepts that are familiar are linked to things not familiar. For example, pain is difficult to express in terms that others can fully understand. Using metaphors such as "burning" or "stabbing" in metaphorical expressions of pain associates a familiar concept with what otherwise cannot be seen nor shared with others. In biomedicine, metaphors are commonly used to describe physical sensations and bodily processes. Before technological developments that make it possible to view the inner organs and processes of the body, science relied on hypotheses created through imagination and reason to understand and explain physiology and the biological processes. In other words, science and biomedicine compared the body to unrelated concepts and structures such as the body as machines and factories (Birke, 2000). Kirmayer (1988) states that, "The dominant metaphor of biomedicine is THE BODY IS A BIOCHEMICAL MACHINE" (Osherson & AmaraSingham; cited in Kirmayer, 1988, p. 57; original emphasis). Other commonly used biomedical metaphors of war, the factory, and electronic circuitry have aided in visualizing the processes that are not visible to the human eye or with the present technologies. As well, metaphors have become so embedded within biomedical discourse that they are not

recognizable as metaphors. We do not think about the extent to which metaphors are incorporated in scientific discourses until we analyze and interpret the meanings.

When scientific metaphors collide with subjective metaphors, the meanings of both may be misinterpreted. The physician's objective use of jargon and metaphors of illness and the subjective use of metaphors by the patient are often not the same. Kirmayer (1992) states that:

Part of what makes the patient's self-description unintelligible to the biomedical physician is the practitioner's tendency to take the metaphoric constructions of illness experience for literal statements within the empirical realm of biomedicine. Language is treated not as a personal expression but as a transparent universal code. (p. 339)

By examining the literature of biomedicine that concentrates on the terminology of FMS/CFIDS, I intend to give evidence that the disembodied nature of metaphor in biomedical literature is in direct opposition to the subjective narrative when one relates the bodily experience of FMS/CFIDS.

The labels and classifications affixed to individuals within a given culture reflect the discourses that surround a given topic. Foucault's *Discipline and Punish: The Birth of the Prison* (1985) and *The History of Sexuality* (1990) inform us that it is partly through surveillance that individuals and groups are labelled, categorized and marginalized. The study of marginalized illness serves to illustrate the various forms of surveillance and the intrusion of biomedicine into the individuals' lives, particularly from a gendered perspective. It has been well documented that women have been marginalized throughout history (Wendell, 1996; Showalter, 1985: 1997). Therefore, FMS and CFIDS, being primarily women's diseases, have a particular form of surveillance and a distinctive form of marginalization within culture and biomedicine.

Culturally and in biomedicine, the marginalized and chronically ill body must not be overlooked. It too is under forms of surveillance both from a biological perspective and from a very personal perspective. Grosz (1994) speaks of the "lived body"; however, care must also be

taken to think of the internal biological body. Birke (1999) argues that we must look at the body as transformable but we must also think about the body as processes and not only the effects of culture on the body. For women with physical disabilities, we must think about “bodies lived *in* culture” (Birke 1999, p. 48; original emphasis). In order to address the multiple symptoms that occur when FMS/CFIDS becomes part of women’s health experience, this study must address the internal biological body using the framework of Martin and Birke without bending to biological determinism.

Biological processes are not distinct and separate from the environment that the body traverses. Rather, to think of the body, internal and external, as processes within other processes alters how the dichotomy of internal/external is currently theorized and perpetuated. Reducing the body to the biology of sex refuses to acknowledge that both biology and culture are factors in individual health. Birke (2003) argues:

We can think about ‘the body’ as existing in, and part of, a nexus of forces, moving through the world and co-creating it. To take that stance de-emphasizes the factors which might ‘act upon’ the body and prioritizes engagement with the world in which we move. Part of that co-creation is of course, how social and cultural forces do indeed write upon the body as surface—but part, too, is how they communicate with the body’s inside. (p. 46)

Thinking of culture as inscribed on the body suggests that a boundary exists and separates the biological body from the external elements and forces within culture. It may be argued creating such a boundary limits the inclusion of the biological body within present discourse. However, addressing the ways existing boundaries have been constructed and re-evaluating whether these boundaries are pre-social, inherent attributes of the individual, particularly for women, are ways of reframing biology (Birke, 2003). To accept that biology is a process where certain aspects of individuals are defined by their genetics or sex does not imply that biology is destiny. What it does suggest is that each part or system within dynamic bodily processes does affect health.

Analyzing chronic disease from the standpoint of biology is not inclusive of many factors that are important aspects of living with a chronic disease. Representing disease as strictly biological negates the impact of social and cultural variables on the body. To date, a workable theoretical framework has not been sufficiently developed to show that social and cultural factors do affect the biological body. However, it is not difficult to argue that there are known environmental problems that impact health, such as dangerous chemicals, toxins and pollution. Why, then, are less visible social forces not understood to be as challenging to bodily health as are toxic elements that can be seen?

Discussing syndromes that have no known cause and are chronic and debilitating requires addressing issues of internal biological processes as well as external social influences. Those who live with either or both syndromes believe that social stress and other cultural factors such as the work environment can increase the severity of their symptoms. Therefore, outside factors cannot be ruled out as possible causes of the syndromes. Simply stated, there is no proof that environmental factors are not the cause, just as there is no proof of viral etiology.

Due to the current power and control of biomedicine within Canadian culture, individuals have come to know their own bodies as having an external surface and internal components; however, the external is more than the layering of skin that shields the body. The skin is not an absolute boundary but a thin porous layer that allows viral agents and infections to move beyond it, causing disease and sickness. Historical analysis of these syndromes indicates that the boundaries between the skin and the outside world were more porous than the way these boundaries are conceptualized today (Duden, 1991). The meanings and functions of those boundaries may again alter with the advances in how the body is viewed from a theoretical and scientific viewpoint. Boundaries may also alter with relation to age, culture and gender.

Boundaries are constructed through language. Even literal language about past and present viewpoints of the body shows that boundaries are constructed through language. Language is the evidence of past and present viewpoints, a language that even in the literal is metaphor (Kirmayer, 1988). Analyzing bodily metaphors and descriptive phrases facilitates thinking about how the body has been socially and scientifically constructed. Once the body is understood as having been constructed through language, it becomes transparent and disease can be understood as cultural and social constructions that alter as new metaphors replace existing explanations of these processes.

Boundaries help in conceptualizing the body in public and private spaces. Frequently, the separation between the public and private domains is socially constructed; these are boundaries that differ for the chronically ill body in contrast to the healthy body. Analyzing the metaphors used by the women who participated in this study will show how the social boundaries alter everyday life. As well, the analysis will show boundaries that are of individual construction that aid in living with FMS and/or CFIDS. The heading above shows that if you have a subheading of a certain level, you must have more than one. The rationale is that you cannot have a list of only one item.

1.3 Overview of Chapters

Chapter Two concentrates on the literature reviewed that informs and shapes the theoretical foundations in the analysis of women living with Chronic Fatigue Immune Dysfunction and/or Fibromyalgia Syndrome.

In Chapter Three, attention is given to the methodology used in the study. Included in this chapter is a discussion of participant selection, the methods used in obtaining the data for my study and the limitations of my research.

Chapter Four, *Symptom Metaphors*, explores the metaphors and descriptions used by the women who participated in the research. This analysis will be divided into sections that address journey metaphors, metaphors of fracture, metaphors of harm, environmental metaphors. Another section is devoted to describing the interaction between the physical and cognitive as the participants describe the effects of FMS/CFIDS in relation to notions of self, change, and the external influences that alter and affect the perceived symptoms of illness.

Chapter Five is devoted to an analysis of metaphors and descriptions used within biomedical and scientific articles and texts. My analysis will show the differences that exist between the objective use of technical scientific language and the descriptive phrases discussed in Chapter Four.

Chapter Six concludes this research. Theoretical foundations will be applied in a critical analysis of the findings in Chapters Four and Five

CHAPTER 2 REVIEW OF LITERATURE

2.1 Introduction

Women who become ill with Fibromyalgia Syndrome (FMS) and/or Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) are challenged on many levels. The personal trauma of acquiring a chronic, painful and debilitating disease is in itself a life-altering event. However, dealing with the skepticism about FMS/CFIDS as diseases by the biomedical communities, as well as from the individual's social networks is perhaps the greatest challenge of the FMS/CFIDS illness experience.

A review of literature has indicated extensive writing about both scientific investigations of the diseases and qualitative studies focused on the experience of living with FMS/CFIDS. However, little has been written on the personal construction of illness, how those with FMS/CFIDS experience symptoms in their everyday lives. Virtually no analyses have focused on the metaphors used by those with FMS/CFIDS to explain how they describe and interpret the diseases. Other disease and syndromes have been studied using metaphor to analyze the scientific literature (Birke, 2000; Martin, 1992:1994) but no literature was found of metaphorical analysis of the scientific literature of FMS/CFIDS in this review of literature.

For the purposes of this research, the reviewed literature will focus on self and identity, disability and chronic illness, metaphor, and the effects of stigma associated with chronic illness. Theoretical foundations will focus on biomedical discourse, including notions of power and subjectivity as well as surveillance.

2.2 Description and Metaphor

The material body is the flesh and substance through which we experience pain and pleasure. The body has been theorized as the discursive body (Butler, 1993; Foucault, 1990), the inscribed body (Grosz, 1994; Butler, 1990; Foucault, 1990), the corporeal body (Martin, 1997), and the lived body (Grosz, 1994; Butler, 1993). The lived body becomes the site of all meaning, expressed through the body and articulated through language. Language expresses feelings inside the body and is, as Kirmayer (1992, p. 323) suggests, “the body’s insistence on meaning” where metaphor is shaped and moulded by the very experience of the body to bring forth the intense feelings of love, fear, and pain.

Physical feelings and emotions are articulated in language with the hope that others understand. Metaphor is the linguistic tool used to convey feeling. As defined by Kirmayer (1992), “Metaphor confers the property of one concept on another and all of our cognitive, affective, and somatic ways of knowing may be brought to bear to elaborate metaphoric correspondences” (p. 332; see also Lakoff & Johnson, 1980; Black, 1962). Kirmayer (1992) further states that “meaning emerges from the capacity to use bodily experience (including socially embedded experience) to think with metaphorically” (p. 334). Metaphors are culturally situated (Kirmayer, 1992). It is through metaphor that the individual articulates bodily feeling; however constrained individual feeling and emotion may be by the inscriptions of culture and the extent of the individual’s situated knowledge.

Often, language restricts communicating pain and emotion to others. In order to communicate these feelings, metaphors are used to describe the significance and impact of these feelings. Analysis of the metaphors and descriptive phrases used by women

living with FMS/CFIDS can articulate the effects of symptoms and the everyday experience of living with chronic illness (McMullen, 2003). As McMullen (2003) states:

[W]hen people are asked to talk about how they view themselves and their experiences . . . they often have difficulty finding the words to convey their ideas and, as a result, they often resort to using nonliteral words and phrases. (p. 18)

Furthermore, McMullen argues that, “scholars of language and culture stressed the significance of figurative language as a window onto shared cultural understandings” (2003, p.18). Metaphors and “figurative expressions should provide a window on to common understanding” (McMullen, 2003, p. 18) of illness, allowing for individual experience while at the same time providing a commonality of the illness experience.

The use of metaphors is prevalent in our society (Lakoff & Johnson, 1980). Sontag (1978) states that we cannot think without metaphors. Not only are metaphors used in everyday language to bring forth our ideas and express our emotions, metaphor informs in the language of science and biomedicine. Indeed, Stepan (2000) argues that metaphors promote creative thought that is vital to science. When one concept is linked to another, it changes the way the initial element is viewed. Thus, the ability to derive new meaning or a significantly different way of observing phenomena can alter the course of scientific thought which is then generated to a wider audience. This change in thought is made explicit in Haraway’s (1999) writings of the bodily immune system as a communication system. Haraway articulates how the biological body has been rewritten and reinvented from a very simplistic model of the immune system to a metaphor of a highly sophisticated bio-medical machine that has become the dominant mechanism protecting the body from harm. Similarly, Martin (1994) also traces the analogies and metaphoric descriptions of the immune system in biomedical history. Martin’s work

demonstrates that the metaphors of militarism, the struggle and conflict are inherent in biomedical language.

What cannot be directly observed by the human eye is often given such a compelling description that we forget the metaphor exists and treat the unobservable as scientific “truth,” since “the dichotomy established between science and metaphor was that obviously metaphoric or analogical science could only be treated as ‘prescientific’ or ‘pseudoscientific’ and therefore dismissible” (Stepan, 2000, p. 38). It is for this reason that often the use of metaphors in science goes unacknowledged.

Metaphor in science and biomedicine may aid in creativity or, as Stepan (2000) argues, be a means to “suppress knowledge” (p. 46) resulting in discriminatory and stigmatizing effects. Sontag (1989) makes this clear in *AIDS and its Metaphors* as she deconstructs metaphors of illness that are made synonymous with evil, purposively attached to a segment of society to demarcate them with sin and shame. Sontag (1989) argues that disease becomes more than the symptoms. The label of AIDS is attached to new and specific meanings. For example, AIDS has become synonymous with sexual deviance; AIDS has become a metaphor of homosexuality, death, and immoral behaviour. These meanings have resulted in a new form of control that requires individuals to think about their sexual preferences and the risk of unprotected sex. AIDS has become a metaphor not only for symptoms of the disease itself, but also a new form of social control that has affected individuals throughout the world. The effect has been different in Africa. Although AIDS is stigmatized, because it affects men and women equally, the homosexual association may be less salient.

AIDS as a metaphor has shaped a new discourse that involves the body and disease. AIDS has become synonymous with the complexities of the body's immune system and the way the body wards off disease. Although the body as a machine metaphor has dominated the biomedical literature for some time, there has been a shift to the concept of the body as a network of regulatory systems (Martin, 1990), with the growth of more complex technologies. There has also been a shift in the way the metaphors of bodily systems have transformed and informed popular media, scientific and biomedical views of the body (Birke, 2000; Martin, 1994). The communications systems model borrows heavily in metaphor from distinct concepts: militarism and circuits (Martin, 1994). Moving past notions of economic theory and analogies to factories, images of the body have evolved into a highly technical, metaphorically symbolic, representation of complex futuristic machines (Birke, 2000). Black (1962) describes this type of metaphor as interaction, where "metaphors that join together and bring into cognitive and emotional relation with each other two different things, or systems of things, not normally so joined" (cited in Stepan, 2000, p. 42). The result, according to Stepan, is that both systems change, altering perceptions of this interaction.

The internal processes of disease are often unseen within the biological body but are understood through use of metaphors (Birke, 2000; Kearns, 1997; Kirmayer, 1992; Martin, 1992; 1994). Metaphors in the scientific language of medicine help to explain the internal body. Invested in this scientific language is the ability to view the body as separate and distinct, separating the body from emotions. Biomedical science is not concerned with, for example, the "broken heart" (Birke, 2000) or the "joyous heart"; the

prime concern of biomedicine is to view the heart as the pumping station, pulsating blood and oxygen out to the vital organs of the body through the circulatory system.

Metaphors of disease follow a trend much like body systems metaphors. The disease metaphors are laden with militaristic terms such as “invaded”, “attacked”, “triggered” where the body is viewed to be “under siege” by an infectious “agent” (Martin, 1990). To describe the body as a military battleground is but one example of the varying ways science has made the body knowable. While the body is at war, the immune system is responsible for the communications that are taking place throughout the battle. These images are powerful and become embodied within culture and are entrenched in the way individuals have come to know and describe their own bodies.

2.3 Discourse and the Social Construction of Medicine and the Body

2.3.1 Discourse

From a postmodernist perspective, “discourse brings together language, visual representation, practice, knowledge, and power relations, incorporating the understanding and experience of embodiment” (Lupton, 2002, p. 50). Foucault (1990) argues that it is through varying discourses that the body is inscribed with meaning, embodied with certain knowledges, defined and categorized. Dominant discourses, such as biomedicine, define and create particular knowledges that further construct the body and, in particular, categories of disease and illness that are vested with power. This discursive power becomes a technique of control.

Discourse is laden with metaphorical meanings that perpetuate power and control. Foucault argues that “all systems of knowledge are discursive events” (cited in McNay, 1992, p. 26). Furthermore, McNay interprets Foucault’s notion of knowledge as “an

effect of a primarily discursive formation” (1992, p. 26); “it is in discourse that power and knowledge are joined together” (Foucault, 1990, p. 123). This discourse of power/knowledge is not merely shaped in words or phrases. For Foucault discourse “refers not to language or social interaction but to relatively well-bounded areas of social knowledge” (cited in McHoul & Grace, 1997, p. 31). Discourse is the speech and the silence, a word or statement and/or the entire text. Discourse is bound in knowledge, yet discontinuous and fragmented. As Turner (1987) states of Foucault’s theoretical perspective:

[W]e know or see what our language permits, because we can never naively apprehend or know ‘reality’ outside of language. Like all forms of human knowledge, scientific discourse is simply a collection of metaphors. Scientific knowledge of the world is a form of narrative (a story) and like all narratives science depends on various conventions of language (a style of writing, for instance). Narrative is a set of events within a language and language is a self-referential system. Nothing occurs outside the language. Therefore, what we know about ‘the world’ is simply the outcome of the arbitrary conventions we adopt to describe the world. (pp. 10 – 11)

Language and metaphor intersect within a field of relations that produce what Foucault calls power/knowledge. Metaphors are produced by discourse and create new or different meanings. Metaphor is contained within every form of discourse and becomes part of common language. The intersection of language and metaphor is where Foucault shapes a theory of power that has given the biomedical science the position within Euro-Canadian culture as “guardians of social reality” (Turner, 1987, p. 11) and control over the body.

2.3.2 Power and the Medicalized Body

Foucault’s focus throughout his work concerned the effects of power on the body. In particular, Foucault (1990; 1995) looked at the medicalized body; the body disciplined and controlled through specialized knowledge derived from studying the body and played

out on the body. He argued that the body became more objectified through, what he termed, the clinical “gaze” or the surveillance and disciplinary regimes that separated the “normal” from the “abnormal” as well as pathology from chronic wellness. The clinical gaze is one of the primary methods employed in biomedicine to gain knowledge of the body and assert the power/knowledge on the body. According to Lupton (2003), the clinical gaze “may itself be internalized by patients, and in some cases, changing the perception of their bodies” (p. 56). Imaging technologies have extended the gaze, extending the physician’s eyes (Kirmayer, 1992) to make visible the interior of the body. Physical examinations and the new technologies have become routine procedures invoking new forms of disciplinary power where biomedical knowledge is expert knowledge.

Overt surveillance and discipline of the body may not be as Foucault theorizes in *Discipline and Punish* (1995). Foucault writes of surveillance and discipline from a very mechanistic and militaristic stance. Discipline is now an embodiment of the accepted cultural expectations and behaviours. However, the more subtle techniques used in society today attain the same disciplinary effects in regulating body movement and body control (Bartky, 1998). Biomedicine and the relations of power invested in the governmentality of bodies regulate and discipline in powerful ways. The discourse of health embodies all aspects of life, from birth to death: these discourses alter with time and space but the power of control remains. Many individuals within our culture have embodied the ideals of health, fitness, activity and nutrition. A body that adheres to routine medical exams and is subservient to the demands of physicians by combating ill health and disease is seen as a healthy and well-regulated body.

These techniques of medical observation and surveillance are not only embodied but also the metaphors that describe our bodily systems are embodied, through the mental images of organs and blood and the fear associated with dreaded diseases. We are medicalized, routinely surveyed and constantly held in check by the power/knowledge of biomedicine. Individuals have become part of the medical gaze and whether they are in the clinic or in their homes, they are under the physicians' care. Foucault (1995) asserts that this is the outcome of disciplinary power. Where once discipline was administered through direct surveillance, now men, women and children in dominant Euro-Canadian culture have internalized the watcher. Therefore, individuals discipline themselves and observe and discipline others through actions and language. Individuals control, through the embodiment of correct behaviour, proper care and vigilance of the body.

Biomedical surveillance is said to identify our ills, fix our hurts and decide our regimes of health. Reliance on a medical diagnosis to define and categorize the symptoms of illness is, in part, shaped by the "truth" of diagnosis. Foucault (1990) would posit that there is no fixed truth; no knowledge that is superior or that is invested with all knowing power. Biomedical knowledge is constructed with a prior history and an embedded agenda to control populations and regulate social bodies (Foucault, 1990). For, as Foucault (1990) has detailed, control of populations is essential in maintaining power and enhancing knowledge through the watch of bodies. This is what Foucault (1990) terms as the docile body: a body made mechanistic and pliable to the regime of biomedical "truth" and the politics of governmentality.

In some feminist works, the concept of the docile body has been extended beyond Foucault's use. Bartky (1998), for example, problematizes Foucault's theoretical work by

insisting that gender is not addressed and argues that women have been shaped by methods “that produce a modality of embodiment that is particularly feminine” (p. 27). This, Bartky argues, results in a situation where “women are far more restricted than men in their manner of movement and in their spatiality” (1998, p. 29). Women are more docile than men and, therefore, under greater surveillance, embodying greater self-discipline and experiencing a more restricted space within culture.

Bartky’s argument is influential and allows a broader analysis of the varying methods employed in creating docile bodies. The creation of docile bodies becomes especially pertinent to a discussion of women’s bodies with relation to gendered aspects of science, biomedicine and health care. Women’s health care and the extensive research support Bartky’s perspective (Parr, 2002; Shildrick, 1997; Grosz, 1994; Armstrong, 1983). Surveillance of women’s bodies and women’s health implies measures of control that strive to normalize the body. Female bodies cannot meet the requirements necessary to meet a standard of normalization because they are compared to the male body. Because women cannot meet the ideals of the normal body, they are suspect and viewed by science and biomedicine as lesser and in need of more regulatory means to maintain some control. The discourse of women’s bodies as lesser produces and perpetuates more invasive health procedures that in turn produce new discourses both in the scientific and biomedical communities. Regulating women’s bodies through health regimes eventually filters into and imposes controls in women’s social and personal space. Bartky’s argument shows that women not only control the material body but also impose social sanctions that further restrict women.

Although McHoul and Grace (1997) argue that Bartky (1998) has misinterpreted Foucault (1995), the argument that women are more restricted has generally enjoyed considerable attention and has advanced new perspectives on women's bodies, docile bodies, and gender-based discipline. Bartky's work has also prompted greater discussion in the areas of disability and illness, the gendered nature of illness and particularly a gendered perspective on disability (Wendell, 1996).

Gendered notions of illness and disability are linked to biological determinism of health. Biological determinism is central in a discussion of women's health, shaping the varying ways that women's bodies are viewed as weaker and more susceptible to disease and illness (Birke, 2000; Grosz, 1994; Martin, 1992; Shildrick, 1997). In terms of illness and disease, biological determinism is supported and perpetuates disease categories and diagnoses that view women by their sex—a sex that is thought to be irrational and emotional (Shildrick & Price, 1997).

It is within the discourses of biomedicine where we locate the history of fatigue-related diseases, the cultural constraints and the social knowledge that shape and define how both science and society view FMS/CFIDS. Central to the discursive knowledges that have shaped FMS/CFIDS within biomedicine are notions of power, the vehicle of that power and the subject. More clearly, we can trace the symbolic meanings and the metaphorical discourses of fatigue to expose attitudes and knowledge of diseases, notions of the body and the power structures that operate on the body.

2.4 Two Different Diseases

FMS and CFIDS have three common and prominent symptoms: fatigue, pain and cognitive dysfunction. However, it is important to differentiate between the two diseases,

both in terms of their epidemiology and symptomology. While there are many symptoms that are similar, science has not yet determined whether the syndromes develop in the same way. The differing explanations of the etiology of FMS/CFIDS that currently exist compound the direction of research, which, in turn, affects how physicians view, diagnose and treat FMS and CFIDS.

The most current clinical case definition of CFIDS, developed in Canada (Carruthers et al., 2003), provides physicians with diagnostic criteria that are patient-centered (Fukuda et al., 1994; Holmes et al., 1988). The Canadian Expert Consensus Panel has declared that CFIDS is a “severe systemic, acquired illness that can be debilitating” (Carruthers et al., 2003, p. 8). Symptoms of CFIDS include recurrent, unexplained physiological and mental fatigue, sleep abnormalities and pain, as well as neurological and cognitive impairment that are persistent for more than six months. The single most identifying factor for a diagnosis of CFIDS is symptom onset most generally preceded by a viral infection (Carruthers et al., 2003). Individuals diagnosed with CFIDS may have an overlapping diagnosis of FMS as well (Berne, 2002; Friedberg & Jason, 2001; Wendell, 1996).

The onset of FMS is believed to be preceded by some form of physiological or life-event trauma (Fennell, 2003; Taylor & Jason, 2002; Turk & Ellis, 2003). FMS is painful, often debilitating and is more pronounced in pain measurement as opposed to the level of fatigue associated with CFIDS. There is also cognitive impairment, sleep disturbance, visual abnormalities, irritable bowel syndrome, a weakened immune response as well as musculoskeletal difficulties (Berne, 2002).

Treatment of CFIDS requires extended periods of rest and limited exercise that may take days to months before symptoms are relieved. FMS also requires extended rest but is made more manageable by a routine of exercise to boost pain-reducing serotonin levels. Depressive incidents are common to both diseases but more manageable with FMS through routine exercise. Tables 1 to 4 in Appendices B through E presents a comparative listing of symptoms of FMS and CFIDS.

2.4.1 Background of FMS and CFIDS

Fatigue-related illnesses are not a new phenomenon. Records indicate that many illnesses with debilitating fatigue have received attention over the course of history (Bell, 1992; Jason et al., 2003; Ware, 1992). Most common to all those found in a review of literature was the lack of what are considered to be objective medical tests to find an underlying cause. Compounding problems of fatigue-related disorders is the scientific understanding that fatigue is the most commonly seen complaint in the doctor-patient setting (Berne, 2002). There is no measure to grade the severity of fatigue and often there is no biomedical cause (Dittiner & Chalder, 2003; Hyde, 1992). Fatigue is subjective and individualistic, both a part of everyday life and a symptom of many diseases. Biomedicine views fatigue as a minor symptom because it cannot be measured scientifically and, therefore, it does not receive adequate attention or research.

The under-estimation of the effects of fatigue brought on by FMS/CFIDS has caused distress for many individuals (Wendell, 1996). Thus, when medical diagnostic testing does not reveal a recognized pathology underlying FMS or CFIDS, the result is often misdiagnosis, precipitating more extensive and invasive testing (Jason et al., 2003; Ware, 1992; Wendell, 1996). This scenario is evidenced in recent history when an outbreak of a then unknown and unlabeled illness occurred in Incline, Nevada in the late

1980s (Fukuda et al., 1994; Hyde, Goldstein & Levine, 1992; Johnson, 1996). What first appeared to be an epidemic was quickly categorized under the fatigue umbrella. As well as exhausting fatigue, individuals who became ill during this time were also experiencing other bodily symptoms without an underlying pathology. These symptoms included confusion, nausea and pain that were not alleviated by any form of medical treatment. At first, there was some indication that the illness was related to Epstein-Barr but after intense investigation by the Centers for Disease Control (CDC), Epstein-Barr was ruled out, though never completely rejected (Hyde, 1998). Even though there were signs of viral activity, the outbreak was stated to be of a less serious nature than was first considered.

The outbreak in Nevada received a great deal of media attention (Johnson, 1996). Before the syndrome received an official name of CFIDS in 1988 (Berne, 2002), the media resorted to many labels, the most well know was the “yuppie flu” (Johnson, 1996). The outbreak affected men, women and children; however, a larger proportion of women than men became ill. The Centers for Disease Control (CDC) continued their investigation, defining criteria for research but, over the course of time, no definite cause has been determined (Holmes et al., 1988; Jason et al., 1997). Similar scenarios were being played out in other locations including Australia, Norway, Sweden, Canada and the United Kingdom (Taylor et al., 2003). After years of investigation and, although many of those who became ill during the initial outbreaks are still affected by symptoms ranging from moderate to severe (Johnson, 1996), research has failed to determine cause or effective treatment for the relief of the symptoms. Medical researchers have explored so

many different possible etiologies that today there is a confusing jumble of literature that only serves to mire CFIDS in controversy around its perceived legitimacy.

Although CFIDS has generated a great deal of attention, FMS is also mired in confusing scientific research. FMS is one of the most commonly diagnosed conditions in rheumatologic medicine today (Berne, 2002; Turk & Ellis, 2003). Current research indicates that FMS begins after either a viral infection or trauma (Berne 2002). Physical trauma to the body such as car accidents, miscarriage, sexual assault, surgery and any form of sharp blow to the body can result in the onset of FMS symptoms at a later point in time (Friedberg & Jason, 2001). Recently, the scope of trauma has been widened to include emotional trauma caused by a major life-event that can be compared to Post Traumatic Stress Disorder (PTSD) (Fennell, 2003). Events such as sexual assault, psychological abuse and the death of a close family member have been cited as the “cause” of FMS. Still other cases are reported to have begun in early childhood and progressed until the severity of symptoms yielded a diagnosis. It is not uncommon to have symptoms of FMS for years that go undiagnosed or are misdiagnosed.

The disease is characterized by widespread musculoskeletal pain, fatigue, disrupted sleep patterns, as well as varying degrees of somatic disorders (Berne, 2002; Jason et al., 2001). There is evidence of body chemical changes, as well as evidence of irregular brain activity, visible through brain imaging techniques, although not consistent enough to be used as a diagnostic measure. Berne (2002) states that the brain appears to be working harder and can be observed in both FMS and CFIDS patients. At present, standard medical tests do not conclusively determine the presence of FMS; however, the Manual Tender Points Survey (MTPS) approved by the American College of

Rheumatology is the most commonly used measure and is the standard instrument used in making a diagnosis (Turk & Ellis, 2003). The test involves the physician's practiced application of pressure to eighteen specific body points. If pain is experienced by the patient in 11 of the 18 points as well as having a history of widespread bodily pain for three months or more, a diagnosis of FMS is probable (Turk & Ellis, 2003). However, skepticism still exists as to the accuracy and reliability of the MTPS and many doctors insist that FMS does not exist as a disease category (Turk & Ellis, 2003).

Skepticism is probable when an illness does not have a definitive test to determine the presence of a pathology. Commonly, illnesses that cannot be defined and have signs and symptoms that appear together without observable pathogens or physiological abnormalities are classified as syndromes (Webster's Medical Dictionary, 1999) and carry a label of "low-status" within the medical community. Both FMS and CFIDS are classified within medical annals as syndromes (Hyde, 2003). Conversely, a disease is "abnormalities in the structure and/or function of organs and organ systems; pathological states whether or not they are culturally recognized" (Young; cited in Kleinman & Seeman, 2000, p. 231). This distinction between a syndrome and a disease needs emphasis here to better understand how FMS/CFIDS is positioned within the biomedical community. Syndromes are low-status conditions that are viewed as either conditions of the mind or the body, often ending in a formal classification of psychological as opposed to physiological problems, in other words, diseases of the mind (Demitrack & Abbey, 1996) and therefore 'not real'.

An important study has recently published the findings of research that may dispel the longstanding belief that CFIDS is no more than a psychological disorder (Pazderka-

Robinson, Morrison & Flor-Henry, 2004). Evidence found in a University of Alberta study shows that people with CFIDS have a higher mean skin temperature than does the control group and the group with major depressive disorders (Pazderka-Robinson, Morrison & Flor-Henry, 2004). In a press release, Pazderka-Robinson (2004) states that, “the findings show that the profile of CFS patients is clearly different from normal controls suggesting there is a clear biological basis to the condition” (Dey, 2004). The study found that electrodes placed on each hand to measure electrodermal activity are in line with a “growing body of evidence showing measurable physiological differences between CFS and depression, joining indications of altered immunological profiles” (Morrison, Flor-Henry & Pazderka-Robinson, 2004). The outcome of the study could be the diagnostic marker that has long eluded an evidence-based diagnosis of CFIDS.

Extensive CFIDS research has been ongoing since the mid 1980s. Studies conducted by the CDC presumed that CFIDS was caused by the Epstein-Barr virus (Holmes et al., 1987). These studies also suggest that the syndrome was more prevalent in White-middle and upper-class women, who were well educated and in well paying positions. The CDC has since ruled out Epstein-Barr. Research by Jason et al. (1997) suggest that CFIDS is prevalent in all age groups regardless of ethnicity, race, and socio-economic levels but that CFIDS is more prevalent among women, contradicting early studies by the CDC. Moreover, Jason et al. suggest there may be a higher overall prevalence of CFIDS than has been shown in prior research published by the CDC in 1994 that estimated CFIDS to be from 4 to 10 cases per 100,000 people (Jason et al., 1997). Jason found the prevalence rate to be 422 per 100,000 people. The CDC has since changed their research methods and have found prevalence rates of CFIDS to be 303

women per 100,000 and 58 men per 100,000 (CFIDS Association of America, accessed 2002). Ongoing research by the CDC may indicate different prevalence rates following their study of four American cities (Bierl et al., 2004).

Recent research studies have also concentrated on the impact of FMS/CFIDS on the lives of FMS/CFIDS patients. In a study by Soderberg and Lundman (2001), the findings indicated that women who lived with CFIDS spoke of a sense of bitterness because they can no longer do things they did before they became ill nor can they do things that other people are doing now. Asbring and Narvanen (2002) note that FMS/CFIDS patients “are shrouded in great uncertainty, which can enhance their stigmatization potential” (p. 29). Asbring and Narvanen (2002) argue that FMS and CFIDS can be distinguished from other diseases and syndromes such as HIV/AIDS that “could be regarded as tainted with shame, socially unacceptable, and also communicable” (p. 149). FMS and CFIDS do not have any visible external signs that indicate impairment or illness that occur with conditions that result in partial paralysis, and “epilepsy [which] is associated with the attack, which may be perceived as shame-ridden” (Asbring & Narvanen, 2002, p. 149). Recent studies have also indicated the economic loss due to the disabling effects of CFIDS. Reynolds et al. (2004) estimate the economic cost of CFIDS in the United States to be “\$9.1 billion, which represents about \$20,000 per person with CFS or approximately one-half of the household and labour force productivity of the average person with this syndrome” (p. 1). The social and economic stress caused by CFIDS does not appear to have been a factor in studies that link stress and depression as the cause or failure to regain good health.

Richman and Jason (2001) state that the contested nature of CFIDS has been attributed to numerous studies that explore psychological causes for the syndrome. Their study also asserts that gender-linked assumptions underlie many of the treatments and misdiagnoses that women with CFIDS have experienced. Wendell (1996) also examines the gendered biases associated with CFIDS and fatigue-related diseases.

Wendell's (1996) text is one of the most commonly cited writings on the personal, social and political aspects of CFIDS. Wendell links CFIDS with disability, the authority of biomedicine and the contested political atmosphere that affects those with CFIDS. Wendell's own experience living with CFIDS informs her writing, linking personal reflection with the difficulty of receiving a diagnosis of FMS or CFIDS. Often diagnosis does not relieve the stress caused by loss of income and the inability to receive disability benefits because of the contested nature of FMS and/or CFIDS.

Berne (2002), who also lives with CFIDS, covers both FMS and CFIDS, linking many studies and personal accounts of the syndromes. Berne states that her text is "an attempt to organize a huge amount of information into its simplest common denominators" (2002, p. xvii). Berne integrates the studies and personal experiences to compile a comprehensive text that details the onset and symptoms for those who need information about CFIDS, FMS and other invisible illnesses.

Moss and Dyck (1999) highlight the impact of CFIDS on patients because it is a marginalized illness. Their study argues that a diagnosis of CFIDS is a damaging inscription that produces discourses that belittle and destroy identity of self. Moss and Dyck suggest that CFIDS be thought of both as a discursive illness shaped within many discourses that "produce and reproduce specific meanings" (p. 377) and a material illness

experienced through the body by the symptoms of illness and meanings that are inscribed on the body.

Richman and Jason (2001) reviewed the scientific literature and found that gender biases underlie certain illness states, in particular FMS and symptoms of illness that have known etiology. Richman and Jason (2001) also found a large quantity of literature that made assumptions as to the cause of CFIDS. They found that:

The medical-scientific literature exploring potential causes and recommended interventions has tended to emphasize factors which are at great variance with the perspectives articulated by CFS patients. (Richman & Jason, 2001, p. 17)

Jason and Richman state that the patient's accounts of CFIDS challenge the existing medical literature and media that largely depicts CFIDS as a "non-disease or an illness which is largely psychogenic in nature" (Richman & Jason, 2001, p. 20). The study concludes that the assumptions and depictions of CFIDS and similar diseases or syndromes are detrimental to women, reducing the symptoms of illness to imagined or psychological in nature.

Women are more commonly diagnosed with FMS than men, although men and children are also affected by the disease. Current research suggests that "FMS is more common in women by an estimated ratio of 5:1 to 20:1" (Berne, 2002, p. 27). While this estimate appears to indicate FMS is a gender-specific disease, others suggest that it may be more dependent on women's health-seeking behaviours (Jason et al., 1999).

Throughout the course of biomedical history, when a range of symptoms with no apparent cause is observed in a patient, there is a tendency to label the disorder as psychological rather than physiological. Many diseases that are accepted as a physiological reality today were also treated with disbelief and skepticism. Such

disorders include Multiple Sclerosis (MS), once labelled as “lazy man’s syndrome,” although, oddly enough, MS is primarily a women’s disease (Richman & Jason, 2001).

Women diagnosed with FMS generally live with the symptoms for the remainder of their lives. The rate of recovery from FMS is very low although cures have been reported (Staud, 2002). More commonly, those who become ill must leave jobs and struggle with varying forms of disability that cause economic difficulties without acknowledgment that the illness is a disability.

2.5 Chronic Illness, Invisible Disability and Stigma

Wendell’s (1996), “reflections on disability” bring an awareness to the struggle of living with chronic illness. To have an “invisible disability,” a disability that is not readily evident to others, is, as Wendell outlines, a difficulty that is hard for others to understand. When invisible disability or illness alters one’s life, at times there is a need to make it hidden, to hide the dysfunction “in the closet” so to speak so that one can pass as “normal” in a culture that does not readily accept disfigurement, chronic illness or disability. However, it is not always hidden; there are times when the disability is apparent and others see an irregularity in bodily or mental function. This may be confusing for those who have identified with the individual as healthy and able-bodied.

Ability, the absence of disease or impairment, is often taken for granted. However, as Wendell (1996) suggests, living without impairment is a temporary state. Bodies become ill with chronic conditions over time and aging increases the chances of becoming disabled. Definitions of impairment and disability are culturally dependent. Therefore, it is important to note that where the cultural ideal is the young, agile, able-bodied individual, the expectations and categories of ability become very restrictive. So

too, it becomes necessary to question at what point an individual is sufficiently different from this ideal to be considered disabled. Clearly, the majority of individuals will experience disability at some point in their lives and, as such, ability should not be considered an uncontroversially given.

2.6 Women and Disabilities

Women with disabilities are said to experience “multiple disadvantages and oppressions” (Lloyd, 1992; cited in Morris, 1996: p. 2). In Canada, 16% of all women are disabled (D.A.W.N., 2001). Globally, more women than men are disabled and many experience poverty and isolation. According to the Disabled Women’s Network of Ontario (2001), the rate of unemployment for women in Canada with disabilities is 74%. The unemployment rate for disabled women in the supposed “developing world” (other than Western countries) is 100%. Disabled women are more often victims of violence, which is unrecognized because disability renders women virtually invisible, hidden within the family home and away from the supposed public sphere. Despite these disturbing statistics, women with disabilities have been “neglected by disability studies and feminist scholarship alike and issues of importance to women with disabilities, for the most part, have been ignored by the disability rights movement as well as the women’s movement” (Traustadottir, 1990, p. 1). Indeed, disabled women face a multiplicity of disadvantages that are complicated by the double bind of gender discrimination and disability.

Feminist perspectives on disability began to emerge in the literature in the mid 1980s. The literature indicates that theoretical perspectives have concentrated on the oppression and objectification of disabled women. Fine and Asch (1985) argue that the

outcome for many disabled women is “[R]olelessness, the absence of sanctioned social roles and/or institutional means to achieve these roles” and that “the absence of sanctioned roles can cultivate a psychological sense of invisibility, self estrangement, and/or powerlessness” (p. 12). In this context, disabled women seem to be without the choices that able-bodied women have struggled for and have made gains toward, thus improving their social positioning. Even the culturally expected roles of women such as motherhood and care giving, are not seen to be choices for disabled women who are perceived as asexual and dependent (Fine & Asch, 1988).

The social and the medical models of disability have not included the varied experiences of the disabled body (Wendell, 1996; Zola, 1983). Wendell expresses concern for the need to include the “negative” body:

We cannot speak only of reducing our alienation from our bodies, becoming more aware of them, and celebrating their strengths and pleasures; we must also talk about how to live with the suffering body; with that which cannot be noticed without pain, and that which cannot be celebrated without ambivalence. (1996, p. 37)

Being a woman with a disability is both the social and the corporeal function of the body.

While feminism has focused on many issues within women’s health, feminism has failed to be inclusive of the disabled body or the body that lives with chronic illness and pain. Without the inclusion of disability, feminist discourse has been negligent in developing literature that comprehends the social needs, desires and everyday lives of women with disabilities. In addition, feminist discourse has not constructed thought that focuses on the specific areas of gender discourse that more aptly applies to disabled women.

2.7 Metaphors of Chronic Illness and Disability

As previously stated, metaphors are a form of expression to articulate greater meaning, an expression that informs others of feelings, pain and emotions. In their study of women who experience CFIDS, Hart and Grace found that the bodily experience of fatigue is framed as the “lack of energy” or disruption to energy flows. Lakoff and Johnson (1980) suggest that these are orientational metaphors that symbolize high and low; high being “up” happy, and low being “down” or unhappy. High and low have great significance in an analysis of the meanings women make of their selves, their bodies and their experiences of illness. As Hart and Grace (2000) state that, “The reference to energy flows that dovetail with references to the circulation of money might be characterized as a contrast between a wellness of abundance and an illness of scarcity” (p. 198). Similarly Sontag’s (1988) analysis of illness metaphors—particularly when attached to fear as was and is the case with AIDS, cancer, and tuberculosis—enjoin a sense of social and economic disorder (Sontag, 1989). Sontag found that the spectre of AIDS was perceived as a threat to the American economy. When AIDS was first reported in the United States, it primarily affected young, affluent, White males who were represented as models of prosperity and achievement. When it was realized that AIDS transmitted through heterosexual relations, the United States feared that the burdening health costs could mean economic disaster (Sontag, 1989). The discourse of AIDS implied meanings that reached into every segment of American culture. AIDS became a metaphor for impending doom and an uncontrollable plague. AIDS was fear and panic that grew, not from the effects of the virus itself, but the social construction of what AIDS represented. The powerful metaphors that surrounded AIDS in the early days of the syndrome have

forever stigmatized homosexuals even though research shows that AIDS affects heterosexual men and women.

Drawing on Foucault (1990), Shakespeare (1996) approaches metaphors as “discursive formations” (p. 97) that create stereotypes through “processes of denial and projection” (p. 98). Shakespeare (1996) argues that metaphors can reflect these negative stereotypes that become socially embedded, affecting the societal view of individuals who are different, perhaps disabled or living with AIDS or cancer. Meaning is ascribed to the disabled or chronically ill body which is discursively produced as an object of and in culture. As embodied subjects, the impact of socially constructed discourses is fundamental to how the disabled and chronically ill feel that they fit into everyday life (Hillyer, 1993; Morris, 1996). How one views self-identity is the product of social interaction and personal knowledge of oneself. Words that negatively describe disability such as “crip” and “gimp” can be embodied metaphors and as cultural categories, these metaphors have an impact on full participation in life and the self-identity that is created from the embodiment of experiencing both the internal pain and fatigue of the body as well as the negative stereotyping of cultural stigmas.

2.8 Identity and Self

Foucault (1990) informs us that the self is intimately linked to the social, that events in our lives imply that we do not have a former self and that self is always in the present and always changing. Kondo (1990) illustrates through her own experience that self is:

[T]he product of a complex negotiation taking place within specific, but shifting contexts, where power and meaning, ‘personal’ and ‘political’ are inseparable. Identity is not a fixed ‘thing,’ it is negotiated, open, shifting, ambiguous, the

result of culturally available meanings and the open-ended, power laden enactments of those meanings in everyday situations. (p. 24)

The shifts and fluxes that shape knowledge and knowing of personal identity suggest that there is no one self. Rather, as Kondo (1990) articulates, interaction in daily life suggests “self” is not an encompassing view; the many layered shifts of interaction in the social and private worlds indicate there are “selves” relating and reacting in relation to specific events and challenges. Moreover, these interactions change notions of personal knowledge of oneself in a continuous and fluid shift; each individual has many facets of self, both knowable and changing. Individual knowing is not simplistic; the self cannot be readily defined as constant and fixed but rather “selves” that constitute participation in social worlds and private spaces.

Identity is a process whereby we negotiate and embody the social and the personal, ultimately determining who we are and who we are supposed to be (Moss & Dyck, 1999). Therefore, identity becomes self-concept, the sense of the self and how we carry knowledge to the world and bring knowledge back to our self, mediated at all levels by the body (Teather, 1999). Self and identity are social, cultural and biological processes, each changing and shifting. Thus, there is neither a static self nor an identity that remains fixed. Many factors influence the changing and shifting self. If the body mediates as Teather argues, then the biological processes occurring within the body must also influence change that affects both self-identity (the self) and also influences the identity that is known or may choose to be hidden from others. Biological processes that occur in chronic illness must therefore influence perceptions of self and how women with FMS/CFIDS act and react, present the self to others and how others respond to the

changing self—the self that is responding to symptoms of chronic illness. Moss and Dyck (1999) state that:

[I]dentities of women with chronic illness are fragmented (both ill and healthy), in flux (sometimes getting more ill, sometimes getting healthier) and contradictory (ill and healthy at the same time)Women with chronic illness have multiple identities that are sometimes place-specific; any one identity is situated in a complex web of unevenly oppressed and privileged power positions. (Moss & Dyck, 1999, p. 160)

In the case of chronic illness, the self shifts from the knowing of chronic wellness to the self of chronic illness and disability. When this shift occurs suddenly, lives are put into a tailspin and what was known of the former selves is altered dramatically, mapping new journeys with a new destination, one that was once known as “other” and now internalized as their self-identity.

For women with invisible disabilities, categories often collide when the invisible becomes known or apparent to others (Goffman, 1963). Internalized “other” is fundamental to the presentation of the self and to the social world that is navigated. Goffman (1963) identifies stigma as an “undesired differentness from what we had anticipated” (p. 34). For the person who becomes ill with a chronic debilitating disease such as FMS or CFIDS later in life, he or she may have a “special problem in re-identifying himself [sic], and a special likelihood of developing disapproval of self” (p. 34). Goffman (1963) also suggests that we use metaphors to discredit those whose attributes are not perceived as “normal” within a given culture: an ill-defined disease and disability receive negative societal acceptance. This discourse becomes internalized and more problematic for one who never anticipated becoming an “undesirable.”

The experience of living with FMS/CFIDS magnifies the susceptibility to internal and external stigma due to the ambiguous nature of the diseases both from a medical as

well as societal perspective. Because the cause of both diseases is unknown and is perceived to be a psychological disorder or even imagined illness rather than a real physical presence of varying and disturbing symptoms, there is a greater chance of women living with chronic fatigue illnesses (WLWCs) to be regarded suspiciously as malingering, calling into question the validity of the illnesses (Vickers, 2000). When diagnosis is not gained through the exact scientific methods, stigma becomes a subjective aspect of how WLWCs perceive themselves as well as how others perceive those with FMS/CFIDS.

2.9 Conclusion

Women living with CFIDS and/or FMS are challenged on many levels. CFIDS/FMS are contested syndromes that primarily affect women. The symptoms are often invisible and difficult to communicate to others. One means of bringing a broader understanding to the meanings of the illness experience is through an analysis of the metaphors used to describe the symptoms. Because we think and communicate with metaphors, an exploration of the metaphors articulates linkages that exist on many levels of illness: relations of power, the authority of biomedicine as well as the social and biomedical constructions of FMS/CFIDS. Metaphors also articulate the detrimental effects of the syndromes, social stigma of the disabled and the stigma associated with FMS/CFIDS.

Becoming ill with FMS/CFIDS is also linked to views of the self, personal change and identity. Self and identity are shaped by social, cultural and biological processes, each shifting and changing. Identifying these transitions is an important aspect of the individual experience of illness and is both the embodiment of cultural and social factors and the effects of changing biological processes within the body. Bodily processes are

significant factors in the presentation of self and identity to others. Internal responses to the symptoms of FMS/CFIDS may not be visible to others, yet interaction within the social fabric is altered and influence the varying ways that others respond to women living with the syndromes.

Individual interaction is also influenced by the power of biomedicine. Biomedical authority is a constructed knowledge of the body that is both external surveillance and individually internalized. The knowledge/power controls the construction of disease and syndromes and categorizes those who become ill. Foucault's (1990) notion of the medical gaze is argued by Bartky (1998) to have a greater effect on the regulation of the feminine body, restricting the feminine body within the social and private space. The regulation on women's bodies is argued to produce and perpetuate more invasive health procedures, in turn, producing new scientific and biomedical knowledge that further restricts women's bodies through new regimes of health.

Power/knowledge of women's bodies is evidenced in the construction of biomedical discourse. Metaphor is an intricate part of this discourse: biomedical discourse produces metaphors which in turn produce new discourses. An exploration of the metaphors used in biomedical language is a powerful analytical tool in exposing and articulating the hidden power of biomedical discourse.

In Chapter Three, I show the methodological issues in developing an analysis of the metaphors in biomedical and scientific language and in the language used by the women who participated in this research. I will also introduce theoretical perspectives that are used to find meanings that are conveyed by the participants and in the scientific and biomedical texts.

CHAPTER 3

METHODOLOGY AND RESEARCH ISSUES

3.1 Purpose

The purpose of this research is to explore metaphors that women with FMS/CFIDS use to describe their experience of pain, fatigue, cognitive dysfunction and other symptoms. Exploring the metaphors in the scientific and biomedical literature that describe the symptoms of FMS/CFIDS will allow a comparison to be made between metaphors and descriptions of FMS/CFIDS offered by the women participating in this research and the technical biomedical and scientific accounts.

One objective of this study is to explore how sociocultural factors and biological processes are perceived by participants to interact. Current feminist discourse theorizes the inscribed body and the embodiment of cultural and social forces. However, the biological body is hardly considered in this theoretical perspective. In order to include the chronically ill body in such a discourse, consideration must be given to the internal and external entire body, the complete embodiment of the cultural and social that does not exclude the biological body. An exploration of the metaphors within the interview texts also aids in revealing the cultural understandings of illness that are produced by discourses that are specific to women in Euro-Canadian culture.

Textual analysis of the participants' metaphors of perceived biological processes is based on the works of Lakoff and Johnson (1980), Johnson (1990), Kovecses (1990; 2000), Sontag (1978; 1989), Martin (1992; 1994) and McMullen (2003). Applying theories of metaphor to meanings of bodily processes is better conceptualized by

structuring these processes as both biological and cultural. Analysis of the body as both biological and cultural is argued by Birke (1998; 1999; 2000; 2003) to be necessary in order to move past the current theorizing of women's bodies as only being inscribed bodies (Butler, 1993; 1999).

In order to draw out these perspectives, 10 Saskatoon women participated in open-ended interviews. This chapter will detail the sampling method used in the selection of women who participated and were interviewed for this research. It includes a discussion of the methods used to develop the main themes within the transcribed interview texts and the means by which I selected metaphors specific to these themes.

In order to develop a comparison between the interview texts and the biomedical construction of FMS/CFIDS, I selected biomedical and scientific research articles of FMS and CFIDS. Metaphors within the texts were selected and analyzed using the same theoretical perspectives as were used in the interview texts.

3.2 Theoretical Foundations

3.2.1 Metaphor Analysis

In her work on the metaphorical analysis of women's depression, McMullen (2003) states that "Qualitative research attends to the details of people's lives . . . by opening up questions about power, about ideologies and practices of gender, and about other social, structural inequities in women's lives" (p. 5). Exploring sections of the transcribed narrative texts using a linguistic method of analysis reveals how these details are articulated through language. This type of analysis "helps us hear more clearly the evaluative undertones in people's words—how language shapes subjectivity and channels their experience of the world" (p. 9). Analysis that delves into the deeper meanings of the

metaphors show that the association with cultural understandings of illness and the experience of FMS/CFIDS emerge and lend greater understanding to the emotional and physical impacts of disease. When it is understood that metaphors convey powerful reflections on the “ups” and “downs” of experience, when language indicates references that are linked to subjective experiences of power, fatigue, pain and resistance, a better sense of WLWCs being in and of the world and living with chronic illness unfolds.

McMullen’s (2003) study indicates the importance of finding meaning in what was being said by participants, not simply taking the words and phrases at face value. McMullen’s (2003) study emphasizes the importance of analyzing what words the women use to describe their experiences with FMS and CFIDS and to look at specific phrases and words that spoke more deeply of the personal, emotional and social meanings that underlie their narratives.

3.2.2 Processes of the Biological Body

It is important to examine both the inscribed body and the biological body. Birke (2000) questions the current methodologies used in the study of feminist research and demands that new ways need to be brought into research of women’s health in order to understand completely that illness is not simply a personal and social problem; it is biological, affected by emotions that change bodily functions, of particular note when researching the disabled body. Millward and Kelly (2003) state that, “In chronic illness the physicality of the body impinges directly on self” (p. 162). The notion of self directly relates to identity, that which one is perceived to be in the social world. These two aspects of chronic illness are significant in developing a methodology that looks at the scientific and personal construction of metaphors. Exploring self and identity in chronic illness is also necessary in order to describe and navigate the social world. As well,

notions of self and identity are fundamental in illuminating how the social world regulates and changes the biological body.

Although other theorists address the body and the processes of illness, Birke brings to a theoretical discussion the view that the biological body is integral to an understanding of chronic illness and disability. Birke's work acknowledges a definitive line between the biological body and the corporeal body that must be rethought. Feminist work has failed to include the internal processes of biology in what Birke (2003) terms a fear of becoming biologically deterministic in exploring aspects of the body that are unseen and as such are not discussed. Birke (1998; 2000; 2003) and Martin (1994) also discuss the nature of scientific and biomedical language that is obscure and technical, entrenched in meaning that leaves those who do not study the body in such detail at a loss in understanding the body in general. By acknowledging the gulf created by this inaccessible language of the body, I show the division between how women with FMS/CFIDS view their body, using common language and metaphors, and the scientific literature that is relatively devoid of the emotional and physical aspects of living with FMS/CFIDS.

I noted this division between participant language and the language used in the scientific literature during the interview process. The women described their symptoms and experiences with FMS/CFIDS in personal, emotion-filled ways. The women's use of descriptions of pain, fatigue and other symptoms often was expressed by explaining their bodily feelings in relation to commonplace things in their lives, for example, describing their clouded thinking in terms of 'fog.' Other examples used by the women such as being laid flat with pain or 'cracking' from excessive fatigue were related to things they

experience within their own lives. These descriptions are contrasted by the research I read before beginning the interview process. The scientific literature seemed devoid of feeling, describing symptoms in very mechanistic terms. While the scientific literature appeared to fragment the body, the women's words included their entire bodies as well as the emotions they felt when and after experiencing their symptoms. Although I did not concentrate on the aspects of language during the interview process, as I transcribed and concentrated attention on each interview, I felt an exploration and analysis of the differing ways of describing symptoms were important to my study of FMS and CFIDS.

3.3 Methodology

The methodology used in this study includes textual analysis of scientific and biomedical literature and qualitative interview-based research to explore the varying ways metaphors are used to describe the bodily processes of FMS/CFIDS. Analysis will focus on the convergence, as well as the divergence, of metaphors between the women participants and the biomedical literature. Ten women from Saskatoon participated in open-ended interviews. The interviews were guided by 64 questions and recorded on tape. The interviews focused on the participants' symptoms of FMS/CFIDS and their personal and social interactions since becoming ill.

I used a triangulated sampling method to attain participants for the study. I advertised within the city of Saskatoon, posting my study in places of public access. I chose Gay and Lesbian Health Services, Saskatoon in order to be inclusive of lesbian and bi-sexual women. I felt this to be of importance in order to incorporate women from varied and diverse backgrounds, to be more inclusive of the difference of women's lives within our culture. Feminist research has, for the most part, targeted heterosexual women.

In order to get a broader picture of the experiences of women, both lesbian and heterosexual women should be included in this study.

I also placed posters in the Frances Morrison Library in downtown Saskatoon; Westgate Books, located on the west side of Saskatoon; Saskatoon Community Clinic, a cooperative medical clinic that serves a diverse clientele, both economically and professionally; doctors' offices; women's groups on campus; campus poster boards; two counselling agencies; and the YWCA where a special exercise program has been designed for women with FMS. As well, I relied on colleagues and associates to spread the word of my study. Participation was strictly voluntary and caution was taken due to the privacy issues of both chronic invisible illness and sexuality. Some referrals were offered by participants who contacted me after reading my posting while others contacted me when my friends and colleagues informed them of my study.

Utilizing this method to locate participants was preferred due to the extra care required in protecting each participant's sexual identity as well as the possibility of participants "passing" as able-bodied. When dealing with marginalized groups, as is the case with chronic illness and sexuality, obtaining participants can be difficult. My own active involvement within the lesbian community and as a person with both FMS and CFIDS helped in accessing participants through my personal and academic associations.

In order to draw out participants' descriptions of the experience of living with FMS/CFIDS, the interview design included open-ended questions. I had no predetermined plan for the research. Instead, I felt that an in-depth exploration of the women's experience would be best done by using the guiding questions in conversation form, allowing a more free-flowing interview session but I was fully aware that

additional questions would alter from interview to interview as women discussed their illness experience. Central to my study was developing a sense of meaning through interpreting the illness as a process, an event and as an ongoing negotiation of living with a chronic disease. Therefore, loosely structuring the interview allowed my participants to tell their experiences in their own way and in a manner that was as comfortable as possible. Appendix A presents the interview guide.

Following each interview, I kept journal notes of my observations as well as the location and the quality of the interview. I also made note of aspects of the interview that worked particularly well and those that required a different approach. Each interview was transcribed verbatim, the printed transcript returned to the participant for approval. Release forms were signed and are being kept on file, as per the requirements of the University of Saskatchewan's Research Ethics Board.

I began transcription of the tapes after completing the last interview. I had no definite design before the interview process and only after an extensive reading of the interviews, did I develop categories that reflected the most common themes in the interviews. In order to be included as a category, the identified theme needed to be present in each interview at least seven times. I focused on how the women described their illness and designed a flow chart to put the information from the interviews into a workable context. From this analysis, I narrowed the scope of my study to include the personal construction of illness and the biomedical construction of illness and surveillance.

After determining the main themes I would use for analysis, I coded each interview using a numbering and lettering system, marking sections of text that were

most applicable to my research. I included the coding in a wordprocessing file and incorporated all interviews within the file. This method was useful both in finding themes quickly and in avoiding repetition of participant responses in my analysis. Each theme was analyzed for specific metaphors that describe the experiences each participant had within the topics.

The metaphors found in the interview texts closely aligned with Lakoff and Johnson's (1980) and Kovecses' (1990; 2000) notions of metaphor. Selection then retained consistency throughout the textual analysis of metaphors used by the women I interviewed and with the biomedical and scientific literature.

The topics I have selected reflect symptoms that are common to both FMS and CFIDS. Because there is not conclusive research to support the idea that FMS and CFIDS are the same syndromes or caused by the same factors, I do not intend to imply that the two syndromes are one in the same in this study. What is evident from the research is the common symptoms that women living with Fibromyalgia and Chronic Fatigue Immune Dysfunction Syndrome experience. The scientific and biomedical research also indicates that often women with FMS will be diagnosed with CFIDS as well (Berne, 2002).

I selected the biomedical and scientific articles for this research by identifying the authors as having influenced the research on both FMS and CFIDS and who were influential contributors to the current knowledge of both syndromes. The contributors have a significant number of published articles from which I made my selections. Twenty researchers are included in this analysis of 23 articles, three of the articles are the work of Jain: one published on his own and two are co-authored articles. The selected material included overlapping symptoms of fatigue, pain and cognitive dysfunction. The

participants in this research have a higher representation of FMS than CFIDS; however, based on the biomedical and scientific research, both syndromes are considered.

Care was taken to select articles that addressed the common symptoms of fatigue, pain and cognitive dysfunction. I explored the research for metaphors used in relation to these three symptoms. I also highlighted the views of FMS and CFIDS that might indicate the researchers' acceptance or their rejection of FMS and CFIDS as "real" syndromes.

Another important point in exploring the biomedical and scientific articles was the ease of readability. I did not want articles that were written in biomedical or scientific jargon that explained the various processes in terms of chemicals and neurotransmitters. These articles would not retain the consistency I sought in order to make an analytic comparison between the biomedical and scientific literature and the participants' texts. Each metaphor was highlighted and selected on the basis of the themes that emerged in the participants' interview texts.

I did find it interesting that a number of the researchers had been diagnosed with FMS and/or CFIDS. I do not believe this caused any disadvantage to the consistency of my findings. I do believe that the researchers may find more significance in their work because of their own diagnoses.

Throughout this research, I noted that many of the social theorists that are included in my analysis also were diagnosed with FMS and CFIDS. This is important to the research of FMS and CFIDS in that these theorists live with chronic illness and may view the body and illness in particular ways that are of great value to future research of chronic illness and disability.

I conclude this section with a brief description of the women who participated in this research. Megan was the only participant that has been diagnosed with both FMS and CFIDS; FMS was diagnosed 10 years before the interviews and CFIDS approximately two years before the interview. Megan, age 45, believes her symptoms began after a physical assault and a flu-like illness. She is unemployed and has been declared disabled, receiving disability benefits.

Of the 10 women who participated, nine have been diagnosed with fibromyalgia. Paula is 55 years of age and was diagnosed with FMS 32 or 33 years ago and has lived with FMS the longest of those I interviewed. Paula believes her symptoms began after a series of car accidents. She is employed and works full time. Jenny received her diagnosis 25 years ago. She does not know what caused her symptoms. Jenny is employed full time. Julia is also in full-time employment. Her symptoms began after a sudden change in her level of physical activity. Julia, a former athlete, is African-Canadian and is 52 years of age. Jackie is a full-time student, age 44. She developed her symptoms following a sexual assault and trauma as a result of being stalked by the same individual. She was diagnosed with FMS five years before the interview. Heather is fully employed. She is 40 years of age and was diagnosed with FMS 15 years ago. Her symptoms began after a serious injury in a car accident. Sarah, age 58, also believes her symptoms began after a car accident. She received a diagnosis of FMS 17 years ago. Sarah is professionally employed. Susan received a diagnosis of FMS nine years before I interviewed her. She believes her symptoms began after trauma received from a fall although she is not certain. Susan is not employed. She is 44 years old. Sasha, age 41, witnessed a tragic event that caused emotional trauma. She began to experience symptoms shortly after the

incident and was diagnosed with FMS 10 years ago. Sasha is employed full-time. Connie is the oldest of the participants at 64 years of age. Connie's symptoms have an unknown cause. She is retired.

Of the sample of 10 women selected for this study, three women are self-disclosed as lesbian, one as a bi-sexual, one undisclosed and five as heterosexual. Educational levels ranged from some college/technical training to a doctoral degree. All the participants are residents of Saskatoon and all have been diagnosed with their disease by medical professionals in Saskatoon. The women range in age from 41 to 64. The mean age of participants is 49.4. I have included a table of demographic information for ease of reference: see Appendix F, Table 5.

3.4 Research Limitations

The interviews with Saskatoon women with FMS/CFIDS yielded rich data on the experience of women living with the syndromes, the sample size of 10 in a small Canadian city is a narrow representation of women living with these syndromes. Consideration of sexuality made the research a more inclusive demographic profile; however, participation was limited to middle to upper-class women, many having been diagnosed by the same physician and receiving treatment from many of the same practitioners. Also, ethnicity and race are not well represented within the study: nine White women and one African-Canadian woman participated in the research. My own diagnosis of both FMS/CFIDS and my sexual orientation as a lesbian woman locates me as an insider meaning, "someone who is similar to their informants in many respects" (Dowling, 2000, p. 32), within the terms of my own participation with the women. Therefore, I bring to this study my own experiences of chronic illness and marginalized

sexuality and consider myself as having inside and personal knowledge of the research topic.

Personal experience of living with FMS/CFIDS may be considered a limitation in developing the guiding questions for the interviews and framing questions within the interview process. But, because of my own experience, there were particular questions I asked that may not have been considered by a researcher who was not lesbian and who did not have FMS or CFIDS. This could be considered limiting or positively affecting the research by directing questions that targeted specific symptoms and experiences.

My position of graduate student researcher may also be considered a limitation. The assumption that I have privileged knowledge may have affected the power relationship between interviewer/interviewee and/or may have altered the way the participants answered questions in the interview process.

Despite these limitations, this research will contribute to alternative ways of theorizing chronic illness. As well, a study of the inscribed biological body is a topic that has had limited feminist research. By intersecting metaphors of illness and the effects of the social and cultural landscape on FMS/CFIDS, this study gives voice to women's experiences of chronic illness from the WLWCs (Women Living With Chronic Fatigue syndromes) standpoint.

3.5 Conclusion

Current research of chronic illness is largely framed in discussion of the inscription of culture and experience. However, chronic illness is also inscribed "in the body" and is written with culturally specific perceptions of being ill. The symptoms of illness described by the women with FMS and CFIDS reflect their perceptions of the varying ways that illness affects and alters their daily lives. Their descriptions prompted

me to show how the women perceived and interpreted their symptoms and the effects of these symptoms on their interactions within their lifeworlds.

Ten women participated in the interview process. I developed questions for the open-ended interviews to explore the personal experiences of living with FMS/CFIDS. I asked each of the women to describe their symptoms as well as whether their symptoms had caused them to make changes to their lives. I believe that the responses I received reflect an excellent account of the FMS/CFIDS experience of illness as well as a broad range of personal descriptions of the women's interaction within their lifeworlds—the environment in which they live. Exploring how the women perceive their symptoms to influence their social interaction adheres to Birke's perspectives. She argues that there is need to include the biological body when thinking about ways that cultural and social aspects are not only inscribed on the body but also 'in' the body. Exploring the descriptions by the women who participated in this study will show their interactions within their cultural framework.

Following verbatim transcription of the interviews, I found that the women used metaphors to convey how the symptoms affected their bodies as well as how they reacted to the varying changes, pain and fatigue that were occurring. Their descriptions indicated that what they perceived to be occurring due to symptoms within their biological body had an immediate and often lasting affect on their interactions within their social and cultural life. This indicated to me that symptoms are more than body surface inscriptions. The symptoms were perceived as biological functions with embodied meanings that reflected personal understandings of illness.

The second purpose of this study is to analyze the biomedical and scientific literature to compare and contrast the accounts of FMS/CFIDS with the interview texts. Following Lakoff and Johnson's (1980) and Kovecses' (2000) work on metaphor analysis, a comparison of the biomedical literature and the participants' accounts of illness showed divergent views of FMS/CFIDS which are influenced by culture, the environment and other culturally specific knowledges.

In Chapter Four, I analyze the metaphors and descriptions of illness from the interview responses. Metaphorical themes are central to this analysis; the experience of illness as metaphors of the environmental, metaphors of fracture, metaphors of invasion and metaphors of journey. I include a section on the body and mind and explore the relationship between biological processes and thought. Chapter Five focuses on the biomedical and scientific literature addressing the particular descriptions and metaphors used to discuss symptoms of pain, fatigue and cognitive impairment common to FMS/CFIDS. I contrast and compare the metaphors within the same themes as analyzed in Chapter Four. I conclude in Chapter Six with a discussion of the commonalities and differences between the participant responses and the scientific/biomedical literature.

CHAPTER 4 SYMPTOM METAPHORS

I have no doubt that it's a dreadful disease; it's dreadful.

4.1 Overview

Birke (2003) suggests that social and cultural events are not passively experienced. Social and cultural events affect and reflect how those with FMS/CFIDS feel and socially react in their lifeworlds. An analysis of what metaphors are used to give meaning to FMS/CFIDS will elucidate those elements of this lifeworld that pertain to the construction of self in light of a unique, relatively invisible and highly gendered chronic illness.

Developing an analysis of metaphors was challenging. Recalling the participants' stories of illness, sometimes experiencing their achievements and, at times, troubled by their deep sorrow and pain, gave resonance to the metaphors the women participating in this study used. However, this resonance is often hard to capture in academic writing. Their metaphors are personal, reflecting their lifeworlds, their situated knowledges and most importantly, their knowledge of their own bodies and the boundaries that define them. Lakoff and Johnson (1980) argue that individuals create boundaries to orient themselves to their exterior world as a direct result of how the body is viewed. In order to mediate our surroundings, "Human purposes typically require us to impose artificial boundaries that make physical phenomena discrete just as we are: entities bounded by a surface" (Lakoff & Johnson, 1980, p. 25).

Boundaries may help orient oneself but boundaries also serve to constrict and impose social and self regulation. The physically sick body often becomes bound in ways that constrain interaction, impose certain effects of control and ultimately affect the course of illness. While these boundaries may be obscure for those with invisible disabilities, the women I interviewed described restrictions that impeded interaction and function in everyday life.

I will also be referencing the biological body and the social body in my analysis. Throughout my analysis, I will refer to “bodily” to describe the biological function of the body or “bodily process.” This is fundamentally different from my use of the term “body.” The term “body” refers to the social, cultural and physical presence of the body. This is the inscribed body that is the product of social and cultural forces. It is also the body that acts and reacts to perceived biological processes that are part of FMS/CFIDS.

In this chapter, I present an analysis of the metaphors and descriptive language used by 10 Saskatoon women diagnosed with FMS/CFIDS. To facilitate this exploration, the analysis will be discussed under sub-headings. In section 4.2, I will analyze metaphors and descriptions of weather and other environmental elements to demonstrate how the participants link common aspects of their daily lives to describe their perceived biological symptoms. Using these categories will also illuminate the participants’ emotions and feelings to convey the way they conceptualize their bodies in illness as well as the world around them.

In order to draw out the experience of illness, I have included a section on metaphors of invasion to illustrate how the women describe pain and fatigue as well as metaphors of fracture where I discuss the impact of cognitive and physical fatigue as it

affects the women in their everyday lives. A discussion will also centre on the body and mind where I will demonstrate, through the women's descriptions, the interconnected nature of bodily symptoms and the embodiedness of social and biomedical constructions that shape how the women come to know and interpret their symptoms. The last section of analysis in this chapter will explore metaphors of journey and the different paths the participants have taken during the course of their experiences of illness. By doing so, I show that the onset of FMS and/or CFIDS determine paths as part of the journey through chronic illness. Throughout the chapter, I will link concepts of self with the embodiment of cultural and social factors that are not only inscribed on the body but are written in the symptoms of the body. The body acts and reacts to these factors and is demonstrated in the words and metaphors of the women themselves.

This chapter intends to show that many factors cause and influence the illness experience. The experience is not lived within a confining shell but is situated in every area and aspect of the lives of the women who participated in the study. I will also show that the experience of chronic illness is part of the biomedical and social construction of the syndromes and symptoms that can only be known and described by the embodied knowledge the women have about their biological processes. This is the embodied knowledge of the body that is linked with the mind and made known through descriptions of their experiences with FMS/CFIDS. These factors affect how women manage their symptoms and in how they perceive changes of their symptoms in response to external life events.

4.2 Fog: Environmental Metaphor

Weather was the most common metaphor used by the women participating in this research to describe their experience with FMS/CFIDS. References to fog—“brain fog,” “living in a fog,” “groping in a fog” and feeling “off-balance and foggy” figure prominently in the descriptions offered by all participants. This metaphor obviously has great explanatory power for these women, capturing their sense of heaviness, fear, impaired clarity and disorientation.

This metaphor of fog situates the women within the broader Canadian cultural and environmental context. Weather talk is part of daily discourse used by strangers and familiars alike as a way of making connection. But the extremes of hot and cold experienced in many parts of the country make the weather an omnipresent force, something with which to be reckoned. The changeable Canadian weather includes rain, snow, sunny days and at times, Canadians experience periods of dense fog. Although fog is not a common weather condition in Saskatoon, experiencing heavy fog and ice fog is something that becomes part of experiencing the environmental variables. The disoriented feeling of being in a fog is an experience that is unsettling and remains in the subconscious, ready to recall. Dense particles of moisture form foggy days that creep in slowly, settling near the earth. Silently the mists envelop structures and landmarks, creating a haze that alters perception, sometimes creating disorientation to surroundings that are familiar, causing feelings of bewilderment and confusion.

The changing seasons in Saskatoon bring periods of icy rain and condensation that creates clouded, foggy windows and iced over windshields on cars. This too distorts and hinders the ability to see. Iced over windshields impede movement and often, a

period of waiting must occur before the windshield is clear and the driver can proceed to her destination. Foggy windows are confining; perception becomes distorted and images are blurred or unrecognizable. When images are distorted and blurred, individuals cannot be sure of distance or recognize faces or familiar objects. Looking in a fogged over mirror hides the image of the face from the individual. There is no recognition of one's own facial features and body.

Fog becomes an immobilizing experience, perhaps causing some panic and instances when one feels endangered. Without vision, there is not a clear perspective and the distorted images may bring on periods of fear or anxiety, particularly if the fog occurs when driving. There is a sense of being out of control and/or being confused by the surroundings even if it is familiar terrain.

The women in this study all experienced fog to some degree. However, their type of fog is termed "brain fog." Megan, a 45-year-old woman has experienced the cognitive "brain fog." Diagnosed with both FMS and CFIDS, Megan first noticed symptoms following a physical assault and a flu-like illness shortly after the assault. Her symptoms progressed to the point where Megan received a diagnosis of FMS approximately ten years ago. This was followed by a diagnosis of CFIDS two years later. Megan is the only participant who is on full disability benefits. During the course of her interview, Megan spoke of the fatigue and "brain-fog" she experiences. This common symptom of both FMS and CFIDS has placed boundaries on Megan's social participation and greatly affected her perception of her self. Megan states:

I don't socialize unless I have this buffer zone around me. Whatever social activity it is and the, even the, I will sometimes start stuttering and lose my place and not be able to have a conversation as well.

The “buffer zone” to which Megan refers entails resting, often many days before she will participate in any social interaction. The “buffer zone” is “around” Megan, an act that aids in maintaining her safety from social and environmental interference. However, the solitude and rest become a boundary that not only constrains her movement but also serves as a form of self-surveillance. This may lead to isolation resulting in loss of social interaction. The disability literature often refers to the isolation that permeates the lives of those who have varying forms of chronic illness. The impaired cognitive functioning evident in Megan’s reference to “brain fog” makes clear the notion that often this isolation is not the only stigma associated with participating in social and employment settings. Megan also experiences isolation from current events, news and other printed information. Megan explains why she experiences isolation in this form: “I read quite a bit and then . . . my eyes are deteriorating so I haven’t read much for the last few months.” Megan feels that she does not approach things from a “position of knowledge” as she once did. Unable to retain information, Megan views new educational pursuits as a “really scary project.” All of these changes in her everyday life have influenced the way she measures herself in relation to others who are able and working. Megan perceives herself as incompetent, internalizing this as a form of stigma—a result of societal expectations of ‘accepted’ performance, not only in the social sphere but in her own home-life as well. Stigma becomes embedded as part of life in these settings and, ultimately, as part of coming to terms with a diagnosis of FMS/CFIDS and her view of the self.

As discussed in the literature review, aspects of self and identity have been studied from various theoretical perspectives. Taking the view that selves are always in

flux, evolving and changing with experience, selves change with regard to how one views his/her physical presence and in how others form notions of the individual's identity.

When changes are taking place in the internal functioning of the body, the self responds.

Birke (2003) argues this interaction is more than the embodiment of cultural and social forces. The interaction between self and society is dramatically affected by the biological functions of the body. Megan's altered way of interaction is a new boundary, developed due to the physiological effects of FMS/CFIDS symptoms. This cause and effect reaction to symptoms—the way symptoms are perceived to be affecting the biological processes of the body—are part of experiencing a new way of knowing the self. The abilities of the body are changing, thus creating altered boundaries as well as new challenges.

New challenges are ongoing with FMS/CFIDS due to the variability of symptoms. Jenny, age 47, diagnosed with FMS, has experienced multiple symptoms for more than 25 years. Jenny cannot relate her illness onset to any specific time or event and feels that she may have had the illness even as a child. Jenny also spoke about her experience of feeling restricted by cognitive dysfunction:

The cognitive impairment is like groping in the fog for things that you know are there but are hidden by this fog and it's like trying to think with cotton baton or with fog instead of the brain um . . . you know you have information . . . you remember studying it but you can't articulate it. You can't recall the concepts, you can't bring information back and it's a lot like a tip of the tongue frustration.

Jenny's thoughts are "hidden" in a fog. Moreover, Jenny is "groping" in the fog, trying to find what is lost. The fog has silently slipped in, suppressing her ability to recall her thoughts or to establish a logical sequencing of events. Jenny speaks of frustration and perhaps confusion because of her "inability to think." Jenny's forward motion has been

temporarily suspended like a ship in the fog, waiting for the haze to lift so she can resume her life.

The inability to touch is part of “groping” in the thickness of fog. According to Lakoff and Johnson (1980), the eyes become extensions of touch. In Jenny’s dialogue, the eyes are groping and extending to the arms and hands. Jenny cannot touch, or perhaps Jenny has lost touch with her familiar self. She is disoriented. Fog surrounds and covers her and a sense of darkness settles within her. Jenny cannot find the boundaries that distinguish her body from the external world.

Jenny feels that clouded thought disengages, making her abilities of thought and action difficult. Kovecses argues that when perceptions are clouded in some way, “the subject of emotion is incapable of cognitive (“higher” mental) functioning” (1990, p. 179). The fog or clouded thoughts are altering Jenny’s perception in what Kovecses (1990) suggests alters rational thought. The fog is a deceiving trickster, clouding judgment and causing the rational self to become a nonrational self. The nonrational self is taken over by an emotional force that cannot be contained by the counterforce—the rational self (Kovecses, 1990). Kovecses (1990) interprets emotions that become intense as overflowing and thus causing the individual to perform an action that he or she would not normally enact. In Jenny’s case, the perception of her surroundings shift, causing emotions that are disturbing and confusing. Jenny conveys feelings of “helplessness” and “weepiness” at times when cognitive “fog” occurs. With these emotions overflowing, Jenny may feel that her thoughts and actions are nonrational. Her wish is to clear the fog so that her perception is clear once again. Therefore, Jenny is “groping” in the fog, past

the boundary where she knows another self she is familiar with will once again emerge and she will return to a rational self.

Jenny's self-perception as able bodied collides with the intrusion of her symptoms. Her disorienting experience also alludes to notions of how this metaphor builds bridges between her past as the able-bodied Jenny, and her present state. Jenny becomes aware of another "self;" her experience demonstrates how individuals come to know more than one self, recalling an able body and self as her disabled body emerges and redefining the self.

Altered perceptions of self are also demonstrated in Megan's narrative. Megan's experiences with "brain fog" and fatigue leave her feeling "diminished:"

[I]n many ways, [the fatigue] diminished yes, I felt diminished . . . I, I can only describe it . . . in sort of a metaphorical [way] . . . [I] kind of diminished into this little speck . . . I can't come up with words to describe that other than diminished, reduced.

Being unable to function at a level that is considered "normal" and productive in our culture has greatly affected Megan's feelings of self and the contributions she makes to the world around her. Megan's metaphorical description of her cognitive state suggests the feeling of being lesser, lacking self-esteem and self-assurance. Kovecses argues that self-esteem is closely related to pride where individuals structure themselves and their "actions, possessions, appearances . . . in metaphorical terms" (Kovecses, 1990, p. 99 - 100). Feelings of being "lesser" and diminished from the effects of "brain-fog" may well lessen her motivational level as well (Kovecses, 1990).

Feeling diminished and lesser may be part of how Megan relates her physical body to cultural space. Bartky argues that women unconsciously compact their bodies, posturing themselves in a way that takes up less social space to "produce a 'practiced and

subjected' body, that is a body on which an inferior status has been inscribed" (1998, p. 33). The subjected and disciplined female body is dominated by a power that is "everywhere and it is nowhere" (Bartky, 1998, p. 36), defining the inferior status of women in a "hierarchy of gender" (Bartky, 1998, p. 36). It could be argued that situating a chronically ill body into Bartky's argument would suggest that women with chronic illness and disability would take even less cultural and social space because of the stigma that is associated with disability. While Bartky's argument must be acknowledged as part of Megan's view of herself as lesser and "diminished" I will argue that chronic pain and fatigue is a greater factor causing Megan to compact her body than is the stigma associated with being disabled. The pain of FMS/CFIDS decreases functional ability. Movement becomes restricted when muscles contract and spasm. Pain and fatigue are the greater controllers of the body. In addition, Megan feels inferior because of her inability to focus and concentrate because of the fatigue. The feelings Megan experiences relate to the self, partly influenced by cultural expectations but partly the outcome of coming to terms with a changing self and the way in which she views a new self that is forming.

A lessening of self-esteem reflects how Megan sees herself. Measures of self-esteem are embodied cultural knowledge that affects Megan's perception of how she lives up to norms and expectations, her motivational capacity, as well as how her disability clashes with societal views of productivity in terms of her levels of energy and performance. Forms of self-surveillance and self-discipline are reflected in Megan's narrative as she speaks of herself as feeling "diminished" and being reduced to a "speck." She has internalized broader expectations of high energy, constant output and an embodied engagement with the world and, in light of such expectations, has judged herself

harshly, exacting on herself the disapproval that able-bodied people around her often express.

As mentioned in the review of literature, fatigue is common to both FMS and CFIDS. Although one of the most common physical complaints heard by those in the biomedical communities, it is not measurable. Often fatigue is dismissed as a symptom of overwork and/or a sign of a stress. Yet, for those with FMS/CFIDS, it is much more. Paula, age 55, was diagnosed with FMS about 32 or 33 years ago. She believes she may have had some of the symptoms of FMS while growing up but a number of car accidents made her symptoms more severe. Although Paula is fully employed, she views her fatigue as the “most frustrating thing . . . this immense fatigue” that often brings on emotional responses and “pulling back” from discussions at work for fear that she will become too argumentative and “emotional” in a job situation where emotional responses are not appropriate.

In the case of FMS/CFIDS, the body cannot endure the stress of constant fatigue. The body becomes an object that is brittle, metaphorically shattering into many pieces. Feeling reduced into shattered pieces alludes to Megan’s comments of being reduced to a “speck.” Megan, Paula and Jenny experience the affects of fatigue in similar and diverse ways. Megan and Jenny suggest that they have become confused both with their physical body and with what extends beyond the boundary of the body. This confusion has led to feelings of inadequacy and an inability to present themselves to the social world as they formerly did—feeling confident and knowledgeable is challenged by the inner physical symptoms associated with FMS/CFIDS. As Lakoff and Johnson (1980) argue, the brittle

object shatters and cannot be repaired. When interviewing the participants, perceptions of the body breaking down, coming apart and cracking were commonly experienced.

4.3 Cracking Up: Metaphors of Fracture

Heather was the only participant that discussed her illness experience in terms of feeling “cracked.” However, the participants used similar metaphors to convey the body or the self as ‘coming apart’ or fractured. When discussing the references to fracture, I believe the participants were addressing states or stages of being ill at a time when they felt their bodies or their selves as less than whole. I believe most people who have suffered a seasonal flu or virus have experienced this feeling; however, for the women who participated in my study, the lack of “wholeness” occurs more often and, at some periods in each of their experience with FMS/CFIDS, the episodes lasted longer than would a flu or virus.

Heather, age 40, was diagnosed with FMS in 1992 or 1993 following three or four years of illness. Heather’s symptoms began following a serious car accident. After returning to work, Heather recounts her feelings of unrelenting fatigue and pain. This is how she described her physical state to me:

I was a full time receptionist, sitting at a desk answering the telephone all day and they helped you know adapt my work space to make it better but about a year and a half into that I just cracked, I couldn’t do it anymore.

Heather’s physical state became so tenuous that she felt she had broken into pieces, she “cracked.” Fatigue, accompanied with pain, became explosive and felt as if it may shatter the body. Feelings of coming apart are common when experiencing an all en-compassing pain that cannot be measured or labelled. In Heather’s case, when the pain could no longer be contained as a private experience, her perception of the bodily feelings of pain

and fatigue emotionally “cracked” her. Heather’s physical state was exposed; pain had entered a visible and public space. For Heather, her private self had broken, leaving her with a sense of being vulnerable and defenceless against pain and fatigue.

The fatigue and pain Heather experienced had reached a level of excess causing too much pressure within her body and her emotional boundaries—emotions that “cracked” the walls of emotional control and control over her self. To what extent Heather has internalized the cultural ideal of women as emotionally weaker than men is not clear. However, Heather’s perception of being “cracked” is an indication that Heather may also feel that the illness is emotional and not physical. As discussed in the review of literature, FMS is often contested as a legitimate physiological disease but rather as an imagined disease, categorized by biomedical communities as an emotional illness. Heather’s emotional reaction to pain and fatigue deters her ability to function in her work environment. Heather may have embodied the negative contexts of FMS and is, at times, fearful that her illness is emotional rather than physical.

Historically, women have been labelled as emotionally and physically weak.

Megan views this detrimental label as part of the problem with a FMS/CFIDS diagnosis:

Culturally, so many illnesses have been pooh-pawed . . . that happens to women It’s just easy to do . . . our literature is full of fainting and little wisps of things who can’t deal with . . . [the] day-to-day things That’s much easier very . . . [It is] typical for a culture to say well that’s an emotional thing, it’s a women’s thing, she’s just not strong.

Living with illnesses such as FMS/CFIDS are an unbearable burden for women. Women are expected to perform many roles in their daily lives, yet there is a societal belief that women are physically and emotionally incapable of doing so. In Euro-Canadian culture, strength and endurance is a masculine trait. These physical qualities also allude to a body

that is without defect, meaning without disabilities. Heather's reference to literature that portrays women as weak suggests her knowledge of the social and cultural meanings that are transferred to women's health patterns and the propensity to blame emotional problems as the root of their symptoms. Viewing women as weaker and emotional may impede a quick diagnosis or cause a misdiagnosis.

Going undiagnosed or a misdiagnosis, as in Julie's case, can lead to self-doubt. Impaired function began for Julie, age 52, as she conveyed to me how her illness began. Before Julie was diagnosed with FMS, she could not understand what was happening to her. A former athlete in excellent physical condition, Julie started to experience pain and inflammation that physicians could not diagnose:

I developed . . . all kind of things. My doctor wasn't sure . . . what was going on. I went for all kinds of . . . tests, and then it just got worse from there. So finally my doctor said, you know, your tests [are] not revealing anything . . . I was in bed anyway for two weeks and at the end of the two weeks . . . I went out [and] the first day, I came back [and] found out my knees were beginning to fail me. Then my hands . . . a whole lot of changes were going on inside my body. I . . . developed serious back pain and became incapacitated for the second time. I called up my doctor and said, look, I don't know what is going on but I'm falling apart.

Julie's description of fracture may address two different viewpoints: failing of the physical body and fracturing of the self. Perceiving the self as "falling apart" aligns with Heather's perception of feeling emotionally "cracked" from pain and fatigue. However, Julie stated her body is "falling," a downward motion that Kovecses (2000) relates to illness and sadness. Illness suggests the body is in a low state, most probably derived from lying down when one feels ill (Kovecses, 2000). Falling may suggest that Julie is experiencing a low period or stage of the syndrome. Falling may also allude to Heather's general mood as being lowered due to the escalation of her symptoms. The illness may

not only be what is happening to Julie physically but may also indicate Julie's emotional state due to uncertainty of what is happening to her. Julie may also feel she has lost some control over her physical body and her self. Lakoff and Johnson (1980) argue that "having control or force is up; being subject to control or force is down" (p. 15). In Julie's case, the force is the symptoms she is experiencing as well as the reliance on biomedicine to find a cause to her physical problems.

Lakoff and Johnson (1980) argue that "understanding is seeing" (p. 48). Julie does not "know" or understand. However, Julie's perception of her varying symptoms suggests to her that something is occurring. Julie's attempt at "seeing" is seeking medical care to determine what is happening inside her body. However, the cause of her symptoms is unknown and her attempts to find solutions for her illness have failed. The symptoms and the unknown are burdens to Julie, weighing her down, thus, causing her body to "fall," a downward motion where Julie has lost some control over her bodily functions and knowledge of herself.

Occurring symptoms appear to be related to emotions that deeply affect notions of the self. The self is challenged to change in order to cope with and realign personal power to meet the needs of chronic illness and disability. Societal influences and cultural norms may regulate the body; however, the body in transition is more strongly regimented by disease processes that are occurring within the body. The point at which feeling able is challenged by the sudden onset of symptoms is the regulating factor in the way that those with FMS/CFIDS participate, withdraw or isolate themselves, determining their participation in a "normal" routine of existence. While it is true that the self is in constant

flux (Foucault, 1990), this flux is not solely regulated by socially imposed controls; rather, it is mediated by both biological and cultural constraints.

4.4 Invasion: Metaphors of Harm

The greatest complexity of being in pain is the inability to express pain in a manner that others can share. Metaphors and descriptions of pain are a means of articulating and defining the intensity of pain. As Scarry states, “physical pain—unlike any other state of consciousness—has no referential content. It is not *of* or *for* anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language” (1985, p. 5; original emphasis). Pain has no reference point but metaphors are used in an attempt to describe the physicality of pain and, in so doing, they describe the body in pain.

Chronic pain is not as common an experience as is acute pain and is often misinterpreted and misunderstood. Chronic pain “extends beyond the normal recovery time, is cyclical . . . or lasts longer than six months” (Jackson, 2003, p. 155). For those with diseases where pain is one of the major symptoms, recounting the constancy and the intensity of such pain is often difficult. According to Scarry, there is a great deal of difference between “having pain” and “hearing about pain” (1985, p. 4). Scarry argues that having pain is to live with certainty, to hear about pain is to have doubt. The women who participated in this study made very clear that the certainty of pain can be made explicit. The certainty, elucidated in descriptions of pain, illustrates pain processes that reshape the lives of women with FMS/CFIDS. Their response to pain reflects beyond the internal processes of their bodies. Pain response affects every aspect of WLWCs lives:

social and personal involvement in their lifeworlds. Pain is not contained within the body but moderates and mediates how WLWCs present themselves and interact with others.

Wendell (1999) argues that, “the understanding of pain can be greatly enriched by the experiences of chronic pain” (p. 326). Although pain is an isolating experience, “it is important to remember that pain occurs in a complex physical, psychological, and social context that forms and transforms our experience of it” (Wendell, 1999, p. 327).

Although Scarry (1985) has noted that pain defies language, having no singular words that are adequate to describe pain, the participants with whom I spoke conveyed their pain in eloquent and descriptive ways that not only addressed their feelings of pain but also illuminated their social and cultural worlds. Therefore, the certainty of pain not only removed doubt of their pain but also allowed a view of the social constructions that shape their lives.

Describing pain in a way that makes pain knowable to others does not remove the way pain affects everyday life. Jackie, age 44, is a full-time university student. She received a diagnosis of FMS for symptoms that began after a sexual assault. Jackie, speaking of the pain that often encompasses her whole body, responded to my question, “do you have pain?” in this way:

I have pain It's sometimes shooting pain but sort of dull like a knife. It's aching but it's not, it's severe aching. It goes down, a lot of it's in my arms and shoulders, my neck, my back. It goes down into the tips of my fingers; they swell, I can't hold a pen.

Jackie speaks of her pain as an enemy invader that has “come into my body and there are times when I can't use my arms.” She continues, “There are times I get depressed from it and I cry and I'm tired of it. It feels like I have energy and I have vitality and I want to use it.” Pain becomes the predator, somewhat unknowable and most unpredictable. For

Jackie, pain removes her source of energy and her feeling of being a viable, productive person. Jackie's thoughts are conflicting. Her want is to be active and follow her desires but the syndrome has invaded her body and is sapping the energy her body requires to do so.

In much the same way, the process of bodily pain alters Julie's plans. Julie states that she "gets very agitated . . . when my mind is all over the world . . . and all I want to do is sleep." Julie, first misdiagnosed with Lupus and later with FMS, says the new diagnosis "derailed" her because she was "feeling comfortable with the [lupus]" and living with the label. Following a new diagnosis of FMS, this invader is a stranger to her; she does not know what to do to help her body and she does not know where the disease will lead.

The invader affects everyday socialization, performance and feelings of self-worth. For Julie, the intrusion of symptoms hinders her ability to work effectively: "I am not able to produce. It works against me all the time, I get frustrated" and "I am not as spontaneous as I used to be." Julie feels that she cannot work as well as she once did. Julie has embodied the cultural construct that measures worth with productivity. Crawford (1984) states that, "work continues as one of our most fundamental social values" that defines a person in 'badges of ability' [and] achievement" (p. 78). Julie feels that she cannot achieve without continuing at the pace she did before becoming ill. Jackie also finds that, "I still grapple with the idea of my self-esteem, like where is it? One day it's fine, one day it's not, one day it's shot down to the bottom of my toes. The next day it's as tall as I am." The use of descriptions by both Julie and Jackie translates into a snapshot of illness. For both women, however, the metaphors depict feelings of being

small, being less than what they previously knew themselves to be, feeling helpless at times and feeling inadequate. Feelings of inadequacy were expressed by Connie as a percentage. Connie, age 64, was diagnosed with FMS nine years before I interviewed her. She described FMS and fatigue: “I was disgusted though because it never moved [the fatigue]. I was living, 17 percent of being alive.” Productivity is an indicator of a healthy body: to produce work complies with cultural assumptions of capitalism and materialism. Living with a body that does not allow one to contribute in the economic or productive sense is having body that defies normative values and is culturally constructed as a devalued person.

Metaphors and descriptions of pain often incorporate weapons as the producer of pain. The weapon becomes the “external agent” (Scarry, 1985, p. 15) of pain. Jackie’s reference to pain as “dull like a knife” adds emphasis to her statement. She relates her pain to injury inflicted on her by an unknown attacker. This is a metaphor that suggests her body has been damaged by a violent intrusion of the bodily boundaries. The body is not safe—the boundary protecting the internal body has been damaged. This descriptor may suggest an association to media that displays events of war and the graphic details of murdered bodies. Invasion may also demonstrate the fear she still feels from her experience of being sexually assaulted and stalked by a male she met briefly at a social outing. Jackie may have a personal experience of violence that has been conveyed in her description of pain. However, women do experience greater fear of violence than do men (Valentine, 1991; Pain, 1997). Since metaphors reflect the social and cultural world at a specific time, space, and place, Jackie may have embodied the negative aspects of a

culture where women feel the threat of sexual violence and violence that includes threats of harm with dangerous weapons.

Metaphors that make reference to weapons and invasion are part of embodied knowledge that Canadians use to think about the body. Biomedicine describes disease and the cause of disease in militaristic terms that include violent attacks by an enemy or enemies on the body. These metaphors become part of learning about the body and how the body wards off disease and functions when “invaded” by disease (Martin, 1992; Martin, 1994). Metaphors that are related to violence are argued by Sontag (1989) to be metaphors that create greater harm, generate more fear of disease and victimize the individual. As Sontag (1989) argues, “Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt” (p. 11). The embodiment of powerful biomedical metaphors of militarism may indeed influence Jackie’s description of pain. How harmful these metaphors are to the physical well-being of women remains unclear but may, as Sontag suggests, be the embodiment of guilt that developing FMS/CFIDS is in some way a fault of the individual.

However, without these metaphors, without language, how would others understand FMS or CFIDS? Indeed, without metaphors, would women living with FMS/CFIDS understand their own bodies? If pain needs to be objectified as Scarry (1985) notes, then to objectify pain is to name it and then to express those feelings, perhaps to alleviate some of the hurt or more pointedly, some of the frustration and conflict. Notions of identity are also brought into focus through the descriptions of pain. Kondo (1990) argues that the fragmentation of the self occurs when the self is defined as “other” (p. 16). In the case of FMS/CFIDS, the self is immersed in its own culture of

illness, a new and strange location where the brain is active and planning but the body is “unwilling” and unable to function as in relative states of health. Otherness, then, is also an invader demanding that the self be renamed and reshaped.

4.4.1 Potential and Loss: Metaphors of Productivity

Megan views the pain and exhaustion she experiences as having affected her socially, personally and emotionally. Megan talks of her feelings of loss:

. . . the loss of my physical capability and my mental processing and probably I was quite, quite suicidal . . . I still do have what they call interests in thoughts of death uh, when I uh let myself think in terms of . . . the lack of potential that I have now at my age. This is the greatest time of our lives you know or supposed to be so I still do get wrapped up in that. Wish I could get out of it.

Megan’s loss is more than simply the loss of energy. It is her loss of potential and her restricted ability to perform at work and in social contexts that has lead to feelings of despair. She feels that, at one of the most important and best times of her life, she has been robbed, invaded by pain and fatigue that is relentless, so much so that she becomes “wrapped up” in feeling that her illness has robbed her of enjoying life. Perhaps, what is not expressed in the above quotation are Megan’s feelings of being rejected and excluded from the life that she once enjoyed. She has become marginalized by illness, house bound, often forced to sleep and live in quiet solitude to control head pain and pain caused by excessive fatigue. Megan thinks of herself in terms of being a lesser person than she once was. Feeling lesser may be the embodiment of productivity as an identifying marker of the social responsibility as was also expressed by Julie. Unable to work and restructuring her personal life due to the dictates of her symptoms have created boundaries. These boundaries are not a choice but the outcome of pain and fatigue that control Megan’s life.

Megan has embodied what Butler (1999) would name as the inscribed body where cultural dictates and norms have shaped the self and her identity. Her identity and self are much different now than the perceived body and self before her illness. But, as Millward and Kelly (2003) state, it is the biology of the body that mediates the social and environmental aspects of the lifeworld. Biology, in Megan's case, as well as with the other women interviewed, mediates actions and agency. The biological body and the processes of pain and fatigue are regulating and controlling thoughts of worth and self, social engagement and pleasure.

The emotions expressed are through metaphors of loss. Kovecses (2000) writes of illness metaphors as negative emotions that are connected to feelings of shame and sadness. Megan speaks of her lack of potential. Lack then becomes metaphorically symbolic of feeling diminished in size, an emotion Kovecses describes as shame. Is there shame in being chronically ill? Disability and chronic illness do not fit comfortably in a society that values the worth of individuals by their accomplishments. Or perhaps Megan is resigned in knowing that her former self and identity have become fixed in disability. Megan's metaphors situate her social position and her life experience where it may show how the biological affects the social context of the individual's life.

Metaphors and descriptive phrases indeed transfer the sensations individuals experience as pain into language filled with emotions and imagery that convey to others the intensity, the chronicity and the volume of pain. As Jackson states, "Pain always comes with a hidden narrative" (2002, p. 9). Pain is "subjective, invisible, multifaceted, and individual" (Jackson, 2002, p. 9). Only by hearing the narratives of those who are experiencing pain, does this invisibility become known.

4.5 Body and Mind

Processes of the body do not occur in separation from the mind. As Berne states, “The process of disease is not merely physical, nor is the process of mood only emotional” (2002, p. 127). To think that there is no link between mind and body in the presence of illness or disease is, as Cousins believes, “archaic” (cited in Berne, 2002, p. 126). All that occurs within the physical body is interpreted and made meaningful in relation to internal bodily feelings, associations with individual experiences, cultural meanings and language. Therefore, what happens within the internal body is interpreted in the mind. Interpretation is logic, imagination, and metaphor. This is what Johnson argues is involved in “putting the body back in the mind” (1987, p. xxxvi). Interpreting perceived biological symptoms is an embodied process drawing on all that one knows and imagines. This becomes personal knowledge that forms meaning from reason, imagination and logic. Furthermore, those who are living with either disease know that the symptoms affect both mind and body, the strange assortment of physiological happenings that disturb and betray WLWCs on a routine basis.

Impaired memory is a common symptom of FMS/CFIDS. The symptom is frightening and first experiences of memory lapse often leave WLWCs feeling as if there is something of a more serious nature occurring. Sasha, age 41, was diagnosed with FMS nearly 10 years ago. She believes her illness was the result of an emotional trauma. Sasha, spoke to me about the various symptoms that required many medical visits before she was diagnosed with FMS:

I just kept persistently going back ‘cause I didn’t feel good and like, I’m not a fainty [sic] kind of person. I can take a lot of pain and you know, whatever, but it was just really weird stuff . . . my jaw would pop out all the time, like on my left-hand side. Uh, saying the wrong word, forgetfulness . . . dizzy, light-headed . . . panic attacks big time.

Like others who become ill with FMS/CFIDS, the inconsistency of her symptoms does not “fit” the “normal” criteria of diagnosis that depends upon measurable and uniform criteria. However, these symptoms are very real and affect her ability to function and to feel confident within the social sphere. Moreover, Sasha fears that she suffers from something more serious such as brain tumour, multiple sclerosis and/or Alzheimer disease emerge as her greatest concerns. The fear that they had developed one of these diseases was also shared by the other participants.

The “weirdness” Sasha is feeling when first experiencing her symptoms is mediated by interactions both external to her body as well as her perceived internal symptoms. Sasha’s experience of “weirdness” is reiterated many times throughout the other interviews. For example, when Jackie was attending university classes at another campus, she arrived on time for her class but was unable to recall where the classroom was even though she had been there many times before. Having the class written in her day timer did not aid Jackie in recalling how to get to her classroom. Jackie reacted to this incident with fear: “I left. I could remember where my car was and I just went home ‘cause I didn’t know . . . Was I going to ask? Are you kidding? I’ve been here for six weeks already but it scared the living hell out of me.” Jackie’s reaction is what Kovecses regards as a “force metaphor” (2000, p. 193). Intense reactions to an event or physiological occurrence evoked the sense that “living hell” was exploding from Jackie’s body. Hell denotes downward movement and a negative event for those of Judeo-Christian belief. Hell is all the negative aspects of living a life in morally corrupt ways. Often, hell is used to denote a form of existence on earth that consists of pure chaos,

emotional and physical upheaval. Hell is a place from which there is no escape and a place of eternal damnation and fire for sinners and those who are morally unjust.

Health and sickness are attached to the moral order of civilizations, and these ideologies of morality remain somewhat entrenched in the modern view of health and sickness (Turner, 1995). Moral meanings have shifted over time to a more secular view of health; however, ill and disabled bodies are now framed in a discourse of self-care. In Euro-Canadian culture, maintaining good health is a regime of self-control, adherence to health guidelines for proper diet, body fitness, and the avoidance of health-risks (Crawford, 1984). Failing to comply with the current standards of health behaviours questions the morality of the individual. For those with chronic illness, the body does not fit the sick role through which individuals are expected to get well (Parsons, 1951).

Acceptable health behaviours become moral obligations (Sontag, 1989). Having an illness that has an unknown cause is not only contested, it also questions the behaviours and obligations the individual has to his or her body. As was discussed in the literature review, AIDS has altered views of illness and disease. Fear and stigma are part of living with diseases and syndromes without organic symptoms. Societal notions of disease and illness are associated with incorrect living and sexual deviance and become the basis of discrimination since these diseases and syndromes do not fit neatly into categories of illness that can be explained and can be cured.

An ailing body indicates a certain type of inadequate management, where the individual has not provided the body with the right nutrition, the proper exercise, and the correct maintenance of the body in order to repel disease from entering the porous skin (Lupton, 2003). Self-blame is the antithesis of the ideal of the maintained body, a body in

control, a body that is not deviant but of good moral graces. Jackie's use of the phrase "living hell" may be an indication that she has in some way been responsible for her sick body. The embodiment of social morals and values reflects in her visions of hell, of her body being trapped in fiery darkness, punished for wrong behaviour. Therefore, Jackie may understand her symptoms as eternally damned.

In their description of FMS/CFIDS, the participants expressed fears and powerlessness that occur when bodily functions do not respond in culturally acceptable and predictable ways. Moral meanings are attached to almost all behaviours, and in the case of Jackie's temporary memory loss, this moral meaning may indicate that unlike a "healthy body [that] becomes a sign of personal achievement; illness is the sign of failure and weakness" (Lupton, 2003, p. 59). Jackie goes on to discuss how family members think she is "nuts" when this kind of memory loss occurs. For Jackie, this perceived weakness is enveloped by feelings of fear and negativity.

Moral meanings of illness carry particular forms of stigma. Jackie's concern for the misinterpretation of her memory loss is a felt stigma that derives from the fear of discovery of this difference and shame about having it. Felt stigma reflects a person's internalized social values about her condition or difference" (Charmaz, 2003, p. 285). The effect of stigma for WLWCs may be increased due to the unknown cause of illness and to the invisibility of symptoms. Stigma plays out in individualistic terms for many people who develop FMS/CFIDS and is specific to their space and place within their culture and social networks: "Whether, when, and how people might acknowledge and act upon illness is embedded in culture and context" (Charmaz, 2003, p. 277). Women who develop FMS/CFIDS integrate the illness in ways that are specific to their lives.

How others respond to WLWCs is dependent upon cultural meanings of illness, expectations of the individual who is ill as well as being dependent upon the type of syndrome or disease that has developed.

The individual notions of stigma brought attention to the discourse of invisible disability and the need to retain the semblance of a “normal” appearance. When I asked the participants whether they would ever consider being declared legally disabled, all but one of the women responded that they would not, nor would most of them even consider themselves as disabled. Paula responded by stating, “I wouldn’t want to be treated . . . as a disabled person” and spoke of her sense of pride as well as her displeasure in thinking of herself as a “gimp.” Julie, felt that as an African-Canadian woman, “you are mediated by your race, by your gender and then add this disability to that . . . a triple whammy.”

Julie went on to say that:

Until you get to a state where you have something that shows it . . . for example, if I rely on a cane or [if] I am in a wheelchair then I will say I’m disabled. At this point, yes, I’m differently abled . . . [There] is still a lot of stigma attached to being disabled. So if you can hide it, hide it.

Julie also feels that allowing some members she works with to know of her FMS has been detrimental: “It works against me all the time.” Julie is positioned between “hiding it” and knowing that she is fighting with the symptoms of FMS. In Julie’s case, she is aware of herself at this moment in time, yet the identity made known to those with whom she is in association identifies Julie in a different sense. In order to remain in control, Julie takes great measures to ensure that her identity is not “spoiled” (Goffman, 1963).

For Paula, the stigma associated with using a cane to help with her mobility may allow the label “gimp” to be applied. Yet, to have negative stereotypes affixed to her by others may impede Paula’s social interaction and participation in daily life, leading her to

cast herself in a negative light by using this derogatory language. Moreover, “The stigmatizing label defines the person and every other defining characteristic she possesses” (Charmaz, 2003, p. 284, original emphasis). Therefore, in rejecting the labels denoting disability, Paula protects her known identity for fear of it being marked as flawed, even though her bodily processes of pain and fatigue may be exacerbated.

Moreover, hiding chronic illness from others can create additional problems (Charmaz, 2003). Hiding illness may increase the chances of over-extending oneself to the point of causing further damage to the sick body (Charmaz, 2003). In turn, these stressors may amplify the symptoms of FMS/CFIDS. Berne notes that, “General stress is an exacerbating factor in about 94 percent of patients” (2002, p. 175). As indicated in the discussion offered by Julie, Paula and Jackie, living with the knowledge of having FMS complicates and confounds notions of self that rest on precepts of health and able-bodiedness. The metaphors depicting shame, loss of control and subjection to cultural expectations enforce issues of self-surveillance and re-evaluation of the self. The self remains in constant flux in order to sustain some form of control of the symptoms and in maintaining an “acceptable” identity.

4.6 Journeys: The Path of Chronic Illness

Most of us form plans about our lives: we choose a path in life. Paths may represent goals, disappointments, or alternative routes we are forced to take. The expression that one has taken the wrong path in life or one is planning a career path, are merely metaphors of journeys that individuals travel during their lifetimes. There are times that the paths least desirable are forced paths: ones that would not be taken had

circumstances been different. Chronic illness and disability are most certainly undesired paths.

The path of FMS/CFIDS is both a physical path that is travelled and a path that exists within thought and imagination. Johnson states that, “Our lives are filled with paths that connect up our spatial world Some of these paths involve an actual physical surface that you traverse [and] certain paths exist, at present, only in our imagination” (1987, p. 113). Whatever the path that is travelled, there is a “(1) source or starting point; (2) a goal, or endpoint; and (3) a sequence of contiguous locations connecting the source with the goal” (Johnson, 1987, p. 113). As has been discussed in the previous sections of this chapter, there are many starting points to the onset of FMS/CFIDS and very individualistic paths that take the women through the journey of illness.

Illness is the source from which different paths are traversed. Symptoms may be similar as I have presented them here, however, many of the women do not have common symptoms. Moreover, the paths chosen are in response to symptoms and embodied cultural and life experiences that change how the participants perceive their symptoms. The source is unexpected, the immediate goal is to become well. As time passes and symptoms have not disappeared, the life goals and plans change.

The previous sections in this chapter indicated that WLWCs begin a journey of illness and uncertainty, initiating altered perceptions of their selves and their perceived bodily processes. Analysis of FMS/CFIDS as a journey illustrates how the experiences of illness from onset and through the progression of FMS/CFIDS symptoms are described through metaphors. The metaphors show how WLWCs navigate the paths of their

external environment and their perceived internal changes. The new paths are obstructed by environmental elements, invasive, sometimes harmful and dangerous events. These forces and elements as discussed in previous sections of this chapter also influence the changes that become part of each new path that WLWCs walk.

Change can occur abruptly and be the outcome of a flu-like illness, accident or trauma to the body. Heather relates this abrupt change and the difficult journey she experienced in finally receiving a diagnosis of FMS:

It was a built up thing . . . and [the physicians] called it . . . chronic pain syndrome. And then it wasn't . . . I saw . . . 25 doctors for everything and therapists and then it wasn't until after I had this surgery on my arm and everything kind of died down and they said the couldn't really do anything for me . . . and then [I was told] I have fibromyalgia.

Heather was caught in a cycle of biomedical uncertainty. Cycles represent time and movement, although the shifts Heather was experiencing did not appear to be helping her. Entering a cycle of medical opinion becomes a disjointed shift from one physician to another where vital information about Heather's body is broken into bodily parts and functions. Functions become privileged, specialized knowledge and the body in ill health is at the mercy of a hierarchical bureaucracy that constructs disease and syndrome categories, allocates research funding and withholds information (Turner, 1987). The bureaucratic paths that are associated with FMS/CFIDS are part of Heather's journey, yet are obscured from Heather's view. What at first appears to be Heather's personal journey of illness is multi-dimensional. Heather's initial path was to seek out a diagnosis and find treatment for her symptoms. Instead, the layered opinions of the biomedical communities frame women as suspect, retaining their authority to diagnosis in light of their uncertainty of FMS. Singer states (2004) that:

Part of the work of practicing medicine consists of convincing patients that their ideas and understandings in the health arena are subjective and thus suspect, whereas those of biomedicine are scientifically grounded and thus incontestably authoritative. (p. 14)

Heather recounted her experience with both biomedicine and the insurance company as being suspect of her symptoms. Heather spoke of the length of time before she finally received a diagnosis:

They gave me shit and abuse and grief for years . . . yet nobody wanted to admit that I was going to have a long-term permanent injury . . . they wouldn't say you have Fibromyalgia It took years to say it because that meant that [it] permanently disabled me and they didn't want to say it.

Heather's experience with the biomedical community and the insurance agency "went on for five years." Her account shows the pattern that often develops while searching for a diagnosis. It is during the search—through the endless number of physician and specialist's appointments—that the medical gaze gains power over Heather's mind and body. For Heather, another form of surveillance was attached to the medical gaze—the insurance company's attempts in denying her injury claims by following and video taping Heather's everyday life.

The medical experts complicated Heather's illness journey by imposing invasive medical tests, painful rehabilitation programs and over-prescribing medications.

Heather's experience was one of personal and emotional trauma, a time when she was drug dependent that left her feeling "weak and . . . not credible." Heather's journey has not ended; she frequently struggles with pain, fatigue and other symptoms that come and go. However, far from submitting to the biomedical power that controlled her life for so many years, Heather has gained back a sense of self once lost in her feelings of going "insane" to one of control, maintaining her body through measures of her own choosing.

A fitness routine and the rejection of prescription drugs for the pain, fatigue and depression have aided Heather in taking back her life.

Heather's fight to regain control over her health illustrates that biomedical surveillance and control is not the only power at play in Heather's journey. Heather has gained her own power. As Foucault argues, power is not hierarchical but is held by many different groups and individuals. Yet, where there is power there is also resistance to that power (Foucault, 1990). In resistance to biomedical authority, Heather has shown her agency, altering the path she travels. Her path is not an unwanted or forced path but a path of her choosing, thus establishing new goals and new views of self.

Heather's journey is not unlike that of other women I interviewed. Surveillance by insurance and disability agencies and physicians' unnecessary over-medicating were also experiences that Paula, Megan and Sarah recounted. Sarah, age 58, was diagnosed with FMS following a car accident 17 years ago. I asked Sarah if she would consider being declared disabled. Her response is a discussion of her experience with insurance agencies and disability benefits:

You have to be more disabled. Like you have to be able to do anything and I was able to do some things. So, they figured if I could do some things, I could do everything. Working with the systems are the most . . . frustrating part . . . dealing with anything like SGI or the government system of Canada Pension . . . I don't think [they] recognize it as a legitimate illness or disability.

Part of the journey of chronic fatigue and pain as Julie recounts in a subsequent section, is to listen to the body. Often exacerbated by external social, environmental and biomedical factors, the perceived changes occurring internally, are questioned by biomedicine, family and friends. Susan spoke to me about her experience with her family members. Susan was diagnosed with FMS nine years ago. Susan's family appears to be

unsupportive of her symptoms, “No, they don’t understand it and they don’t want me to talk about it They feel I should be getting better and they feel that I should get out in the workforce and do my part.” Although Susan is working to integrate the chronic illness into her life, her efforts are not recognized nor does her family acknowledge her disability.

Megan also related events that are somewhat similar to Heather’s experience. However, Megan’s symptoms are not as manageable and are less severe than Heather’s. Realizing that the symptoms are not going to disappear and are part of a life with chronic illness can be a difficult thing to accept. Paula spoke of this difficulty:

I think I had a bit of denial too . . . as far as, oh well, this will come and go and I can live with it. I was not aware that it would never go away. I wasn’t aware that eventually I would have pain continuously and that I would have to take medication all my life, for the rest of my life . . . that realization was very hard once I recognized that.

For Paula, although diagnosis of FMS is a relief, with that sense of knowing there is also a mixed sense of sadness and realization that life has changed, that self will also change. Sarah found that changes in her everyday life were aided by a diagnosis. Sarah described her diagnosis of FMS as a “relief” and “when I did some research on it. . . . It wasn’t a terminal thing, so that was a relief Now that they have put a name on it I can find some stuff about it and see how to manage it.” It is not easy to embrace the impact of knowing that the life journey will be altered bodily functions that mean alterations to everyday life. Acceptance is part of the integration of illness. Duff (2003) argues that for some, acceptance never does occur. Fennell (2003) believes that without acceptance, the symptoms will be more pronounced and fully integrating FMS/CFIDS into one’s life cannot occur.

Heather, Megan, Paula and Sarah have different life paths but similar journey scripts. Knowing that there is no cure for FMS/CFIDS has been a difficult adjustment for each of them. However, the different locations where they have found themselves on the illness journey make each of their illnesses unique as they adjust and navigate the symptoms, social influences and their personal life choices. As the previous sections have demonstrated, there are difficult and confusing symptoms that make up the syndromes. How the women in this study perceive those symptoms is their truth.

As Birke states, “Living the body means experiencing it as transformable, not only as cultural meanings/readings, but also within itself” (1998, p. 199; original emphasis). For those who experience good health, the internal body is taken for granted. Its integrity and consistency is assumed. For those who experience chronic illness, the biological body is not complacent and demands attention. Julie speaks about her experience of coming to terms with FMS:

I didn't make a deliberate effort to, to change anything You find that your body cannot take it so it's your body that forces you to change, [so] you can accommodate. In a way then, I'm going to listen now, I am going to change this, this, this.

The demands of the body require Julie to “listen” to her body. The shifting processes of illness are invisible, the physiological shifts and changes are not detectable, even by some of the most advanced technologies used in biomedicine and yet, they are known by those with FMS/CFIDS. Moreover, when the shifts and changes occur in well-being and ability, the self is also shifting and transforming.

Part of the transformation process is rejecting the dominant discourses that doubt FMS/CFIDS as diseases/syndromes. This may be difficult if the physician is dismissive about the symptoms the individual experiences. Jackie states that, “I hear the voice of

authority saying, yeah, it's still in your head Jackie, and then I go no, no, it's not." By thinking, "no," Jackie is resisting her internalized physician's view of FMS. There are times when Jackie feels that she does not have "importance and a status . . . [I] don't mean a status financially or a position or that but just the status of being a person." Yet, Jackie mobilizes herself past the negativity in order to resume her daily life.

Daily life means living out the demands of the biological body. The body that is suffering from FMS/CFIDS imposes limits and controls for Jackie and the other participants. The constraints imposed by the disabled body suggest that the biological is both agent and resistor, determining the life of the self. The self is entwined in both the body that is lived in culture and the body that is becoming after the onset of FMS/CFIDS. The internal bodies of women with FMS/CFIDS have changed in ways that do not adhere to the current biomedical criteria of disease. These are bodies that resist the techniques and theories of physicians and scientists. Those with FMS/CFIDS experience a problematic, unruly, and deviant body within a cultural framework that is vigilant in the surveillance of all aspects of life from birth to death.

That the biological body is not thought of as the mediator or as the controlling agent deeply affecting the individual self within a culture dominated by biomedical science is denying the presence of the internal fabric of being and becoming. The self and the body are transforming within culture and in terms of the biological processes that have altered function.

Culturally embodied understandings of biological processes are firmly entrenched in the belief that an adult healthy body does not experience biological change. It is only the body under some state of duress whether disease or harm that biological processes

undergo some form of altered function. Thinking of altered bodily processes as negative changes does not allow extending thought about how and what influences and transforms the body. Viewing the body as transformable means to acknowledge that the body does change and that social and biomedical constructions also change in ways that consistently render the body as transformable.

The transformable body is one that is constructed and understood not merely by the embodiment of culture on the skin but one that is written within the very depths of the internal processes—and is understood in relation to the situated knowledge that constructs meanings of health and sickness, diseases and functions. The transformable body exists within vast relations of influence that change in accordance to political objectives, technology and economics. Yet, in spite of this, the body continues to work out all the details that differentiate between life and death, health and disease, most often changing without apparent visible signs (Birke, 1998).

The internal organs that make up the human body are in constant fluctuation. Yet, biological models depicting the body illustrate the body as removed from daily cultural experience. The organs and tissue that constitute the living body function on their own accord. This is the agency of the body and it is also resistance. When symptoms influence WLWCs to rest or “pull back” from certain situations, the body is indeed acting on its own accord and not in accordance with current biomedical models.

4.7 Conclusion

This chapter has shown that WLWCs experience their symptoms in the context of their social and personal lifeworlds. By including their everyday life experiences while living with the symptoms of FMS/CFIDS lends to a broader understanding of the varying ways that the women I interviewed perceive the effects of the biological processes

underlying the unpredictable symptoms of FMS/CFIDS that alter and change their everyday lives. By incorporating their individual experiences and knowledge, their metaphors and descriptions reflect these experiences.

Although these are subjective accounts of illness, the WLWCs convey the difficulties of the illness journey, through the movements and changes that are occurring within their bodies and the cognitive difficulties that impede interaction and movement, yet they also demonstrate that the women in this study are not without power. Changes in life caused by chronic illness have caused disruption and some powerlessness but each small act to gain personal knowledge about the syndrome in itself illustrates agency. It is only when one does not act that there is true powerlessness. Considering the severity of symptoms that are part of FMS/CFIDS, there are periods when movement of any kind is difficult. To seek out alternative forms of treatment or consult with others who are knowledgeable is agency, even if measured as action on a limited scale.

The women's accounts articulate the frustration and fear that is, in part, due to the disbelief and stigma attached to FMS/CFIDS. Disbelief has affected Heather, Julie and Megan in significant and invasive ways. They have demonstrated through their accounts that the medical gaze is powerful and extending. The medical gaze is not limited to biomedical specialists and physicians but also extends to surveillance by insurance and disability agencies. Becoming ill with a contested syndrome appears to give power to these agencies, invading privacy and challenging personal accounts of pain and fatigue.

Those interviewed also demonstrate that external social and cultural forces do influence the women's participation, degree of isolation and control. Whether their symptoms are perceived or real is not cause for speculation here. The accounts describe

the knowledge of their biological bodies. Changes and external influences challenge them on personal levels that in turn affect how they feel and navigate their lifeworlds.

Most importantly, the women in this study have shown that mind and body are not separate and the connection between them becomes most apparent in times of pain, extreme fatigue, confusion, nausea and the other symptoms of FMS/CFIDS. The biological body cannot be taken for granted or ignored. Maintaining function requires renegotiation that may alter many facets of life for women living with FMS/CFIDS. As these renegotiations occur, the self is transforming in response to the changes in everyday life.

Their everyday lives are part of the journey and the paths on their journey are not always of their own choosing. The experience of living with FMS/CFIDS involves pathways to new goals that are not direct routes but instead negotiated in response to the events that transpire. Moreover, these paths are multi-layered: the construction of FMS/CFIDS by biomedicine and governing agencies such as the CDC who define and categorize syndromes are dimensions of the current health care system—research and care are entangled in different bureaucratic controls that determine the journey women with FMS/CFIDS will be forced to travel.

The women participating in this study incorporated metaphors of journey into their descriptions of FMS/CFIDS to describe how they navigate through the pain, disability, fatigue and medical obstacles that they routinely face. In doing so, some reflect the notion of ‘journey’ that is similar to that found in biomedical discourse, as will be discussed to much greater length in the next chapter. Others, such as Heather, departed from the biomedical text by emphasizing the traumatic aspect of their journey. The notion

that the illness is a form of trauma is decidedly absent from the biomedical discourse of FMS/CFIDS. Indeed, in Chapter Five, the individual experience of living with FMS/CFIDS is overshadowed by biomedical discourse that tends to blame women for the symptoms, often psychologizing FMS and CFIDS as imaginary maladies. I approach the section of journey in Chapter Five with greater emphasis on the movement and change that occurs over the course of the illness. I also compare the women's experiences as discussed in this chapter with the biomedical and scientific texts, to explore the metaphors used in this chapter in order to broaden the analysis of competing descriptions of FMS and CFIDS.

CHAPTER 5

THE LANGUAGE OF SCIENCE AND BIOMEDICINE IN FMS/CFIDS

5.1 Overview

In the previous chapter, I discussed metaphors and descriptions used by the women in this study to explain and interpret their symptoms of FMS/CFIDS. In this chapter, I will explore the use of language to describe the symptoms of FMS/CFIDS from the perspectives of the biomedical and scientific texts. In order to draw these comparisons, the categories of fracture, harm, journey, and environmental elements used in Chapter Four will also structure this chapter.

Although the biomedical and scientific literature use many phrases common to lay literature and the accounts of the women I interviewed in Chapter Four, scientific imagery conceptualizes the biological body outside of the social and cultural fabric where the biological body lives and interacts. In this chapter, I will illustrate how the biomedical and scientific descriptions are taking place within a contained environment. Storms become biological storms and journeys reflect symptom patterns that correspond to biological processes that are moving and changing within the body. These processes are shown as if the biological body is in a state of disorder, where changes are not viewed as progressive but rather as disruptive mechanisms that influence symptoms of illness. The literature frames these processes as imaginary or as psychological dysfunctions. This is often not made explicit; however, the suggestion of FMS/CFIDS as a psychological disorder figures prominently throughout each section of analysis within this chapter.

Also figuring prominently in literature are the ways that the symptoms of pain and fatigue are described in objective terms, but these symptoms are not easily measurable. Like other contested diseases, biomedical and scientific research use violent and invasive descriptors and metaphors. At the same time, patient accounts are often used by physicians and researchers to describe pain severity within the body. Common descriptors do not imply that the patient and physician use common meanings. Because metaphors are specific to knowledge and prior experience, the physician's meaning is based on his or her knowledge of science, whereas the patient uses the metaphor based on knowledge and experience that may not be based on scientific knowledge. Therefore, common metaphors have different meanings that can lead to misinterpretation and consequent communication breakdown between WLWCs and the physician.

Although common metaphors may indeed have different meanings based on personal and specific knowledge, there would appear to be a cross-over of knowledge between the patient and the physician. Common metaphors indicate that there is an element of knowing that is shared. This would question whether the binary between biomedical and scientific knowledge and women's experiential knowledge is complete. Moreover, the physician's use of metaphors to describe pain and fatigue that are borrowed from women's accounts suggest that knowledge is not distinct. Common metaphors indicate that language is not specific to one type of knowledge but shifts between different forms of knowledge.

Metaphors and descriptions of FMS/CFIDS symptoms used in the biomedical and scientific literature are based on hypotheses and theories that are stated as biological facts although there are as yet many unknowns as to the cause or treatment of FMS/CFIDS.

Yet these scientific assumptions become truths when compared to subjective accounts of illness by patients.

Scientific and biomedical accounts of FMS/CFIDS may also reflect the perspectives that exhibit a hierarchical division of labour. These hierarchies reflect the expertise, knowledge and rank of the scientist, biomedical researcher/specialist, physician, psychologist and psychiatrist:

The hierarchies of medicine are complicated and multiple. Some are based upon the nature of intervention: intensive somatic intervention is more highly prized, hence surgeons have more prestige and higher compensation than family doctors or psychiatrists. The treatment of women, children, and older people all carry less prestige in biomedicine as well as usually lower compensation. (Gaines & Davis-Floyd, 2003, p. 3)

In biomedicine, “its fundamental principles, generative rules, and social identities mirror the discriminatory categories of the wider society in terms of gender and sexual identity, and ethnicity, social class, and age” (Gaines & Davis-Floyd, 2003, p. 3). As such, these discriminatory notions affect women’s access to treatment and biomedical education (Gaines & Davis-Floyd, 2003, p. 3). These embedded practices within complicated and multiple hierarchies must make themselves evident, not only in treatment but also in the levels of discriminatory thought in scientific biomedical research and the literature that articulates the findings.

It is critical to remain aware of the underpinnings that are part of scientific knowledge. Regardless of the position within the hierarchy of biomedical science, it is doubtful that researchers, physicians and specialists would view FMS and CFIDS differently. FMS and CFIDS are gendered and categorized in such a way that reflects thought that is based on historical knowledge about women’s health that is perpetuated and remains fixed in categorizing women’s bodies and women’s symptoms. This bias is

reflected in the metaphors that are assumed, in Euro-Canadian culture, to be value-free and disembodied from cultural reality. In this chapter, I will demonstrate otherwise.

5.2 The Journey: Destinations and Movement

Developing a chronic illness such as FMS or CFIDS alters life in varying ways. These changes do not take place immediately but can be thought of as points along a journey. Not only are there new experiences but these may connect with the past and aid in seeing and accepting changes. Journey metaphors are about change, the movement from one place to another, detours and, ultimately, a final destination. FMS/CFIDS is about change, relocating the self in new experiences and reshaping life and reaching a final destination where the symptoms may become part of everyday life. In Chapter Four, journey was shown to be a structured event that suggested movement and change. According to Brown (2003), journeys are “undertaken by people” (p. 14), have a starting point and a destination point, follow a specific route facilitated by some means of travel, can be difficult at times and one might lose one’s “way and go in a direction that will not lead . . . to . . . [the] destination” (p. 14). Brown elaborates on journey metaphors, stating that the concept of a journey is “not a single idea but a collection of related ideas, forming a structure” (p. 14).

The biomedical and scientific FMS/CFIDS literature also makes use of related ideas to form the structure of a journey, depicting FMS/CFIDS symptoms as shifting and unpredictable, coming and going and/or migrating to different areas of the body.

Carruthers et al. (2003) state that, “patients may feel sudden waves of depression, which just come and go erratically, and are not tied to any definite external context” (p. 27).

Carruthers, an internist and researcher, is the principal author and co-editor of *Fibromyalgia Syndrome: Canadian Clinical Working Group Case Definition, Diagnostic*

and Treatment Protocols - a Consensus Document'. According to Berne (2002), “symptoms tend to wax and wane but are often severely debilitating” (2002, p. 16). And, Carruthers et al. (2003) state that, “There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms” (p. 11). These biomedical descriptions portray FMS/CFIDS as processes within the body that are ‘chaotic’ and disordered. The natural rhythm of the ‘healthy’ body is defective and changes occur as unexpected and ‘sudden’ events. Becoming ill with FMS/CFIDS is an unexpected and unplanned journey without a definite destination.

Carruthers et al. (2003) describe the onset of illness as developing “Within days or weeks of the initiating event [where] patients show a progressive decline in health and develop a cascade of symptoms” (p. 9). The “initiating event” is the presumed cause or “trigger” (Carruthers et al., 2003, p. 9) that begins the symptoms of illness. Describing the cause of illness in this way distracts from the fact that the cause is as yet unknown although there is some consensus as to what the “triggering” events may be (Turk & Ellis, 2003; Berne, 2002). The journey begins, followed by a progression of symptoms that “cascade” or fall, burdening the body as the symptoms pour down and altering bodily function.

The idea of FMS/CFIDS as a metaphorical journey is found in Fennell’s (2003) method of viewing the syndromes as having stages. Fennell’s Four Phase model of FMS/CFIDS “maps a process that most individuals do not enter into willingly” (2003, p. 156), thus, “serving as a narrative or cognitive map” as those with FMS/CFIDS move from one stage of illness to another until reaching the completion of their journey. The “cognitive map” is the vehicle that guides WLWCs on their journey toward integrating

chronic illness. However, there are blockages on the journey. “Patients ordinarily proceed through the phases in sequence, but as in other nonhierarchical stage models, they can slip back into a prior phase or recycle, sometimes several times” and “attainment of integration . . . is not a permanent condition” (Fennell, 2003, p. 157). Thus, according to Fennell (MSW, CSW), the journey is one that is ongoing as symptoms move in and out of the “locus of control” (2003, p. 168). As integration occurs and each phase is reached on the journey, the self changes to the demands of these processes.

Accounting for how the self changes in response to symptoms and chronic illness is not commonly found in the biomedical and scientific literature. The journey occurs inside the body; the self and identity are erased as the literature concentrates on the various organs increasing or decreasing in function, developing a dialogue between body organs and processes. The in and out movements of these processes compromise the journey that happens exclusive of the social context of illness. The syndrome becomes an entity taking on characteristics that reflect the scientists’ and researchers’ own embodied knowledge, concepts and experiences of their cultural and professional spaces. Lakoff and Johnson (1980) state that “our experiences with physical objects (especially our own bodies) provide the basis for an extraordinarily wide range of ontological metaphors, that is, ways of viewing events, activities, emotions, ideas, etc., as entities and substances” (p. 25). Although this type of metaphor is widely used, it is difficult to notice these expressions as metaphors when they are so abundant in Euro-Canadian thought and language. Ontological metaphors “are necessary for even attempting to deal rationally with our experiences” (Lakoff & Johnson, 1980, p. 26). Therefore, as part of human thought and rationalizing bodily processes, scientific and biomedical language must also

be abundant with this type of metaphor. The transfer of a certain degree of personification and objectification to the syndrome is therefore used in order to explain how these bodily processes are identified and how they perform within the body.

Altered processes are the result of “agents” of change within the body. According to Brown (2003), “The role of an agent involved in a change is conceptualized in terms of a familiar role played by humans in the social domain” (p. 18). Komaroff’s, Professor of Medicine, Harvard Medical School and one of the principal researchers in the CFIDS outbreak in Incline, Nevada, demonstrates causation as an agent and attaches meaning to this by discussing the body as if in a state of war, a subject I will address. Komaroff’s states that, “Some of us who study the syndrome [FMS/CFIDS] suspect that it can be triggered, in susceptible patients, by chronic infection with any of several agents that are difficult or impossible to eradicate” (2000, p. 170). As this statement suggests, the onset of FMS/CFIDS is hypothesized as an enemy that travels into the body, taking on characteristics that are personified. Komaroff’s reference to “agents” is often implicated in the cause and ongoing symptoms of the syndromes.

Movement, change, and journeys describe the fatigued body. However, for the most part, these examples of metaphor do not address the individual and social aspects of becoming ill and adjusting to FMS/CFIDS. Fennell’s (2003) Four Phase Model does view these aspects as part of readjustment and coping with FMS/CFIDS. This model more closely reflects Chapter Four’s descriptions by the women in this study.

The scientific and biomedical literature hypothesizes the cause of FMS/CFIDS as physical and/or emotional trauma (Jain et al., 2003), depression (Ray, 1991) and immune dysfunction (Carruthers et al., 2003). However, interviews showed that the women’s

“initiating event” was a cause and effect situation where the women knew what had prompted the onset of their illness. The social and cultural influences became part of how the participants both experienced their symptoms and managed their illness. Although the symptoms were changeable, the women did not speak of chaos and disorder within their bodies. The disorder appeared to be caused by the significant impact the symptoms had on their lives in terms of employment, social isolation and the negotiation of living with chronic and often debilitating symptoms.

Their illness journey is also about change and movement; however, these changes occur within their body, which in turn, forces a change in the physical location of their bodies. Fennel’s Four Phase Model is based on the theory that once the symptoms are accepted and they are accommodated, the degree of severity will lessen and there will be some integration of FMS/CFIDS into women’s lives. The unexpected and ever-changing nature of the syndromes as part of the experience for the women in this study suggests that integration may be partial, although full integration is not possible due to the unpredictability of symptoms and the impact on their lives.

5.3 Cracking Up: Metaphors of Fracture

Fatigue disorders without detectable cause have a history of psychological categorization. These histories tend to overlap when new syndromes such as FMS/CFIDS are named and remain unexplainable and untreatable. The scientific and biomedical literature may understate the association of FMS/CFIDS as a psychiatric or psychological illness; however, much of the past and current research tends to imply a psychological basis of FMS/CFIDS.

Some of the FMS/CFIDS literature argues that the syndromes are depressive illnesses (Abbey & Garfinkel, 1991; Manu et al., 1988). Moreover, the syndromes receive considerable attention in biomedical and scientific research attempting to show a correlation of symptoms to those of somatoform disorder, affective disorder and other labels of psychological disorders. Psychologist, Donald Dutton, for example, argues that, “the notion CFS was caused by depression was seductive for medical practitioners CFS is the perfect candidate for a psychosocial basis . . . [and it] is understandable how research on CFS, with depresso-mimetic qualities, was subsumed under the depression/somatization paradigm” (1992, p. 504). This seduction has framed past notions of women’s symptoms as emotionally based and that women are generally more susceptible to psychological illness. In other words, the researchers intend to prove that women are emotionally, and not physically, ill. Emotional illness hints at the historical view of women as hysterical and irrational. There is no physiological basis for the symptoms; therefore, the symptoms are viewed as women’s inability to cope with day-to-day life. Emotional illness differs from psychological illness in that there is an underlying physiological cause such as chemical imbalances in the brain or symptoms as a result of a severe trauma. There is a clear distinction between categorizing FMS and CFIDS as emotional illnesses as opposed to a psychological illness. To date, however, neither emotional illness nor psychological illness are known to be the underlying cause of the syndromes.

The conceptual framework of metaphors that hide behind the jargon of biomedical and scientific language are new metaphors that describe “mental illness,” a term now considered a dead metaphor because it has been so entrenched into everyday

language (Kirmayer, 1992). Somatoform, depressive, affective and psychological disorders are terms used extensively throughout past and present FMS/CFIDS research and reflect language that perpetuates past notions of unexplained illnesses such as neurasthenia and hysteria (Dutton, 1992).

Dutton's use of "seductive" is curious wording to describe the motivation for physicians to label women with CFIDS/FMS as having a psychological illness. To be seductive implies power or allure. Most often, the meaning is sexual; the object of the seduction is enticed against his or her will. The objects, in this case, are women with CFIDS; sexualized objects dominated by biomedical labels that reduce women to their biological sex. Women, then, are viewed as reproductive bodies with unpredictable personalities and emotional disorders.

Personality defects that imply psychological disturbance are viewed as causative factors of FMS/CFIDS. According to Abbey and Garfinkel's 1991 conversion model theory:

People with CFS, especially women, feel compelled to achieve in all major life domains, including vocational, family, exercise, volunteer, and social activities . . . [T]his 'do everything' work ethic [that] arises from the new lifestyle options generated by the women's movement; however, these options become subverted into obligations to perform well in every respect. (cited in Friedberg & Jason, 2001, p. 437)

Blaming the victim is present in this passage. Moreover, the FMS/CFIDS 'victims' are by a greater percentage, women. The suggestion appears to be that women are "compelled" or driven persons who are attempting to 'do everything' and are causing their own ill health. The authors identify a nexus of relations in which women strive to achieve perfection in all domains. Embedded in this nexus of relations are idealized notions of heterosexual, middle-class femininity. Moreover, the fact that the authors attribute these

desires to the women's movement, particularly liberal feminist goals, is also a comment on the state of gender relations. That is, the women's male partners are not contributing equally to the household, family and community relations. In this way, they are able to blame the victim.

Changing women's roles should not be a prominent event in searching for the cause of FMS/CFIDS. Yet, Abbey and Garfinkel state that, "Such impossibly high standards of accomplishment" that "propel women into a disabling conversion-like illness that unconsciously allows them to escape from overwhelming responsibilities and consequently receive the family and social support they have been lacking" (Friedberg & Jason, 2001, p. 437). Women "escape" their newly defined goals without realizing they want to return to the expected "performance" of women as wives, mothers and caretakers.

Much is hidden in the meaning of this interpretation. The metaphors may depict something much more about the researchers' personal viewpoints than about 'value-free' scientific research. Furthermore, the power of the biomedical communities to enforce and regulate women's bodies and women's health is also suggested in Abbey and Garfinkel's research. The scrutiny of women's health and behaviours is part of the history of biomedicine. Out of the need to control populations, women's health became a primary concern for physicians. Reproduction and birth have been surpassed by more invasive measures to monitor women's health. The gender-bias within the biomedical communities has influenced the fascination for blaming women's health problems on behaviour to the extent that little research has been done in areas of women's health other

than reproduction. Therefore, statements that reflect this sex-bias are not surprising however unwarranted they may be.

Sadly, though, Friedberg and Jason state that “many physicians have abdicated their role in helping these patients because of the difficulties involved in diagnosis, treatment, and ongoing care” (2001, p. 434). “Abdicate” means to “relinquish a position without further interest in resuming the function” but most commonly implies “a giving up of sovereign power” (Merriam Webster Dictionary, 1993). Abdicating suggests that the role of the physician is of the highest authority: stepping down from their medical obligation to cure the sick may imply a refusal to accept FMS/CFIDS as valid physical illnesses. On the other hand, it may suggest that when the guidelines make diagnosis and treatment of WLWCs difficult, doctors would prefer not to see the women as patients. When doctors cannot provide care and maintain control over WLWCs health, they do not have power over the women’s bodies; therefore, in some respects, power is defeated.

Metaphors of fracture differ in the biomedical and scientific literature from those used by the women’s descriptions discussed in Chapter Four. The state of feeling “cracked” or coming apart was shown to be a complete breakdown of both the physiological and the emotional functions of the body. Recalling Julie’s description, “I don’t know what is going on but I’m falling apart” where Julie conveys that she feels like her body is literally coming apart, is significantly different than the FMS/CFIDS research that implies some form of psychological disorder, for example, somatoform and affective disorders that do not correspond with the description of the symptoms offered by WLWCs.

In Chapter Four, it was explained that the women may have felt that they were imagining symptoms, perhaps overdoing things to the point of being unwell; however, in contrast to biomedical explanations, none of the women interviewed suggested that “impossibly high standards” and compulsive needs to achieve were the cause of their illness or the reason for their ongoing symptoms. Rather, there appeared to be a greater sadness due to lack of their former ability, the need to get on with life and the anger and frustration in learning to reconstruct their lives because of symptoms.

The powerful emotions in the women’s descriptions help differentiate between the personal meanings of a contested category of diseases and the scientific and biomedical research that too commonly assumes a psychological basis for the illness. I believe the statement made by Komaroff negating a psychological association warrants attention.

Komaroff states that findings are:

[I]nconsistent with the hypothesis that chronic fatigue involves symptoms that are only imagined or amplified because of underlying distress—symptoms that have no biological basis. It is time to put that hypothesis to rest and pursue clues . . . in a quest to find answers for patients suffering from this syndrome. (2000, p. 171)

Komaroff’s statement is affirmation for many women who live with FMS/CFIDS.

Perhaps research will find answers to the enigma that has spawned considerable research, ending the stigma and distress that conflicting biomedical opinions have created.

There is an excessive amount of FMS/CFIDS research that relies on inferences based on gendered notions of women’s behaviour with illness such as that stated by Abbey and Garfinkel with less emphasis on recent research that negates a psychological basis for the symptoms of FMS/CFIDS such as Komaroff’s. Unfortunately, until this

debate is decided by scientific evidence of a pathology, the stigma associated with FMS/CFIDS as an imagined illness or affective disorder will be ongoing.

4.2 Environmental Metaphors

In Chapter Four, I used this category to demonstrate the varying ways that WLWCs used environmental metaphors to describe their symptoms. There are overlaps between personal accounts of symptoms and those described in the scientific and biomedical literature. Environmental metaphors are part of embodied understandings that are shared by both scientific and non-scientific communities, yet the meanings attached to these metaphors differ between scientific and non-scientific communities as Brown has observed:

Although scientists ordinarily have essentially the same emergent physical experiences, they may have significantly different social developments and therefore may have different understandings of social values, forces, and interactions. These differences doubtless lead to differing conceptualizations of events in the physical world based on metaphors drawn from the social domain. (Brown, 2003, p.24)

Differences of understanding are evident in the environmental metaphors used by Hyde and Jain (1992) to describe cognitive dysfunctions as “symptom storms” (p. 43):

There comes a period in the disease process when these symptom storms settle down and the patient becomes acquainted with his [sic] internal environment and, when that occurs, the primary lack of concentration ability becomes obvious. (Hyde & Jain, 1992, p. 43)

Hyde and Jain, researchers associated with The Nightingale Research Foundation, refer to the internal body as the “internal environment” that has processes affected by “storms.” It is common to speak of the environment that surrounds us; however, taking common metaphors and applying these to bodily processes demonstrates that science may view the body as having its own environment. It is a contained system where “storms” occur and then “settle” much as an electrical storm with lightning, wind and

rain. At the height of the storm there is “noise in the head,” “hissing,” and “crackling sounds” (Hyde & Jain, 1992, p. 43) much like the static that charges the air during lightning storms. In environmental terms, violent weather disturbances are termed as storm systems, the parallel to “symptom storms.”

Hyde and Jain (1992) also refer to the storms of pain associated with FMS/CFIDS. They describe this kind of storm as, “The multiple ‘hit and run’ pain storms that frequently torment the M.E./CFS patients” (1992, p. 46). A storm is a disturbance in the environment that is sometimes violent. It can define weather such as snow, rain or hail but it can also define rushed movement or a disturbed or agitated state (Merriam Webster Dictionary, 1992). Applying this meaning to the metaphor of “pain storm” and recalling that the body is an environment of its own, then, within the body, there is a “tormentor” or illness (Kovecses, 1990) that causes the pain. When adding “hit and run” to the type of “pain storm,” Hyde and Jain are referring to sudden and violent disturbances, much like being hit by something elusive, perhaps unseen and unknown, yet causing considerable upset or damage and then fleeing, not to be found. The “tormentor” is a villain as pain is the villain to WLWCs.

The “hit and run pain storms” is an environmental metaphor but also overlaps with metaphors of invasion and bodily damage. Imagining the body as a closed environment that is subject to all forms of disturbances suggests a common knowledge of the external environment where the body dwells. The elusive cause of the storm of pain is much like weather storms. The force of a storm defies any human intervention: it is unpredictable and unstoppable. Describing the pain that WLWCs experience is the

internal weather storm: the scientists do not know how to control the variables that produce this symptom.

Communication between WLWCs and the biomedical and scientific communities suggests there is a possibility of conflicting interpretations when describing their symptoms to physicians and researchers. The concept of ‘storm,’ as WLWCs imagine it, may be fundamentally different than that used in the scientific and biomedical literature. This type of language fracture illustrates how common metaphors can have multiple meanings, specific to location, time and space. Misinterpretation of this nature can create a barrier between the physician and patient. The outcome of misinterpretation may mean misdiagnosis or dismissal of the symptoms WLWCs are experiencing, or in some cases, stigmatizing the symptoms that may increase self-doubt and greater isolation.

This type of misinterpretation is evident when comparing descriptions of “brain-fog” as were examined in Chapter Four. The biomedical and scientific literature uses “brain-fog” and similar terms to describe the subjective symptom of FMS/CFIDS. Jain et al. (2003), for example, uses the term “cognitive ‘fog’” (p. 13) within the category of “Neurocognitive Dysfunction” (p.12 – 13), a dysfunction that “is of or relating to the neural processes and structures involved in cognition” (OED Online, June 2003), or Fan’s (2004) description for this symptom, “cognitive disturbances.” Fan states that “Cognitive disturbances such as short-term memory loss are common in many patients and are often referred to in the lay literature as ‘fibro-fog’” (2003, p. 221). Berne (2002) describes ‘brain fog’ as “difficulty with concentration and memory, impaired calculation ability and word usage” (p.17). Friedberg and Jason assert that “memory and concentration

difficulties as well as mental confusion in CFS/FM are sometimes so profound that they may disable an individual from working” (2001, p. 439).

The objective manner in which “brain-fog” is discussed in the biomedical and scientific literature does not convey the disruptive and often frightening effects this symptom renders in the lives of WLWCs. Jenny’s description of brain fog in Chapter Four shows that metaphors are powerful language tools that enables others to comprehend the way that “brain-fog” disrupts and disables. Jenny’s use of ‘brain fog’ reflects an embodied experience incorporating physical and emotional elements of the disease. In contrast, scientific and biomedical literature constructs brain-fog or fibro-fog as concepts of physical health being in a state of highs and lows. One-word descriptors such as “dysfunction,” “disabled,” and “impaired” express the bodily health as being impeded and as a low. Jason and Friedberg’s use of “profound” expresses the depth or importance of the symptom for WLWCs. The biomedical and scientific literature reflects an objective rather than subjective account of illness and differentiates between experiencing versus observing a symptom.

5.5 Harm: Metaphors of Invasion

Pain and fatigue are categorized as the two primary symptoms of FMS/CFIDS. Including both in the category of invasion is logical due to the interconnected nature of the symptoms, which is based on the premise that pain fatigues the body whereas fatigue increases the risk of experiencing more painful symptoms (Berne, 2002; Clauw, 1995). Therefore, both symptoms become invasive and are depicted within the biomedical and scientific literature in common metaphors, most notably, war and invasion.

Within the literature of FMS/CFIDS, metaphors of war proliferate, partly because both syndromes have been hypothesized as immune dysfunctions and, in part, due to the history of war and the weapons of war that have been integral in shaping biomedical discourse (Birke, 2000; Martin, 1994). As was discussed in Chapter Four, women with FMS/CFIDS describe “battling” with fatigue and pain that is “stabbing,” or “shooting.” In the biomedical and scientific literature, there is reference to “shooting,” “stabbing,” and “triggers” that produce pain and fatigue. These descriptions are linked to other military metaphors. I will turn now to consider the metaphors of pain.

5.5.1 Pain

Scarry (1985) indicates that the most common way to describe pain is to envision an object that causes pain. In this way, others can more readily understand the experience of pain. Duff, (2003) psychologist, describes symptom pain as being like “long thin knives twisting into the neck, groin, or underarms and may be so painful that patients cannot move their arms or legs without crying aloud” (p. 177). Hyde and Jain (1992) describe “spike-like pain” as a “severe pain [that] occurs anywhere on the scalp and sometimes the extremities and is described by the patient as a nail being driven into the body” (p. 59). Hyde and Jain (1992) describe muscle pain:

The patient complains of feeling as though he [sic] had been beaten with an axe handle. He [sic] feels bruised and hurt. . . . The patient will describe a severe pain, usually in the main muscle mass in the leg It is described as a nail or as though a knife or arrow had been stuck into the leg. (p. 63)

Patient accounts enable physicians to conceptualize the magnitude of pain. The passage illustrates how pain can make WLWCs feel as though they have been physically beaten and attacked by an unknown assailant who forcibly drives a nail or knife into the body. The metaphor creates an imagery of a brutal attacker and the patient is powerless to

defend herself. This is a type of metaphor that locates both the patient and the physician in a time and culture where violence is known, either as first-hand knowledge or from accounts and depictions of violence in the media. The description of pain can become a shared experience, one which the physician can more readily relate to and understand the full scope of the patient's pain.

The embodiment of cultural and personal experiences shapes language and the terminology used to define processes within the body. That science has invested heavily in the terminology of war is simply the embodiment of those specific scientific and everyday life models that are within the scientist's realm. According to Jackson (2002):

Pain is the Sasquatch of science, never witnessed, only endlessly speculated on. We can't agree on the species. Man [sic] or beast? A sensation or an idea? It doesn't help that *ideas* about the meanings of pain are double-barrelled abstractions that soon drift away from experience itself into an epistemological fog. (p. 11; original emphasis)

Jackson is comparing pain to a "huge, hairy, man-like monster supposedly inhabiting the north-west of the U.S. and Canada" (OED Online, 1989). Whether sasquatches are myth or truth has not been determined; however, they have rarely been seen and I would assume a very frightening experience if one does glimpse one. Pain, too, is rarely seen and may also be a frightening time for the individual if it occurs suddenly or is prolonged, as is the case with chronic pain. More importantly, the questions that surround the sasquatch are much like questions and concepts of pain; that is, is the pain real or is it myth and imagination? The subjective nature of pain is argued and theorized but often the best that can transpire is a fleeting, blurred understanding before the meaning and intensity of pain is lost in an "epistemological fog."

5.5.2 Fatigue

Fatigue associated with FMS/CFIDS is not simply feeling ‘tired’. It is a fatigue that, as Berne states, “defies description and measurement. It is described as debilitation, exhaustion, or feeling drained, washed out, weak and unable to function mentally or physically” (2002, p. 65). But, Bell (cited in Berne, 2002) believes that:

‘Fatigue’ is used incorrectly in this context. Fatigue is defined as a state brought about by activity or exertion that is relieved by rest. In CFS and FMS, fatigue may be present without recent exertion or activity and is unrelieved by rest. (p. 65).

David Bell is a one of the leading experts of CFIDS and was one of the pioneering physicians working in Incline, Nevada during the CFIDS outbreak. The varying and contested views of fatigue as a symptom do not encompass the incapacitation that FMS/CFIDS can cause.

Fatigue is poorly defined because it is associated with many other clinical conditions and with depression. Fatigue is also linked to the degree of pain WLWCs experience as well as cognitive dysfunctions such as “brain-fog” and memory confusion. Shepherd, medical advisor for the ME Association, England and Chaudhuri (2001), biomedical researcher, name fatigue as the “core symptom . . . which usually affects both physical and mental functioning” (p. 6). This symptom might be thought of as being at the very heart of the illness—that innermost experience that makes up FMS/CFIDS. Or can it better be thought of as being at the center of the syndrome’s contested nature in the biomedical communities and the “cultural response to fatiguing illnesses” (Duff, 2003, p. 176)? Certainly, from a patient’s perspective, fatigue is one of the most troubling of the symptoms that prompted Megan to describe the effects of fatigue as feeling “diminished into this little speck.” The impact of fatigue as an invasion into previously held

expectations of self, of the ability to perform at a prior level of function, and the invasiveness of discriminatory responses by physicians and culture are only part of what makes up the “core symptom,” fatigue.

Fatigue is often associated with post-exertional malaise, one of the symptom specifications that is necessary for a diagnosis of FMS or CFIDS (Fukuda et al., 1994). However, according to psychologist, Jason et al., to date “no clear operational definition of this symptom exists” (2003, p. 16). The literature shifts between pain and fatigue when referring to malaise. Duff suggests that:

The term *malaise* is defined as an “indefinite feeling of uneasiness, or lack of health” in medical usage. It does not even hint at the extremity of the experience—the burning muscles, splitting headaches, leaden exhaustion, fevers, and despair that develop within hours of physical activity and last for weeks, if not months. At best, the symptom descriptors of CFS are inadequate to the lived reality; at worst, they minimize and deny the full horror of it and betray a medical bias against unexplained illnesses. (2003, p. 177, original emphasis)

The “burning” and “horror” emphasized by Duff, are hidden by terse medical descriptions of fatigue and many of the other symptoms of FMS/CFIDS. Even in the name itself, CFIDS or Chronic Fatigue Immune Dysfunction Syndrome, may be misleading. There are those that argue that fatigue is not the primary symptom (Berne, 2002; Bell, 1992; Hyde, 2003; Jason et al., 1997), and, therefore, the current framing of the syndrome is not given credence or the respect of the biomedical and scientific communities.

5.6 Embedded Meanings

The descriptions and metaphors that represent bodily processes are grounded in the embodied experiences of the researcher. Though the language of biomedical science may use metaphors and descriptions that can be linked to common experiences within the

social fabric, these phrases are embedded with meanings that reflect scientific training and the medical canons that have developed from the beginnings of biomedical knowledge (Kirmayer, 1992). These descriptions are not literal meanings but are translated into objective knowledge that supersedes the descriptions and metaphors used by women with FMS/CFIDS to articulate their symptoms.

Martin (1998) suggests a new way of thinking about the body—not as biology or individual but as the biological individual. New ways of thinking about the body must extend beyond corporeal inscription. Women living with chronic illness experience bodily changes that are too often discounted in constructionist approaches. Current theories discount the magnitude to which bodily changes affect participation in the social and cultural fabric. Moreover, cultural and social values are not only embodied, they are inscribed in the body and affect the way that the body functions in both health and illness.

Biomedicine acknowledges social and cultural factors but more often refers to them when there is a negative impact on one's health. When symptoms do not fit with the biomedical constructions of illness, social and cultural factors become central to the cause of the syndrome or disease and the response to the symptoms by those who become ill. As a contested disease category, FMS or CFIDS become a problematic diagnosis for women. With no apparent physical cause, the symptoms must be imagined and, therefore, the social and cultural factors as well as self become part of the biomedical discourse that has stigmatized and categorized FMS/CFIDS as a psychological “dysfunction.”

The medical gaze captures a very different image of FMS/CFIDS when it is constructed as a psychological disorder. Although there are known chemical irregularities as well as organ and brain functions that are altered (Berne, 2002), FMS/CFIDS is often

portrayed as emotional weakness which itself is embedded in gendered discourse that links women with nature, women as weaker. Abbey and Garfinkel's description of FMS/CFIDS as a symptom of changing cultural values that blames women for wanting to be productive, capable human beings who wish to achieve in the workforce as well as in the household, genders disease and illness.

Viewing FMS and CFIDS as gendered disease categories not only insults women who are ill, such views within biomedical discourse inform cultural thinking about the syndromes. It is necessary to reject thinking that is embedded in outworn notions of women and women's health behaviours. There is enough difficulty in living with the symptoms of FMS and CFIDS without the unnecessary stigma that is associated with biomedical discourse that blames women and imposes significant barriers to the integration of FMS and CFIDS into everyday life.

Achieving becomes difficult when physical and cognitive symptoms are caused by fatigue and pain. The experience of living with these symptoms demonstrates the incapacitation that FMS/CFIDS renders. However, the scientific and biomedical literature relies too heavily on the psychological effects of the symptoms without acknowledging the ways in which these psychological effects may be physically inscribed in the body. Women who live with fatigue and pain can describe the feelings in ways that reflect the serious nature of these symptoms. They indicate there are fear and feelings of violation to the body. Emotions of this kind are not part of the technical language of science and biomedicine or it would not adhere to the objectifiable, value-free agenda that it claims.

5.7 Conclusion

The language of science and biomedicine is often clinical and emotionless. Descriptions and discussion of symptoms are most commonly based on theory and hypotheses; however, the literature implies these to be truths about FMS/CFIDS. In effect, hypotheses and theories are scientific, tentative, assumptions based on known facts, therefore, partial truths as yet proved or disproved. Women living with FMS/CFIDS also use descriptions of symptoms, believing these descriptions to be their truths and the facts of the illness. In the hierarchy of knowledge, abstracted scientific knowledge abundant in metaphors and descriptions takes precedence over the metaphors and descriptions of the lived experience of FMS/CFIDS.

In the final chapter, I will address the theoretical foundations discussed within the review of literature and apply these in the concluding analysis of metaphors and descriptions by both the women interviewed and in the biomedical and scientific literature.

CHAPTER 6

HIDDEN MEANINGS: DESCRIPTIONS AND METAPHORS OF FMS/CFIDS

6.1 Overview

Throughout this research, I explore the use of language to describe the symptoms of FMS/CFIDS. My objective is to show that descriptive language and metaphors convey powerful truths. These truths are intended to illuminate the impact of social and cultural factors on perceived symptoms experienced by the women living with FMS/CFIDS who participated in this study. A second objective is to show the divergence and convergence that presently exists between the WLWCs' descriptions and metaphors and those used in the biomedical/scientific literature.

The descriptions and metaphors used by the WLWCs are intended to reflect the impact of the social and cultural factors that influence the biological bodily processes and the extent to which those influence how WLWCs feel and socially react in their lifeworlds. As previously stated, I cannot measure the degree of biological change experienced by the women who participated in this study; however, I feel that their perceived changes are representative of their bodily knowing.

In Chapter Four, I looked at the descriptions and metaphors used by the women in this study to illuminate their experience of chronic and often debilitating effects of CFIDS, FMS or both syndromes. In Chapter Five, I explored the biomedical and scientific literature to develop an analysis of metaphors and descriptions of FMS/CFIDS and drew comparisons with the women's descriptions in Chapter Four. I found that the participants' use of descriptions and metaphors not only helped develop a sense of being

able to share the effects of their symptoms, but also imparted a glimpse into their personal worlds. Thus, a broader understanding emerged to describe their journeys with chronic illness.

My interpretations of the metaphors used by the women are structured on my own personal knowledge and experience; thus, they may not reflect the meanings that were conveyed by the participants. However, metaphor is open to interpretation as is any part of language and is dependent on cultural and personal experiences. I have structured my analysis in a way that I believe, captures the messages the participants imparted during their interviews.

6.2 Rethinking the Chronically Ill Body

The embodiment of culture is conveyed through language that speaks of personal experiences. This is most evident in the descriptions that the women who participated in this study use to describe pain and fatigue that is associated with FMS/CFIDS. Their metaphors capture the pain as an invasion or attacker, illuminating pain so that it is a shared experience. Although Scarry (1985) suggests that others cannot experience pain when it is being described to them, the vividness of their metaphors allowed me to share their meaning of pain. The participants' metaphors are subjective, incorporating their personal knowledge and emotions that are absent in the metaphors found in the biomedical and scientific literature.

The fatigue that the participants describe is also a very different symptom than the biomedical and scientific texts describe. The type of fatigue the participants speak of is associated with pain and cognitive impairment or "brain fog." Although the biomedical texts did reference the symptom as fog, it is difficult to know whether the use of the term was at first a biomedical metaphor or described as "brain fog" by the participants as part

of their own experience. The scientific and biomedical texts do not associate fog with pain and fatigue. Moreover, the symptoms are described as separate events; the magnitude of the combination of these symptoms is not addressed in the metaphors of biological processes

The participants speak about the fatigue, pain and cognitive impairment as symptoms that were invasive, frightening and often disabling. They perceive their symptoms as internal processes that create boundaries, restricting their participation in work, social and personal activities. Their metaphors describe biological processes as agents of control to which they must respond in order to integrate FMS/CFIDS into their daily lives. The response of their perceived biological processes suggests that the internal body has agency. Birke refers to the changing internal body that acts in response to internal and external forces as the “transformable” body (1998). In theorizing the body as transformable, Birke’s perspective moves beyond Butler’s (1993; 1999) notion of the inscribed body where the inscription of culture does not permeate the skin but is written on the surface of the body.

Surface inscriptions do not take into account the chronically ill body or disabled body. The WLWCs have demonstrated that the body is always changing, internally and externally, although with FMS/CFIDS the external body often shows no signs of change. Yet, the participants perceived processes taking place within their bodies that required the women to withdraw from social and employment settings and placed more strain on their symptoms, notably the symptoms of fatigue and cognitive dysfunction. Those who participated in this study illustrated how biological processes are explained and interpreted through cultural events and elements that are always and forever changing,

suggesting that the participants perceived biological functions as also changing and unpredictable. Embodied knowledge is more than a surface inscription. The biological body is interpreted through metaphor that illustrates an understanding of the culture and the environment in which the body lives. This is also evident in the biomedical metaphors that describe the body as chaotic and fluctuating, referencing the body to common occurrences of weather or metaphors of militarism where the attacker is the agent of change and the body is fighting off the attacker's intrusion. Biomedical metaphors that explain the body have become embodied knowledge, so much so that they are barely noticed as metaphors but as scientific language.

I argue that the self changes in response to processes occurring within the body. As Foucault (1990) would suggest, the self must change in relation to any and every event in the women's lives. The self is not static: change is inevitable. The women spoke of before and after illness. Following Lakoff and Johnson (1980), Kovecses (2000) and Brown (2003) who state that the journey is a progression of events shown in phrases such as "before" and "going through" that indicate the self is on this journey as well. It is not only the biological body; it is the woman in the biological body as Martin argues, that perceives and alters life according to changes caused by the symptoms of CFIDS. The extent to which cultural and social factors are implicated in changes within the biological body is based upon the women's responses to their perceived changes.

The women's descriptions and their uses of metaphor to share their experiences of pain and fatigue allow for an understanding of the significance of these symptoms. They have demonstrated that fatigue is not about being tired but a symptom that includes both physical strength and a cognitive ability. The participants described pain, relating the

symptom to violent events and described with metaphors that include imagery of weapons puncturing the body. The biomedical/scientific literature also makes use of violent events that are enacted on the body but borrows heavily from patient accounts in order to describe pain. Violence and war metaphors are more often used in the biomedical accounts of symptoms. War and violence typify descriptions of science and biomedicine as masculinized professions with a prior history of the biological body and disease as a gendered construction.

The knowledge the women have of their bodies and their bodily processes is a constructed knowledge, based on the social and cultural context in which they live. However, the social construction of fatigue-related illnesses as imagined or psychological by biomedicine or as the outcome of perfectionist ideals has created stigma that affects each of the women on a very personal level. Concepts of self are influenced by the embodiment of a culture that has imposed these derogatory labels. These labels do not simply happen but are a reiteration of the way in which biomedical and scientific literature describes the symptoms and the causes of the syndromes.

There is significant power in scientific and biomedical language that naturalizes metaphors that appear as common elements and events within Euro-Canadian culture. Appearing as simplistic language, the theories and descriptions of disease/syndrome symptoms underlie an agenda to classify FMS/CFIDS as psychological dysfunctions similar to other fatigue-related illnesses that have a long history in the medical construction of disease.

Comparing the subjective accounts of illness to the descriptive and metaphorical passages in the biomedical literature leaves room to contemplate what the word

subjective serves in relation to FMS/CFIDS. Although the biomedical/scientific literature carries considerable weight, much of the literature relies on assumptions, hypotheses and imagination to theorize the cause of the syndromes and to describe the biological processes that are part of the makeup of symptoms. Without metaphor, it would be difficult for the scientific and biomedical researchers to write articles about FMS/CFIDS, yet the metaphors they used have had life-altering affects on the women who participated in this study.

The metaphors and descriptions offered by the women in this study indicate a situated knowledge (Haraway, 1999) and a truth that they know of their bodies and their biology. As Foucault (1990) would argue, there is no one truth but many truths dependent upon time, place and space. The biomedical and scientific literature offers another truth, one that is thought to be rational and objective. However, the biomedical/scientific theories and hypotheses present truth as superior to the situated knowledges of WLWCs, based on embedded social and cultural values as well as the expectations that medicine can cure and correct sickness and injury. Biomedical knowledge is a privileged truth in Euro-Canadian culture and as such, the metaphors and descriptions often go unnoticed.

6.3 Unravelling the Mystery: Metaphors, Biology and Culture

The purpose of this research is to show that the biological body interacts within the social and cultural fabric, responding to social and cultural factors and acting back into the cultural fabric as part of these internal responses. The women who participated in this research have demonstrated that symptoms of FMS and CFIDS are not simply biological nor are they cultural. The women I interviewed demonstrated the use of aspects of their culture to describe the biological processes of pain, fatigue and cognitive dysfunction. Johnson (1987) argues that in order to make meaning of processes occurring

within the body, these processes must first be brought into the mind. Because we understand biological processes by metaphorically linking them to social and cultural experience, biology cannot be separated from culture nor can culture be separated from the body. Cultural and social inscriptions are not as Butler (1993) argues, written on the skin. Culture and social factors become part of the experience of FMS and CFIDS, an embodied knowledge. Biology then is not strictly internal processes; biology also conceptualizes thinking about the social and cultural space.

Social and cultural factors are also significant in the language used in the biomedical and scientific texts. Although biology has been subsumed by the sciences and biomedicine, metaphor constructs scientific thought by first conceptualizing the internal body processes as metaphors linked to the personal knowledge of researchers, scientists and physicians. Biomedical and scientific language convey different interpretations of the body in order to maintain control of bodies and appear as value-free disciplines.

The language that is used to capture the nature of FMS and CFIDS is multiple and complex. Symptoms are not easily illuminated through language. Pain and fatigue have no measure and can only be understood by drawing on other concepts to convey the magnitude of suffering these symptoms inflict. This is also true of cognitive dysfunction. Metaphor articulates and produces meanings that others can share.

The women who participated in this study have shared their journey of illness with me and allowed me to bring attention to their experiences. I have learned through their journeys and have grown in my awareness of the personal and powerful nature of language. Sharing their experiences has enriched my understanding and knowledge of FMS and CFIDS.

My exploration of FMS and CFIDS began with the intent of educating myself about FMS and CFIDS and with the hope of finding answers to questions about the syndromes that were not forthcoming from physicians and specialists I met along my journey. I have learned the answers to some of those questions but there are far too many questions still unanswered. Often, the scientific and biomedical texts simply generated more questions.

As discouraging as my exploration of FMS and CFIDS felt at times, the rewards are numerous and I do not regret having undertaken the challenge. In meeting that challenge, I have discovered important new ways of viewing my own journey that resonates in the words used by the women who participated in this research.

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Appendix A

Interview Schedule

When did you receive a diagnosis for Fibromyalgia/Chronic Fatigue Syndrome?

How long had you been ill before that?

And what kinds of things were happening to you?

Did you go to many physicians before receiving a diagnosis?

How did the diagnosis make you feel?

How has the illness affected your association with family and friends?

Were you on or still presently on medication?

Describe to me any alternative therapies you have tried.

Do you exercise?

Do you feel you have had a personality change as a result of your illness?

Was there every any question that it was an imaginary illness?

Did you see a psychiatrist?

Did you ever apply for full disability insurance?

Would you ever apply for disability insurance?

How many medications have you been on?

What other things have you done to change your lifestyle?

Were you working when you became ill?

Are you working now?

What changes did you have to make as far as employment to accommodate your symptoms?

What symptoms do you experience on a regular basis?

How have your symptoms changed since first becoming ill?

Are the symptoms better or worse due to the changes you have made in your life?

Have you ever gone to a support group for FMS/CFIDS?

Could you tell me about your experience with a support group?

There has been a lot of media coverage on both FMS and CFS. Have you read any information on the illness?

Have you ever experienced any visual problems?

Do you think it is a progressive illness? Why or why not?

Were you born prematurely?

When you first became ill, did you feel isolated?

Tell me how that made you feel?

Do you arrange schedules and appointments in order to work around feeling unwell?

How do friends respond to your illness?

Is it accepted at your workplace or do you remain silent about having the illness?

Can you tell me about the strange symptoms you experience?

Does anyone else in your family have FMS/CFS?

What advice have you received about managing the symptoms?

Do you experience any allergy problems?

If yes, did you have them prior to becoming ill or have they become a problem since you were diagnosed?

Do you smoke marijuana?

Were you afraid?

What is your sexual orientation?

Are you out to your physician?

What do you feel about your future?

What level of education do you have?

Which of the symptoms would you consider to be the most difficult?

How do changes in the seasons/weather affect you?

Do you experience any numbness?

Have you ever experienced a panic/anxiety episode?

How would you say your short-term memory is? Has it been affected by the illness?

Have you found a lot of information on the illness and if so where have you looked for information?

Can you describe what the fatigue feels like?

How do you think this has/did affect your relationship?

Did anyone ever discuss the effects of trauma/surgery with you?

Do you think you have a different tolerance to medications?

Do you think the illness will cause death?

Does it bother you to be alone and living with this illness?

Did you ever have a miscarriage?

What advice would you have for someone who has been recently diagnosed with FMS/CFS?

Please describe the cognitive impairment you experience/brain fog?

Have you experienced any problems with language, forgetting words, twisting words around, sort of like being dyslexic?

Do you ever experience any nausea?

Do you have anything to add that I may have missed?

Can you tell me about any other health problems you may have?

Tell me how this has affected you financially?

APPENDIX B

Table 1 – Cognitive Symptoms in FMS and CFIDS (By Percentage)

Cognitive	FMS	CFIDS
Cognitive problems (general)	40-90	80-100*
Confusion, inability to think clearly	75-100	--
Short-term memory deficit	70-85	80-90
Losing train of thought (mid-sentence)	75-85	80-90
Aphasia (e.g. word-finding difficulty)	70-75	79-95
Comprehension deficit	45-65	80-90*
Attention deficit	40-90	75-85
Frequently saying the wrong word	30-60	50-70
Long-term memory deficit	25-45	50-60*
Difficulty speaking	15	60-75*
Calculation difficulty	45-55	75-80*
Difficulty following written instructions	25-40	70-75*
Difficulty following oral instructions	35-60	80-90*
Concentration deficit	70-85	70-100*

Percentages in all tables marked with an (*) indicate a major difference in symptom prevalence.

Spaces indicate information was unavailable

(Berne, 2002, pp. 53-56)

¹

¹¹ The percentages used in the Tables have been collected from a compilation of research in three surveys: Kansas City, Missouri and two in Phoenix, Arizona, as well as information reported by Drs. D. Bell, P. Cheney, H. Fukenburg, D. Goldenberg, J. Goldstein, C. Jessop, A. Kamaroff, B. Massau, R. Olin and D. Peterson. (Berne, 2002)

APPENDIX C

Table 2 – Neurological and Ocular Symptoms of FMS and CFIDS (By Percentage)

Neurological	FMS	CFIDS
Spatial Disorientation, dizziness, vertigo	25-90	40-90*
Light-headedness, “spaciness”	70-85	70-100
Photosensitivity	65-90	--
Muscle twitching, involuntary movements	15-70	55-80*
Low blood pressure	20-30	60-85*
Difficulty swallowing	55-60	--
Heart palpitations	30-70	40-60
Staggering gait	40-50	60-85
Coordination problems, clumsiness	60	60-85
Ocular (Eyes and Vision)		
Changes in visual activity	45-70	70-80*
Eye pain	55-75	30-60
Visual disturbances	45-55	--
Blind spots in vision	5-15	20-25

APPENDIX D

Table 3 – Pain and Fatigue Symptoms of FMS and CFIDS (By Percentage)

Pain and Associated Symptoms	FMS	CFIDS
Muscle pain	100	65-95
Meet tender point criteria	100	55-70*
Headache	60-90	46-95
Morning stiffness	60-100	--
Joint pain	80	70-80
Muscle weakness	20-80	45-95
Migraines	15-50	--
Eye Pain	30-60	--
Fatigue		
Fatigue	65-100	95-100
Post-exertional malaise	80-90	Up to 100
Activity level less than 50% of pre-illness level	70	100*

APPENDIX E

Table 4 – Other symptoms of FMS and CFIDS (By Percentage)

	FMS	CFIDS
Infectious or Flu-like Illness		
Flu-like onset	--	50
Recurrent flu-like illness	45	70-85*
Fevers, chills, sweats or feeling hot often	20-70	60-95*
Recurrent illness and infection	15-50	70-85*
Painful or swollen lymph nodes	20-50	50-80*
Hoarseness	20	50
Cough	10-20	40-50*
Sore throat	40-50	60-80*
Gastrointestinal		
Irritable bowel	30-75	50-90
Sleep Disorders		
Sleep disorders (general)	70-95	65-100
Psychological and Psychiatric		
Irritability	60-90	70-90
Depression	15-85	65-90*
Anxiety	5-75	55-90*
Panic attacks	20-30	45-75*

Appendix F

Table 5 – Demographic Profile

Pseud.	Age	Diagnosis	Duration of Illness	Believed Cause	Employed	Disabled
Julia	52	FMS	17 Years	Sudden Change in Physical Activity	Yes	No
Megan	45	FMS/CFIDS	FMS - 10 Years CFIDS 2 Years	Physical Assault Flu-like Illness	No	Yes Disability Insurance
Sasha	41	FMS	10 Years	Trauma	Yes	No
Susan	44	FMS	9 Years	Unknown	No	No
Sarah	58	FMS	17 Years	Car Accident	Yes	No
Paula	55	FMS	32 - 33 Years	Car Accidents	Yes	No
Connie	64	FMS	9 Years	Unknown	Retired	No
Jenny	47	FMS	25 Years	Unknown	Yes	No
Jackie	44	FMS	5 Years	Sexual Assault	Student	No
Heather	40	FMS	15 Years	Car Accident	Yes	No

Appendix G

Consent Form

My name is Joanne Bowditch. I am a researcher on a project entitled *Framing Chronic Illness: Fatigue Syndromes, Metaphor and Meaning*.

This project is part of my Master's Program in the Department of Women's and Gender Studies at the University of Saskatchewan.

I am the principle researcher of this project and can be contacted at (306) 221-7747 should you have any questions or concerns. If you have concerns that I have not adequately addressed, you may contact my supervisor, Dr. Pamela Downe, at 966-4327 or the Department of Research Service at (306) 966-8576 (fax (306) 966-8597).

Thank you for your willingness to participate in this research project. Your participation is greatly appreciated. Before we begin with the interview, I would like to assure you that, as a participant, you have several specific rights. Please read and sign the following:

- Your participation in this project is entirely voluntary.
- You are free to refuse to answer a question at any time.
- You are free to withdraw from the project at any time and all data will be returned or destroyed.
- This interview will be kept strictly confidential and will be available only to the supervising professors and the interviewer.
- The tapes and transcripts of all interviews conducted for this research will be stored by Professor Pamela Downe (the supervising faculty member) at the University of Saskatchewan for the requisite period of 5 years. After this period of time, all documents will be destroyed.
- Excerpts of this interview may be made part of the final research report, but under no circumstances will your name or any other identifying characteristics be included in this report.

I would be grateful if you would sign this form to show that I have read you the contents and that you have received a copy for your own records.

(signed)

(printed)

(date)

Would you like a report on the results of this research project? YES NO
(circle one)

Do you agree to having our interview taped? YES NO (circle one)
If yes, please sign here: _____

APPENDIX H

Transcript Release Form

I, _____ have read the transcripts from my interview for the project, *Framing Chronic Illness: Fatigue Syndromes, Metaphor and Meaning*. I acknowledge that the transcripts accurately convey what I have stated in the interview with Joanne Bowditch. I hereby release the transcripts to be used by Joanne Bowditch in the manner described in the consent form. I have received a copy of this transcript release form for my own records.

Participant

Date

Joanne Bowditch, Researcher

Date