An Institutional Ethnography of Living with and Managing Multiple Sclerosis

by

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B.A., Simon Fraser University, 2009

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

MASTER OF ARTS

in the Department of Sociology

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University of Victoria

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Abstract

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Using an institutional ethnographic approach, this research explores the everyday experiences of women living with Multiple Sclerosis and the work they do to understand and manage their illness. Starting with the women's own accounts of their everyday experiences with MS, this research analyzes and explicates the social relations that are involved in their everyday taken-for-granted lifework. An exploration of the ruling institutions coordinating with the everyday work of these women provides insight to some of the struggles and problems people with MS encounter. This project explicates and problematizes the disjuncture between the actual lived experience of having MS and the biomedical institution's authority over the illness.
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Acknowledgments

I would like to take this opportunity to thank the many people that made this thesis possible.

First I would like to extend my greatest appreciations and thanks to the women who volunteered their time to talk with me and share their experiences. This work could not have gone on without them and I admire the strength and honesty of every one of them. Thank you.

The MS Society chapters in Victoria, B.C. and in Duncan, B.C. were a valuable part of this research and I am very grateful for their help and support. Many of the women I interviewed had, at one time or another, been involved with the MS Society, either through their informative brochures, their services or their fundraising activities.

I would also like to acknowledge and thank my supervisory committee, Dr. William Carroll and Dr. Dorothy Smith for the time they spent reading, re-reading and providing feedback in order to make this thesis a success. Thank you, Bill, for your ongoing support, encouragement and guidance, you are truly inspiring. Thank you, Dorothy, for taking the time to make the wise and insightful contributions you did to this thesis and to my personal journey that ensued.

I would also like to thank Dr. Marilyn Gates for always supporting me, encouraging me and guiding me through my academic career. Your friendship and mentorship has made this work possible. Thank you.

Finally I would like to thank my incredible family and my friends. Thank you, Mom and Dad, for supporting me in every way throughout this academic and personal journey. I could not have done it without you, I’m certain. I would also like to thank the incredibly beautiful and supportive women I met throughout my graduate career; you are an amazing bunch and you continue to encourage and inspire me.
Prologue

I have decided that, before you read the bulk of this thesis it is important to include a brief reflective piece centering on how this research came to be and the emotional struggles I faced throughout the research process.

I am a woman living with Multiple Sclerosis.

The above statement is difficult for me to write and to read. At the beginning of my Master’s program I was going down a very different research path; I was going to research welfare workers in the downtown eastside of Vancouver, BC. When I wrote a course paper for Dr. Dorothy Smith on the topic of MS and Institutional Ethnography, she encouraged me to take on the topic for my thesis. I struggled with that decision. At that time in my life I did everything I could to ignore and hide the fact that I have MS and I knew that by taking on this research I would have to face my own illness and admit, publicly, that I, Sheri Watkins, have MS.

I was diagnosed with Relapsing Remitting Multiple Sclerosis in 2006 when I was 26 years old and working full-time at the Scotia Bank in Calgary, Alberta. At the time of my diagnosis I experienced vision loss (optic neuritis), numbness on the left side of my body, fatigue so bad I was bed-ridden, muscle spasms, tingling and spasticity and my left hand became useless (useless hand syndrome, as was termed by my neurologist) which meant it was virtually paralyzed with zero strength and zero feeling. This relapse lasted approximately three months and once diagnosed, I was prescribed a high dose corticosteroid treatment which meant taking a large amount of oral Prednisone. Over the following three weeks all of my symptoms gradually disappeared and I, to my
overwhelming relief, was in remission. Since my diagnosis I have had approximately eight relapses of varying severity but never as bad as the first one. In 2007, after trying various natural approaches to healing, I decided to start Copaxone (a ‘disease modifying therapy’ or DMT) and have had one (usually somewhat minor) relapse a year since then. I have also gone on intravenous prednisone to treat my relapses three separate times over the last five years.

The research I have done for this thesis has been life changing. I have learned an indispensible amount about the illness, about how to understand the illness and about how people, including myself, live with the illness. I have learned how to talk about my own MS and I have overcome so many fears that I thought were impossible to overcome (like revealing that I have MS while presenting my research at an International conference in San Francisco and at an intimate colloquium with close colleagues who did not know I have MS).

While I have made these personal strides and while I am the sole researcher on this project, I want to make it clear that my experience is just that, mine. Although I have included the above bits of information about myself in order to convey my commitment to the project, I do not wish to imply that my experience is the same as that of any other person with MS and throughout the research I have continually kept in the forefront of my mind that the participants’ experiences are theirs. I have made every effort to ensure my own experience does not interfere with my analysis or dissemination of this research. Although I do include some of my own personal experiences I intentionally made the experiences of the women I interviewed central to this thesis.
Chapter 1 - Introduction

This chapter is dedicated to introducing you, the reader, to the people who were kind enough to offer their time for interviews. I interviewed five women with Relapsing Remitting Multiple Sclerosis ranging in age from 31 to 58 and each with their own unique experience of the illness, which is indicative of the nature of Multiple Sclerosis. Three of these women were contacted through my personal social network, all friends of friends whom I had not previously met; the other two were contacted through the MS Society when a staff member kindly forwarded an invitational email from me to some of their clientele. In order to provide a better understanding of these women’s experiences I will begin by outlining some basic knowledge about the illness itself.

1.1 What is Multiple Sclerosis?

Multiple sclerosis (MS) is difficult to define. In researching MS I have found that most definitions or explanatory literature are comprised of dense and science-specific terminology and predominantly informed by biomedicine. Some literature describes MS simply as an autoimmune disease, others an “immune-mediated” disease or an inflammatory demyelinating condition, among many other descriptions. The best definition I have found that makes sense to me reads, “Multiple sclerosis (MS) is an inflammatory central nervous system disorder resulting in a wide range of neurological symptoms and associated disability” (Boggild and Ramtahal 2007). I like this definition because it’s clear and understandable, it emphasizes the wide range of symptoms that characterize MS and I prefer the word disorder used in this definition rather than disease; the importance of language will be discussed in upcoming chapters.
Although the information surrounding MS is heavily laden with medical jargon and can be somewhat contradictory, this section will outline the basic and generally accepted notions surrounding the defining features of MS and the body.

It is widely believed that when a person has Multiple Sclerosis, their body's immune system attacks myelin, the fatty tissue surrounding and protecting the nerve fibers in the central nervous system, leading to demyelination and producing scar tissue (sclerosis) (Compston and Coles 2002).

Figure 1 - How Multiple Sclerosis Works: Demyelinization

(Freeman 2008).

When the myelin sheath and/or accompanying nerve fibers are damaged, nerve impulses traveling to and from the brain become interrupted, producing the array of different symptoms felt by people with MS. These symptoms can be mild, such as numbness in limbs or dizziness, or they can be severe, such as extreme fatigue, paralysis or vision loss.
People with MS are generally diagnosed between the ages of 25 and 35 but the disease can appear in youngsters, teens and older adults (Compston and Coles 2002). Multiple Sclerosis is two to three times more common in women than in men and there are significantly more cases of MS in countries located in the Northern Hemisphere (Compston and Coles 2002). It is a chronic and generally debilitating disease that continues to puzzle scientists and physicians.

This research concentrates on people with Relapsing Remitting Multiple Sclerosis (RRMS). Eighty percent of people with MS have and are living with, dealing with and negotiating this form of MS (Compston and Coles 2002). Relapsing Remitting Multiple Sclerosis is characterised by relapses and remissions. Relapses, also known as “flare-ups”, “exacerbations” or “attacks”, occur at random intervals during which time new symptoms can appear and old ones can resurface or worsen. Relapses can last for days, weeks or months with recovery being gradual or nearly instant (Compston and Coles 2002). The majority of people diagnosed with MS (typically in their twenties or thirties) are first diagnosed with RRMS and twice as many are women than men (Compston and Coles 2002). Relapses are followed by periods of remission at which time full or partial recovery occurs. Time between attacks is extremely variable but generally can last for months or even years.

People with MS take up a specific type of work in coping with and managing their illness and accompanying difficulties. What is unique about MS, specifically Relapsing/Remitting MS, is that the extent or severity of a person’s symptoms comes and goes. This means that periods of relapse can be both emotionally and physically straining, whereas periods of remittance can be symptom free or symptoms can become markedly
reduced and life often becomes much more functional and pleasant. This also means that the ‘experience’ of having MS varies from person to person and the mostly ‘invisible’ nature of MS has its own unique aspects and issues. Because no two people have the same experience, MS can look very different from person to person; it may not be clear to physicians which type or which course of MS a person is experiencing.

1.2 The Multiple Sclerosis Society of Canada

According to their website “the MS Society provides services to people with multiple sclerosis and their families and funds research to find the cause and cure for this disease. [They] have a membership of 28,000 and are the only national voluntary organization in Canada that supports both MS research and services” (MS Society, About Us 2012). The Canadian MS Society is governed by a national board of thirteen volunteer directors and includes seven regional divisions and approximately one-hundred and twenty chapters which are also governed by elected volunteer boards of directors (MS Society, About Us 2012). The MS Society receives very little government funding and is primarily funded through donation. These donations come from individuals, companies and foundations in communities across Canada; “we raise 96% of our revenue independently through personal and corporate\(^1\) donations” (MS Society, Donate with Confidence 2012).

The MS Society provides “services to people with multiple sclerosis and their families” (MS Society, About US 2012). These services include everything from informational pamphlets to tax services, exercise and counselling classes to mobility-equipment loans. The primary involvement that people living with MS have with the MS

\(^1\) Chapter 5 discusses the questions that arise with corporate donations, especially pharmaceutical corporations.
Society is fundraising, especially the MS Walk which happens once a year in towns and cities across Canada. The MS Society currently divides its funds almost equally between services and research grants. Although “in 2010, over $10.6 million was spent on services for our clients including MS clinics and an additional $10.3 million was spent on research to find the cause of and cure for multiple sclerosis” (MS Society, Donate with Confidence 2012), it has not always been this way (Blackford 1993).

In an article written about the feminization of the MS Society, Karen Blackford provides a brief but telling historical account of the MS Society of Canada (1993). Blackford states that the MS Society, during its earlier stages of development in the 1950’s, held its main purpose as: raising money “for biomedical research into the cause of multiple sclerosis” (1993:124). Blackford argues that the MS Society was, at the time, working within the paradigm of the “male-centred Western notions of rationality, individualism, and normalcy” through the medicalization of the “normal” (male) body (1993:124). At the time, the MS Society’s board members were all members of the medical community and the society’s mission was based on their wishes (Blackford 1993). Raising funds for medical research was the Society’s sole fundraising mission until 1982 when “the Medical Advisory Board enlarged its mandate to include policy issues” but physicians continued to maintain control “by presenting themselves as servants searching for the key which would help unlock the mysteries of MS (Blackford 1993:125 emphasis added).

As an increasing number of women-led MS Society chapters opened up across the country, objections were made to the continual medicalization of MS. These women began making demands that insisted the Society pay more attention to the experience of
living with MS (Blackford 1993). Between the years 1956-58, chapters pushed to “retain most of their funds in their own communities for patient services work” at a time when the board required chapters to submit 75 per cent of all funds raised to the national research programme (Blackford 1993). In the 1960’s and 70’s, as the women’s movement and the disability rights movement materialized, biomedical research directives at the MS Society slowly became overshadowed by the service requirements of people actually living with MS. Finally, in 1976, women with MS “gained an unlikely ally in the Liberal federal government” and the “Ministry to Health insisted that federal research money, if allocated, must be used to seek improvements in the present life condition of persons with MS” (Blackford 1993:126).

In 1979 a woman executive director was hired by the MS Society and a branch of the Society, The Individual and Family Services Division (IFSD), was formed to provide literature on family life to people with MS - a woman at its head (Blackford 1993). These initiatives expanded the MS Society’s focus from a solely biomedical research focus to an emphasis on living positively in the present; a “priority of caring not just curing” (Blackford, 1993:126). In 1979, there was finally “a move to allocate resources equally between the financing of biomedical research and IFSD” (Blackford 1993:126).

The MS Society has made impressive strides to include the voices and concerns of people living with MS. Through my own experience with the MS Society, which is admittedly limited, there is certainly information and services available to those most in need; people with progressive MS. However, people with the less severe forms of MS, notably RRMS, often do not get as involved with the MS Society for reasons I will explore throughout this thesis.
1.3 Introducing the Respondents

This research and the ideas that have surfaced are primarily grounded in the interviews I conducted with the five women mentioned earlier. At this point I will introduce each participant (using pseudonyms to protect their identities). Their experience with their form of Relapsing Remitting MS (RRMS) will be touched on here and throughout this thesis.

1.3.1 Lanette

Lanette is an inspiring, sweet and dynamic forty year old woman who, in 1999 at the age of 29, was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS). Lanette currently holds a professional job, working twenty-eight hours a week. She is married with no children and currently no desire for children. Before Lanette began her DMT (disease modifying therapy) she experienced approximately four attacks. She began her DMT ten months after her diagnosis and has not experienced any noticeable attacks since. Lanette reports that all her symptoms have been sensory (loss of sensation in different areas of her body) but those sensory symptoms occurred before starting the DMT. Since starting the DMT, she has dealt with a couple minor bouts of fatigue but no other (noticeable) symptoms.

The DMT that Lanette is on is called Rebif® (a self-injected interferon beta-la)². According to Lanette, being on the medication involves a subcutaneous self-injection three times a week. She finds the self-injections quite stressful; she was advised to take the medicine before bed to avoid side-effects (sleep through them) but said, “I found, for

² “Rebif is an interferon therapy. Interferons belong to a family of proteins that naturally occur in the body. Rebif contains specifically interferon beta-1a. This type of interferon is identical to the body's natural human interferon beta. The exact way Rebif works is not known” (EMD Serono, Inc. and Pfizer Inc. 2011).
me mentally, it’s too stressful going through the whole day knowing that at the end of the day I still had to do that needle!”. Besides the medication, Lanette manages her health by taking vitamin D, eating mindfully and exercising. She also quit smoking shortly after her diagnosis.

Lanette has a doctor, a general practitioner, with whom she has a good relationship and whom she trusts to be the mediator of her wellness. By that I mean that she trusts that if she needs information or referrals he will act appropriately and help her in whatever ways she might need. For Lanette, her MS is not a central aspect of her life, she says, “it’s just there, in the background.”

1.3.2 Nina

Nina is an articulate, kind and driven thirty-one year old woman who, in 2005 (after experiencing symptoms since 2002) was diagnosed with Relapsing Remitting Multiple Sclerosis. Getting a diagnosis was a frustrating journey for Nina. Nina is currently unemployed after her neurologist, in 2010, advised her to stop working indefinitely. She has gone to great lengths to secure government assistance in order to sustain some sort of income and has encountered numerous problems in trying to establish a reliable and empathetic medical team.

Nina reports that in regard to her MS, “daily, it’s manageable but it’s definitely impacting my quality of life”. Her legs and feet are “usually constantly numb these days…and right now, on my left side, from my hand to my foot I have neuropathic pain, the burning, and it varies in intensity depending on the time of day and what I’m doing; if I’m stressed or tired or whatever”. Nina also has bladder problems and has had bowel
problems, vision loss or blurriness, balance issues, tingling in her legs and occasional coordination problems.

Nina has tried a lot of different DMT’s since her diagnosis. She tried Betaseron\(^3\) (another interferon that is self-injected once every forty-eight hours) but it did not work for her. Next she tried Copaxone\(^4\), which is injected once a day, in combination with Mitoxantrone, a chemotherapy agent. Nina said she “had to go through preparations to do the chemotherapy, which was really intense…because it can make you infertile and so I was 27 looking at the possibility of becoming infertile”. Nina experienced abnormal and painful injection site reactions\(^5\) while on Copaxone and had to stop that DMT as well. At this point, Nina’s last option was a DMT called Tysabri\(^6\). She had been receiving Tysabri injections every four weeks for seven months prior to our meeting but had stopped due to having a cold. Tysabri lowers a person’s immune response so it is important that the injection be given when the person is in good health. Another concern with Tysabri is that a person should only receive injections for two years, after two years a person’s

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\(^3\) “BETASERON is indicated for the treatment of relapsing forms of multiple sclerosis (MS) to reduce the frequency of clinical exacerbations and is shown to delay the progression to clinically definite MS (CDMS) when used from the first event suggestive of MS. BETASERON is a type of protein called interferon. Interferons occur naturally in the body. They are signaling proteins that the cells in your body use to communicate with one another. Interferons are key communicators in the immune system” (Bayer HealthCare Pharmaceuticals 2011)

\(^4\) “COPAXONE\(^\circledR\) (glatiramer acetate injection) is indicated for the reduction of the frequency of relapses in relapsing-remitting multiple sclerosis, including patients who have experienced a first clinical episode and have MRI features consistent with multiple sclerosis.” (Teva Neuroscience, Inc. 2010)

\(^5\) An injection site reaction is a common side effect with COPAXONE\(^\circledR\) (and many subcutaneous injection medications). Injection site reactions happen in the area where you’ve been injecting and can include redness, swelling, itching, pain, or a lump.

\(^6\) Tysabri is “a prescription medicine approved for adult patients with relapsing forms of MS to slow the worsening of disability that is common in patients with MS and decrease the number of flare-ups (relapses)”. Tysabri is “generally recommended for patients that have not been helped enough by, or cannot tolerate, another treatment for MS” (Biogen Idec and Elan Pharmaceuticals, Inc 2008-2009)
chance of developing Progressive Multifocal Leukoencephalopathy (PML or brain infection)\textsuperscript{7} increases significantly.

After feeling like the medications were failing her, Nina decided to research and pursue the controversial Chronic cerebro-spinal venous insufficiency (CCSVI) treatment and the week after our meeting she had plans to fly to California to have the procedure. CCSVI and its supporters posit that an “abnormal venous drainage due to stenosis or malformation of the internal jugular and/or azygous veins may play a major pathogenetic role in MS” (Ghezzi, Comi and Federico 2010). According to Ghezzi et al., this abnormality could result in “increased permeability of blood brain barrier, local iron deposition and secondary multifocal inflammation” (2010)\textsuperscript{8}.

Information on the CCSVI treatment or procedure (often termed ‘liberation treatment’) is somewhat difficult to discern. According to my own neurologist, this is because the procedure is approached somewhat differently from clinic to clinic and from country to country and does not, as of yet, have a standard attached to it. From what I have learned, through discussion with my own doctor, other people with MS and from various other informative sources, I can say with confidence that the procedure involves an angioplasty of veins in the head and/or neck. “During a venous angioplasty, with the help of imaging devices, a long, thin plastic tube, capped by a deflated balloon is inserted in a vein and advanced to where the vein is narrow or blocked. The balloon is then

\textsuperscript{7} Progressive multifocal leukoencephalopathy or PML occurs in immune-compromised individuals and is a rare and usually fatal viral disease in the white matter of the brain; it is commonly known as a “brain infection”.

\textsuperscript{8} This pathogenesis is at odds with the more commonly believed auto-immune aspects of MS. As mentioned on page 4, it is widely believed that when a person has Multiple Sclerosis, their body’s immune system attacks myelin leading to demyelination and producing scar tissue (sclerosis) (Compston and Coles 2002). However, according to the premise of CCSVI, it is abnormal venous drainage which comprises the pathogenesis of Multiple Sclerosis.
inflated to open the vein, deflated and removed. The procedure may also involve stents which are intended to keep the vein open” (Multiple Sclerosis Expert Advisory Group 2011).

Nina has worked hard at building her medical team yet continues to be quite sceptical of the western medical community, including the drug companies and the MS Society and thinks there needs to be more “emphasis on being pro-active and helping people while they’re in their early stages or when they’re healthier”.

Nina: I wish that there was more support for people that are trying to help the system, you know? [Support people who] take care of themselves and eat well and exercise and take vitamins and you know, things that are going to help the healthcare system in the long run, but the mindset doesn’t seem to be on that and it seems to be more on writing prescriptions and making profits and that’s why I’m kinda at the crossroads with re-assessing where I’m at with the players in this health venture”.

This sentiment was echoed throughout the interviews I had with these women. While they all, in some form or another, acknowledge their gratitude towards their healthcare practitioners, government assistance and the occasional help they receive from the MS Society, these women seem to be feeling disheartened at the difficulty to attain the services, funding and support they require. It seems that the faith we have in doctors growing up is challenged in their situations when there is no cure, no real sustainable treatment plan and a real lack of assistance with anything outside pharmaceutical treatments.

1.3.3 Elle

Elle is a good-spirited, lively and hilarious fifty-eight year old woman who was diagnosed with RRMS in 1983 at the age of thirty. Elle stopped working as a nurse in
1986 because of her health concerns. Elle is separated from her husband, as of two years ago, and lives alone (with her little dog) in a small community in BC. She has two grown children, one whom she and her husband raised and the other who was adopted at an early age but with whom she has recently reunited. She had her second son at thirty-seven after being symptom-free for five years.

Elle’s MS has been very up and down. She has had to learn to walk three times; she has lost the use of her hands and legs, prompting her to use a cane, a scooter and a wheelchair at different times throughout her life. Today, Elle walks unaided and uses her wheelchair as an office chair! Through the years MS has very much affected her family life:

Elle: It just went out the window, and I mean, when I was up and down, up and down, I mean I’ve had my eyes go, my hands go, like I said, my legs not working, I used my scooter a lot for when Rick was at home, it just seemed like, so much busier, well, obviously more than this, this is bliss” (referring to living alone).

She now very much enjoys living alone and attributes her healing to this solo living. The stress and lack of empathy displayed by her family, for her, was detrimental to her well-being;

Elle: [I’ve been] separated for a couple, two years now...and it’s amazing what the lack of stress will do. I’ve gotten so strong, I do five pound weights, I do one-hundred of those everyday...same with swimming...I’m definitely concentrating on me, and I never did, you know, when you got family you’re worried about everyone else...and I mean, MS was not considered – not an excuse but – well, they didn’t give me any slack, they were just on my case all the time, actually they were off my case, locked in the basement, so, in my own house they locked me in the basement...[I] lived like that for a year or two, then I finally just
said GET OUT! (Elle laughs).

Elle takes some medications to manage her health but has never been on a DMT. Instead, she manages her MS related and non-related symptoms with three pharmaceutical medications (having taken herself off “all sorts of other ones”). She takes Clonazepam⁹, Zoloft¹⁰ and Lipitor¹¹. She also exercises, eats mindfully and finds that smoking marijuana every evening helps her immensely. She loves beer and indulges herself every once in a while and thus, does not deny herself life’s pleasures. When I asked Elle whether she actively searches for information about MS she replied, “No, the less I know the better... why anticipate something that might never happen? [M]y blood type is B positive and I think I am very positive, as far as – I just don’t give a shit what other people think”. When I asked her how she felt about her medical team she said “I don’t listen to my doctor ... Well, I do, selectively, kinda like doctors and men, same thing, right? Selective hearing – I’ll selectively tell him what I want to. But no, I don’t, he knows everything about me and he’s great. He knows I smoke [marijuana]; that really helps. It really does”.

Elle was a real treat to chat with, her outlook on MS and the western medical community is quite blasé yet informed and realistic. The next woman I will introduce

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⁹ Clonazepam relieves symptoms of anxiety and also acts as a muscle relaxant.
¹⁰ ZOLOFT is a pharmaceutical that is used to treat adults with Major Depressive Disorder (MDD), Obsessive-Compulsive Disorder (OCD), Panic Disorder, Posttraumatic Stress Disorder (PTSD), Premenstrual Dysphoric Disorder (PMDD), and Social Anxiety Disorder (Pfizer Inc 2008-2010)
¹¹ LIPITOR (atorvastatin calcium) is “a prescription medicine that is used along with a low-fat diet. It lowers the LDL (“bad”) cholesterol and triglycerides in your blood. It can raise your HDL (“good”) cholesterol as well. LIPITOR can lower the risk for heart attack, stroke, certain types of heart surgery, and chest pain in patients who have heart disease or risk factors for heart disease such as age, smoking, high blood pressure, low HDL, or family history of early heart disease” (Pfizer Inc. 2006-2011).
stands in stark contrast to this, she is politically motivated, embedded in the health and wellness community and quite objectively-minded regarding MS, western medical approaches and healing. Her name is Patty.

1.3.4 Patty

Patty is an educated, science-minded, thoughtful and passionate forty-nine year old woman who was diagnosed with MS in 1988, when she was 28 years old. Patty currently works as an educator, a wellness coach, an inspirational speaker, manages six suites and just finished writing a book. Along with her work, Patty is also a mother and a wife. In 1988 she had her first serious MS symptoms, optic-neuritis and weakness in her legs and, as a result, was “pretty taken out by it for a while”. Her mother-in-law introduced her to a book called The Yeast Connection, written by William G. Crook in 1983, and Patty learned about Candida (or fungal overgrowth). Over the years Patty has researched the topic extensively and changed her lifestyle accordingly. She has not had another relapse since that initial episode in 1988 and attributes that to the health and wellness regimen she has researched and developed.

Patty manages her MS by keeping the Candida overgrowth in her body down and says “it’s just a chronic natural thing and as you keep that infection (Candida) down, your disease (in her case, MS) symptoms are gone”. She keeps the Candida in her body down through nutrition and a healthy lifestyle and has developed a four pillar approach to wellness which is comprised of (1) optimizing nutrition, (2) minimizing silent infections (e.g. fungal overgrowth or Candida) in the body, (3) minimizing toxins in the body, and (4) building a healthy lifestyle. And that’s it, according to Patty, “you do those four things, I haven’t found anything else that there is, so it’s not a mystery”. For Patty, it is
these four pillars that have enabled her to stay symptom free for twenty-three years and she is passionate about sharing the information and helping others in their own wellness journey; this is her reason for writing her book and for being a wellness coach and inspirational speaker.

Through her research and health management, Patty has become somewhat sceptical of mainstream western medicine, pharmaceutical companies, government health initiatives and the MS Society. She makes it clear that none of these organizations contain “bad people” but are comprised of people following a specific medical (and/or business) model.

Patty: The pharmaceutical industry has such an influence on Western medicine – they’re just good business people, that’s all they are, it’s not that they’re evil, they’re – they have products they have to market, they are training – the doctors are the ones who are selling the drugs, they’re able to put ads on TV in the States so that people can pick what kind of drugs they want – you know, they’ve seen it on TV and they ask their doctor about it – so they’re very, very good marketers and they are one of the most lucrative industries in North America over the last 10-20 years. But like I said, we’re paying a big price for it, we, financially, we cannot afford our healthcare system, it is unsustainable, and if we do not start to make some different changes we are going to hit a brick wall.

Patty has dedicated much of her life to researching and implementing natural wellness strategies and is very well-versed in the area. Jane, the last participant I will introduce, is also well-versed in wellness but relies on pharmaceuticals to improve her quality of life while she struggles with the symptoms of her MS.

1.3.5 Jane
Jane is a thoughtful, intelligent and soft-spoken fifty-four year old woman who was diagnosed with RRMS in 1998 at the age of forty-one. When I commented on that diagnosis being later in life she stresses that she was “under forty when it first started”. Her diagnosis was difficult to reach as she had a number of one-time symptoms that were not solely specific to MS.

Jane lives in a small community in BC with her husband and, temporarily, her son, daughter-in-law and grandson. Her MS has been gradual and her symptoms definitely affect her quality of life. Early on, her symptoms were “a lot of years of just odd things” but the worst, when her children were growing up, was “intermittent bouts of fatigue”. Jane also had Bell’s Palsy, a symptom of MS, which is “when half of your face is paralyzed” which didn’t clear up entirely and “would show up if [she] had more than one glass of wine”. When Jane woke up one morning and one of her arms wouldn’t work, it was “just completely dead” and her other arm she “could use a bit”, she knew she was in the midst of another relapse. At another time her voice was affected; “one of the vocal chords was paralyzed, and that was for a long time. That was terrible”. She went to voice therapy for that but it “didn’t really help”. Jane says she had “optic neuritis and ... I can’t think of all the different things, but they pretty well went away each time with a little bit of residual each time”.

In response to her diagnosis and her symptoms, Jane has been on a number of pharmaceutical medications over the years. She has “had Solu-medrol\textsuperscript{12} quite a few times

\textsuperscript{12} Solu-medrol, also known as Methylprednisolone, is “one of a group of corticosteroids (cortisone-like medications) that are used to relieve inflammation in different parts of the body. Corticosteroids are used in MS for the management of acute exacerbations because they have the capacity to close the damaged blood-brain barrier and reduce inflammation in the central nervous system” (National Multiple Sclerosis Society). Solu-medrol is administered intravenously.
... [and] oral prednisone\textsuperscript{13} to treat her relapses. Jane was also on the DMT Copaxone but during a bad relapse when she experienced full-body neuropathic pain, her doctor “put [her] on Betaseron and a year of the three-day steroids every three months”\textsuperscript{14}. Jane “cut that one short because it wasn’t helping anymore, and it even made [her] feel worse”. Jane was then tested and told her body had “developed antibodies to the drug (Betaseron) so they felt that it probably wasn’t working anymore” so she began taking Tysabri and that was over a year ago.

Besides the DMTs, Jane takes other pharmaceuticals to manage her day-to-day symptoms of fatigue and neuropathic pain. For the pain Jane takes Lyrica and says “I couldn’t live without it – it’s not approved under Pharmacare... [but] only Lyrica helps...I’ve even tried cutting down, you know, so it’s not so expensive...but I always say I would commit a crime [for Lyrica]...and I’m the type that if a store gives me too much change I’ll give it back, you know? ... I would have to have it”.

For Jane’s fatigue she now takes Methylphenidate – “it’s actually Ritalin” – and has to plan her day around it. She takes one at 6:30am, so she can get up in the morning, and then every four hours, five times a day, modifying the routine if she knows she will be needing more energy at a specific time, “like if Louie’s coming over [(grandson)] I’ll gauge it so that I take one of the doses just before he comes so that I have a longer time”. For the pain she also takes Methadone and says “I don’t think a lot of people realize it but it’s effective as like an add-on for neuropathic pain”. Her doctor “had [her] try a lot of

\textsuperscript{13} Oral prednisone (or Deltasone) is also one of a group of corticosteroids (see note 10) but is taken orally in pill form.

\textsuperscript{14} This is called Pulse Steroid treatment which is Intravenous supra-pharmacological doses of corticosteroids used in MS (and many other conditions) because they are cumulatively less toxic than sustained steroid treatment at lower quantitative dosage (Sinha and Bagga 2008).
different things...like Oxycotin and stuff that just makes you feel so weird but this one, it doesn’t make me feel weird and it gives that extra bit of help”.

Jane also takes Baclofen\textsuperscript{15} for leg cramps, which she says is “up and down but right now it’s pretty bad, you can feel it in the background, like, tightening, kinda like something’s in there and then if you move the wrong way or something, it will go into a cramp...like a Charlie-horse”. Jane also manages her MS through “mindful eating” and taking vitamins.

Although Jane relies heavily on pharmaceuticals she is fairly critical of her medical community, especially that lack of patient centred care she has experienced:

Jane: I think they don’t have the time to really listen to your concerns. You go in, even the MS clinic, you can tell them one thing, maybe, or they do your exam, and, well at least mine, I mean he’s a really top doctor, but they just don’t want to be bothered with anything, he doesn’t want to explain anything. He’ll talk on and on about Tysabri or CCSVI or a topic that he’s educated about or well versed in, but nothing about you, like I said about quality of life or things like that. But, what can they do anyway (laughs) but you know... they’re always quick to refer you to another specialist or something like that. But, I guess it boils down to the same thing, if there isn’t something on a test then...

This feeling of being disregarded is fairly common among all the women I spoke with, especially in regards to MS Clinics and the neurologists from whom they are seeking advice and knowledge.

\textsuperscript{15}Baclofen is used for “treating severe muscle spasms due to a variety of causes, including multiple sclerosis or brain or spinal cord injuries. Baclofen is a muscle relaxant and antispastic agent. It reduces the frequency and severity of muscle spasms that occur as a result of neurological disorders such as multiple sclerosis”. (Baclofen 2007-2011).
These women and the lifework they do every day/night to manage their MS is where the research for this thesis begins. Exploring the work they do every day/night to increase their quality of life and manage their illness has provided me with detailed information that enables me to explicate their experiences and explore the ruling relations in which they participate.
Chapter 2 - Institutional Ethnography

Institutional Ethnography (IE), developed by one of Canada’s leading feminist sociologists, Dorothy Smith, is a unique mode of sociological inquiry used to discover the ways in which social, political and economic relations organize and coordinate people's everyday doings. IE provides a particular way of looking at the world by examining the relations of ruling\(^{16}\) that coordinate people's activities. It is a mode of discovery, of learning and of knowledge sharing (Smith 1996, 1999, 2006 and Campbell and Gregor 2008). It is distinctive among modes of inquiry in its commitment to connecting everyday happenings that we may take for granted, as being immanently linked to institutional relations. In other words, IE provides a way to understand how what is happening to one person in one location is coordinated with and organized by the doings of other people in other times and places.

Institutional Ethnography does not begin with “the categories of formal sociological discourse” but instead begins with people's everyday doings in order to explore how their doings are coordinated by other activities and relations (Mykhalovskiy and McCoy 2002). IE expands traditional ethnography to consider institutions and organizations of power beyond those that are locally observable.

Institutional Ethnography is grounded in the everyday experiences of people, therefore, giving people who are involved in the research process a voice, acknowledging that they are the experts of their own activities and that the researcher has something to

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\(^{16}\) Relations of Ruling is defined by Dorothy Smith as a concept that “directs attention to distinctive translocal forms of SOCIAL ORGANIZATION and SOCIAL RELATIONS mediated by TEXTS of all kinds (print, film, television, computer, and so on) that have emerged and become dominant in the last two hundred years. They are objectified forms of consciousness and organization, constituted externally to particular people and places, creating and relying on textually based realities” (Smith 2005:227, emphasis in text)
learn from them. Because of this grounding, IE does not aim at the production of theory nor does it begin in theory. This is deliberate as IE avoids any form of ruling or mastery in order to acknowledge the dynamic and ongoing nature of the social; of people’s actual experiences (Smith 2006, Mykhalovskiy and McCoy 2002). IE is not an investigation making generalized or causal statements about a population; instead, it is an account of ongoing coordinations of actual activities in actual places at a specific time (Smith 1987). It is an investigation to discover the character of the organization and of the relations involved in processes of life experience (Smith 1987). Institutional ethnography not only examines what people do, but how these doings coordinate with others. This encourages a wider view of peoples’ doings, enabling us to understand how people's activities are social and coordinated\textsuperscript{17}.

Institutional Ethnography has roots in the North American women's movement of the 1960's and 70's. After discovering how women's understandings of their own experiences differed significantly from mainstream and academic discussions and ideologies surrounding women, IE was developed to give voice to their actualities (Mykhalovskiy and McCoy 2002). It follows then, that an important aspect of IE is the critique of ruling processes that speak for others (Mykhalovskiy and McCoy 2002).

In a similar way to women in the 1960s and 70s, common ideologies, discussions and discourses surrounding MS are, generally, quite different from people’s actual lived experience with the illness. Institutions, like the MS Society, tend to speak for the illness

\textsuperscript{17} \textbf{Coordinate, coordination} has specific meaning within the Institutional Ethnographic framework. Dorothy Smith helps us understand this term by stating that “rather than treat the \textit{SOCIAL} as existing over and above individuals and determining their behaviour, \textit{INSTITUTIONAL ETHNOGRAPHY} takes the social as a focus on how \textit{ACTUAL} people are coordinating their activities. The focus on coordinating is extended to language so that it is understood as coordinating individual subjectivities, providing us with a way to avoid using concepts that hide the active thought, concepts, ideas, and so on in people’s heads” (Smith 2005:223, emphasis in text).
and to provide the most accessible information available to Canadians with MS and their social networks. This information is very general, homogenized, categorized and universal while the lived experience of having MS, and its many symptoms and variances, is significantly different from person to person. By employing IE and beginning with people's everyday experiences with MS, the lived experience can be explored and explicated beyond the individual’s everyday knowledge of it.

People are experts of their own actualities; by learning from people, from their work and their experiences, I have been able to better understand the institutions that organize the lives of people with MS. IE acknowledges that to study people and societies, research must be rooted in actualities. It must start with actual people and not from abstract theories or abstracted conceptual realities (Smith 2006).

By employing IE throughout my research and analysis I have been able to better understand and explore what it is like to live as a person with MS, the ruling relations that coordinate people’s everyday life experiences with MS as well as the way people with MS have come to understand and manage their illness the way that they do.

2.1 The Generous Notion of Work

Institutional Ethnography has a specific conceptual understanding of work which is important in grounding the way an institutional ethnographer is looking at what they are seeking to understand; important things that may not otherwise be seen can be realized through this lens. Work is understood as accomplishing or doing something, whether it is paid labour or waiting for the bus. Work processes are instrumental in understanding the social relations involved in coordinating and connecting people. Anything we do that invests time, effort and intention can be considered within the
concept of work in order to ground research in people's activities and locales (Smith 2006, Campbell and Gregor 2008). This understanding of work is central to my research. An exploration of the 'lifework' involved in living with MS, and managing the illness, is best achieved through this lens, just as aspects of the lifework of living with AIDS, as proposed by George W. Smith, Erik Mykhalovskiy and Douglas Weatherbee (2006), were discovered using this understanding of work. Understanding activities like researching your illness, discovering how to manage it, thinking about the medications available, assessing proper nutrition, learning about vitamins, and so on, as work, enables connections to be made between individual everyday activities and the activities of other people at different times and places. Relating these activities to the processes of other people and institutions allows the researcher to make connections to the ruling relations involved in this lifework (Smith 1999, 2006).

This understanding allows the researcher to include, within work, subjective individual experience (Smith 1999). Thinking, planning, feeling; these are all important processes of a 'generous notion' of work and of how people organize their lives and activities (Smith, Mykhalovskiy and Weatherbee 2006, Smith 1999, 2006). Thoughts, feelings, actions and places must be understood as real processes, as aspects of work and of work organization that are interdependent: in real life they occur together and so they must be considered holistically when doing this type of research.

Using IE as a mode of inquiry enables the people involved in the research to expand their understanding in regard to their own lifework and to identify dimensions of power throughout this lifework (Smith 2005). Ruling relations are an important aspect of IE and, according to Dorothy Smith, “are a complex and massive coordinating of people's
work” (2005:183) which must be considered throughout one’s research in order to identify the “translocal forms of SOCIAL ORGANIZATION and SOCIAL RELATIONS mediated by TEXTS of all kinds” (2005:227, emphasis in text) that have become so dominant in our contemporary lives. By understanding the ruling relations in our lives and our lifework, it is possible to uncover both opportunities and restraints that arise for people with MS throughout the process of coordinating with other people and institutions (Smith 2005).

2.2 Texts

Institutional Ethnography allows us to explore those text-based ruling relations that exist in our lives in order to organize and construct representations of how people with MS understand and manage their illness (Smith 2005). The term “text” is used in IE to refer to materials that can be reproduced (printed texts, films, electronic texts and so on) at another time or in another space that are present in our lives and which connect our social relations (Smith 2005). Texts can be understood as “the bridge between the everyday/everynight local actualities of our living and the ruling relations” (Smith 1999:7). Texts coordinate people’s doings across time and space. For example, the informational pamphlets and booklets that are made available through the MS Society (on the website and at the varying chapters throughout Canada) inform and coordinate how people with MS understand their illness and how they manage the various aspects of their life with MS. The act of reading this type of information connects the reader to the Society, the work the Society is doing and the ruling relation in which they are embedded. The people who write these pieces of literature are connected to people with MS through the work they do. This kind of text-mediated connectedness is important to
consider, and to map out, in order to understand and uncover the ruling relations involved in people’s lifework.

An additional aspect of texts is that they make people accountable as they become a running record of activities, conditions, instructions and so on (Smith 2005). Texts are also representations designed, often, by governing organizations or institutions; texts often provide an actuality into which people must 'fit' themselves. Once 'fitted', this text can override individual perspectives (Smith 2005). In the case of MS, symptoms are often changing week-to-week, month-to-month or year-to-year, so when I send in forms that are required to 'prove' that I have a permanent disability, that form says that I have lost sight in my right eye and that I have numbness in my left hand which is no longer correct as my symptoms have changed or gone into remission. When asked in 2008 about my 'disability', there was a discrepancy in the text (form), compared to a year earlier. I had to then be reexamined by my doctor and to resubmit this form. I still receive documentation on vision and writing aids to help me cope with my 'permanent disability'. Texts are not lived actualities. Though part of reality, as ruling practices texts ‘stand in’ for the totality of reality. As such, they cannot reflect reality accurately yet they coordinate real lives and activities of people.

To explicate further, disability and illness can be understood as textual enactments worthy of sociological investigation. Let me explain. Text is more than simply words on a page, text conjures up meaning. We, as products of social and cultural relations, interpret text, orient ourselves and others around the text and act according to text. If we genuinely contemplate the matter of meaning-making embedded in texts, we can begin to refuse the power in “current ways of organizing and treating social differences and social identities,
such as disability” (Titchkosky 2007:23). Competent comprehensive reading “is a practice which helps accomplish this refusal, since reading competence is achieved through a dis-attention to the activity of reading and a focus on that which is read or, more precisely, that-which-is-read-about” (Titchkosky 2007:23).

The taken-for-granted idea surrounding texts is that they simply talk about the world; this is not the case. Texts are always “oriented social action, producing meaning” (Titchkosky 2007:21). Texts are social products, actions taken, and insofar as they appear, are our world (Titchkosky 2007, emphasis added). For example, for the word ‘disability’ to make sense to a reader, the term gestures at a whole world that allows for the idea of disability to be understood as it is. Thus, “texts act on us and help constitute our social contexts” (Titchkosky 2007:21). As a reader, an author, an interpreter of text, we participate in meaning-making and thus, in reference to disability text, we enact difference.

Texts organize our contemporary lives. In treating text as a context of inquiry, meaning can be uncovered and enactment can be better understood. Through text, bodies and disability become matters of medicine. Textual context constructs social relations; Titchkosky explains:

The condition of the text’s emergence is empowered by, and simultaneously empowers, the genre, or language game, of medicine. The sensibility of the text reflects that which has conditioned its existence just as much as the text activates a form of medical language and seduces the reader into a taken for granted relation to this language use. In the context of the text resides the ongoing activity of not only making up the meaning of people and issues, but also construction the appropriate relations between these people and those issues. I am speaking here of the issue of ‘governmentality’ or, as Foucault puts it, the
conduct of conduct, which governs our governing of ourselves…Operating at the confusing intersection between science and technology on the path of everyday life, medical discourse seems to offer all who attend to its directions a clear organized relation to embodiment. The text can thus be made to disclose how it serves as one way women are made into problems, just as disability’s iconic status as abnormal lack is made to exist as if beyond question (2008:83).

Throughout this thesis I will be analyzing the context of various texts and taken for granted language in order to uncover and explicate hidden meanings and enactments in the hopes of discovering some of the ways texts coordinate the lifework of people with MS. The guiding problematic of this thesis will become explicated and realized through the analysis of textual enactment.

2.3 Ruling Relations and Discourse

The concept of “ruling relations” refers to the complex of relations that are textually mediated and provide a social connectedness across time and space (Smith 2005). Ruling relations organize our everyday lives – “the corporations, government bureaucracies, academic and professional discourses, mass media, and the complex of relations that interconnect them” (Smith 2005:10). The concept of ruling relations must be understood as “a new and distinctive mode of organizing society” and not as a mode of domination (Smith 2005:13). The “ruling relations are forms of consciousness and organization that are objectified in the sense that they are constituted externally to particular people and places” (Smith 2005:13). So women with MS and their everyday activities surrounding life and illness management exist locally but those activities are influenced by, and connected to, external organizations and the forms of consciousness
embedded within those organizations.

Multiple voices and interests are at work within the ruling relations but generally the terrain of the ruling relations does not include, nor is it open to, the influence of the exploited, marginalized, or subordinated (Smith1999). I argue here, that the biomedical institution is at play within the larger ruling relations that operate this way. One of the frustrations that was expressed to me by the participants of this research was that doctors and nurses were not open to hearing the concerns of the patient (unless the concerns were medically symptomatic) and if they were, they were quick to administer a test or prescribe a pharmaceutical solution rather than attend to and understand the concern in any other way.

Jane: The fatigue and the pain play off one another so um, and a lot of things too, unless it shows up in the exam or on a test, a specific test, to them it’s not valid. So, there’s not even any empathy or – that’s the thing, if there’s no validity on something then you kind of feel like, even if you had a little empathy or somebody discussed it with you, it wouldn’t seem so bad. It would feel like somebody noticed, a little bit – you don’t want sympathy or anything, you just want somebody to say “hey, yeah that’s, yeah, we hear about that and that’s caused by blah, blah, blah” and sometimes, personally, if I get an explanation of where in the brain it originated and a little bit of information then that’s good enough – it’s not like I want to mull over it, it’s just, you know, I don’t know, but an example: about a year, I had this peeing problem that some people have, they keep peeing a bit, but mine was the opposite, especially if I went out somewhere, I couldn’t pee, and even here at home, and so I went for the test where they blow up your bladder – first they test for how much is already in there, then they fill it up to capacity. It’s a really horrible test. And they put a catheter, I think, or no, they put some wires and then you have to sit on this thing in front of them and pee and nothing would come out. Like, for ages - or never did.
So they were getting annoyed, I guess their next appointment was probably there or something, and so that test, the specialist, the neurologist, he couldn’t even assess it because they had to test how much came out – test how much they put in and how much comes out and so, it didn’t follow the thing. And so that’s sort of a - sometimes test results isn’t what they want to see, or sometimes, I think, tests don’t show the true picture. Sometimes you think something’s, or you know something is a certain thing and it doesn’t show it.

The frustration Jane is discussing displays the problematic gap, or disjuncture, between the patient experience (the one who is ruled) and the doctor’s actions (biomedical institution operating within the ruling relations). This disjuncture evidences how extensive the biomedical institution is, how far it reaches into the organization of people’s lives and their actual lived experience. It shows how limited the voice of the patient is and how the biomedical institution, operating within the ruling relations, does not allow the experience of the patient to be heard; it does not give credence to the experience or expertise that Jane has concerning her own body.

Discourse is an important aspect of ruling relations. Discourse, in the Foucauldian sense, locates “systems of knowledge and knowledge making independent of particular individuals”; therefore, what is spoken or written is framed within and regulated by the discourse within which it is framed (Smith 2005:17). This is important in explicating systems of information and how the MS informational literature, which is framed within the biomedical science discourse, is coordinating the ways people with MS understand and manage their illness and their life with their illness. Understanding the ruling relations, and the discourse in which information is framed, enables this research to explicate the frustrations women with MS are feeling in regards to so many unanswered
questions surrounding their MS and the homogenized and universalized information available. During my interviews with these women with RRMS, discourses (such as the biomedical discourse) were acknowledged as governing discourses that informed the ways in which the interviewees experienced the healthcare services and information they received.

Patty: I think that we have to understand that our medical doctors are trained in the medical paradigm – it’s not the best paradigm, it’s not the only paradigm but it is the paradigm that controls all our healthcare funds and I really believe that we are really out of balance. There are times when pharmaceuticals are important, they’re very, very important, but I think we are so out of balance and I don’t think that we can expect our doctors to understand this because they haven’t been trained at all in this, they haven’t been trained in nutrition, they don’t – all that they know how to do is take symptoms, give it a name, and prescribe a drug for it – or prescribe like a treatment as far as surgeries.

Patty, through her extensive research and years of assessing the institution of biomedicine, is able to understand and articulate the social organization that doctors and people with MS are participating in. Not all people living with MS have reached this conclusion. More typically, people living with MS experience an ongoing series of frustrations as their lifework is shaped and constrained by ruling relations that are often insensitive to, or outside of, their concrete needs and interests. This research aims at explicating those social relations and coordinating aspects that exist for people living with MS.

**2.4 The Research Problematic**

The problematic helps the institutional ethnographer identify her own stance in
relation to the inquiry (in contrast to claiming to be methodologically removed from it). It requires the researcher to “notice and name the relations in the research setting into which she is stepping” (Campbell and Gregor 2008:46). It locates “the discursive organization of a field of investigation that is larger than a specific question or problem” (Smith 2005:38). In thinking through my own experiences of having Relapsing Remitting Multiple Sclerosis (RRMS) I have been able to draw out some troubling aspects of my work of managing my MS and this has contributed to the formation and articulation of the research problematic (Campbell and Gregor 2008).

As Campbell and Gregor explain (2008), the problematic in IE is not a problem that needs to be specifically addressed and understood with an informant’s accounts, nor is it a formal research question. The concept of the problematic enables the researcher to differentiate between the complexes of relations beyond actual everyday doings and the present and organizing actualities that are often not visible to them in the present (Smith 2005).

A focus on the actual work done by women with RRMS in regard to managing their illness reveals aspects of actual, real-life experiences, thoughts, actions, feelings, and so on that seem to be missed, or not captured, throughout the institutional processes that describe this work. The personal anonymity that I have striven to maintain in regard to my MS and managing my MS, are aspects that are not present, in my experiential opinion, in institutional discourses and processes. This, to me, is a troubling aspect of MS lifework that I wish to explicate and thus is the overarching problematic for this research. As my research progressed the research problematic also developed. I began to think about why I found it so difficult to discuss my MS and through that self-exploration and
explication I discovered that there was no one to talk to about it. No one whom I knew or had access to understood or could relate to my experiences. Even though I had done many hours of research on MS, I did not understand it; this made it even more difficult to discuss (or easier to avoid discussing). The information I read about MS did not relate to my experience of it. The research problematic became a question of the information and services available to people with RRMS. Why can I not identify with what the mainstream literature is telling me? Why are there no services for me? The information and services provided by the MS Society and the MS clinics (nurses and neurologists) are limited and RRMS patients are grouped into the homogenized umbrella category of Multiple Sclerosis sufferers. This presents roadblocks regarding information and services for people with RRMS because services like exercise programs and family counseling are designed and implemented with progressive types of MS in mind. So, for example, if an RRMS patient participates in an exercise program at the MS Society in Victoria, they can expect modified exercise programs like the “Chair Exercise Class” (South Vancouver Island Chapter MS Society 2011). The following excerpt is directly from the South Vancouver Island Chapter MS Society website:

What is the Chair Exercise Class?

It is a class that consists of exercises and stretches that are all done while in a sitting position.

** It’s great for people in wheelchairs and scooters!

** It includes stretches, exercises, self-massage, and guided relaxation.

** The benefits include increased flexibility and strength, enhanced balance &

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18 By services I am referring to services focused on the social, emotional and physical aspects of living with MS.
coordination, increased mental alertness, and more relaxed muscles.

** Some assistance will be available if needed.

(South Vancouver Island Chapter MS Society 2011)

As you might imagine, a person with minor symptoms (or no current symptoms as is common with RRMS – especially the newly diagnosed) may not relate to this kind of exercise class. Not only would a person not relate; she may, as I do, feel uncomfortable attending a class like this, which confronts someone with RRMS with the kind of progression the illness *could* take, leading to feelings of anxiety, fear, and so on.

Throughout this research I have had this problematic in mind and I have striven to explicate this gap by talking with women about the way they manage their MS.

The overarching problematic surrounding the need to keep MS hidden became increasingly explicable as my analysis developed. Throughout the journey of this thesis (the reading, writing, interviewing, etc.) my analysis moved from everyday actualities, to a deeper understanding of the social connectedness surrounding life with MS. As this thesis progressed, my own keen intention of keeping MS hidden became easier to explicate as I learned to read and understand illness differently.
Chapter 3 - A Standpoint Outside of the Ruling Relations

3.1 Introduction

This chapter begins with a discussion surrounding standpoint theory (as it applies to institutional ethnography) and sets the stage for more analysis by exploring the standpoint of biomedicine and the MS patient. Standpoint is an important aspect to include in this thesis for at least two reasons. It is important to understand the standpoint of those who participated in the study, but it is equally important to understand and explore how that standpoint differs from, but coordinates with, the standpoint of the specific ruling relations involved in healthcare and illness management.

From the data I have collected I can say with confidence that the women with Relapsing Remitting Multiple Sclerosis (RRMS) that I interviewed genuinely understood or actively tried to understand the standpoint of their medical team and pharmaceutical producers. I can also say with confidence that these women did not feel that their medical team, their pharmaceutical provider nor the administrative staff involved genuinely understood or tried to understand their standpoint, and that created frustration and angst. Including these standpoints is important in understanding this research and in helping explicate the social relations and coordinations involved in living with MS.

3.2 Standpoint Theory and Institutional Ethnography

Standpoint Theory is a controversial method of analysis and has been presented by different authors in different ways; it has been presented as a methodology, a philosophy, an epistemology and a political strategy, and is generally framed within

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19 The standpoint of the women who participated in this study is explored here as the standpoint of ‘the patient’ but in being ‘a patient’, their standpoint remains coordinated with the ruling standpoint through avenues of language, illness management activities and so on.
feminist social theory (Harding 2007). Standpoint, according to Harding (1988), is a way of doing new discursive work that examines the social position of the subject of knowledge, the knower and the creator of knowledge (Smith 2005). For Harding, standpoint invites a feminist perspective to understand nature and social life that is not possible from the perspective of men’s distinctive activity and experience (1986). In institutional ethnography, and in this research, standpoint means something a bit different from Harding’s account.

Standpoint, in institutional ethnography, creates a point of entry into explicating the social while holding onto the knowing subject as expert of her everyday activities (Smith 2005). Standpoint, Dorothy Smith (2005) explains, “does not identify a position or a category of position, gender, class, or race within the society, but it does establish as a subject position for institutional ethnography as a method of inquiry, a site for the knower that is open to anyone” (Smith 2005:10). In this interpretation, standpoint informs a method of inquiry that enables the researcher to work from an understanding of people’s everyday lives and to move towards the explication of the social as it extends beyond the everyday (Smith 2005). In this research I have worked from the experencial aspects of managing illness progression in the lives of women with RRMS in order to discover and explicate the organization beyond the local of the everyday (Smith 2005). It is, therefore, imperative to understand the standpoint of these women in order to explore their experiences and reach beyond their everyday activities and into the ruling relations that coordinate aspects of their lives.

3.3 Insights into the Standpoint of Biomedicine
The institution of biomedicine is enmeshed in our Western histories and
objectively written into our understandings of our bodies and our world. Medical-science
and its inductively produced objective knowledge, supersedes much of our individual
experiential knowledge; a person’s experience with illness is second in authority to what
is written in the medical-science texts. In this section, some important aspects of the
institution of biomedicine will be highlighted and then its authority will be problematized
by explicating some excerpts from my interviews.

Between 1770 and 1870 practitioners began making sense of medical symptoms
and formulating treatment plans (Annandale 1998). At this time, practitioners serviced
predominantly the fee-paying elite. Fostering personal rapport was paramount in securing
business and success depended on the physician “recognizing the patient as an integrated
psychosomatic totality in which physical and emotional disturbances were indivisible”
(Annandale 1998:5). In the early nineteenth century during a period of great social
change associated with industrialization, hospital medicine developed, initially in France.
With its development came a ready mass of patients; this ultimately led to the decline of
person-oriented cosmology as “medical elites were no longer dependent upon their
patronage” (Annandale 1998:6). The unique qualities of the whole person fell by the
wayside while attention grew in the area of studying “organic lesions and malfunctions”
(Annandale 1998:6). By the mid-nineteenth century laboratory medicine was developing
and the patient went from being viewed as a sentient being to being understood as a
“material thing to be analyzed” (Annandale 1998:6). Concurrently, illness became a
physio-chemical process to be explained by natural sciences (Annandale 1998).
For the sake of this research and in the hopes of clarifying what is meant by *biomedicine*, I am borrowing, from Ellen Annandale (1998), an outline of biomedicine which incorporates three main characteristics. First, in adopting a *reductivist* approach, biomedicine “assumes that health and disease are natural phenomena which exist in the individual body, rather than in the interaction of the individual and the social world” (p.6). From this perspective, signs and symptoms are seen as objective and “independent of the symptomatic experience of the patient” (p.6). The second characteristic is the *doctrine of specific aetiology*. This is a corollary of the reductivist approach arising at the end of the nineteenth century and refers to the shift towards disease being produced at will by the “mere artifice of introducing a single specific factor – a virulent micro-organism – into a healthy animal” (p.7). As you might imagine, this doctrine has been subject to criticisms, but nonetheless remains a part of the biomedical model.

The third characteristic of the biomedical model is “the claim to *scientific neutrality*”; “that medicine can be rational, objective and value-free, treating each individual according to their need and irrespective of any sense of their moral worth” (p.7). According to the biomedical model, and critiques of it, being *healthy* means being free of disease, pain or defect. This model of ‘health’ is historically modelled after the healthy *male* body (Annandale 1998). Social factors and individual experience are not considered within the biomedical model; it is this medical science model that predominates and coordinates our healthcare funding, our healthcare services and our understandings of illness.

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20 Yet this ‘claim’ has been developed by social, moral and value-ridden people.
Today there is an enhanced profit-making agenda as well but that aspect of social coordination is beyond the scope of this research\(^{21}\).

Within the institution of biomedicine, people with MS are generally marginalized and present only as an ‘unhealthy’ body. The resources and research that go into MS is generally aimed at preserving and advancing biomedical initiatives and not in recognizing or understanding the thoughts and work processes of the persons living with MS\(^{22}\). This lends itself to maintaining a division between people’s experiential knowledge of living with MS and the objectified and authoritative knowledge of the medical expert (Smith 1999). Experiential knowledge is rarely recognized as knowledge in the realm of medical science discourse; instead, experience is made sense of symptomatically, in terms of scientific knowledge. Before Jane was diagnosed with MS she experienced an array of symptoms (as is common) and consulted with a neurologist:

Jane: When I had the Bell’s palsy, there was also some other symptoms along with that but I saw a neurologist and he, well, he acknowledged the Bell’s palsy, but the other things, he called and asked to see my husband and I in his office and so I thought “oh, oh my God, there’s something really wrong, he wants to see my husband as well”. So we went in there and he spoke to Ivan – didn’t look at me – and said that, said like point blank, that they were all in my head. And that I should have counselling or anti-depressants or something – like, to my husband, not even to me.

\(^{21}\) For further information on this, please refer to the works of Vincent Navarro (2004 and 2008) for his discussions regarding the political variables surrounding health policy and health outcomes. Also, see David Coburn’s (1999 and 2000) influential writings on aspects of capitalism, welfare states and neo-liberalism in regards to their influence on income inequality and health status.

\(^{22}\) See chapter 4 for more discussion.
Jane’s experience is a perfect (and unfortunately quite common) example that shows how physicians (informed by the biomedical discourse) tend to exclude experiential accounts of the person with MS that lie outside of what is written in the authoritative and authorized texts of biomedicine. In other words, biomedically informed activities and initiatives can discredit experiential accounts of the patient and their symptoms.

Nina had a similar experience during her diagnosis:

Nina: There’s a long list, but basically from the time I had tingling in my legs, then from that point it was kind of an interesting journey, with having doctors that were like “oh, it’s all in your head” or “it’s not in your family so it can’t be MS” or “it’s from dancing, that’s why your feet are numb” or to doctors being like, “yeah, this is definitely, probably going to be or if it’s not already MS” so it took, yeah, three years of different tests, I had several relapses during those years.

Nina’s diagnosis and treatment only came when the biomedical tests, administered by certified experts could verify her experiences.

I have come to understand the biomedical sciences as comprising objective methods of thinking and writing texts. Because this objectivity rules the discipline and the discourse, subjectivity (e.g. thoughts, desires, emotions, feelings, beliefs, etc.) falls short. Arguably, this is what is missing in the ruling western healthcare practices. By objectivity I am referring to not only the methodological inclination towards reaching objective knowledge through inductive logic, but more importantly for this research, the assumption that objectivity must always be satisfied by value-neutrality (Harding 1986). This is important in fostering an understanding of the ways the medical-science
community oversees and subtends predominant ruling relations in the lives of people with MS. Science and medicine are powerful aspects of the ruling relations “operating in contemporary society at a level abstracted from the everyday/everynight particularities of our local worlds” (Smith 1999:31). The objective methods used within institutions presents a problematic gap between lived experiential knowledge and objectified ways of understanding it. Two goals of this research are: (1) to identify the social relations involved in day-to-day life with MS and, (2) to explicate the activities a person with MS does as fully social and connected. These goals are achieved by dismissing the objective\subjective duality and instead, beginning with the actual everyday/everynight experience of people with MS.

In a (socially defined) illness as complex as MS, riddled with unanswered questions and unknown attributes, the gap between the objectively guided biomedical model and the actualities of living with MS can lead a person with MS to experience a lack of confidence in doctors and pharmaceuticals.

Patty: I don’t know about you but I grew up thinking doctors were everything and doctors knew everything and doctors would fix me and when I came down with MS and they couldn’t fix me, I was shocked, like I was like “what do you mean you can’t do anything for me?” Right? So, what I’ve come to realize is that it is not the only way or the best way.

Patty, who has learned to manage her MS through her diet and vitamin regimen, does not even visit doctors anymore, she has lost any confidence she had in the institution of biomedicine and has learned to rely on herself and her own research and the illness management techniques that she has discovered work for her. She has tried to talk to doctors about the way she has learned to control her MS but is immediately dismissed.
Patty: When I was in University I went to see the neurologist, I didn’t have any MS symptoms but I just wanted him to write me a letter, just in case – if something ever happened when I was in University I could drop to a lower load and still have student loans – cause otherwise they don’t let you have student loans. And when I talked to him I said, “are you interested in what I’m doing? ‘Cause I haven’t had any symptoms in probably, close to 10 years”. And he was like, wasn’t interested at all, “your MS is just in remission for no reason”. And I said “well no” and I told him some of the stuff I’m doing and he says “your stomach has nothing to do with your nerves” so, I really believe that probably a lot of doctors go into that profession because they do want to help people but at the same time they are trained in a certain methodology.

The experience Patty shared shows the disjuncture between the lived experience of the person living with MS and the biomedical institution that closes the door to any experience outside of the ruling discourse on the illness. This discussion on standpoint is meant to open up the often concealed and taken for granted ruling standpoint of biomedicine. This standpoint coordinates the ways we speak of illness and the language people with MS use to explain and understand their own bodies and their lives with the illness. In the next chapter I will elaborate on the ways people with MS participate in the institution of biomedicine as well as the points of disjuncture that exist and must be negotiated by the people living with MS.
Chapter 4 – The Bifurcated Consciousness of the Patient

4.1 Introduction

This chapter begins with a discussion surrounding the bifurcated consciousness; how people with MS are constantly negotiating between the reality of actual lived experiences and the typified, homogenized and categorized ‘patient’ reality. From there, a discussion of how people with MS participate in the institution of biomedicine through the language and illness management techniques they use will show how the institution of biomedicine is coordinating the work people with MS do everyday/evverynight as well as informing the way people with MS understand their illness. I will provide and explore some examples of MS authoritative literature and then explore and evidence the overarching disjuncture through excerpts from my interviews. The chapter concludes by exploring the lifework involved in creating a personal treatment plan for MS (by people with MS) and highlight how this work process is a negotiation of the disjuncture.

4.2 The Bifurcated Consciousness

Dorothy E. Smith discusses the bifurcated consciousness in terms of locating women’s standpoint (2005). She identifies the disjuncture that she became aware of in her own life when she found herself negotiating between her everyday life as a mother and her participation in the academic world (2005). Smith describes how “two modes of subjectivity and activity coexisted” in her life and the lives of women like her who were at work both in the home and in academia (2005:21). Negotiating between these two realms of her life, Smith says, was a “daily organization and reorganization of subjectivity” but that she did not “cease to be present and active in the everyday world when [she] went to work” (Smith 2005:21).
The bifurcated consciousness exists in the lives of people with MS as we negotiate between everyday life and the life of being a patient. The biomedical schema provides the language, categories and theories from which people with MS shape their own understanding of life with MS. Biomedicine and its methods, theories and homogenizing nature has built up an itemized inventory of symptoms and treatments. However, the social and political aspects of living with illness are dismissed as subjective and moral aspects and thus do not fit into the scientific, objective and inductive nature of biomedicine. There is a disjuncture then, between how people with MS experience life and living with their illness and the concepts and theories that guide biomedicine and, thus, inform the literature and services available to people with MS.

Another difficulty that exists here is the unequal relations between lived experience and biomedical knowledge. In the world as it is constituted by science, science stands in authority over individual lived experience. In other words, biomedicine is the authority over the lived experience of people with MS. Our kind of society is governed by science and it is from science that our everyday doings begin. The life of a person living with illness stands in dependent relation to science and is subordinate to it (Smith 1974). Persons living with MS can become dependent on biomedicine and the workings of biomedicine to provide them with the answers and solutions to their everyday experiential struggles.

Biomedical science, holding objective knowledge as the only valid knowledge, coupled with its stance as the authority over people living with illness, creates a world in which biomedicine has become the conceptual and homogenized worldview that people
living with illness must understand their lifework from (Smith 1974). Therefore, in these terms, people living with illness are alienated from their own experience (Smith, 1974).

A person who has been newly diagnosed with MS is faced with learning biomedicine: how to talk the talk and take the drugs. We learn which categories we are supposed to fit into and which terms to use to express our symptoms and experiences. We learn that our experience is not always valid in terms of the ruling relation of biomedicine and to exchange our experiential knowledge for the categories and topics that are recognizable to our doctors and to their way of thinking. The experiential knowledge of people living with illness is discredited and deemed unreliable within the ruling relations and we must learn to confine our insights within the framework of biomedicine (Smith 1974).

Entering into the realm of biomedicine, a person living with illness is lifted from the immediate local and particular place in which she acts and lives in her body and moves into a place ruled by conceptual order and homogenized categories (Smith 1974). This creates a bifurcation of consciousness for all people participating in the ruling relation by being labelled patient. There exists “two modes of knowing and experiencing and doing, one located in the body and in the space which it occupies and moves into, the other which passes beyond it” (Smith 1974:9). Science is written in and aims at this second mode (Smith 1974).

For a person living with MS, the relation between ourselves as experiencing illness and ourselves as patients of the practitioners of biomedicine is visible to us to the point that the bifurcation of consciousness becomes “a daily chasm which is to be crossed” (Smith 1974:10). On one side of this chasm is the “special conceptual activity”
of homogenized, categorical and objective information we are negotiating as the patient and on the other side is the world of concrete practical activities surrounding the management of symptoms and listening to our bodies; these are aspects of the experience of living with MS that are inescapable.

It is also very clear to people living with MS that we do not occupy the same space as the authoritative figures within biomedicine (e.g. general practitioners, neurologists and MS researchers). We enter and occupy a space within biomedicine as the patient; the ‘problem' body that needs to be ‘fixed'. The frames of reference which order the terms upon which diagnosis and treatment are conducted originate with the authoritative figures and texts (Smith 1974). The subjects of biomedicine are the people living with illness and those people are excluded from the process of determining and defining their own diagnosis. People living with MS, however, do not fully enter into biomedicine as its subject since we must suspend our knowledge of ourselves in order to ‘fit’ into the homogeneity and categories set out for us.

4.3 Participation in the Ruling Relations

The biomedical institution, which is located in the complex of ruling relations, exists in the lives of people with MS and coordinates the ways in which the work is done to manage the illness, as well as the way it is understood and talked about in everyday activities. During data collection for this research, the women with RRMS who participated in the interviews used biomedical language often in order to explain their symptoms, their medications and their understandings of their own experience with MS. Along with the language used, the actions taken by these women to manage their illness are also informed by and thus coordinated with the institution of biomedicine to some
degree (e.g. DMTs and other medications). I will first discuss the language used by the women I interviewed in order to show how using such taken-for-granted terminology is one example of how people with MS participate in ruling relations. The works of Tanya Titchkosky (2007) and Rod Michalko (2009) have been incredibly influential in this part of my analysis. Their work centres on understanding disability differently as they explore and criticize the social and cultural relations involved in the taken-for-granted ruling discourses of disability. After a discussion on language I will show how the lifework of managing MS participates in the ruling relations.

4.3.1 Language inside the Ruling Relations

When I began interviews with the women, the first thing I asked was “can you tell me about your experience with MS”. The responses were repeatedly framed with biomedical language. The language of the institution seeps into the telling of the MS experience, and thus, is embedded in how participants understand their own experiences and their own bodies.

All the responses to this question began with the time of their diagnosis.

Lanette: I was diagnosed about a, well, just over eleven years ago, um, just after I turned 29. I think I had, from the time of diagnosis to the time I started taking medication, I had about 4 attacks, about 10 months later but then I started the medication, uh, since then I don’t think I’ve had any noticeable attacks, um, the only thing I’ve dealt with in the last couple years has been a little bit of fatigue, minor, but that’s about the only thing I’ve had that has been noticeable.

This excerpt deserves some careful analysis. First, the concept of diagnosis is specific to the biomedical standpoint. A medical diagnosis involves measuring a person’s current condition against the normal ‘healthy body’. Once the signs and symptoms are identified
as outside the ‘norm’ and the degree of departure is evaluated and diagnostic tests (usually an MRI or spinal tap for MS diagnosis) are administered to deny or confirm the ‘category’ (ailment) the patient will be placed in. Once the diagnosis is made and the patient has been placed in the category of having MS, the physician is able to provide a treatment plan to fix the ‘problem’. The diagnosis is “medicine’s authoritative ability to name the condition, to claim the condition as some-thing wholly within the purview of medicine, and impart to medicine the power to slip from saying ‘what’ the problem is to describing what the problem means” (Titchkosky 2007:91, emphasis in text).

Lanette begins her description of her MS the same way that her biomedically informed physician began his investigation into her health concerns: with the goal of naming and defining her ailments through an investigation of the objective signs and symptoms occurring in her body. By beginning her explanation of her MS by highlighting the point in which her MS diagnosis became medically official, Lanette’s account evidences how the institution of biomedicine is informing and coordinating how she understands and talks about her illness.

This process of diagnosis, or naming, can be understood as more than naming a problem condition but also depicting a life conditioned by such problems (Titchkosky 2007). MS is made to appear as a problem to be diagnosed and treated but also, as a way of being; illness is rendered as a life that is abnormal and short-changed. Diagnosis represents the abnormal thing found that must be ‘fixed’ but in making illness or disability a problem “we make it appear to and for us as such” (Titchkosky 2007:91; Michalko 2009). This understanding of diagnosis lends itself to understanding the embodiment of illness and, therefore, the ways people with MS understand their lives with illness.
Diagnosis of illness can be understood as a product of “interpretive social processes of the ‘normal body’ and of the ‘abnormal’ one” (Michalko 2009). It is the institution of biomedicine that has emerged “as the self-proclaimed-storyteller of the human body and what has gone wrong with it and what might go wrong with it” (Michalko 2009:67).

When Lanette, and others, begin their account of their MS with their time and experience of diagnosis we can understand this as the defining moment when they not only learned (rooted in a history of culture and social relations) that their bodies have a problem, but that their lives were now troubled (Michalko 2009).

The second point that arises and deserves attention in Lanette’s account is how she uses the term “attack” to describe the sudden appearance of MS symptoms. This term, also known as a “flare-up” or an “exacerbation”, occurs throughout the mainstream literature about MS. The term “attack” is a very aggressive and threatening term and its use can be understood as signifying an attack on the ‘normal’ body and an attack on ‘normal’ life. I will reiterate, then, that in a relapse the body becomes, as it is understood in our culture, a problem and, therefore, so does our life the way we and others understand it (Titchkosky 2007). When a person with RRMS goes from remission to relapse they go from ‘normal’ functioning to an altered functioning. Perhaps a person’s sight gets blurry or their arm goes numb or extreme fatigue sets in; this altered state can feel like an attack on our body but it is also an attack on our ‘normal’ functioning life as it is interrupted and transformed. In a relapse we are forced to face our MS, the changes

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23 When there is a socially-defined problematic aspect of our body or the functioning of our body, it becomes seen and culturally understood as the individual person being the problem, their life (or living) becomes a problem that needs to be ‘fixed’ as it is assumed it is a life-less if it remains un-fixed — something to be pitied or catered to. This is a taken-for-granted aspect of illness and disability that will be explored further in upcoming chapters.
that occur in the body and the ‘problem’ we *have* and the problem we *embody* as a member of contemporary society. Lanette’s (and others’) use of the term ‘attack’ represents more than a relapse; it represents the experience that we embody (Titchkosky 2007). In this passage, Lanette also acknowledges the time she started her medication as the time her attacks lessened, thereby displaying her confidence in the medication and how the medication, she feels, is helping lessen the attacks on her body and on her life.

In telling me about their MS, the women I interviewed often used the medical term for the symptom followed by their own explanation of it; showing how they are not only using the terminology but understanding and translating the medical terms into their own experience and understanding of their illness.

Nina: Right now, on my left side, from my hand to my foot I have the neuropathic pain, the burning, and it varies in intensity depending on the time of the day and what I’m doing; if I’m stressed or tired or whatever.

Patty: Back in 1988, after I had the first serious optic neuritis and also had weakness in my legs and I was pretty taken out by it for a while.

Nina and Patty are explaining their symptoms to me using medical terminology (*neuropathic pain* and *optic neuritis*), another example of how the person with MS is connected to, and informed by, the institution of biomedicine. By using medical terminology, Nina and Patty are able to articulate their experience to me using the language that is acknowledged as legitimate within the biomedical community. Because this is the overarching institution that people with MS operate within, it becomes natural to speak of their experiences using this language. This ‘naturalness’ shows just how connected the person with MS is to the authoritative discourse of biomedicine. In the contemporary world we live in, “our experience of the ‘gone wrong’ in relation to the
body, mind and senses, is governed by our adoption of the dominant ideological version of our bodies, minds and senses held by biomedicine. Our conduct is conducted by our own biomedical sense of our own bodies” (Michalko 2009:67).

The language that is used by the participants of my research is telling but so are their individual actions. What these women are doing in their everyday/everynight lives to manage their illness shows, again, just how much the institution of biomedicine coordinates the actions taken by people with MS.

4.3.2 ‘Treatment Plan’ and Participation in Ruling Relations

According to biomedicine, after the diagnosis comes a treatment plan. In regard to illness progression management of MS, the first recommendation from the diagnostic physician is, generally, to begin a Disease Modifying Therapy (DMT). At this point, the person with MS is faced with the decision of choosing which therapy to try. This is a decision with long-term commitments. Whichever therapy is chosen, the person with MS must remain on that therapy for at least a year before the effectiveness of the therapy can be assessed by the neurologist. Once assessed, if the therapy is shown to be effective, the patient remains on the therapy indefinitely.

The current DMTs available all require injections (most are self-injection) and this can be daunting. Three of the five women I interviewed are on a DMT. Their choice to begin and maintain a DMT regimen is another way that the biomedical institution informs and coordinates their everyday activities as they manage their life with MS.

Lanette’s experience with Rebif, her DMT of choice, provides a great example of the work involved in adopting a DMT regimen:

Sheri: So you’re on medication you said?
Lanette: Yes.
Sheri: What kind of medication are you on?
Lanette: I’m on Rebif, umm, I don’t recall exactly...I know there’s a low
dose and a high dose and I’m on the high dose of it, um, three injections a week
and I’ve been doing that for probably about ten years now, ten years or so. I never
had any real troubles with side effects, um, so shortly after I got up to full dosage
I changed it to doing it in the morning, so generally what I do is take out my
medication out of the fridge the night before, just so that it’s not cold when I do it,
and, I don’t like needles so it took me a while to get used to, I can’t really use the
auto-injector because it injects too quickly and it stings too much so I have to do it
myself. So I usually have to mentally work myself up to it every single time
(laughs) but I, I do it, but it’s also become...I used to think that I’d rather
somebody else do it for me but it’s become something that I feel like I have to
control myself, I have to, for two reasons, I’m afraid of not being able to go back
to doing it and also I don’t trust anyone else (laughs) because the medication, I
find, needs to go in really slowly, otherwise it, it stings, and if it stings then I’ll
decide I don’t want to do it anymore. So, I have this fear that somebody won’t
understand that and putting them in control of doing it, I feel like I need to...cause
I just put a little bit in and wait a sec and try a little bit more, cause if I just, even
slowly, inject it, um, I may not feel it right away but as more seems to go in then
it starts stinging and it starts stinging more and more so I kinda have to stop it and
start it a number of times. I don’t trust anybody else to.
Sheri: How long does it take, that process?
Lanette: Um, it depends, I mean some spots tend to be better than others
so sometimes I can inject it a lot faster but I would say - for the most part, maybe
five minutes, sometimes it will take me 5-10 minutes to get - to find an actual
decent injection site at this point. But, it just depends, I mean, once in a blue
moon I find a really good spot but I’m running out of them (laughs). But, I, I
mean, it generally doesn’t take that long to actually get the medicine in but I can’t
consistently, like, I can’t just, even if I slowly was pressing the plunge I can’t do
it consistently, it seems like I need a break in there, otherwise it tends to start
stinging and I don’t like it (laughs) I’m a real baby.
Sheri: (laughs) Interesting

Lanette: And I have this fear if it starts hurting I won’t do it and I, even though I have the experience that the medication obviously helps me, I’m afraid that if it starts hurting me I won’t want to do it (laughs) so, um, mentally it, more than anything else, tends to slow me down cause if I don’t find a good spot right away then I tend to get frustrated and stress myself out a bit

Sheri: Does it go into the muscle? Is that the one that goes into the muscle or is it subcutaneous?

Lanette: No, it’s subcutaneous

Sheri: So what’s involved in your mental preparation?

Lanette: I don’t know...um...I don’t really know if I think a heck of a lot about it..um..other than I have to get it done.

Sheri: Is it more of a feeling?

Lanette: I think it’s more me and...I have this, I’ve never really been a big fan of needles so it’s more just...even though I’m better than I used to be I don’t think I’m ever going to get to the point where I feel like it’s easy, it’s always a struggle but I think it’s...um...just me getting the needle in, I don’t like sticking that needle in me and - so I just have to sit there and have a moment with myself (laughs) and I..yeah..I don’t know. I don’t know whether I really think about anything in particular or do anything in particular. I think I just need to kinda sit there and give myself a moment to ...I kinda have to talk myself through it sometimes, I mean, when I’m trying ... cause I’m also, one time I hit something once where it really hurt so now I don’t just, I can’t just automatically jam it in, I’m slow, so as soon as I get a spot where it tends to feel like it’s gonna be more painful I stop and try a new spot so it takes me a while to find a spot that’s acceptable in my little brain (laughs).

The work process that Lanette describes is clearly not something she enjoys but it is something that she does because it was recommended by her physician and because she is seeing positive results. The above exchange with Lanette provides insight into the kind
of mental and physical work involved in maintaining a DMT regimen and how she is acting and participating in the institution of biomedicine.

It is also important to note in Lanette’s account that she has changed parts of the procedure to fit her own needs and experience. It is usually recommended that a person inject the medication at night in order to avoid (sleep through) unpleasant side effects like pain, stinging and swelling at the injection site. Lanette says that she “never had any real troubles with side effects” so she changed to morning injections to fit her own life experience. She also states that she likes to have the control of doing the injections herself and doesn’t trust others to do it for her. This is a telling statement: while she trusts the professionals enough to maintain the DMT regimen, she does not trust that they will be gentle or listen to her concerns at the time of injection. Lanette participates in the ruling relations through the act of self-injection and by remaining on a DMT. She maintains self-control of this activity by administering her own injections, no matter how much work is involved in the process. While Lanette’s actions are informed by and coordinated with the institution of biomedicine, she affirms herself in the decision-making and injection-doing by adapting the instructions to fit into her own lifework and, therefore, makes the final decisions about her treatment adherence (Mykhalovskiy and McCoy 2002).

As illustrated above, people with MS do participate in the institution of biomedicine through their everyday activities, thoughts, understandings and language surrounding MS. The ways that people with MS manage their illness are variously coordinated with, and informed by, the knowledge produced through the social relations

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24 Also known as injection site reactions.
embedded in biomedicine. The ways in which people with MS understand their life with illness is informed by the wider social and cultural relations they live in (which holds science and medicine as the authority). It is these biomedically informed social and cultural aspects that can influence a person with MS to feel like they have a problem and having a problem can make a person feel like they are a problem (Titchkosky 2007 and Michalko 2009). Next I will highlight aspects of the disjunction that exists for people with MS as they negotiate the space between biomedical knowledge and literature and their own lived experiences.

4.4 Disjunction

A prominent disjunction exists for people living with Multiple Sclerosis and this disjunction has become realized and explored throughout my research. The issues of disjunction “is between different versions of reality – knowing something from a ruling versus experiential perspective” (Campbell and Gregor 2008). The disjunction that motivated this research centered on how I, as a person with MS, knew that what I read about MS in the authoritative texts was very different from how I experienced and understood it in my everyday life. In order to explicate this disjunction further, I will first set the stage by showing how MS is discussed in the ruling literature. From there, I will provide examples and discussions arising out of my interviews that display how people with MS negotiate and respond to this disjunction.

4.4.1 Multiple Sclerosis in the Ruling Literature

Throughout the ruling discourses on MS, symptoms, treatments and services are repeatedly categorized and homogenized to the point that it becomes very difficult for a person with MS to relate to or gain appropriate knowledge from them. The homogenized
information available conditions the emotional work that people with MS do as they negotiate the institutionally informed information and services. As emphasized in chapter one, every person with MS experiences the illness differently. People experience different severities and durations of symptoms, different combinations of symptoms and the illness progresses differently for everyone. Biomedicine, however, requires that the illness and symptoms be categorized in order to prescribe a treatment plan that follows the model of the mainstream knowledge and literature. This requirement locates the main contour of disjuncture; when these categories inform the services and information available to people with MS yet people with MS cannot relate to such services and information because they don’t ‘fit’ into the homogenized categories.

The literature is informed by biomedicine and this institution has created the categories that the person with MS is supposed to ‘fit’ into. But the nature of the illness, being different for every person, makes these categories, to a considerable extent, irrelevant to the experience of many people with MS. The literature generally consists of definitions of what MS is, but the explanations of what MS is does not relate to the experience of it. For example, the MS Society website says this under the heading “What is MS?:

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system which is composed of the brain and spinal cord. The disease attacks the myelin which is a protective covering wrapped around the nerves of the central nervous system.

(MS Society, About MS 2011)
This definition of MS, from the MS Society which acts as the public face of MS\textsuperscript{25}, is a very general description of what occurs in the body but includes nothing about the experience of living with MS, nothing about how different it is for everyone with MS. Moreover, by stating that it is an “often disabling disease”, the text may trigger feelings of fear and anxiety in a person living with MS. Donna Haraway’s (1991:189) concept of the “god trick” and Tanya Titchkosky’s (2007) application of it to disability studies, can help inform a different and important understanding of this definition here. The “god trick” is Haraway’s way to draw attention to contemporary knowledge production and the taken-for-granted practices found in informative texts (Haraway 1991). Titchkosky explains further that “a text’s unbiased or objective knowledge claims are activated by a variety of practices, such as making the author, and other signs of concerted human action, disappear, while making it apparent that knowledge is produced by a disembodied, even other-worldly, stance of an authority seemingly seeing everything from nowhere” (2007: 32). The above definition of MS, provided by the MS Society, is a perfect example of this. The definition hides the social beliefs and practices that organize knowledge; it makes truth claims that convey no sense of grounding in human activity and organization (Titchkosky 2007). The ‘facts’ being stated in this definition have been reached through social activity but the producers of this knowledge and the social process of reaching these ‘facts’ are omitted. The definition is made to appear as if objectively given; “as if it is unencumbered by any touch of the mundane reality of the place and people of its making” (Titchkosky 2007:33).

\textsuperscript{25} See Chapter 5 for more on this.
Much of the biomedical research and information on MS is publicized using the god trick. It is common to read passages regarding MS that begin with ‘The data shows’, ‘statistics say’ or ‘research reveals’ and by providing information using the god trick, the social production of that knowledge and the beliefs underlying it, is hidden and repressed (Titchkosky 2007). Texts on MS that employ the god trick make absent their “ongoing participation in the reproduction of the discursive regimes that support their knowledge claims” (Titchkosky 2007:33). The information becomes taken-for-granted ‘fact’ but the reader of these texts are encountering “knowledge without knowers” and ‘facts’ disconnected from their own social organization (Titchkosky 2007:33). As Dorothy Smith urges us to realize; “texts are the mediators and bases of discourses and ruling relations that regulate and coordinate beyond the local setting of their reading and writing…the act of reading is very deceitful in this respect, it conceals its particularity, its being in time and place” (1999:80). Although we are encouraged to read these texts as if the truth is in them, it is important to be critical of these texts and to realize, as the reader, that they are the result of embedded beliefs, values and social relations that occurred in a time and space other than our own.

The above discussion is just one example of how the mainstream literature can be misleading and difficult to relate to; it shows just how far written text can deviate from lived experience. When I asked my respondents to describe their MS to me their descriptions were always about the symptoms they experience and never about what was happening in their central nervous system – this is a problematic disjuncture that exists in and is perpetuated by, the biomedical text.
Literature informed by biomedicine often lacks the kind of information that a person living with MS wants to learn.

Nina: I feel like its kinda the same information all the time, over and over again, except, there’s not a lot around what to do if you relapse but I realize that there’s not a lot around that because the options for assessing and treating relapses are very limited, or so it seems in my world. So, ya know, you go on Prednisone pills for a little bit, or you go to the hospital for an IV or you wait it out. That’s all I know so far but I’d like to know more information on what to do during a relapse, or if you’re having one but most of the information is kind of all the same, like, different sensory symptoms or things like that. And I, I don’t know, I wish there was a little bit more out of that realm, like, I don’t know how to explain it, I did got to a conference with my Mom through the Society in the fall, which was great, but again, it was very geared towards people that are more advanced and so, maybe, I guess, I would like to see more information and support in various ways, for people like yourself and myself that, you know, we’re in our early stages or hopefully these will be stages we stay in, or you know, I’d just like to see more helpful – and um, up-to-date information on MS.

The information available offers the steps to take in a relapse, which are all pharmaceutical solutions, but absent is what the person *experiencing* the relapse can do on their own to help the situation. Again, a disjuncture exists between the biomedical solution (pharmaceuticals) and the patient experience. By creating a discourse on MS that is categorical, homogenized and presented as ‘fact’, biomedicine has organized information on MS that is largely disconnected from the experience of living with MS. The alien character of categories makes the work of researching and managing the illness very disjointed and confusing. The consequence can be avoidance and feelings of fear and frustration.
Nina’s statement that “information is kind of all the same, like, different sensory symptoms or things like that” reflects the categorical nature of the information. The information does list the different symptoms you can, potentially, experience (like sensory symptoms) but once you ‘fit’ yourself into that category there is no follow-up information available regarding how to manage it on your own.26

Often, when I am researching MS, I am trying to discover what I can do now to avoid problems in the future. Often, when reading about MS, you will read how stress and poor living conditions can aggravate MS symptoms. Although the authoritative texts do acknowledge the importance of maintaining a healthy diet, getting daily exercise and reducing stress levels, only the ‘food-guide specific’ and ‘science-approved’ advice is offered. For example, the MS Society has a pamphlet available to the public entitled “Healthy Eating: A Guide for people with MS”. The first page of the pamphlet reads:

“This booklet explains what is meant by a ‘well-balanced diet’, why we should all be aiming for one and how to get one. You might find that symptoms of MS affect what you can eat or how you prepare meals. Learning new ways of cooking, or using energy-saving tips can help you carry on eating what you enjoy. Adjusting to MS will not always mean changing your diet, but sometimes it can help. Many special diets have been proposed as treatments, but none have been proven to prevent MS or affect the way it may develop. Special diets are best approached with caution as some may be expensive or even harmful. Most people do not need to use expensive supplements either. You can usually obtain the nutrients you need through your daily meals. With careful planning, perhaps with the help of a dietician, you can make sure you meet your dietary needs – even if they change over time. Many people with MS report that they feel better when they eat well” (Bailey 2008:3).

26 See Appendix A
This kind of information is a typical example of what is found within the biomedically informed literature. It acknowledges the importance of eating well (eating according to the Canada Food Guide) but does not go further than surface information. It does not address how different diets can affect the body, how removing gluten or dairy or sugar from your diet can possibly affect a person’s MS – in fact, the referenced literature tends to discourage even trying these options. Why is there no research in this area within the ruling relations and the authoritative texts? Why haven’t the impacts of food and nutrition on MS been studied, and approaches validated? Why is there mystery surrounding the simple, everyday activity of eating (as expressed in the above excerpt)? This topic is quite commonly addressed in alternative therapies and information sources but is not addressed within the institution of biomedicine. Although a discussion surrounding why this is the case falls outside of this thesis, I will point out that pharmaceutical companies don’t make money if illness can be managed through diet. This is a direction in which I would like to take this research in the future.

Now that we have seen examples of MS in the ruling literature, my analysis will move to how actual people with MS negotiate, respond to and work around the disjuncture surrounding lived experience and the ruling perspective.

4.4.2 Language and Disjuncture

People with MS respond to the disjuncture between the ruling perspective and their own embodied experience by creating modifications of the ruling discourse in order to make sense of their experience and find solutions that they can relate to. Although participants used biomedical language throughout the interviews,
many of the women I spoke with took serious issue with aspects of this mainstream taken-for-granted language. This is one way the disjuncture was evidenced in the interviews.

Nina (in reference to the MS Society): There is support but it doesn’t really trickle down to the patients – or, no, I don’t like that word – the people that need it, people with MS.

Nina is taking issue with the term “patient” that is placed on people living with MS. Even though Nina, or anyone with MS, may not identify with the label of “patient” it is, nonetheless, ascribed by the ruling institutions to any individual who falls outside the “normal, healthy body”. She is problematizing the biomedical terminology by choosing to bring attention to the label of “patient” and with this correction she is acknowledging that people living with MS are more than just “patients”, as the biomedical model implies; they are quite simply “people with MS”.

During my interview with Nina she told me about a study she participated in and the process of getting in touch with the doctor heading the study. She highlighted another problematic use of language that is so taken for granted in mainstream medical discourse.

Nina: There was this thing on Facebook asking for more “healthy volunteers” but I didn’t read the “healthy” part, or maybe I did but I still applied, and then Dr. Motts, this guy out there, called me and was like “oh, I saw your application, you’re a healthy volunteer?” and I was like “oh, I’m sorry, I must have filled out the wrong one but I do want you to know I consider myself a “healthy volunteer” ...but...I have MS”. And then he’s like – I was just trying to get my point across (laughing), not to rip everything apart, you have to choose
your battles, but it was just that moment ... I said I’d really like to be part of the study.

The term “healthy” serves as a distinguishing, yet problematic, category that people with MS are placed outside of. Although Nina problematizes this terminology, in wider society it is a taken for granted term that is used with ease to re-present the ‘normal’ body and to mark people living with illness as outside of it or not healthy. Language use of this sort reflects a recurring disjuncture in the life of a person living with MS. For Nina, she is healthy and is not afraid to represent herself as such. The terminology used throughout the biomedical discourse does not translate to actual lived experience and can be quite oppressive and marginalizing to the person living with MS. Locating a person with MS as existing outside the realm of “healthy” does not often translate to lived experience, especially for people who live most of their lives symptom-free with occasional relapses (as in RRMS).

4.4.3 The Emotional Work of Having MS

The disjuncture between lived experience and the ruling perspective can become incredibly frustrating for people with MS as we are living it, negotiating it and trying to plan our wellness around it. This frustration leads to a specific kind of lifework; emotional work. Next, I will explicate these frustrations and how emotional responses are connected to the overarching disjuncture.

From the perspective of the biomedical community, which understands a person with MS as a grouping of symptoms,²⁷ services tend to be oriented towards people whose MS contains all or many of these symptoms; people with progressed or advanced MS.

²⁷ See Appendix A
Being faced with these oriented services\(^{28}\) can create an emotional response, notably fear, anxiety and avoidance as the person with RRMS is faced with the worse-case-scenario: the form the illness \textit{could} take and the realities that \textit{could} ensue. The women I interviewed commented on this problem often, identifying the disjuncture as a gap in the information and the services available to them.

Nina: I think what they (the MS Society\(^{29}\)) do is important but I’m just not feeling like it’s as easy as it should be for people with MS to get help with things through them and also it just seems like they’re based in giving people drugs and things like that versus being more pro-active and offering more physical things like, there’s a gap in terms of people with my level of MS, like, I go to this gentle-fit [class] sometimes but I don’t go a lot of the time because it’s not really that much of a workout for me and it’s because the majority of the people are very progressed and I feel like a lot of the physical programs through the MS Society, here anyway, are catered more towards people who are way more advanced and so there’s the gap there. That’s why I’m, kinda pulling away from my involvement with them and also ‘cause it’s hard to be around people, especially some of the people that just complain all the time. So, anyway, I’m gonna keep trying to get what I can if I want anything from the MS Society, like, but, um, I’m gonna probably just kinda re-examine, or, closely weigh out my relationship with them, just like the MS Clinic and stuff, at this stage.

Claiming that the MS Society seems to be “based in giving people drugs” suggests that the MS Society is also participating in, and coordinated with, the institution of biomedicine. I will elaborate more on this in Chapter 5 but want to draw your attention

\(^{28}\) Whether these services are targeted this way because of urgency, essential need or lack of funding for other types of MS is unknown and outside the scope of this research. That said, the impact of the services being targeted in this manner is, nonetheless, very real for people with MS (especially RRMS).

\(^{29}\) See Chapter 5 for discussion regarding the MS Society as the public face of MS and how it is, in many ways, embedded in and informed by biomedicine.
to this issue. Nina’s experience with the MS Society has led her to “re-examine” her involvement with them since they don’t seem to be providing the services she needs or can relate to.

Nina also mentions the difficulty that presents itself when encountering people with more progressive types of MS; a feeling, the emotional work process that can exist for a person with RRMS. The authoritative and homogenized texts say that MS can be all of these terrible symptoms in one body so when a person with RRMS is faced with the reality of a person with Progressive MS it triggers an emotional response, expressing the fear of what could be; what the texts say could happen. This emotional work process pertains to services available for people with MS but also to the anxiety around, and avoidance of, the literature on MS.

Sheri: Do you read about MS?
Lanette: Not a lot anymore, I did in the beginning, more so for general information when I was first diagnosed, on what kind of things to look for or what kinds of things to expect. Along the way, for me, it got to the point – you know, a lot of people would tell me about things they’d heard or that they’d seen something, suggest all these different things for me to read and – which was great – but after a certain amount of time I just felt like it was too much – I didn’t want to dwell on it – sure, I have a disease but it isn’t who I am so I needed to pull back from that.

Lanette’s and Nina’s comments reflect the emotional work that people with less severe cases of MS (especially RRMS) can experience when faced with the kind of biomedically informed literature and services that are available. The feelings that can arise in a person with a less severe case of MS (like Nina, Lanette and myself) can lead to avoidance of the literature and the services that have been made available to them (us). Although Lanette
is just commenting on literature in general, this shows that she feels that staying informed about MS means dwelling on it. This is a reflection on how the literature, created from a biomedical perspective, can make her, the person experiencing MS, feel. The literature is informed by biomedicine and this institution has created the categories that the person with MS is supposed to ‘fit’ into. But the nature of the illness, being different for every person, makes these categories, to a considerable extent, irrelevant to the lived experience of many people with MS, as well as evoking an emotional response.

Elle elaborates on the same concerns:

S: Do you actively search for information about MS?
L: No, the less I know the better.
S: Yeah? This seems to be a theme, a lot of people are saying that to me. Why, why the less you know the better?
L: Well, why anticipate something that might never happen? I find – you know – who knows what’s gonna go next? I can’t sit around and go “oh am I gonna be okay today? Oooh, I have to...oh I don’t know...maybe I’ll have...maybe my legs’ll go, I can’t go, I can’t go out...okay I’ll stay home”.

Elle’s comments are, again, telling about the type of information that is available on MS and how the emotional work of having MS can lead to avoidance. If all that is available to read about is what could happen and why read it? Why engage with it at all when there is nothing in the literature that provides information on how to improve or potentially deal with your situation?

Lanette: When I’m happy and healthy – or I feel I’m happy and healthy – sometimes I don’t want to be constantly reminded of what could be, you know?
Lanette’s concern in the above passage is exemplary of the kind of avoidance-feelings that come with the possibility of spending time with people with progressive MS, which is unavoidable if someone with a less severe case of MS was to participate in the modified exercise programs available. Ultimately, these feelings and actions of avoidance create a roadblock for people with less severe cases of MS who are seeking services.

4.4.4 Negotiating the Disjuncture

An interesting part of the lifework of living with MS is finding your place between the ruling perspectives and your lived experience. Negotiating this disjuncture can be best understood and exemplified by exploring the activities people with MS engage in with regard to the management of their MS.

Reaching outside of the ruling discourse by searching out management techniques other than pharmaceutical options, respondents limit their own participation in the biomedical discourse in order to find alternatives that could help them. The act of illness management itself is often adapted to individual experience. The approaches to illness management offered by the mainstream discourse are generally limited to maintaining a disease modifying therapy (DMT) regimen and managing symptoms through the use of an array of prescribed pharmaceuticals. All my interview participants adapted their illness management techniques outside of this discourse to some extent and all of them reported their use of vitamins, exercise, a healthy diet and alternative methods to some degree.

When I asked Elle whether she was on any medications to manage her MS she replied:

Elle: Yeah, I take some medication, yeah. I have small, (walks into next room to get meds) yeah, I have to get my meds blister-packed now, that’s one thing, well, I was [spending] $360 for medications every month, and that was a
wad more pills, I’ve taken myself off all sorts of pills and these are the ones I take now, I take Clonazepam, I take Zoloft, and, oh yeah, Lipitor, that’s the other one.

Sheri: Are any of those for MS?
Elle: Yes, well, they’re...well, they don’t have any drugs that are for MS. They say they do but if you don’t know what causes it how do you cure it?
Sheri: Yeah, well, the “disease modifying drugs”
Elle: Yeah, no, I don’t take any of those, interferon or any of that crap.
Sheri: (laughs)
Elle: No thank you.
Sheri: And you never have?
Elle: No. I never have. No, I find I do just fine with those (points to her meds). Every now and then I might need an extra Clonazepam but I can take it!

In choosing not to participate in a DMT, taking herself off some medications and being in control of the times she takes the other medicines, Elle is adapting the biomedical discourse and practices to fit her lifestyle and her specific needs. Elle also employs other management techniques that fall outside (or on the fringe of) the biomedical discourse, notably smoking marijuana. Elle told me that smoking really helps her feel better:

S: How does it help you?
L: Well, in MS, I find your nerve endings are stripped raw and I find it really makes you shaky the more tired you get and it just instantly calms my nerves, just instantly, and like “oh, that’s better” (laughs).

The use of marijuana for managing MS symptoms is debated in the biomedical realm. My neurologist told me that a prescription of medical marijuana is a last resort and patients need to be displaying intense pain symptoms of which pharmaceuticals are not
proving sufficient to manage the pain (in reference to a conversation with my neurologist in March 2011). Elle does not have a government-approved prescription for medical marijuana, but she is a member of the Compassion Society.

L: I’m not on the, what is it, my doctor just gave me the prescription and I joined the Cannabis Club down in Victoria so that’s where I get it down there. I’m not government approved to get it, if that’s what you mean.

S: I don’t really know how it works.

L: Well, they do...oh you gotta do, in quadruplicate, um, and you have to have a couple of doctors tell you that you need it.

According to the Vancouver Island Compassion Society’s website (2010), Elle would have had to get her doctor (GP) to complete two forms, one recommending the use of marijuana and one releasing her medical information to the Society. Elle would have had to fill out a third application form outlining some of her personal information. These three forms submitted to the Society would enable Elle to purchase marijuana and marijuana products from the Society (Vancouver Island Cannabis Society 2010). This is an interesting work process in accessing a therapy like Elle has chosen. Although marijuana use is controversial within the ruling institution of biomedicine (in Canada), obtaining it legally does involve authorization from a member of the institution. Although Elle does not have a prescription for medical marijuana, and therefore has to pay for it herself, she has “permission” from the authoritative figure within biomedicine. For Elle, the work process of obtaining “permission” was worth it as it helps her manage her MS.

Elle’s activities to manage her MS fall both within the institution of biomedicine (the pharmaceuticals she takes to manage symptoms) and outside of it (the marijuana).
This inside/outside participation reflects how Elle negotiates the disjuncture and designs her own treatment plan. Nina provides a great example of being faced with the work of finding a management regimen that works for her. She is still in search of what could work for her. For Nina, the biomedical illness management regimens have not helped her so she has gone outside of that discourse to try to find other ways to help herself feel better.

Nina: I feel, at this stage, when the drugs have failed me, I don’t think that that’s supposed to be my course. I don’t think they were supposed to work for me. Unless Tysabri is, but even with Tysabri, there’s a maximum of two years that I can be on it because of the risk of developing PML, the brain infection. So basically, yeah, it’s just up to me to figure it out I think, at this stage, and I’m open to suggestions and I’m trying to just kind of pick and choose things, without obsessing over them or them exhausting me, but I’m gonna step it up a bit. I might also dabble a bit more in the vitamin field, well, with the diet and exercise regime, lifestyle, when I get back from California! [Nina is referring to her trip to California for CCSVI treatment].

Nina’s experience of the pharmaceuticals failing her has created a lot of work for her. Her experience shows how it can be easier to remain within the biomedical institution because the work involved in negotiating the disjuncture (the space between biomedicine and alternative therapies) is extensive. Seeking out information, services and financial assistance has become a work process that has consumed a lot of her time and energy. The quote below follows a long discussion on negotiating healthcare providers, financial aid and service providers like the MS Society:

30 Chronic cerebrospinal venous insufficiency (CCSVI) treatment discussed in Chapter 1, pages 9-10.
Nina: It’s my full-time job and a half! And I, yeah, I feel bad cause people are probably so sick of me talking about my MS and stuff cause like, even my sister said to me at one point, a few months after I came back, she was like “[Nina], we care about you and we want to hear about it, we’re interested but it seems like it’s kind of taken over” and I was like “whoa, really?” I knew that but it had to, in a way, because I was, it became my job, you know, like doing all this paperwork, following up on all these phone calls, and getting information, like, it became kind of, I don’t want to say consuming but it’s been a lot of work. But now I’ve accepted that there’s a lot of room for changes in the medical system, the MS Society included, but I can’t take it all on my shoulders and try and like obsess over it or be like some people I know on Facebook who pump out like 50 articles a day on MS, cause that, to me, is not conducive to healing and being well. So, I’m kind of looking towards, looking forward to getting the surgery (CCSVI) and just kinda moving past it and continuing to do what I can, you know, with diet and exercise and go to my appointments and not have it be at the forefront and I think learning about all this, this kind of social work aspect...

Nina, exploring resources available to her, has reached outside the mainstream biomedical institution. The chronic cerebrospinal venous insufficiency (CCSVI) treatment is an experimental procedure and as such, its effectiveness is debated within the biomedical discourse and in Canada it is not (yet) a procedure that is available to people with MS. With other treatments (DMTs) failing her, Nina’s lifework has increased as she tries to find a way to better her own experience with MS. Her choice to go to California for the CCSVI treatment has cost her time, energy and a lot of money but when faced with no other options in Canada for disease modification, she has reached outside of what her local biomedical discourse was providing. The institution of biomedicine creates
work within it and when it fails to provide solutions, it leads to working outside of it. Because the CCSVI treatment has not been added to the authoritative texts in Canada, Nina’s lifework surrounding the CCSVI treatment lies outside the Canadian medical-science community and as such, lies outside the ruling institution.

The above two examples from Elle and Nina reflect the search for alternative therapies that people with MS can face. It is important to note here that the search for alternative therapies is often made alone with little or no support from medical professionals working within the institution of biomedicine.

The discussion throughout this chapter shows how people with MS participate within the ruling relations as well as how their work can deviate from them. This negotiation between the institution of biomedicine and the information available that lies outside those relations presents an interesting example of the bifurcation of consciousness; a person with MS lives within the knowledge of themselves as bodily, experiential beings and as text-based objects of biomedicine.

This research has begun to unravel the biomedical categories that I and others like me are placed in as people living with MS. This research, starting with the everyday/night experience of women with RRMS, has enabled me to understand the experience of living with MS as a personal and private one, and one that requires some negotiation between life experience and that which is written in the authoritative texts. Being aware of this division has allowed me to give myself permission to hold my experiential knowledge as the authority in my life.
Chapter 5 – Institutions Participating in the Lives of People with MS

To go a final step further in my analysis I will introduce and incorporate some insights into the institutions that organize the lives of people living with MS. These institutions are an integral part of the work experience for someone with MS, as you will see in interview excerpts. Because I chose to do an institutional ethnography on women with RRMS, the bulk of my writing and explication has centered on their experiences and the overarching institution of biomedicine that these women coordinate with and participate in. The insights to follow arose from the interviews I had with the women living with RRMS and their experiences negotiating the authoritative and regulatory systems that have entered into their life since being diagnosed with RRMS. The women with MS that I interviewed did not explicitly reflect on how their lifework was socially and institutionally shaped but “the organizing presence of institutional relations is visible in how people spoke about what they do” (Mykhalovskiy and McCoy 2002).

Erik Mykhalovskiy and Liza McCoy, in their exploration of the social and institutional aspects of living with and managing HIV/AIDS, show that although people “with HIV/AIDS live lives of individual complexity…they do so within a common field of institutional relations” (Mykhalovskiy and McCoy 2002:23). Throughout this thesis I have described the work that is involved in living with and managing MS. In the following chapter I aim to explore the ways in which the concerns of people with MS can become coopted by ruling institutions; their ways of knowing are too easily overshadowed by the interests of the institutions participating in ruling relations (Mykhalovskiy and McCoy 2002). Including this as part of the substantive analysis of this study explicates further the institutional relations coordinating the actual lived
experience of people with MS. I hope that these final connections will create a better social understanding of the lifework surrounding MS.

The section that follows concentrates on the three institutions that were repeatedly mentioned and acknowledged as problematic by the women I spoke with. Although the discussion around these institutions is just scratching the surface and a more in-depth analysis is beyond the scope of this thesis, I wanted to provide points of contention that exist and that should be studied further.

5.1 The Government in Relation to MS Lifework

“The government” was often referenced as a roadblock to funding and a source of homogenization that is informed by and participates in the institution of biomedicine. “The government” here is referring to the state and many of the frustrations and complaints from the women I spoke with centered on a critique of the state’s allocation of funds for public health. A lot of frustration exists for people with MS who would like to try managing their MS using more natural options.

Patty: So, what frustrates me is that, if I followed the normal protocol in North America, the medical community, it would cost tax payers anywhere between $1000 and $1500 a month for my medication and right now the tax payers pay nothing and I have an excellent quality of life and it frustrates me that the government, well, and that’s why I want to be a really big advocate for this, this information has to get out and that we need to start really supporting people if they want to choose this route to make it more affordable for them because there are very specific things you can do to get infections down and they’re much more cost effective than treating somebody with MS for the next 30 years on medication - and the quality of life right? That’s huge.

Living a wellness regimen as Patty does requires a lot of money and it can be very difficult to pay for the vitamins, organic foods and supplements. Since Patty has a very
minor case of RRMS she is able to perform wage-earning work in order to pay for her wellness choices but this is not always an option for people living with MS. The state-funded health care system does not fund these types of alternative health management techniques and, as Patty implies, these avenues to health need to be more affordable. In this way, people with MS come up against a roadblock that limits their health management choices, leaving them only with pharmaceutical options.

Nina: I also want to change my diet and I eat healthy but it could be healthier and I could cut out red wine or beer, you know, like, alcohol, or I do believe there’s a connection with diet, in terms of dairy sensitivities or gluten and I know a lot of people are jumping on that bandwagon but I almost died when I was a kid and they thought I had celiac disease and I’ve always had food sensitivities so it’s something that is on the back-burner which I should really move forward and make a priority but it’s difficult when you’re not working and you’re surviving on government assistance which is minimal. To try and live this lifestyle that’s really – I don’t know – I’m trying to figure it out.

Here, Nina is talking about the natural ways she wants to manage her health but mentions how the government assistance she receives is not conducive to being able to live this way. Again, state funding (or lack thereof) is creating a roadblock for Nina. A healthier diet could be exactly what would help Nina but because she can’t afford it she is not able to even test that idea.

Jane shared a similar experience but her experience is with pharmaceuticals; she struggles to get funding for the medication she needs to alleviate her pain.

Jane: LYRICA is the pain one, I couldn’t live without it – it’s not covered under Pharmacare either, it’s not approved for neuropathic pain in MS, but it is for diabetes and even for Fibromyalgia.

Sheri: Really? And not MS?
Jane: No, and they did their own study that proved that Gabapentin was just as effective and yet the MS Clinic in Victoria said that there’s so many people in my boat that only LYRICA helps. It’s kind of the same as Gabapentin but there’s no comparison, and yet, I don’t know, I read what they, well no I haven’t read anything about the study so I don’t know how they did it or how many people or anything – just that they did it.

Sheri: Who is ‘they’?

Jane: The Pharmacare, BC Pharmacare.

Sheri: oh, I see, of course.

Jane: Um, so they’ve made the decision that Gabapentin is just as good and – it’s not.

Sheri: Have you tried the Gabapentin?

Jane: Yeah, and I couldn’t even take it, I couldn’t even take the dose at which it requires because of the side effects were so bad, made me feel so weird. So anyway, that’s about, over 300 bucks a month, about 400 bucks a month. And yet they approve it for fibromyalgia but maybe there’s too many people with MS, but when LYRICA first came out, it’s not that old of a drug, the sales reps were handing it out, like free samples, left and right – so between the MS clinic and my doctor, they were supplying me with all of it free, ‘cause they said that it would be approved soon, but then it never was, and then the reps, it started to dwindle down until they finally don’t give any free samples anymore – or at least not that I get – the nurse at the MS clinic anyway, she, it got to where I had to ask, and you feel like you’re begging, now she won’t even give me any (laughs sceptically).

This is not only an issue of government funding but Jane’s experience shows how the life experience of a person living with MS is not seen as valid within the perspective of authoritative institutions. Jane’s statement that “they’ve made the decision that Gabapentin is just as good and – it’s not” shows how biomedicine can speak for the people living with illness and disregard their expert experiential knowledge.
State healthcare funding and living assistance programs fall short in addressing the needs of people living with MS. The voices of the people living with and managing MS are not heard by these ruling institutions. This is extremely problematic as it creates roadblocks to healthcare and prevents people from living the healthiest they can.

5.2 Experiencing Pharmaceutical Companies as a Person with MS

People with MS experience the practices of extra-local pharmaceutical companies in their day-to-day lifework. The everyday activities that are enacted to manage MS and the biomedical institution that people with MS participate in are connected to and coordinated with pharmaceutical companies. The women I spoke with were aware of both of these roles and while they are grateful for the research and medications that help them manage their symptoms they are also sceptical of the role they play as a profit making enterprise within healthcare.

Patty’s comments (below) began with a discussion about whether she participates in fundraising activities targeted at MS research but show how she views pharmaceutical companies.

Patty: I’m not against pharmaceutical companies – if I’m in an accident I will take a painkiller if I need to but ...we have false expectations, unrealistic expectations of pharmaceutical companies. They are companies that are in business to make money for their shareholders and they make way more money if they have me on an MS drug for the next 30-40 years than if they cure me. So, our whole system is not set up right, it’s not set up to find a cure, it isn’t, these companies cannot survive if we find cures. So their best way - they want to find a patented product that they can market for as long as possible and make a profit – and that’s nothing sinful, it’s just business, right?

Patty chooses to act and manage her MS outside of the pharmaceutical arena and
has developed a realistic understanding of this institution. Pharmaceutical companies are huge businesses and because they are attached to the economy in a profit-making capacity. They have stake-holders and therefore must show that profits are being pursued (although I would argue that profits are being pursued at the expense of people living with illness). Ongoing treatments are more profitable than cures. But this understanding is just one part of the story; although they are profit driven, pharmaceutical companies do make medications that are incredibly helpful for people.

Patty: There are times when pharmaceuticals are important, they’re very, very important, but I think we are so out of balance and I don’t think that we can expect our doctors to understand this because they haven’t been trained at all in this, they haven’t been trained in nutrition.

Doctors are generally not trained in nutrition but are provided (by drug companies) with all sorts of information (and often free samples of medications) regarding medications and treatment plans. A study of pharmaceutical companies would be incredibly interesting, though challenging methodologically, since in my experience these companies are not transparent about their inner workings. Pharmaceutical companies reach into the lives of people with MS through many channels, much of which are not made explicit.

Because I am on a DMT called Copaxone, I am contacted once every three months by a nurse in Toronto. This nurse is employed by a branch of the pharmaceutical company. When she calls me she usually asks how I am feeling and whether I am experiencing any injection-site reactions. Sometimes she offers complementary products like an auto-ject (a device that you load your needle into and it injects the medication for you), a cooler to keep my medication in or a small device that clips the sharp point off the
needle for safe disposal. When I began this research I asked this nurse if I could interview her for my thesis research\textsuperscript{31}. She said she would have to check with her employer. I never heard back from her.

The scope of this thesis did not allow for a full analysis of pharmaceutical companies but I include this section just to acknowledge these companies as institutions that are involved in the everyday lives of people living with MS.

5.3 The MS Society

The MS Society of Canada, as discussed in the thesis introduction\textsuperscript{32}, is an organization with the primary shared goals of finding a cure for MS and enhancing the quality of life for people with MS. I want to explicate further how the Society figures in the lifework of people with MS by examining comments from my research participants and then including some information about the organization that I gleaned from its website. Some of the women I spoke with expressed scepticism about the organization.

Jane: I mean, I’m kinda getting to where I’m questioning the MS Society, like, it seems like all the money raised, they put a lot towards research I guess, but I think there’s a lot of, a lot of it goes towards the running of the MS Society itself, you know, like anything. So, um, I’m starting to question how much they actually do for the actual people who have MS, you know, there’s, there’s all the research but the research is funded by the drug companies and then even the MS Society I think is probably funded by the drug companies or it’s sort of like the government, one hand washes the other and then the people that need whatever...

This is one example of the scepticism mentioned in our interviews with regard to

\textsuperscript{31} I had hoped to interview the nurse in regard to her daily routine at work in order to explicate that work and map out how it connects to the lifework of people living with MS. This is an important part of explicating the ruling relations and the taken-for-granted happenings surrounding the problematic in Institutional ethnographic work.

\textsuperscript{32} Page 6
the MS Society. There are other examples shown in previous chapters, but what is important here is that people with MS question the institutions they participate in. This scepticism led me to investigate the MS Society further.

5.3.1 The MS Society’s Participation in the Institution of Biomedicine

The MS Society is the primary source for information and services on MS in Canada. Many times, when a person is first diagnosed with MS, they will be referred to the MS Society for support. In every effort to explicate the everyday/night activities of women managing their MS I examined the text-based information available on the MS Society website in order to gain knowledge about the organization. I found many examples of how the MS Society participates in and is coordinated by the institution of biomedicine.

The MS Society organizes numerous fundraising activities such as the MS Walk and the RONA MS Bike Tour. The funds that are raised at these events go to the services they provide, research into the illness and MS Society employee wages. The following discussion will revolve around the research the MS Society funds.

On the website you can find information on how to apply for research grants as well as a list of past recipients. Under the heading “Apply for a Research Grant” the following information is offered:

The Multiple Sclerosis Society of Canada is open to research which will lead to major advances in our understanding of the causes of, and potential treatments, for MS — such as new drug therapies, CCSVI, and myelin repair strategies. The MS Society has funded medical research into multiple sclerosis since the first grant of $10,000 was approved in 1949. It is now, along with its related MS Scientific Research Foundation, the single largest funder of MS research in Canada.
Of the research projects currently funded, about half are targeted at myelin biology and repair. Particular attention is focussed on finding ways to stimulate central nervous system cells to produce new myelin. Other significant areas of MS research are genetic susceptibility, immunology, MRI studies, Clinical and Population Health Research and treatment effects. The MS Society also funds young researchers just beginning careers at the masters, doctoral and postdoctoral levels.

(MS Society, Research, 2011)

This information, framed entirely within biomedical language, implies that research within the biomedical realm is the only research needed. The “young researchers” the Society funds are individuals studying in the natural science realm (this thesis project would not qualify). This qualification is evidenced in the guidelines for application:

IMPORTANT THEMES IN MS RESEARCH

The MSSOC will consider any bona fide request for research or training support relevant to the MSSOC’s mission. Research and training with direct applicability to individuals with multiple sclerosis (MS) is encouraged wherever practical and possible.

For Investigator-initiated support requests, no topic restrictions are imposed, other than the required demonstration of relevance to MS. The grants and awards that are available fall under two main streams that seek an understanding of the cause, prevention and cure:

BIOMEDICAL RESEARCH

Biomedical research grants are available to encourage studies into the biomedical aspects of multiple sclerosis, myelin biology and neurobiology, with a focus on basic and applied knowledge that will lead to control of myelin breakdown, neuroprotection, restoration of myelin and neurophysiologic and functional recovery, immunologic basis of MS, including pathophysiology, measures of disease activity, including imaging technology and the identification and use of surrogate markers.
CLINICAL AND POPULATION HEALTH RESEARCH

Clinical and population health research grants are available to encourage research studies into the population health aspects of MS, such as studies of epidemiology, outcomes research, health economics, monitoring of disease activity and treatment, susceptibility to MS, including genetic, gender-related, and other factors, health care delivery/policy, cognitive, psychosocial and rehabilitation research aimed at improving quality of life for those affected by MS.

(MS Society, Research Funding Programs and Awards Policies and Procedure 2011)

These details show that only research that falls within biomedicine can be approved for funding. My research, focussing on the life experience of people living with MS is outside the objective, homogenized and natural-science-oriented paradigm. This shows, again, how life experience is discounted in the biomedical realm and that the MS Society works within this realm.

The list of grant recipients (MS Society, MS Research Summaries 2011) includes Biomedical Research Grants, Clinical and Population Health Research Grants, Foundational Awards, Donald Paty Career Development Awards, Postdoctoral Fellowships and Studentships. All of the recipients are physicians, foundations or students of natural science. While I acknowledge that these are important people and projects to fund, the absence of everything outside of natural science is, for me, problematic.

With all research funded by the MS Society being provided to “experts” within the biomedical realm, (which holds scientific knowledge as authoritative over the individual experience of having MS) the MS Society reinforces the dominance of the institution of biomedicine. Perhaps this lends insight into the apprehension the women I
spoke with experienced; however, a deeper analysis of the MS Society would be needed to explore this further.

The biomedical model also informs the services and funding available to people with MS through the MS Society.

Nina: I actually tried to get funding for it (healing session through a Cree elder) from the MS Society last year to see her, ‘cause she was $80 a session and I wasn’t able to afford it, and I filled out this extensive application and said it was the only thing that seemed to be helping me even though I know there’s no concrete data showing it, to get any assistance for it, and they said that they couldn’t cause they can only support things like massage therapy or chiro or things that are more, ah, I don’t know the word, more conventional or believable in terms of medicine, to the patient.

Nina’s experience provides experiential evidence of funding through the MS Society being allocated to only services that fall within the biomedical authoritative knowledge.

One last thing to mention about the MS Society and its involvement in the institution of biomedicine is a simple but telling observation I made about the literature provided by the MS Society. When I went into the MS Society in Victoria to talk with someone about my research and the possibility of their helping with recruiting participants, one of the lovely staff members offered to gather up any information pamphlets that might be of interest to me. I asked if she could provide me with the package of informative literature that they would give to someone who was newly diagnosed with MS. In this package was an array of different instructional and informative pamphlets, a magazine called *MS Dialogue* and a CD ROM entitled “Virtual Library”. I noticed that on the back of this CD ROM was the same brand logo that was on my DMT medication; Teva. Teva is an international pharmaceutical company. The brand
logo on the back of the CD ROM was: *Shared Solutions*. Shared Solutions is an organization that is the care and information resource for Copaxone (which is owned by Teva). The nurse in Toronto who calls me every three months is employed by Shared Solutions. Shared Solutions “is a registered trademark of Teva” (as the fine-print reads on the back of the CD ROM). So while the MS Society is “an independent, voluntary health agency and does not approve, endorse or recommend any specific product or therapy” (as the disclaimer reads directly below the pharmaceutical brand logos), its own literature contains pharmaceutical brand logos. The brand logos also appear on some of the pamphlets and the bi-annually published magazine *MS Dialogue*, included in the information package supplied by the MS Society.

In the hope of providing insight into the kinds of research that could be informed by this thesis, the above discussion is meant to offer starting points to future inquiry into the institutions that shape the lives of people living with MS. This thesis opens the door to further inquiry into the multitude of institutional factors involved in the lives of people with MS.

5.4 Conclusion

This thesis has explored the work experiences of people engaged as ‘patients’ with biomedical institutions and begun to explicate that work. I have shown how the institution of biomedicine coordinates the lifework of people living with MS. The ethnography has explored the standpoint of people living with MS and examined the bifurcated consciousness that people with MS negotiate between their lived experience and the ruling perspectives of biomedicine. Finally, this research has discussed insights
into the regulatory institutions that reach into the everyday lives of women living with Multiple Sclerosis.

For this research, all of the participants were women; this was not intentional but is somewhat representative of the population of people with Relapsing-Remitting MS as it is roughly “three times as likely to occur in women than in men” (MS Society, Who Gets MS 2012). Also, as noted in Chapter one, eighty percent of people with MS have Relapsing Remitting MS (Compston and Coles 2002).

Although I cannot speak specifically to a man’s perspective of living with MS, this inquiry lends insight to the lifework of all people with MS, in general, and the institutional connectedness operating within those lives. There are social expectations of performance in our contemporary Western world; “the physical and social organization of societies [is designed] on the basis of a young, non-disabled, ‘ideally shaped’, healthy adult male paradigm of citizens (Wendell 1996:8). As a community of people with MS, we are all socially constructed as ‘unhealthy’ and/or ‘disabled’ and undergo similar lifework as such. Certainly there are different and varying aspects to a person’s lifework, depending on their specific form of illness, the extent of their disability, their sex, their gender and so on. The aim of this research, however, is to focus on and explicate the actual lived experience of these five women with RRMS and how they manage their illness. As such, this research provides a stepping stone for further research and analysis regarding aspects such as sex and gender.

Institutional Ethnography offers a way of producing knowledge for the people that complicates ruling discourses. By employing IE for this thesis, I have been able to explore the social relations and social connectedness in the lifework of MS that would
otherwise remain predominately unrecognized or unseen. The conceptual framework of IE, which informs and organizes the research, enables the explication of social connectedness. Realizing this social connectedness or “socially organized character of experience” (Mykhalovskiy and McCoy 2002:33) prompts us to engage with the politics of knowledge and see ourselves as socially engaged participants.

In exploring the connectedness of the work people do and the medicalized discourse that informs that work, I hope this thesis complicates the taken for granted notion of disability and living with illness. I hope this lends insight into thinking about our own bodies differently because it is you who are the expert of your own body. Change needs to occur both at an individual level as well as at the institutional level. I am not necessarily suggesting a radical transformation of biomedicine but I am suggesting that people living with MS value the expertise about their own bodies and life experiences and approach biomedical practitioners armed with the knowledge of their own bifurcated consciousness.

To conclude, I would like to revisit the problematic that inspired this research: my own lifework, in regard to keeping my MS hidden. This problematic has enabled me to explore notions of socially organized definitions and embodied terminology. One important aspect that I hope readers will take away from this research is the notion that contemporary understandings of illness and disability are socially organized through a dense connectedness of people and institutions. To think about “disability is to think of some individuals with some functional problem; it is not to think about how the notion ‘functional’ is a socially organized term with a highly contingent usage that presupposes a rather mechanical version of the body and is sometimes even used to imagine
embodiment as somehow separate from the socio-politico milieu within which bodies always appear” (Titchkosky 2007:55-56). Although we often think of science and medicine as objective and impartial, science is truly a social construct composed of real people doing real work based on their own needs, morals and values.

The taken for granted proposition that a medical diagnosis can be used to foretell life trajectories only makes sense insofar as “both the writer and reader conform to a set of taken for granted beliefs provided to us through group life informed by a medical sensibility” (Titchkosky 2007:91). I implore you, the reader, to consider this: illness and disability are made to appear as a problem condition but also as a way of being, a life which is abnormal and short-changed. They become understood this way through “the enduring power and authority of biomedicine to reproduce bodies as predictable collections of matter, fixed and held in place by empirical scientific analysis (Price and Shildrick 1999:147). Let me remind you that illness and disability are socially defined by people and it is people (not collections of matter) that are ascribed this status. Therefore, it is people that can choose to live outside of these socially created ideas of disability and illness and instead, choose to appreciate the body in all its manifestations.
Bibliography


Appendix A - MS Symptoms

Multiple Sclerosis Symptoms may include:

- Balance and Dizziness
- Bladder dysfunction
- Bowel Constipation, Diarrhea and Incontinence
- Cognitive Impairment
- Depression
- Dry Mouth
- Dysarthria, or difficulty speaking
- Dysphagia (difficulty swallowing)
- Fatigue and Fatigability
- Gait (difficulty in walking)
- Hormonal Influences for women with MS
- Inappropriate Affect (also known as pseudo bulbar affect, emotional incontinence, involuntary emotional expression disorder-IEED)
- Incoordination
- L’hermitte's (Electric shock sensation radiating down spine with neck flexion)
- Mood Liability / Bipolar Affective Disorder
- Optic neuritis (inflammation of the optic nerve)
- Pain
- Paroxysmal Symptoms
- Sensory Impairment, Numbness / Tingling
- Spasms
- Spasticity
- Tremor
- Uhthoff’s Phenomena (Heat Intolerance)
- Useless Hand Syndrome (of Oppenheimer)
- Weakness

(MS Society, Managing MS Symptoms 2012)