

HEALTH PROMOTION EXPERIENCES AND IDEAS FOR HEALTH  
PROMOTION IMPROVEMENTS: AN INTERPRETATIVE  
PHENOMENOLOGICAL STUDY OF NOVA SCOTIAN WOMEN WITH  
MULTIPLE SCLEROSIS THROUGH A FEMINIST, DISABILITY  
RIGHTS LENS

by

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## **Dedications**

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## **ABSTRACT**

Most research in health promotion uses quantitative methodology to better understand the health promotion experiences of people with disabilities. This qualitative thesis study used Interpretative Phenomenologist Analysis and semi-structured interviews as the study method. Six women with MS, aged 44 to 64, were recruited from a Multiple Sclerosis, outpatient clinic, in Halifax, Nova Scotia. Participants shared background and health promotion experiences of MS and their ideas for health promotion improvements. Four themes were constructed from the data including: contextual experiences; health promotion participation; health promotion challenges and strategies and; health promotion improvements. Results provide rich description, of participants' experiences of MS and health promotion participation, their suggestions for improvements and implications for health promotion and future research.

## **LIST OF ABBREVIATIONS USED**

CDHA:	Capital District Health Authority
DMSRU:	Dalhousie Multiple Sclerosis Research Unit
EDSS	Expanded Disability Status Scale
MS:	Multiple Sclerosis
NSRC:	Nova Scotia Rehabilitation Centre
REB:	Research Ethics Board
WHO:	World Health Organization

## CHAPTER I. INTRODUCTION

Multiple Sclerosis (MS) is an acquired neurological disease (Ennis, Thain, Boggild, Baker, & Young, 2006; Isaksson & Ahlstrom, 2006; Short, Wang, Walker, Bruno, & Thomson, 2009). Current research suggests that MS is caused by an immune system disorder, which attacks the myelin sheath (nerve covering) (Short et al., 2009). The most common type of MS is relapsing-remittent, where symptoms go into remission and then come back (Flensner, Ek & Söderhamn, 2003; Koopman & Schweitzer, 1999; McLaughlin & Zeeberg, 1993). MS affects approximately twice as many women as men (Ennis et al., 2006; Isaksson & Ahlstrom, 2006; Short et al., 2009). Rates of MS are very high in Canada (Poppe, Wolfson & Zhu, 2008). In Nova Scotia the female to male ratio for MS is 2.9 women for every 1 man (Short, 2010).

Due to high rates of MS in women, there is a need for research which focuses on the challenges women with MS encounter when accessing community services that support health, including access to health promotion facilities, private and public recreational facilities and public spaces (Bethune-Davies, McWilliam & Berman, 2006; Nosek et al., 2004). In addition, there is a call for research that focuses on attitudinal barriers (Becker, Stuifbergen & Sands, 1990) and social-psychological barriers women with MS encounter while participating in health promotion activities in an effort to better understand their health promotion needs (Becker et al., 1990; Bombardier, Wadhvani & LaRotonda, 2005; Koopman & Schweitzer, 1999).

### **Health Promotion Models and Programs**

**Health promotion.** This study adopts the World Health Organization's (WHO) Ottawa Charter (1986) definition of health promotion, which is "the process of enabling

people to increase control over and improve their health” (para., 4). Health promotion for this study is defined within this ‘enabling and increased control’ context. This study sought to understand what factors within women with MS’s lives enabled them to experience increased sense of control over their own health and well-being as well as to understand the factors that undermined this; this aim was supported by enabling the women to define health promotion for themselves within this study.

**Models.** The Barr et al. *Expanded Chronic Care Model* (ECCM) (2003) is used to frame the research question. This model calls for the development of a health promotion model, which includes a focus on population health, health promotion, disease prevention and collaborative partnerships (Barr et al., 2003). The ECCM is intended to help guide health system reform and encourage the adoption of population health principles; however, it does not address the systemic, environmental and attitudinal barriers experienced by women with disabilities or disabling conditions including MS. Through exploring the participants’ experiences, this study gives voice to the firsthand accounts of women with MS (Small, 1995), within a health promotion context.

**Health promotion programs.** The Barr et al. *Expanded Chronic Care Model* (2003) shares commonalities with recent literature on health promotion programs and interventions for people and women with disabilities (Bombardier et al., 2005; Hughes, 2006). Commonalities across the ECCM and the health promotion literature pertaining to programs and interventions include a shared vision for creating supportive environments that work collectively with persons who have chronic disabling diseases or conditions to increase control over their own health (Barr et al., 2003; Hughes, 2006). Increased control is achieved, in part, through access to affordable and accessible health promotion

facilities and activities (Bombardier et al., 2005; Hughes, 2006). However, some health promotion programs tend to manage program development from a ‘top-down’ approach, where healthcare providers design and direct activities and do not include the firsthand accounts of women with MS. Given that these programs do not address attitudinal challenges participants may encounter related to disability and gender stigma (Becker et al., 1990) there is a need to understand the impact these have on women’s health promotion efforts and experiences.

### **Critical Disability and Feminist Lens**

The research question for this study was framed by critical feminist and disability rights lens, both of which focus on how social disabilities, such as stigma and stereotypes, as well as environmental and attitudinal barriers impact women’s overall ‘lived experiences. As argued by Kushner and Morrow (2003), critical feminist researchers engage with participants to seek “reflection by women about their lives” (p. 36) as a means of “conscious-raising” (p. 36) related to women’s experiences of power in their lives. Similarly, disability rights researchers seek to address power and “the marginalization of persons with disabilities...to empower them to take control of their lives so that they may influence social policy development and inclusion of people with disabilities into the societal mainstream” (Winter, 2003, p. 1).

Some of the health promotion programs reviewed for this study explicitly or implicitly adopt a disability rights and/or critical feminist lens related the empowerment of women with disabilities within their communities (Bombardier et al., 2005; Hughes et al., 2003; Hughes, 2006; Nosek et al., 2004; Stuifbergen, Becker, Rogers, Timmerman & Kullberg, 1999). Empowerment for this study is defined as the ability of community

partners to work with women who have disabilities, to foster a sense of self-determination (Sprague & Hayes, 2000). Empowerment from a feminist and disability rights perspective is also closely linked to giving voice to those who may not otherwise be heard or whose voices are overlooked.

### **Statement of Problem and Research Questions**

There is limited research available regarding the experiences of women living with MS in accessing health promotion services and supports in their communities. Moreover, the research—and health promotion models—that do exist have not explicitly adopted critical feminist or disability rights perspectives. There is a need to investigate the systemic and attitudinal barriers experienced by women with MS through a critical feminist or disability rights lens. Therefore, the overall aim of this study was to investigate the health promotion needs of women with MS from critical feminist and disability rights perspectives. Literature regarding health promotion models and programs was also used to frame the research questions; this literature embraces principles within disability rights and feminist literature related to stigma, collaboration, inclusivity and empowerment.

The overall research question guiding data collection and analysis was: How do women with MS describe their health promotion experiences, preferences and needs? The sub questions for the study are: How are contextual experiences of MS related to health promotion experiences? What barriers or challenges to engaging in health promotion activities do women with MS experience? What ideas are important to women with MS for improvements to health promotion programs and opportunities?

### **Study Design**

The study was conducted with six outpatients recruited from the Nova Scotia Rehabilitation Centre (NSRC), MS Clinic, Capital District Health Authority (CDHA), located in Halifax, Nova Scotia. Permission to undertake the thesis study was obtained from the CDHA, Research Ethics Board (REB). The project started in mid-November 2012. This study employed Interpretative Phenomenological Analysis (IPA) as the methodological design (Smith, Flowers, & Larkin, 2009). In-depth, semi-structured interviews were conducted with women who have MS. Critical feminist and disability rights literature, including empowerment literature, and health promotion literature provided the theoretical lens to interpret themes constructed from the participants' accounts. IPA researchers assist participant with deliberate controlled phenomenological reflection (Smith et al., 2009). This reflection is undertaken by the participants when they are asked to think back to an experience, reflect and share their thoughts about how they perceived what had happened to them or to think about their experience. Through use of this method, deep insight into what it is like for women to live with MS and participate in health promotion activities emerged. Data collection involved in-depth, semi-structured interviews.

### **Summary**

Through utilization of disability rights and critical feminist lenses, the researcher and research participants were able to contribute valuable insights into how women with MS experience gender and disability in relation to their health promotion experiences, preferences and ideas for health promotion improvements. Findings presented within this study are important, as most of the existing health promotion literature pertains to the general experiences of disabled women and is survey data driven. Current research

therefore does not explore the lived health promotion experiences of women with MS from their own perspectives; nor does it explore how living with MS impacts women's health promotion participation. By exploring women's lived accounts through a critical feminist and disability rights lens, this current study can contribute to a better understanding of these gaps in the health promotion literature.

### **Organization of the Chapters**

This first chapter introduced the reader to: the main ideas derived from the literature review, the research question, and the research methods used within the study. The second chapter outlines literature which has framed the thesis research including health promotion, MS literature and feminist and disability rights literature, which includes specific literature pertaining to models of disability, stigma and empowerment. The third chapter outlines the research method and design and the fourth chapter describes the thesis research results. The final chapter discusses the thesis research findings in context to the research literature, contributions, implications for health promotion, study limitations, ideas for future research and the study conclusions.



## CHAPTER II. LITERATURE REVIEW

### Description of MS

Multiple Sclerosis (MS) is an acquired neurological disease that affects approximately twice as many women as men and is most common in young women (Ennis et al., 2006; Isaksson & Ahlstrom, 2006; Short et al., 2009). Rates of MS in Canada are very high (Poppe, Wolfson, & Zhu, 2008). In Nova Scotia the female to male ratio for MS is 2.9 women for every 1 man (Short, 2010). The prevalence rate of MS in Nova Scotia is 212 per 100,000, which is one of the highest rates in the world (Short, 2010). The typical disease course of MS is uncertain, as symptoms may go into remission or are experienced differently by each individual (Flensner et al., 2003; Ford, Gerry, Johnson & Tennant, 2001; Koopman & Schweitzer, 1999; McLaughlin & Zeeberg, 1993).

MS is a difficult disease to diagnose and there is no known cure. Current research suggests that MS is most likely caused by an immune system disorder, which attacks the myelin sheath (Short, et al., 2009). The myelin sheath is a nerve-covering insulator in the central nervous system. There are several different stages of MS including: 1. Progressive (symptoms get worse), 2. Remittent (symptoms go into remission), 3. Relapsing-remittent (symptoms go into remission, and then come back), and 4. Relapsing-progressive (symptoms go into remission, then get worse with each reoccurrence) (Flensner et al., 2003; Koopman & Schweitzer, 1999; McLaughlin & Zeeberg, 1993). Physiological symptoms of MS may include muscle spasms, weakness, mobility impairment, coordination issues, fatigue, visual distortions, bladder, bowel or sexual dysfunction, memory loss, anxiety and/or depression (Flensner et al., 2003; Koopman & Schweitzer,

1999; McLaughlin & Zeeberg, 1993; Short et al., 2009). MS symptoms may occur at any stage, in combination or alone (Short et al., 2009) and typically present as relapsing-remittent (Short et al., 2009).

People with MS experience a range of impairments and disabilities (Ford et al., 2001). Mobility can range from almost completely independent to requiring some assistance with walking, such as using a walking aid, to very limited mobility, requiring the use of a wheelchair (Kurtzke, 1983). Those who have relapsing-remittent occurrences may only suffer periodic symptoms and are usually able to function in everyday life with minimal assistance when not experiencing a remission (McLaughlin & Zeeberg, 1993). The more progressive stages of MS severely impair mobility and speech and may also affect cognitive function and contribute to greater incidences of neuropsychiatric symptoms including depression and anxiety (Short et al., 2009). The most severe cases lead to death (Kurtzke, 1983).

Chronic diseases, such as MS, have significant impact on individuals (Cotler, 1996). Persons with more severe MS symptoms, such as limited mobility and fatigue, must make lifestyle adjustments. These adjustments include living a more structured life and learning to request assistance from others, related to tasks of daily living (Flensner et al., 2003; Koopman & Schweitzer, 1999; McLaughlin & Zeeberg 1993). People living with MS may therefore struggle to maintain a sense of personal autonomy as the disease progresses (Kirkpatrick, Ottens & Fisher., 2009).

**Challenges for women with MS.** Above and beyond the physical, cognitive and emotional impacts described in the previous section, women with MS may experience profound emotional impacts while living with MS, including fear of the unknown future

or feelings of being betrayed by their own body (Flensner et al., 2003). Feelings of shame and uncertainty are often experienced by women with MS and may be compounded by the fact that many women with MS may first be told by their family members and healthcare providers that their physiological symptoms, including fatigue, loss of muscle strength or cognitive function, are psychological manifestations (Isaksson & Ahlstrom, 2006; Koopman & Schweitzer, 1999).

Once diagnosed, women with MS also struggle with coming to terms with the unpredictable disease course of MS, and with re-negotiating roles within their families (Flensner et al., 2003). Although men and women with MS may share commonalities in their experiences of MS and health promotion participation, women with disabilities or disabling conditions, including MS, may have unique health promotion needs. These include higher instances of weight gain, limited financial resources to access health promotion programs and healthy food, and limited access to supportive services for household tasks (Becker & Stuijbergen, 2004; Bethune-Davies, McWilliam & Berman, 2006; Bombardier et al., 2005).

Social support for is also important, as women with MS often suffer from ongoing fatigue related to their MS symptoms. As indicated in a study by Isaksson and Ahlstrom (2006), women with MS may feel unsupported or forgotten by family and friends. These experiences are often the result of family and friends wishing for their own lives to get back to normal, rather than assisting women with tasks of everyday living (Isaksson & Ahlstrom, 2006). Other authors have argued that resources that help support and empower disabled women's health include access to social networks and financial support (Nosek et al., 2004) and access to transportation and accessible public spaces

(Bethune-Davies, et al., 2006). Those who distribute funding, however, often fail to provide the necessary resources to support health promotion programs and facilities for persons with disabilities (Bethune-Davies, et al., 2006; Sprague & Hayes, 2000), leading to potential feelings of disempowerment for disabled women who wish to participate.

**Summary.** As outlined above, MS is a complex, sometimes severely disabling disease with an array of possible symptoms. MS most often results in some form of disability. Because of this, people living with MS need access to services and supports that not only address functional impairments but also help them live well with their health condition. The next section presents health promotion models and looks more closely at health promotion initiatives developed for women with disabilities and specifically for women with MS.

### **Health Promotion Models**

In order to explore the potential role of health promotion in addressing the needs of women with MS it is helpful to frame this discussion in relation to models of health promotion. This section summarizes health promotion as defined within the WHO, Ottawa Charter (1986) and then briefly outlines a national, population based health promotion model specific to chronic disease management (Barr et al., 2003).

**WHO and the Ottawa Charter.** Health, as defined within the WHO, Ottawa Charter, is a resource for everyday life (1986). In order to maximize support for health, the Ottawa Charter stresses a ‘charter of action’, which reorients health services to be inclusive for all people (WHO, 1986, 2010). To achieve this reorientation, the Ottawa Charter calls for advocacy on behalf of marginalized citizens, the creation of supportive environments and the strengthening of community action to ameliorate health disparities,

related to such issues as poverty and unequal access (WHO, 1986). In the example of persons with disabilities, activities to achieve these goals include such things as enhancing wheelchair accessible public spaces, accessible transportation or ensuring all citizens have access to affordable, healthy food. The Ottawa Charter also states that, “people cannot achieve their fullest health potential unless they are able to take control of those things which determine their health” (WHO, 1986, para. 4).

**The Expanded Chronic Care Model.** Barr et al. (2003) proposed an Expanded Chronic Care Model (ECCM), which included WHO definitions of health and health promotion, to build on other chronic disease models (Glasgow, Orleans, Wagner, Curry & Soberg, 2001). These authors argued for an expanded health promotion model for chronic disease management that moves beyond focusing only on disease management to focus on: population health, health promotion, disease prevention, and the collaboration between healthcare systems, individuals and community partners. In order to achieve optimal functional and population health outcomes, these authors stress that collaboration amongst those working in healthcare systems, individual citizens and community partners are essential.

Barr et al. (2003) suggested ways to facilitate community and individual empowerment, through focusing on the needs of individuals within communities. One of the many examples of this facilitation includes helping all citizens, including persons with disabilities or chronic conditions, to secure fair access to public space (e.g., public parks, recreation facilities, etc.) and public transportation, while additionally helping these individuals to develop self-management skills (e.g., coping with fatigue and pain or limited mobility). Barr et al. (2003) also called for the integration of strategies to help

mitigate social determinants of health including such issues as poverty and unemployment. In the ECCM model people work closely with the community, including workplaces and local organizations, toward developing and enhancing self-management skills (Barr et al., 2003). Self-management skills as contextualized within the ECCM move beyond traditional health education to include an emphasis on education that recognizes social determinants of health (Barr et al., 2003).

For the purpose of this study, the Ottawa Charter (WHO, 1986) and the Expanded Chronic Care Model (Barr et al., 2003) represent the macro level or broad, inclusive health promotion models that share many commonalities with health promotion research and health promotion programs within the disability rights and feminist literature. Commonalities within the literature that focus on health promotion for persons with MS (Bombardier et al., 2005), for women with disabilities (Hughes, 2006; Nosek et al., 2004), and for women with MS (Stuifbergen, et al., 1999) are discussed next.

### **Health Promotion Needs of Persons with Disabilities**

In order to address the health promotion needs of women with disabilities, including MS, there is a need to first understand the meaning of health for women with disabilities. This section reviews research that has examined this.

Nosek et al. (2004) asked 18 women, between the ages of 18 and 65 years, to describe their views of health and wellness. Participants were specifically asked to describe the psychological, social and environmental experiences they encounter in everyday life. The women in this study situated their experience of health and wellness in relation to five domains, which included: 1. Functional capacity and ability to conduct activities of everyday life; 2. Mental state, related to stress management and having a

sense of control to fulfill social roles; 3. Social support, which included the experiences of positive attitudes and relationships with others; 4. Disability related challenges, including fatigue levels or pain management; and 5. Positive interactions with healthcare providers. Positive interactions with healthcare providers included: feeling that healthcare providers understand the details of their particular disability, trusting their healthcare providers, and feeling empowered to participate in decisions about their own treatment course (Nosek et al., 2004). Finally, from a broader systemic perspective, participants felt that their health behaviours were negatively affected by lack of choice and fair access to public and private health promotion facilities and programs.

Similar to Nosek and colleagues (2004), Stuifbergen (1995) questioned how persons with MS select and sustain health promotion behaviours. People within their study rated lack of access to health facilities and lack of time as the most likely reasons they would not participate in health promotion activities. In a related study, Becker and Stuifbergen (2004) conducted a 10-year community-based research project to gather information related to intrapersonal and environmental challenges experienced by persons with polio or MS. These authors concluded that fatigue and limited personal and financial resources were the top challenges reported for failure to participate in health promotion programs.

Research has also been conducted to investigate the challenges people with disabilities, including MS, encounter while participating, or attempting to participate in health promotion and health prevention activities (Becker & Stuifbergen, 2004; Bombardier et al, 2005; Rimmer, 2008). For people with MS, these include, physical or disease associated challenges, including fatigue or mobility limitations (Flensner et al.

2003). Persons with disabilities may also encounter environmental challenges to health promotion participation including limited access to transportation (Short et al., 2009) and every day challenges related to experiences of living with symptoms, including limited mobility and fatigue (Becker, Stuifbergen & Sands, 1990; Bombardier et al., 2005; Koopman & Schweitzer, 1999).

Health promotion participation is also affected by attitudinal challenges participants encounter, related to family and healthcare provider's apathetic or stigmatizing attitudes (Becker et al., 1990). Of the many health promotion challenges encountered by persons with disabilities, stigma may be the most damaging. Stigma is considered "a mark of disgrace associated with a particular circumstance, quality or person" (Oxforddictionaries.com, accessed July 2014). Disability rights literature shows that persons with disabilities regularly encounter attitudinal challenges related to stigmatization (Denton, Prus & Walters, 2004; Gerschick, 2000; Taub et al., 2003). Schur (2004) reported that non-employed, disabled women are more likely to report discriminatory attitudes, including verbal abuse from people in their community when compared to employed, disabled women, disabled men and non-disabled persons. Furthermore, in an article pertaining to older women with disabilities, Bethune-Davies and colleagues (2006) outline that, "individuals living with chronic disabling conditions, in particular women, continue to face considerable social discrimination and stigmatization" (p. 206). Social discrimination therefore affects daily living and the disabled person's 'social world' (p. 206), which also encompasses people's leisure, health and wellness 'worlds.' Social discrimination and stigmatization may result in poor self-



image and may affect the ways in which persons with disabilities are taught about such issues as healthy living (Bethune-Davies, et al., 2006; DAWN, 2008).

Additionally, Bethune-Davies et al. (2006) argue that societies' negative attitudes and stereotypes of disabled women may affect healthcare providers' decisions to suggest health promotion activities for women with disabilities. More specifically, Sprague and Hayes (2000) suggest that healthcare providers and healthcare systems are not impervious to the affects of pervasive stereotypes about disabled persons' abilities. Stereotypes about disabled persons may therefore directly or indirectly affect the prioritization and funding for health promotion programs, which target the needs of disabled persons, disabled women or persons with chronic disability conditions.

In reference to women with disabilities, Bethune-Davies et al. (2006) also argue that "despite advances in the women's health movement, little has been done to promote the health of elderly women with chronic disabling conditions" (p. 205). These authors argue that "individuals living with chronic disabling conditions continue to face considerable social discrimination and stigmatization" (p. 205). Although social injustices, such as having limited access to health services, living with stigmatization, social isolation and poverty are more prevalent in older women with disabilities, these injustices are also experienced by younger, disabled women (Sprague & Hayes, 2000), including younger women with MS. These attitudinal challenges related to stigmatization, vulnerability and shame are important to discuss in a health promotion context, as these experiences may contribute to the underrepresentation of older and younger disabled women in health promotion programs and activities (Chevarley, Thierry, Gill, Ryerson & Nosek, 2006). Women with disabilities, including MS, also

continue to fight for fair access to health preventative services (Bethune-Davies et al., 2006; Chevarley et al., 2006; Nosek et al., 2004), including access to accessible doctor's offices and medical equipment (Short et al., 2009).

In summary, health promotion needs and challenges are important to explore as they may hinder the participation of women with MS in health promotion activities and programs. Participation in health promotion programs and activities is important, as it is known to improve overall health for women with MS (Ennis et al., 2006; Stuifbergen, 1997c). Literatures pertaining to current health promotion programs for persons with disabilities, including MS, are discussed in the next section.

### **Health Promotion Programs**

Some health promotion programs and wellness interventions for persons with disabilities or MS share commonalities with the ECCM (Barr et al., 2003). All identify the importance of creating supportive environments, while additionally emphasizing collaborative partnerships with healthcare providers and persons with chronic conditions (Hughes, 2006; Stuifbergen et al., 1999). Health promotion programs for women with disabilities or chronic conditions also explore ways to overcome barriers to health promotion participation (Hughes, 2006; Stuifbergen et al., 1999). Very little research has specifically addressed the health promotion needs of women with MS (Stuifbergen et al., 1999); however, there have been some efforts to develop programs for persons and/or women with disabilities. These are discussed next.

**Health promotion for women with disabilities.** Similar to key themes outlined in the Ottawa Charter (WHO, 1986) and the Barr et al. (2003) Expanded Chronic Care model, Hughes (2006) argued that health promotion programs designed for women with

disabilities should work toward the elimination of social disparities. She recommended that health promotion programs include strategies for improving disabled women's access to education, employment and freedom from violence (Hughes 2006). Hughes also suggested that the health of women with disabilities could benefit from enhanced decision-making responsibilities and community participation (2006). Based on this, she argued that health promotion models designed specifically for women with disabilities should seek to adapt feminist definitions of empowerment, which focus on connectedness to others, while also fostering women's self-efficacy skills (Hughes, 2006).

Hughes (2006) outlined six key principles for health promotion practitioners to follow when developing health promotion programs for women with disabilities. Among these principles is the need to prioritize the creation and funding of public health programs for women with disabilities and to ensure that women with disabilities are involved in health promotion program planning and implementation (Hughes, 2006). Hughes advocated for programs to be built on existing evidence-based theory in health promotion, which incorporate process and outcome evaluation.

Hughes (2006) further recommended that health promotion programs for women with disabilities be tailored and customized to suit the needs of women with disabilities. Tailoring may include discussions about the experiences of poverty, violence against women and women's sexual and reproductive health (Hughes, 2006). A final principle is that program developers consider contextual factors that may limit women's abilities to participate, including dependency on others for transportation, or lack of access to public transportation and accessible facilities (Hughes, 2006).

**Health promotion programs for people with MS.** Bombardier et al. (2005)

argued that most health promotion activities targeted specifically for persons with chronic conditions are “entirely initiated and maintained by the person with chronic illness,” (p. 557) or are “prescribed, and delivered by health care” (p. 557). These authors suggested several key components for enhanced health promotion programs designed specifically for persons with MS to combine elements of self-management in addition to peer and professional support. These include suggestions for: teaching customized exercise programs, stress reduction, building social support networks, developing coping skills, compliance to disease modifying therapies, diet improvement and how to avoid substance abuse.

Bombardier et al. (2005) provided suggestions for designing a health promotion program to address coping with fatigue and uncertainties related to disease course. An example of customized exercise programs might include a focus on pacing to avoid exacerbation of MS symptoms, graded exercise for fatigue management and cooling of the body before, during and after exercise (Bombardier et al., 2005). Regular exercise for persons with MS is shown to improve mobility (walking), bowel and bladder function, and moods (Petajan et al., 1996; Petajan & White, 1999; Sutherland & Andersen, 2001). Persons who exercise also experience a greater sense of social integration and report higher instances of leisure activities outside of exercise programs (Petajan et al., 1996; Petajan & White, 1999; Sutherland & Andersen, 2001). Regular exercise has also proven beneficial for persons suffering from mild and progressive MS symptoms (Bombardier et al., 2005). Finally, Bombardier et al. (2005) argued for strengthening community, peer and professional support. These authors suggested that health promotion interventions

that incorporate follow-up telephone calls might be beneficial to participants and some may benefit from peer support groups, especially if they are given an opportunity to provide support to others with MS. The positive effects of peer support are corroborated in other, similar research studies (Maton, 1988; Nosek & Hughes, 2003; Reynolds & Prior, 2003; Schwartz & Sendor, 1999).

The final reviewed article specifically pertains to a health promotion intervention for women with MS. Stuijbergen et al. (1999) created a wellness intervention based on previous research studies they had undertaken (Stuijbergen, 1995; Stuijbergen 1997a, 1997b, 1997c). They tested the wellness intervention with nine women who have MS. This study included an eight week, lifestyle change program that included topics pertaining to maximizing health, lifestyle adjustment, exercise in everyday life, stress management, healthy eating, sexuality, reproductive health and building healthy relationships (Stuijbergen et al. 1999). After the women completed the eight-week program, a nurse specialist conducted bi-monthly follow-up phone calls. The nurse talked to participants about their successes in life-style change (e.g. maintaining exercise at home) and helped participants' to problem solve. The nurse also asked participants if they had encountered challenges to health promotion since finishing the program. The overall findings of Stuijbergen et al. (1999) found that women with MS experience positive benefits from participating in wellness interventions that specifically "address self-perceived challenges to health promotion, [that] work toward building participants' sense of mastery of their health behaviors" (p. 75). These authors argue that pro-active health promotion models may be more effective than passive programs, which only provide health and wellness information without including follow-up support. Finally, consistent

with the other research, these authors emphasize holistic, collaborative approaches to health promotion programs for women (or persons) with disabilities or chronic disabling conditions or diseases. Their final recommendations include a focus on the unique needs of women with MS including: fatigue management, lifestyle adjustment, stress management, exercise and nutritional health and developing positive personal relationships (Stuifbergen et al., 1999).

**Summary.** Models such as the Barr, et al. ECCM, that focus on population health promotion, the social determinants of health, collaboration and fair access are helpful to explore the potential role of health promotion in addressing the needs of women with MS; however these models do not provide context for how to address systemic barriers encountered by women with MS, including issues related to gender and disability.

Much of the reviewed literature pertaining to the health promotion needs of persons with disabilities indicates that positive interactions, social support and fair access are indeed important to people with disabilities and that stigma may play an important role in negative experiences. Although a few researchers have begun to investigate the health promotion needs and experiences of persons with disabilities, few have specifically investigated the experiences of women with MS. Health promotion programs for persons/women with disabilities have begun to be developed; however these tend to approach program development from a ‘top-down’ approach where healthcare providers design and direct activities or are offered over a limited period and implemented by healthcare providers. These programs however do not include the firsthand accounts of women with MS, from their own perspectives. There is a call for research that pertains to

the health promotion needs of women with MS and that incorporates a critical feminist and disability rights lens.

### **Models of Disability**

While the health promotion models and programs described previously are intended to address the needs and rights of persons living with chronic conditions or disabilities for equitable access to services and supports that will enable them to optimize their health and well-being, these models do not directly address what it means to live with a disability in society. To better understand this, a review of models of disability is warranted.

The concept of disability has been defined within four historical models (Kaplan, 1999). The first of these models is the moral model. This model associates disability with sin and as something that brings shame upon the disabled person and their families. Historically, persons with disabilities were excluded from society or hidden away within institutions. The second is the medical model, which was developed as modern medicine advanced (Kaplan, 1999). This model views persons with disabilities from a medical perspective, where they are seen as an amalgam of their bodily functions and limitations and are viewed as having little to contribute to society (Kaplan, 1999). The third model is the rehabilitation model, which is an extension of the second model. In this model, persons with disabilities are viewed as defective projects to be rehabilitated or fixed (Kaplan, 1999). Implicit in this model is the idea that persons with disabilities are inferior to 'normal,' non-disabled persons. Most disability rights groups have adapted the fourth and final disability model (Kaplan, 1999). This model shifts the focus from the individual to the social constructs of disability, which focus on environmental and attitudinal

barriers that stigmatize disabled persons and the disabled body and overlook the inclusion of persons with variant abilities to fully participate in society (Kaplan, 1999). Kaplan (1999) therefore argues that ideas of disability are culturally constructed, thus leading to deeply embedded stereotypes of what it means to be disabled. Kaplan (1999) states that:

When we consider bodily differences-deviations from a society's conception of a 'normal' or acceptable body-that, although they cause little or no functional or physical difficulty for the person who has them, constitute major social disabilities. (p. 357)

This fourth model of disability informs the research study through shifting the focus away from viewing women with disabilities as projects to be fixed, to focus on how social disabilities, such as stigma and stereotypes as well as environmental and attitudinal barriers, impact women's overall lived experiences. Lived experiences also include health promotion participation experiences and subsequent preferences and ideas for what improvements are important. These include not only preferences related to improving or maintaining physical health while living with MS, but also related to improving conditions for inclusivity, access and empowerment experiences through health promotion participation.

### **Critical Feminist and Disability Rights Theories**

There are many schools of critical theory (Kincheloe & McLaren, 2005). Disability rights and critical feminism are two schools of critical theory that helped set the theoretical lens used to address the research questions. These two theories are appropriate for the phenomenological method used within this study as both perspectives are interested in how women with disabilities interpret and make meaning of every day



experiences. Each perspective also emphasizes how disabled women's experiences are manifested through issues of unequal power relations and through the standpoint of privileged, non-disabled persons in positions of authority and power (Sprague & Hayes, 2000; Weaver & Olson, 2005).

For example, in critical feminist literature power and decision-making are seen to be unequally distributed in favour of the patriarch (e.g., male dominated social systems) (Zimmerman & Hill, 1999). In critical disability rights literature research shows that disabled women, as similar to able-bodied women, are more vulnerable to poverty when compared to men (Bethune-Davies et al., 2006). Disabled Nova Scotian women also experience poverty (The Nova Scotia Disabled Persons Commission, 2008). It therefore may be very difficult for women with MS to participate in health promotion programs that are fee based, such as yoga classes, fitness classes or any type of class, which promotes healthy living. This is especially true for women with limited mobility or transportation options.

In disability rights literature, power and decision-making are seen as being in the hands of able-bodied persons (Bethune-Davies et al., 2006; DisAbled Women's Network Canada, [DAWN], 2008; Reid & Tom, 2006). For example, public spaces are often inaccessible. Lack of accessible space may in part be due to abled bodied persons' assumptions that people with disabilities have limited capacity to participate in society as 'functional' citizens and are not 'worth the effort' or public investment (DAWN, 2008; Hughes, 2006; Neri & Kroll, 2003). Public and government apathy are also reflected in people's failure to demand equal access to health promotion programs for all citizens (Weaver & Olson, 2005).

Societal assumptions about disabled person's capacity to participate in health promotion activities also represent an example of a taken for granted social norms made 'real' through tacit, everyday social interactions (or the failure to interact) with disabled persons. These assumptions are manifested through public apathy, exclusion by omission or hostility toward disabled persons. In context to this study, examples of public apathy or hostility toward women with MS may include such issues as the public's failure to: 1. Build healthcare facilities that include the perspectives and voices of disabled women; 2. Offer affordable, inclusive health promotion programs that fully integrate the health promotion needs of women with MS; 3. Consider women's experiences of gender and disability stigma, which may hinder or impact their full participation in health promoting activities; and 4. Provide health promotion classes that consider all body types, and whose instructors are aware of potential patronizing or hostile language.

**Gender and disabled women.** In addition to experiencing 'social disabilities' as outlined by Kaplan (1999), women with disabilities, as similar to all women, are also subjected to culturally constructed gender role stereotypes of what it means to be a woman. These stereotypes characterize women as natural nurturers and caregivers, who are socially rewarded for neglecting their own needs for the needs of their families (Gerschick, 2000). Women's care giving roles may include, care giving for children, elder parents and husbands, grocery shopping, cooking and other household tasks, in addition to paid labour roles. Fulfilling gendered tasks may be particularly challenging for women with MS, due to physical limitations and MS fatigue.

Gerschick (2000) argues that, "stigmatization is embedded in the daily interactions between people with disabilities and the temporarily able-bodied" (p. 1264)

and that gender stigma and disability stigma intersect (Gerschick, 2000). For women with disabilities, this may mean that they feel stigmatized as being incapable of fulfilling their duties as wives, caregivers or mothers. Disabled women are also often stereotyped as being needy, childlike or helpless, leading to feelings of guilt, shame and a struggle for personal autonomy and independence (Asch, Rousso & Jefferies, 2001; Taub, Fanflik & McLorg, 2003). For women wishing to participate in health promotion activities, gender stigma may lead to feelings of shame or guilt for neglecting their family ‘duties’ to participate in health promotion activities. By bringing in a disability rights and critical feminist lens, this study is able to focus the research questions to address how women with MS experience disability and gendered stigma in a health promotion context.

### **Empowerment**

Empowerment is one way to address or mitigated gendered stigma and other forms of social exclusion and discrimination, including disability stigma. Zimmerman (1995) defines empowering processes as the freedom of persons to choose from options available to them and to “control decisions that affect their lives” (p. 583). Empowering processes also “provide opportunities for shared leadership, development of a group identity, skill development and participation in organizational tasks” (p. 583). For this study, empowerment is defined as the ability of community partners to work in partnership with women who have disabilities, to give voice to their concerns and to foster a sense of self-determination (Sprague & Hayes, 2000). Empowerment outcomes for women with MS are the result of empowerment processes including their sense of gaining control, resource mobilization and participation in activities that are readily available to non-disabled persons. Specific to women with MS, this includes having

access to health promotion activities that facilitate informed decisions about their health and wellness needs.

Empowerment is achieved in part through the community's (healthcare, educational and government institutions) willingness to facilitate disabled women's sense of self through relationship development that are mutually beneficial and affords disabled women the opportunity to freely choose and interact with their peers (Sprague & Hayes, 2000). Sprague and Hayes (2000) therefore do not view access to one's own power as solely contingent upon narrow concepts or innate personality traits, such as will power and self-discipline. Based on these arguments, one can therefore argue that 'empowerment' messages, embedded in traditional health promotion discourse, that are singularly based on behaviour modification techniques are incomplete, as these techniques overemphasize the individuals' responsibility for controlling their own behaviours (e.g., as reflected in the Health Belief Model; Becker, 1974). According to Sprague and Hayes (2000), women's sense of empowerment can be increased by, "sharing skills and removing obstacles" (p. 679) that impedes participation. A sense of empowerment is also enhanced through "access to resources" (p. 679). These authors concluded that a sense of empowerment may be achieved once society chooses to commit to supporting the social conditions required for women with disabilities to succeed, such as access to supportive environments and accessible activities (Barr, et al., 2003; Bombardier, Wadhvani & LaRotonda, 2005; Hughes, 2006; Sprague & Hayes, 2000).

Sprague and Hayes (2000) explain that disabled women's experiences of disempowerment are related to how society tends to negate the actual opportunities women with disabilities have in society. These authors argue that disabled person's

access to resources are impacted by the effect of exploitative relationships, “that allow some to accumulate resources and maintain control” (p. 674) over others. Moreover, Sprague and Hayes explain that, “in our stratified society... race, class, and gender inequality interact to create categorically distinct matrices of opportunity and constraint” (p. 675). Power, in their view, is a “possession of the individual” (p. 674). As outlined above however, women with developmental disabilities, or other disabling conditions or diseases such as MS, often struggle to maintain a sense of personal autonomy, which leads to feelings of disempowerment.

### **Summary**

From the health promotion, disability rights and feminist literature reviewed it is clear that women with MS face multiple jeopardies that may affect their health promotion participation. In summary, these include such issues as: their MS symptoms, including fatigue and loss of mobility; their experiences of stigma related to the disabling symptoms of MS; pervasive stereotypes which deem disabled women as needy or inept; attitudinal and environmental challenges they encounter in everyday life, including negative attitudes of others; and financial and access disparities, which hinder their ability to fully participate and engage in health prevention and promotion programs and activities. Women with disabilities, or disabling conditions such as MS, may feel unsupported by their family (Isaksson & Ahlstrom, 2006) or have few social networks and financial supports to engage in health promotion activities (Nosek et al., 2004). Women with MS who wish to participate in health promotion activities do not do so in a vacuum, as they must contend with stigmatizing experience related to gender such as feeling guilty for not fulfilling family duties or being dismissed or overlooked

(Gerschick, 2000) and stigmatising experiences associated with disability, such as being viewed as medical projects to be fixed (Kaplan, 1999). Moreover, as evidenced in the disability rights and feminist literature, women with disabling conditions such as MS not only struggle with symptoms, but also are not afforded the same access and opportunities as non-disabled persons to fully engage within their communities (Bethune-Davis, et al., 2006; DAWN, 2008; Zimmerman & Hill, 1999). This in part is due to systemic stigma and social disabilities which fail to ensure equal opportunities for disabled persons (DAWN, 2008; Kaplan, 1999).

This current study responds to the call for the health promotion researchers to adapt feminist and disability rights definitions when undertaking health promotion research (Hughes, 2005). Models such as the ECCM (Barr et al., 2003) help to guide health system reform through use of population health promotion principles; however, this model does not address systemic gendered barriers encountered by women with disabilities, including MS. Although a few researchers have begun to investigate the health promotion needs and experiences of persons with disabilities, few have specifically investigated the experience of women with MS. Nor has most current health promotion research incorporated a critical feminist and disability rights lens when investigating the health promotion experiences and preferences of women with disabilities. Finally, it seems that an empowerment orientation to addressing these issues, through a critical feminist and disability rights lens, should include a discussion of empowering processes from women's own perspectives, including exploring their ideas for improving shared leadership opportunities with health promotion.

## CHAPTER III. RESEARCH METHOD AND DESIGN

### Introduction

I became interested in investigating the health promotion experiences of women with MS, while working in a rehabilitation centre in an Atlantic Canada city. At the onset I was frustrated with the lack of supportive services and health promotion programs available for women with MS and felt compelled, as the research to advocate on behalf of women with MS. As part of my inquiry, I discovered that MS occurs most often in women and affects twice as many women as men (Ennis, et al., 2006; Isaksson & Ahlstrom, 2006; Short, et al., 2009). Upon initial investigation, I also discovered that few current research studies explore the specific health promotion experiences, needs and preferences of women with MS, from their own perspectives. Through use of interpretative methodology, I sought to address these gaps in the literature. As my analysis progressed, I discovered that women with MS participate in health promotion activities in a variety of settings, including their homes, and that their ideas for health promotion activities moved beyond for fee programs to include a variety of leisure and health prevention activities.

Guided by interpretative phenomenology the purpose of the study was to explore the health promotion needs and preference of women with MS. The overall research question guiding data collection and analysis was: How do women with MS describe their health promotion experiences, preferences and needs? The sub questions for the study are: How are contextual experiences of MS related to health promotion experiences? What barriers or challenges to engaging in health promotion activities do women with MS experience? What ideas are important to women with MS for

improvements to health promotion programs and opportunities? Therefore, the overall purpose of the study was to gain deeper insight into not only the health promotion experiences of women with MS, but also how their contextual experiences impact their health promotion participation and preferences and what is most meaningful and important to them for improvements to health promotion activities, programs and opportunities.

### **Study Site**

In Nova Scotia, patients who meet the criteria for referral are referred to the Nova Scotia Rehabilitation Centre (NSRC), MS Clinic, usually by their family doctor. Medical treatment offered at the NSRC may include: (a) medications to control pain, muscle spasticity or depression; (b) specialized physiotherapy programs, which provide exercise routines; and (c) occupational therapy, which provides fatigue management and pacing advice early on in the disease course (Dr. Christine Short, personal communication, July 6<sup>th</sup>, 2011). If the disease has progressed (that is, the patient has low functional mobility), patients may also have access to physical therapy programs which teach them how to safely use mobility aids, including braces, walkers and wheelchairs. Through occupational therapy, patients also have access to safety equipment for their home, such as bathroom rails (Dr. Christine Short, personal communication, July 6<sup>th</sup>, 2011). Health promotion education may or may not be included in treatment and, if offered, is usually provided by a physician, nurse or dietician, not a health promotion practitioner (Dr. Christine Short, personal communication, July 6<sup>th</sup>, 2011).

### **Methodological Approach**



To address the research questions, IPA was adopted as the methodological approach. Developed by Smith, Flowers and Larkin (2009), IPA researchers assume that: (1) The lived experiences of individuals are subjective; (2) Themes that emerge from the research data are interpretations, which are produced by the participants' accounts and the researcher's interpretations; (3) Meanings that emerge from the data are co-constructed between the research participant and the researcher; and (4) That it is impossible for researchers to set aside their own beliefs within the research process (Dombro, 2007).

Specific to the third point, in IPA methodology the researcher is thought to be linked to the research participant in what is referred to as the *double hermeneutic*, where the researcher reads and re-reads the data. In this method, the researcher first begins to document or code the research participants' firsthand accounts of their lived experiences. This is often referred to as 'staying close to the data,' which means that data is coded as it is stated. The researcher next attempts to interpret these codes through a specific theoretical lens (Smith et al., 2009). In this study, health promotion literature (pertaining to health promotion models and programs for persons/women with disabilities and women with MS), critical feminist and disability rights theoretical lenses are used. My interpretations are constructed, subjective, and made accessible through the developing relationship of the researcher and the participants' firsthand accounts of their own experiences and are interpreted through these lens.

IPA draws upon interpretative phenomenology as established by a 20<sup>th</sup> century philosopher, Martin Heidegger. Heidegger was interested in how knowledge is re-created thorough ongoing social exchange and language (Smith et al., 2009). Much of

Heidegger's work focused on how peoples' relationships unfold within everyday activities. Heidegger was also interested in how humans make meaning of their everyday experiences (Smith et al., 2009). Heideggerian theory is suited to the research questions, which explore how women with MS experience MS and health promotion activities. Analytical techniques used within IPA also fit well within critical feminism and disability rights theoretical perspectives by giving voice to the perspectives of women with MS.

Smith et al. (2009) argue that researchers might not necessarily be aware of their own preconceptions in advance of undertaking the data analysis. These authors suggest that IPA researchers therefore employ a cyclical approach to data analysis, which involve self-reflexive practices, through use of memoing and annotations, continuous check in with the thesis advisor and through a cyclical review of the literature. The researcher's thoughts and interpretations then become intricately intertwined within the research analysis and the thematic development.

Researchers who employ IPA do so to understand the experiences of their participants and to engage with them on a deeper level, through use of in-depth interviewing techniques (e.g. as compared to surveys or structured interviews). In addition, IPA researchers interpret research findings from a theoretical perspective, which is grounded in thematic results that have arisen from the "central accounts" of their participants (Smith, et al., 2005).

The theoretical lens for this thesis research draws upon critical feminist and disability rights perspectives. These theoretical lenses are appropriate to the study questions, as disability rights feminist methodologies recognize the importance of listening to and validating women's and disabled persons' experiences (Hall & Stevens,

1991; Kaplan, 1999). IPA researchers believe that it is important for people to share their experiences from their own perspectives, to gain deeper insights into meanings people make of their experiences. Currently, few health promotion models and programs have incorporated the voices of women with MS into the discussion, to add context of women's lived experience of health promotion to the discussion.

### **Research Design and Study Context**

Methodological tool and techniques appropriate for an IPA research design were used. This included the use of in-person, semi-structured participant interviews as the primary methodological tool. The study was conducted with outpatients recruited from the NSRC, MS Clinic, Capital District Health Authority (CDHA), located in Halifax, Nova Scotia. Permission to undertake the thesis study was obtained from the CDHA, Research Ethics Board (REB). The project started in mid-November 2012.

**Sample.** Research has shown that women are more likely to have MS and that onset of first MS symptoms usually occurs in early adulthood (Flensner, et al., 2003). In order to obtain feedback from a variety of women from various age ranges and mobility levels, a purpose sample was identified. This sample included women: (1) Within age ranges of 44 to 64 years, (2) who had a range of mobilities (ideally seeking 2 women who are mostly mobile, 2 women who are moderately mobile and 2 who have limited mobility), (3) who had MS for at least one year, and (4) who presently participate (or have attempted to participate in health promotion programs or activities). Women with limited cognitive ability were excluded from the study at the referring clinician's discretion, due to the nature of the study tool. Finally, to participate in the study, participants had to speak English.

Six women who fit the above sampling criteria were recruited to participate in the study and all consented to participation; they were between the ages 44 and 64 years of age. While this best reflected the average age range of women at the MS clinic, the research had hoped to recruit women from a broader age range of 20 to 65 years (see limitations section of this study).

**Standard of care.** Mobility can affect physical and psychological health in women with MS. To ensure that the sample was representative of the range of the mobility and disability the clinical director therefore used the mobility scales to identify a purposeful sample from which to recruit. To determine the mobility levels of women recruited to participate in the study a standard of care disability measure was used: the Kurtzke Expanded Disability Status Scale (EDSS) (Kurtzke, 1983). It is used by clinicians with outpatients who attend the MS Clinic. This is a disability status scale, which ranges from 1 to 10, where 1 represents a normal neurological exam and 10 represents death due to MS. Those rated within the lower middle end of the scale are mostly mobile, with moderate disability. Those rated within the higher middle end of the scale are moderately mobile, with use of an aid and are able to walk within a variety of distances without rest (see Appendix B for details of the EDSS). Patients who had limited mobility, moderate mobility and who were mostly mobile were identified as potential study participants. To represent this range, the six participants recruited for this study therefore included two women who have limited mobility (in the 6.0 to 7.5 range), two women who have moderate mobility (in the 4.0 to 5.5 range), and two who were mostly mobile (in the 2.0 to 3.5 range).

**Recruitment.** The standard CDHA, REB rules for approaching potential participants is to ask the clinicians, or healthcare providers who care for the outpatients, to initiate first approach. Therefore, during the recruitment phase, Dr. Christine Short, Associate Professor, Department of Medicine, Dalhousie University and Division Chief, Physical Medicine and Rehabilitation NSRC, first approached outpatients (potential participants) and provided an introductory letter to the study (See Appendix D, for Introductory Letter). The names and contact information of interested outpatients were then forwarded to the researcher, with their permission. Recruitment for the project took longer than expected, due to finding participants of a variety of ages and mobilities, with the last interview occurring in October of 2013.

**Informed consent process.** The researcher contacted potential participants by phone or in person at the MS Clinic. At this time, the researcher provided a detailed consent form (See Appendix C). A time and place was arranged to review the informed consent process. Participants were told they could take part in the study in one or two interviews, at the MS clinic or in their homes. All six participants were provided time to read the consent form in advance of their interview. Each signed the CDHA-REB informed consent form, prior to their participation in the study.

**Interview guide.** In 2011, three pilot interviews to test the interview guide were conducted in advance of undertaking the thesis research. These pilot data were not incorporated into the thesis data, but did inform the refinement of the interview guide, through obtaining feedback from the participants regarding the clarity of the questions.

The interview guide was set-up in two parts, comprised of descriptive, narrative, feelings, conceptual questions and direct questions. Prompts and probes were interjected

throughout the interview, where required. For example, “Can you tell me more about that? What do you mean by that? This is what I have just heard from you, is this correct?” (Smith et al., 2009). In the first half of the interview, simple demographic information was collected from participants pertaining to their age, place of residence, number of children (children living at home, marital status and the duration and type of MS). The focus of the next interview questions asked the participants to recollect their background histories of MS and feelings related to having MS. The next half of the interview questions asked participants to think about and share: (a) Their background experiences of MS and interactions with family, healthcare providers and the community; (b) their health promotion experiences and preferences (e.g., what activities they participate in, what participation means to them); (c) challenges they may have faced while attempting to participate and maintain health promotion activities and strategies they employ to overcome these challenges; and (d) their suggestions for improvements for health promotion opportunities (e.g., activities, programs) for Nova Scotian women with MS. (See Appendix A, for Interview Guide).

**Participant interview procedures.** All six participants opted for a single interview, as each had busy schedules. Three participated at the MS clinic, two participated in their homes and one participated at her place of employment. All interviews were conducted in a quiet, private location without anyone else present. Each interview lasted approximately 1 ½ hours, depending on the direction and scope of the emerging discussion. Prior to each interview, participants were reminded that they were free to end the interview or withdraw from the study at any time. They were also reminded that they could decline to answer specific interview questions if the questions

made them feel uncomfortable or were non-applicable to their situation. The interviews were recorded using a digital voice recorder. The participants were asked permission to record the interview as part of the consent process. The researcher conducted all six interviews.

**Data management.** Research assistants were hired by the researcher to transcribe the participant interviews verbatim. The research assistants, in advance of transcription services, signed the appropriate Transcription Confidentiality Agreement. All transcribed interview data were saved into Microsoft Word documents. These documents were then uploaded into QSR International NVivo 9 qualitative data analysis software as a research project. Electronic data and paper data were then stored in a locked office at the NSRC as required by the CDHA, REB. Electronic data were erased from the digital voice recorder and saved to an encrypted USB thumb drive; this will be physically destroyed after the required 7 years storage.

**Data analysis and memoing.** The interviews were collected in an iterative, ongoing manner. Data analysis began immediately, once the first interview was transcribed and reviewed for accuracy by the researcher. Using open coding (in the first stage), I first explored the participants' attempts to make sense of their own experiences (Miles & Huberman, 1994a, 1994b; Smith et al., 2009). As the data were explored in the first stage of analysis, I stayed close to the data (coded NVivo). During the first level of analysis, I also recorded my own impressions and thoughts pertaining to the interviews, using annotations features available in QSR International, NVivo 9 software. My thoughts and impressions were incorporated into the data analysis, using open-ended coding and memoing (Miles & Huberman, 1994b; Smith et al., 2009) and through

dialogue with my thesis advisor. I actively engaged with the data through reading and re-reading of the verbatim transcriptions. Preliminary descriptive codes were then developed. The preliminary coding started with the first interview, and then went across interviews until thematic patterns in the data began to emerge.

In the next level of analysis, I began to introduce my own thoughts and interpretations, through use of further memoing techniques and a higher level of interpretative coding structure (Smith et al., 2009). Thick description and interpretation of the data was achieved by reviewing: (1) the language the women used to describe their experiences, including metaphors and analogies; (2) how the women recollected their experiences related to time sequence (as their MS symptoms unfolded); and (3) meanings the women attached to their experiences. As the analysis progressed, I then began to develop conceptual frameworks, through use of tables and summaries mailed to the participants for validation and feedback (2 of 6 participants provided minor feedback). These tables and summaries informed the final thematic structure, presented in this thesis paper. This structure was also informed by regular dialogue with my thesis advisor and through continuous literature review in reference to the chosen theoretical framework (e.g., critical feminism and disability rights theory).

The count function within QSR International, NVivo 9 was used to assess frequencies of key terms and key words (Smith et al., 2009). Portions of the final thematic analysis were also incorporated into visible representations, including figures and tables. (See Figures 1 through 8 and Table 1). Smith et al. (2009) defines this final level of analysis as the level of theme development (overall framework) (Figure 2). Here the researcher incorporates the “unique idiosyncratic instances” (p. 101), which includes



the unique and common experience of the individual participants, within themed relationships, in addition to the overall shared order of the developed themes.

**Data write-up and dissemination.** Writing of the initial thesis draft was completed in conjunction with the data analysis. The results section is rich in thematic description and provides a comprehensive discussion of how women with MS describe their experiences with MS and their participation experiences of health promotion. Health promotion literature, critical disability rights and feminist literature informed the theoretical perspective used to interpret data. The data write-up also provides a rich description of how the research literature framed the thesis questions and resulting discussion. The final thesis will be shared with the participants (who have requested a copy), and the MS Clinic, NSRC, CDHA.

### **Criteria for Trustworthiness**

**Researcher's perspectives.** The researcher's personal value system is based on a firm belief that there are multiple, inter-subjective truths of reality that are co-constructed through human interactions. I therefore fully acknowledge that my academic and worldviews have influenced the data analysis, interpretation and thesis write-up. (Kincheloe & McLaren, 2005). Moreover, my worldviews are also strongly influenced by my undergraduate studies, which included an in-depth study of the sociology of the body and the sociology of health and women's studies. Some of my assumptions were that the women in my study would report participating in few health promotion activities, however these viewpoints shifted as women began to share a vast array holistic activities, a broad definition of what they do to remain healthy and how they contextualize health

promotion. I also discovered that several of them had begun to self-initiated activities to improve fair access and peer support activities within their communities.

This stated, I did however feel confident in my professional training as a qualitative researcher to critically reflect on my world viewpoints; I endeavored to make these transparent at every stage of the data analysis and interpretation, through annotations and continuous dialogue with my thesis advisor and through maintaining detailed records (Hall & Stevens, 1991).

**Trustworthiness.** Qualitative standards were employed to address rigor and trustworthiness (Guba 1981; Lincoln & Guba, 1985). Data analysis followed rigorous criteria, testing for credibility, transferability, dependability and confirmability (Stringer & Genat, 2004).

Trustworthiness and credibility were addressed through: (1) Prolonged engagement with the participants (during their interviews) and the data (through deeply engaging with the audio and verbatim transcripts); (2) provision of summarized versions of interview results, mailed to participants via registered mail, as an opportunity for participants to verify how their transcripts were interpreted and to provide feedback (refute, confirm or clarify); and (3) in-depth literature review. Transferability is ensured through a detailed explanation of the research setting, process and design as illustrated in this Chapter. For auditing purposes, confirmability and dependability are ensured by maintaining detailed records of the research analysis, including multiple back-ups of the research projects, and detailed tables of the research analysis, as it progressed.

**Harms and benefits (ethical concerns).** Due to the detailed, intimate nature of the interviewing style, participants could have found the interviews upsetting or

distressing. The researcher and the site investigator assured participants that someone would be made available if it was required (e.g. a counselor). None of the participants required counseling services because of participating in the research. Names of participants and any other identifying information were omitted from the research analysis (e.g. the location in which participants lived, their doctor's names, their husband and children's names, their place of employment, etc.). Participants had no direct benefit from participating in the study, other than potentially feeling a sense of therapeutic effect, through sharing their lived experiences with the researcher. Participants were also provided a list of available resources in their communities, as a thank-you for participation.

## CHAPTER IV. RESULTS

### **Introduction**

Chapter Four is divided into five main sections. To help the reader understand who the participants are, the first section provides a brief introduction to the participants (e.g., demographic information). The next four sections describe themes that were constructed through, within, and across analysis of the participants' interviews. These themes are: (1) Contextual experiences of MS, (2) health promotion participation, (3) health promotion challenges and, (4) suggestions for health promotion improvements. Themes and subthemes are described in each section. Ellipses are used to indicate when portions of participant's quotes were omitted for non-applicable or repetitive dialogue.

### **Introduction to the Study Participants**

Six women with MS participated in the study. Their ages ranged from 44 to 64 years old. Four participants were married, one was widowed and one was living in a common-law relationship. All who were married or in common-law were in heterosexual relationships. Three were retired, one was a stay-at-home mother and two were working in paid labour. Three lived in an urban setting and three lived in a rural setting. Three had relapsing remitting MS and three had secondary progressive MS. Only one participant did not use some form of assistive device. Table 1 (on the next page) provides a summary of the participants' age, marital status, number of children, if their children live at home, working (paid labour) status, whether they live in an urban or rural setting, their type of MS and whether they use assistive devices.

*Table 1. Participant attributes*

	<i>Age</i>	<i>Marital Status</i>	<i># of Children</i>	<i>Child Residence</i>	<i>Working Status</i>	<i>Urban Or Rural</i>	<i>Type of MS</i>	<i>Assistive Device</i>
1	64	Married	1	Outside of home	Retired	Rural	Relapsing Remitting	Uses cane and walker predominantly/ wheelchair sometimes
2	51	Married	1	Outside of home	Retired	Urban	Secondary Progressive	Uses cane
3	44	Widowed	5	3 in home, 2 outside of home	Stay at home mother, pensioner	Urban	Secondary Progressive	Uses cane, walker and wheelchair as required
4	50	Married	1	Lives in home	Works in Paid Labour	Rural	Secondary Progressive	Uses four armed cane, walker and scooter as required
5	55	Common-Law	1	Outside of home	Retired	Rural	Relapsing Remitting	Mostly mobile, does not require assistive device
6	48	Married	1	Lives in home	Works in paid labour	Urban	Relapsing Remitting	Uses cane, uses walker sometimes, uses scooter sometimes

Below is further introduction to each of the participants:

**Participant One** is married, has one grown child, lives in a small town and drives her own vehicle. She is diagnosed with relapsing remitting MS and is moderately mobile (EDSS of 4.0 to 5.5; see Appendix B for the EDSS), and is reluctant to use assistive devices. She avoids talking about MS with others, including members of her immediate family. She reports having a strong relationship with her husband. Her husband, however, seems reluctant to talk to her about MS, especially in relation to their future

plans. She participates in regular aquacize classes and socially engages with other women in her community on a regular basis.

**Participant Two** is married, has one grown child, lives in an urban setting and is able to drive her own vehicle. She has secondary progressive MS, with moderate mobility (EDSS of 4.0 to 5.5). Although she is close to her grown son and feels supported by her husband, she is often reluctant to ask her husband for help. She struggles with her need to remain independent and her family responsibilities and often feels that her family does not comprehend the full limitations of her mobility and fatigue levels. She admits that she sometimes hides her symptoms from her family in order to remain independent. This participant was employed for many years, but was forced into early retirement when her employer failed to modify her working role, setting and working hours. She describes herself as a perfectionist and task orientated. She participates in Zumba classes at home and in her community. She also participates in multiple leisure activities at home, including gardening and cooking.

**Participant Three** is a widow with children who live at home. She lives in a central, urban location. She is unable to drive; however there is an accessible bus route in her community. She also relies on friends for transportation. This participant uses multiple assistive devices, including a walker and scooter and has secondary progressive MS, with limited mobility (EDSS of 6.0 to 7.5). She reports being financially secure. She prides herself on maintaining her independence and utilizes supportive services for tasks of everyday life to enhance her independence. She mostly prefers health promotion activities within her home, including yoga and physiotherapy exercises, but does enjoy socializing with her friends, in her home and out in the community.

**Participant Four** is married, and has one grown child. She is in a loving relationship and feels fully supported by her son and husband. She has secondary progressive MS, with limited mobility (EDSS of 6.0 to 7.5). She lives in a rural area, is employed, able to drive short distances, and uses multiple assistive devices. This participant has access to a gym at work, which she uses on a regular basis. She engages socially within her community with her friends. She describes herself as proactive and positive. Participant Four advocates for fair access to public facilities within her community and subsidizes her medical therapies with alternative therapies.

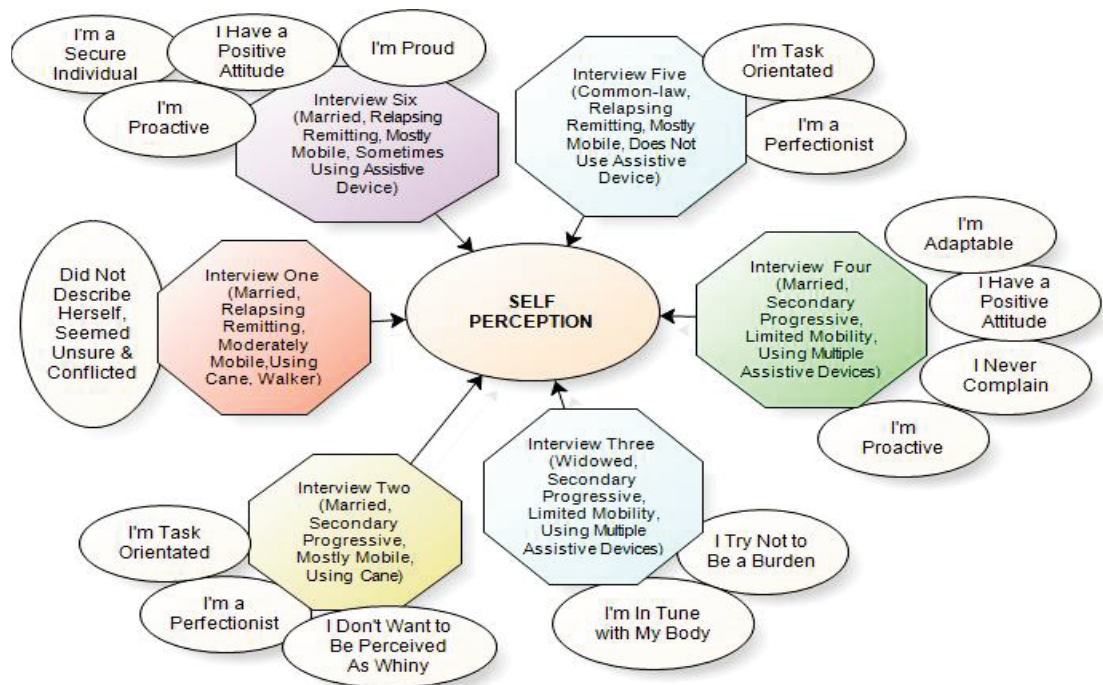
**Participant Five** lives with a common-law husband and has one grown child. She has a good relationship with her son and common-law husband. She is mostly mobile, has relapsing remitting MS, and does not use an assistive device. Her MS symptoms are therefore not visibly manifested, so people cannot tell that she has MS. (EDSS of 2.0 to 3.5). She lives in a rural area and once worked in paid labour, but was forced to retire early, due to her MS symptoms. Her most prevalent MS symptom affects her cognitive function. She describes herself as a perfectionist and as task orientated. Participant Five is a strong advocate for persons with MS.

**Participant Six** is married, has one young daughter, and lives in a suburban area. She reports having a strong and loving relationship with her daughter and husband. She has relapsing remitting MS, is mostly mobile (EDSS of 2.0 to 3.5), and sometimes uses assistive devices. She is employed full-time and describes herself as a positive, secure and proactive person... She feels fully supported by her employer, family and friends, but participates in few health promotion activities outside of her home. Non-participation in

health promotion activities is partially due to convenience and working hours, but is also due to her fear of falling.

Figure One (below) show how participants describe themselves as self-confident. There was also a sense that each participant shared commonalities in valuing positive attitudes and being proactive. For example, some participants described themselves as task orientated, proud or as perfectionists.

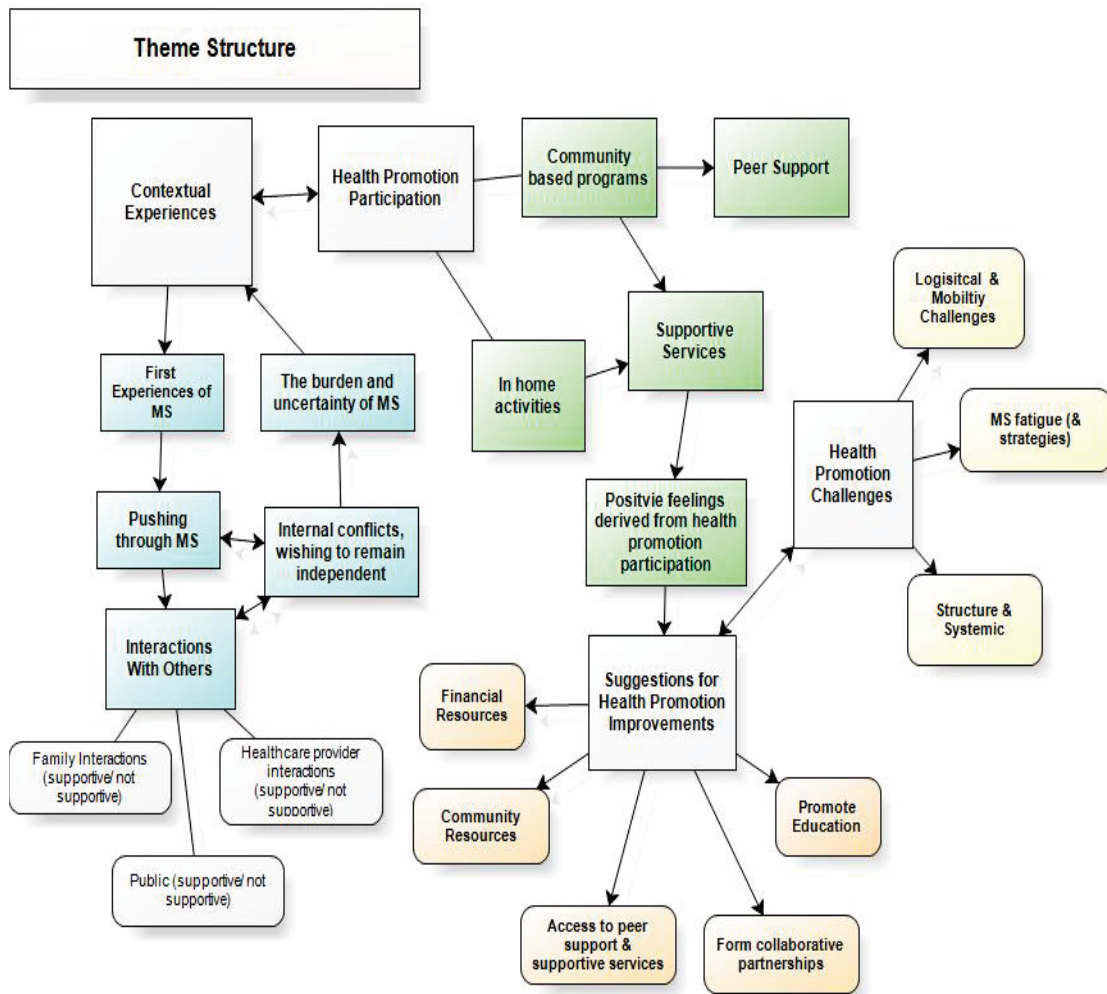
Figure 1. Participants' self-perceptions



This next section describes themes that arose from data analysis. Figure two (below), provides a visual representation of how themes are linked, starting from contextual experiences (blue), flowing into health promotion participation (green), challenges (yellow) and participants' suggestions for health promotion improvements (orange).



Figure 2. Overall thematic structure



### Contextual Experiences of MS

During the first half of their interviews, participants were asked to recollect their contextual experiences of MS, which included their first experiences of symptoms of MS and how symptoms impacted their everyday life. Following this, participants were next asked to describe their interactions with family, healthcare providers and with the public. These accounts of their contextual experiences set the initial framework of the analysis to provide a clear understanding of the meaning that participants make of their everyday experiences of MS.

Five interconnected themes were constructed from the participants' contextual experiences. The first three of these themes represent retrospective accounts of how participants first found out they had MS and how MS affected their daily life during this time. The first three themes include: (1) first experiences of MS, (2) pushing through MS, and (3) interactions with others (with subthemes: interactions with family, healthcare providers and the public). The next two themes represent how the participants described living with MS. These include: (4) internal conflicts and wishing to remain independent and, (5) the burden and uncertainty of MS.

**First experiences of MS.** All six participants described nebulous symptoms occurring in early adulthood. The most common symptoms included: fatigue, muscle weakness, limb numbness, described as a 'pins-and-needles,' tingling sensation or complete loss of feeling, deterioration of motor dexterity (e.g., clumsiness, dropping things), nausea and/or dizziness, incontinence or urgency, temporary blindness in one eye or peripheral vision loss and loss of normal cognitive function, described as a fogginess or memory loss. As an example, Participant Two described experiencing profound fatigue in early adulthood and leg numbness as her symptoms progressed:

*Well, it was the fatigue... I can remember just being tired all the time, going to school and doing sports and coming home and sleeping and I can remember my parents giving me a hard time because I slept so much. But I could never seem to feel energized, no matter what I did...[later in life as she began to work in paid labour] ...I had woken up on Christmas eve morning to go to work, and I thought, 'gee I must have slept on my legs or something,' [be]cause they were numb. I*

*went into work ...and someone spilled hot coffee on my leg and I had my head turned at the time and I didn't feel it..*

Each participant felt that the experience of MS-related fatigue is very difficult to describe to others. Participant One, for example, described experiencing overwhelming fatigue, which made it very difficult to function and enjoy everyday life:

*It's hard to explain, it's just exhaustion... it's very difficult, sometimes I just can't do it, I can go a whole week, stay in bed a whole week, can't get out ... it's wicked hard. I just want to stay home, with my housecoat on.*

Participant Four shared a similar sentiment:

*The big thing for me was the fatigue, was huge. I'd say I could just put my head down on the desk and I could just go to sleep [be]cause I was so tired, and I think what a lot of people don't understand the fatigue that comes from MS is different, than just feeling tired. Someone says, 'oh I'm feeling tired,' it's like, you don't know what tired is until you feel this way... it's horrendous. I think it's probably one of, despite all the physical things, I think that's one of the worst things.*

In her feedback of the summary data, Participant Three reiterated how alarming and confusing her first symptoms were. She shared a story about a dizziness episode she experienced as a young mother, which left her bed ridden for two weeks:

*I [couldn't] get up at all, the world totally swims, and I [couldn't] eat [be]cause I'm throwing everything up. The baby's suckling just fine, I'm somehow producing enough to feed him... I'm in bed, for two weeks, with dizziness, and I had no idea what it was all about. Dizziness had run in my family so I suspected, just a weird family thing, never even thought of MS.*

Similar to dizziness and fatigue episodes, other MS symptoms, such as numbness, muscle weakness and loss of eyesight were also reported as occurring in short, inconsistent durations or as separate episodes. When asked to recollect their history almost all of the participants felt that their first experiences with MS symptoms were signs, or were described as attacks, as if the body was giving clues. There was a sense that some of the participants felt guilty for not recognizing these bodily clues, as if earlier recognition may have helped to defer their disease course. For example, Participant Three noted, *“I never even thought of MS...I did not put the two together, dizziness seemed very different from loss of eyesight...I hadn't paid attention to the signals I was given.”*

Most participants were frustrated during their first experiences of MS symptoms. Definitive diagnoses by healthcare providers often took a long time and were described as a ‘wait and see’ scenario. Waiting for diagnosis exacerbated frustration. MS was described by Participant Six as having a ‘mind and personality of its own’:

*[Diagnosis] took a long time ... I had some very, very slight symptoms like numbing and then basically I went into the hospital, they ran the tests and they just basically said to me ‘we think it’s MS but we won’t know for about five years’... The thing is that MS has a mind and a personality of its own. So, basically I mean every test that I took came back negative but given their experience and what they had seen over the years, they kind of said, ‘well that’s how it plays out initially.’*

When looking back on the progress of their MS symptoms, most of the participants recognized that they had MS for several years before they were definitively diagnosed. This is reflected in Participant Five’s recollection about her past:

*I was diagnosed in 1990, and the more I learned about MS, I know that I've had MS symptoms several years before then and likely into my teens but where some of them didn't last a whole long time that they were kind of just dismissed and forgotten about.*

**Pushing through MS.** When signs of MS first begun to appear, participants reported ignoring symptoms or pushing symptoms aside, as they focused on family and career responsibilities. They described difficulties navigating their responsibilities while coping with symptoms in every-day life. Participants Five and Three described difficulty with loss of eyesight while trying to work and take care of their young children. There was a sense from these participants that they pushed through their symptoms in order to 'get on with life':

*Participant Five. I had lost my eyesight in 1993, which I think that in itself with a young child was really, really hard, because I worked full time. I looked after him and there were troubles in the marriage. So it's trying to keep everything all held together and I found it very difficult at work to read and found it very difficult to read to my son because I had lost total vision in my left eye, and so I used to get him to read to me.*

*Participant Three. I lost sight in my left eye, and I took a month and rested as much as I could, and the sight came back, and we just continued on with our life, and hoped that that would be the end of it. People had mentioned MS, but we didn't really look into it any further than that...my memory is that I had no other symptoms, and life was busy. There were two kids, we decided to have a third...I*

*kept pushing it and kept going and didn't stop. I ended up losing the ability to use this hand; it just got numb, the whole arm all the way up into my rib cage.*

Participant Five also described her struggles with continuing with her regular duties at work while also making up for loss in productivity, by working overtime hours and weekends:

*[There were] hardships in the workplace because I wasn't pulling my own weight... I really didn't want to put any stress on my peers...so I would go in on Thursday nights and Saturdays and try to do catch up with my work. So, there I was Monday to Friday, Thursday night Saturday. Come Sunday I was done, only to get up Monday morning to do it all over again.*

Overcompensation, feelings of guilt and a need to prove herself to her colleagues by pushing through her MS symptoms at work, lead to crisis in her private life:

*So it certainly was really pressured on my own private life and personal life I had no me time or anything like that, it was quite difficult, so something had to change before something happened to me... So it was a struggle, in the workplace, but I always did 110% because I felt, well I knew my outcomes were only like 75-80% but I was pushing the limit, because that's just who I am, but it wasn't doing me any justice.*

Although her employer did offer her an alternate position and attempted to accommodate her needs at work, Participant Five ultimately decided to opt for early retirement. Similar to Participant Five, Participant Two also reported early retirement after working for 17 years. Her employer did nothing to accommodate her disabilities.

Alternatively, participant six felt supported by her employer who arranged the conditions within her working environment to enable her to continue working.

Participant Six. *Listen I'm very fortunate cause I work in this environment that's incredibly, we have a very proactive organization, it's a race relations cultural and discriminatory so we're very active and militant about any type of barrier.*

**Interactions with others.** After talking about their first experiences and pushing through MS participants were next asked to share their experiences of how being a woman with MS impacts their interactions with others. They were asked to recollect insights about interactions with family, healthcare providers and people in their community. The women were free to talk about whatever interactions were most significant and meaningful to them.

**Interactions with family.** In the context of family interactions, some participants felt that their limited energy impacted daily interactions with family, related to their perceived family responsibilities. For example, Participant Two described being overwhelmed by her responsibilities, having no time for herself and expending her limited energy on taking care of her family needs, before her own:

*Sure, you have MS, you have a small amount of energy, you have a family, you have a husband, you have a son, I have a mother and a mother in law.... there's no time for you. What energy you have, what little energy you have, must go to the family, so you're the last person on the burner. By the time you look after everybody else, there is no time and no energy for yourself. You're the last person on the list, always.*

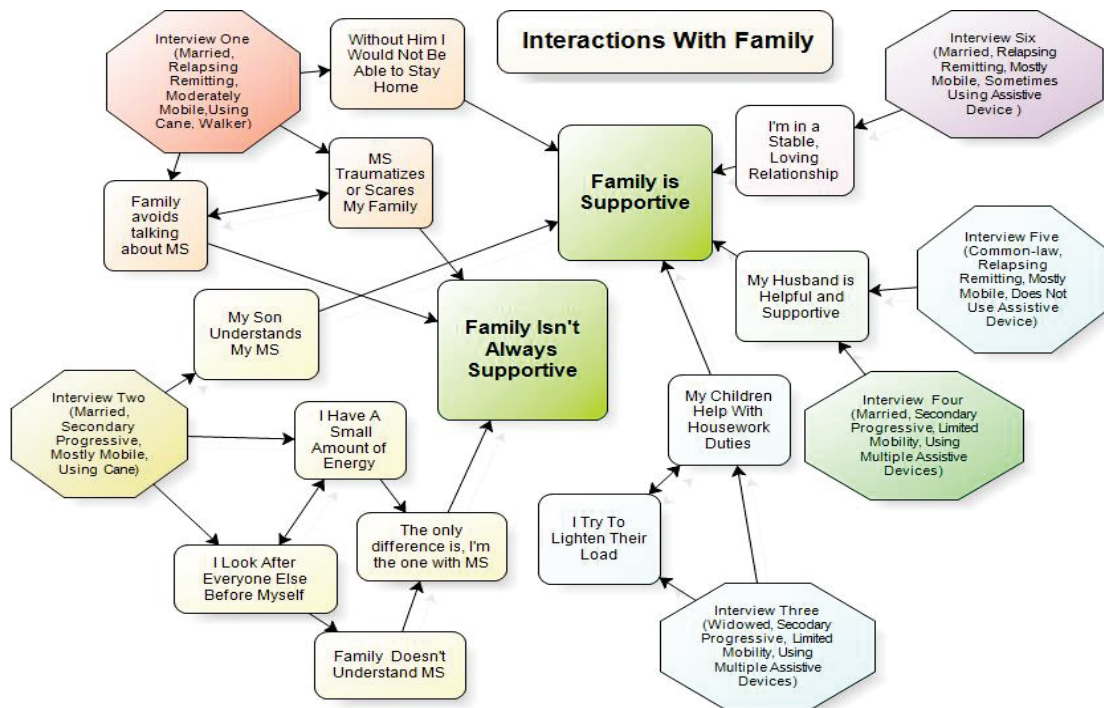
Participant Three also reported having limited energy for everyday tasks and shared her strategies for meal planning for times when she wishes to engage in community activities.

*If I take something else on, then that means that my energy is less for whatever goes on at home... I did a workshop this fall, and I warned the kids 'I'm going to be really tired when I get home, so ... you guys are going to be putting supper on the table.' Now I make sure that I have things that were easy to put on the table in the freezer that I could just throw in the oven and put on, and I didn't insist that there was a beautiful salad every night, but I came home from the workshop and I laid down for half an hour... When supper is being put together I might sit down and chat with the daughter or son that is helping me do that. But they know... that it's important for me to get out and do other things... I know I'm relying more on them, so that I try to make sure I have everything in place at home so that it's actually not any burden.*

In general, most participants felt supported by their family. Those who were married or living common-law reported being in stable, loving relationships. Figure Two (below) further illustrates participants' interactions with their families. For example, most women reported that their family members help with everyday tasks and are emotionally supportive; however there is a sense from some participants that some family members didn't fully comprehend the extent on their physical limitations. There were therefore both positive (supportive) and negative (not always supportive) interactions with family (See Figure 3 below).



Figure 3. Interactions with family



**Interactions with healthcare providers.** When asked about interactions with others as a woman with MS, Participants Four and Five chose to share stories about dismissive interactions they experienced with healthcare providers. When their first symptoms of MS appeared these participants often felt dismissed by healthcare providers. They also felt that their healthcare providers implied they were overly anxious or that they were worrying too much:

Participant Four...*when I think back to my original doctor... [when] we talked about me having MS, I felt like he was very dismissive of me, worrying about things, and I kind of felt like I was a woman that was worrying too much... and that's why he was so dismissive with it, I don't know whether that's true but that's how I felt.*

Participant Five. *As a woman, I've felt that you know I'd be looked at [as], 'am I complaining too much.' ... Before my diagnosis when my female GP was looking at my anxiety levels, and I looked at her I said 'what anxiety,' and she said, 'well you have lots of anxiety,' and I said, 'this is the first you've ever mentioned it' ... It wasn't long after that, you know other things were happening, and I had said to her ... 'you're making me feel like I'm an idiot. I can't explain what's going on, I can just tell you how I feel...anyway she was a perfect doctor with everything else, but she and I didn't see eye to eye on MS.*

At other times, participants felt that their doctors were insensitive or that they conveyed a defeatist attitude when communicating with them about the eventual outcome of having MS. For example, as Participant Four explained:

*[What the doctor] told me when I was diagnosed with MS was I'd probably be in a wheelchair in ten years, that's the first thing he said to me....and it basically was, 'go home, there's not much I can do for you right now [be]cause you're in the relapsing remitting phase of your disease, and just keep an eye out for things that might change.*

Alternatively, some participants also described positive interactions with their healthcare providers. For example, in addition to her negative interactions as outlined above, Participant Four also shared a story about a positive interaction with her family doctor, who supports alternative therapies:

*[My doctor] ... he's actually an MD, but he actually does alternative plant therapies, and he's absolutely wonderful, when I first, I switched doctors, I used to go to a doctor in town here, ... who was too much of a pill pusher, and I wanted a*

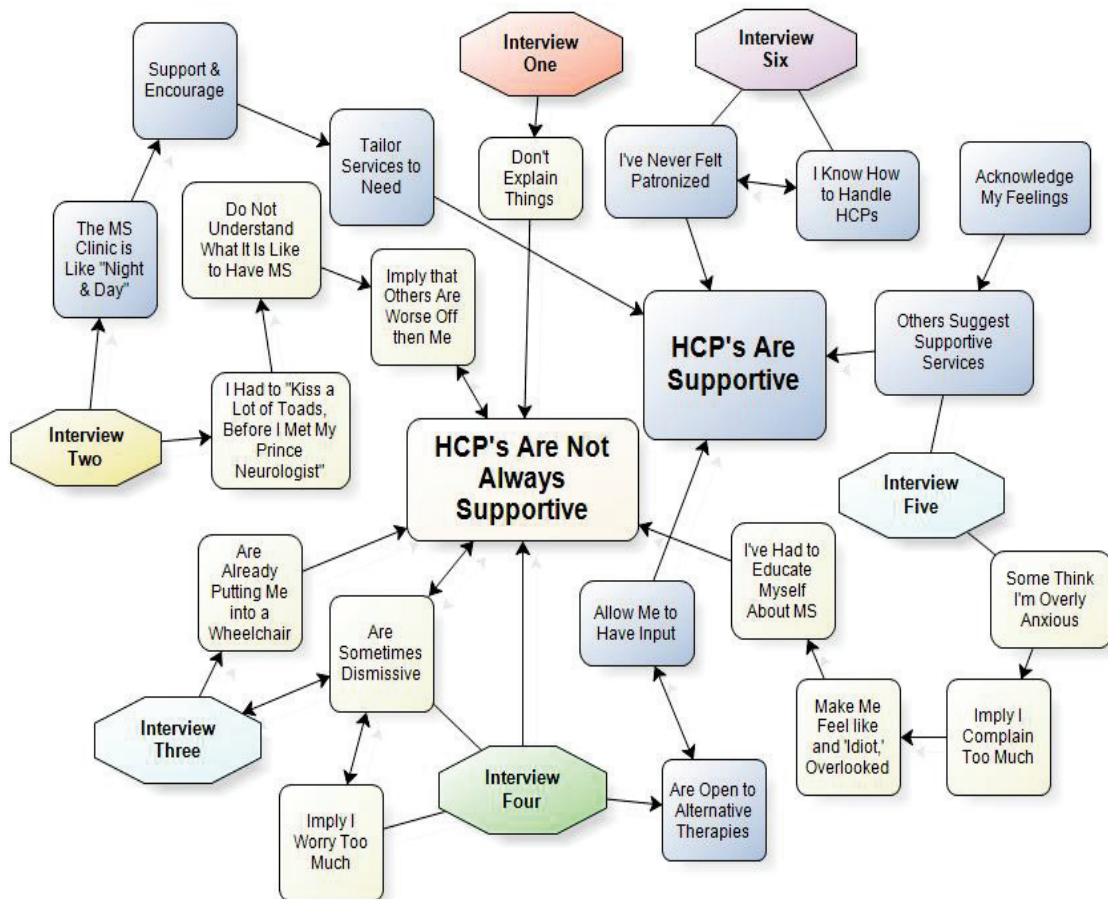
*different way to look after myself. So, with [names doctor] we tried a lot of alternative type therapies that for one reason or another just didn't work for me.*

Participant Two shared a story about the positive experiences she had at the MS Clinic. She reported experiencing efficiency, kindness and encouragement from healthcare staff:

*Efficiency, big time. There's no wasting the time here, it's a bang, boom. Organization, compassion, I think because it's dealt here every day, I think the understanding for disabilities is so much more here, it's done with so much kindness and caring, that isn't done in the other parts of the healthcare system here in the city. This place is wonderful, I thank my lucky stars that my GP fought for me to get in here to see [names doctor]. It's like night and day. I've gone to physio[therapy] here, I've seen occupational health, I had to go to see Nova Scotia Hearing and Speech because of a minor dysphasia, and I've not had one issue at this [MS]clinic.*

Figure Four (below) further illustrates participants' stories about non- supportive and supportive interactions with healthcare providers. Non-supportive interactions included feeling dismissed patronized or discouraged by healthcare providers. Supportive interactions included feeling that healthcare providers are open, listen and encourage input.

Figure 4. Interactions with healthcare providers



**Interactions with the public.** Some participants reported stigmatizing interactions in the public where they felt embarrassed in front of people that they did not know. Participant One, for example, explained “... some people don't know I have MS, especially young kids, I just felt like [they were saying]... ‘oh my goodness, who's that old lady staggering all over the place?’”

Participant Three shared two stories of how she sometimes feels stigmatized in her community, mostly by other non-disabled women. She felt that women sometimes tend to overcompensate or do things to draw attention to her disability. As an example, she described one poignant memory of being seated in a restaurant:

*So it's almost like you are walking in this wake, everyone's moving away from you before you even get there...because I walk so slowly, they see me coming, they want to be helpful. So, they're moving things out of the way, more than they actually need to, but they don't know what else to do. So, it's a kindness, and sometimes I feel like I must be like an ogre or something. Mothers have sometimes kept their kids back from me, because you know how kids can be, they move around too quickly, but I love kids. They're over compensating.*

This sense of stigmatization led to feelings of being excluded from everyday events or interactions, such as being able to sit down at a table in a restaurant (without feeling self-conscious) or freely interacting with children. Participant Three shared a second story of when she felt stigmatized while participating in a yoga class, where she experienced patronizing, 'well meaning,' comments from other participants. Her feelings of being patronized eventually led to her giving up her yoga classes:

*When one of the participants said it's so good that you get out, I stopped going after that... It was kind of patronizing actually... But yeah, it just made me feel down. You put all this effort into going out to have someone tell me 'it's so good that you get out,' as if you're not expected to go out... 'Do I look that pathetic when I'm going around that you can't believe I would even bother to come, is that what you're implying?'*

In other instances, Participant Three reported positive interactions with helpful people (in the community who interacted with her in a non-patronizing manner (open doors, help with groceries, etc.)). Some participants however said that they generally do not feel comfortable or supported by people in their communities. Participant Two shared a story

about an abusive verbal exchange she experience while attempting to cross the road to visit a friend:

*Well yesterday I went to visit a friend for a cup of tea, and I crossed the street to her house and this man came barreling up over [the street], doing 90, and I was trying to get across the street. Well, he put down the window and I'm trying to hobble across the street, and he's laughing. He said 'move yer fat arse.' Well my friend was standing out on her porch, she came flying down the steps, he was laughing, [be]cause she was ready to jump on his head, like she was going right at the car. She said, 'oh my god, I've never witnessed anything like that!' I said, 'welcome to my life', ...there is no, no compassion at all for people with disabilities!*

**Internal conflicts and wishing to remain independent.** In addition to sharing stories about their first experiences of MS, pushing through MS and interactions with others, participants were also asked to describe what it is like to live with MS. Some participants described MS as a separate entity, or as a part of them that must be beaten. 'Normal' people are perceived as people who do not have MS. Self-conscious feelings and feelings of being stigmatized (related to first experience and interactions) were linked to participants' longing for independence and autonomy. Several of the participants talked about the struggles they encountered in everyday life with wishing to remain independent and viewed as 'normal' people. These struggles for independence often occurred in their homes while interacting with their spouses.

For example, Participant Two shared her frustrations with having to ask her husband for help with tasks she could no longer perform herself. She talked about her

frustration with having to wait for her husband to complete these tasks in a timely, manner:

*I've created my own monster, as far as my husband goes. Emotionally and physically he is 100% there for me, but he doesn't understand the physical limitations I have, because I always manage to get it done... If I say to him 'will you do that,' he'll do it in his own time, it may not be today... but I have to shut my mouth, because then it won't get done at all. So it's very hard and frustrating...I've always managed to do it, and do many things that normal people don't do, because I'm determined ...sometimes I almost feel like I'm trying to make up for the fact that I have this disability, to the world.*

This story helps illustrate the sense of the internal conflicts women with MS may have when wishing to remain independent versus asking for help. Withholding requests for help in this account meant being strong and making up for feelings of guilt about being disabled. Similar to Participant Two, Participant Five also described her struggle with asking for help as conflicting with her need for independence. She described herself as being stuck between her own sense of self and perceived capability and the limitations she must face in everyday life due to MS symptoms:

*Right, and I am very, I'm a hard one to ask for help. I am used to being independent, and I am used to doing for myself and now for the last little while I've been in an area of my life where I can't do it or I shouldn't do it for safety reasons and I'm not used to that, relying on somebody. When I even look at myself I feel like I'm perfectly capable of doing something. So I'm stuck, I'm stuck in between myself and the disease and it's not a good place to be.*

As reflected in this account, withholding requests for help is linked to the participants' desire for 'normality' and independence. When asked about whether her expectations for tasks she wished to complete were realistic, Participant Two described asking for help as synonymous with giving in to MS, as if her MS was something outside of her body to be battled with. Furthermore, when asked how she typically goes about accomplishing her desired daily tasks, Participant Two responded by saying:

*...[desired tasks are] not realistic for someone who's normal, and healthy, let alone somebody that has MS. But I don't want to give in to that either...I want to do those four things. That's it, and that's the way I've always approached this disease, 'you're not going to beat me.'*

**The burden and uncertainty of MS.** Several of the participants described MS as a burden and reported having a very difficult time when thinking about their future and the uncertainty that comes with having MS.

*Participant Six... it's a disease that systematically alters and takes away things from your life over time.*

*Participant One. ... it's difficult, we have a big home, our house must be 200 and some years old, the first house we looked at when we got married, nice house, nice spot, big yard, and it's going to be hard to, [be]cause I said to [to my husband], we might have to leave, and that's going to be hard.*

Participant Three shared her regrets about being unable to do the things that she had planned to do after her children have grown. She described feeling both 'saddled' with MS but also challenged to draw upon her resourcefulness and determination:



*...there are things that I'd like to do, like I said, the idea was, I was [going to] support my husband so that he could do his wonderful work that he was doing ...and I would raise the kids, and take care of the house. So there's a part of me that wants to do all these things that I've realized I can do now, because the kids are grown, growing, and they don't need me around as much... At 40, as a woman, you have a sense of who you are, more than you did when you were 20, and I have a confidence about me that I didn't have when I was 20, and...now I'm totally saddled with this MS, I can't do those many things, I can't do them that easily, that is a downer, but it's also a challenge, how am I going to do [what I want to do].*

**Summary of contextual experiences.** To summarize, this first section included participants' descriptions of their first experiences with MS symptoms, pushing through MS, and interactions with others (family, healthcare providers and the public). Participants also shared their accounts of internal conflicts and wishing to remain independent and their experiences of the burden and uncertainty of MS. These experiences are represented by the blue-coloured blocks in Figure 2.

Participation in health promotion activities, which is described in the next section, is also closely related to the participants' need for independence, normality and for overcoming (or avoiding) stigmatizing experiences. Health promotion participation and subsequent themes within this chapter are framed within the participants' contextual accounts.

### **Health Promotion Participation**

This next section describes some of the themes constructed from asking participants to share stories about their health promotion activities. As noted above, themes related to health promotion participation were constructed with attention to themes that emerged from the background, contextual data. Most participants valued the importance of participation in health promotion and prevention activities. In fact, all six participants described participation in some sort of health promotion activity. Participants were encouraged to think ‘outside of the box’ and to define what they feel promotes their own health and wellbeing. The first four themes within this section describe participants’ experiences and stories related to their participation in: (1) community-based programs, (2) in home activities, (3) supportive services, and (4) peer support. The final theme within this section describes (5) Positive feelings derived from health promotion participation. These themes are represented in the green blocks in Figure 2.

**Community-based programs.** Participants One and Four both reported engaging in organized, community health promotion activities outside of their homes. Participant One lived in a small community with an accessible public pool. At the time of her interview she was moderately mobile, was able to drive a car for short distances and had many friends within the community to support her. She shared her experiences of attending an aquasize class for older women, where she felt engaged and comfortable with members. In contrast, she had recently stopped attending a local fitness facility, as she did not feel comfortable exercising with younger adults. Her reluctance to participate was linked to feeling stigmatized and self conscious in the presence of able bodied persons. Before leaving this facility, she first attempted to modify the time of day she attended, as a strategy to avoid younger able bodied members:

*Well I've been going to the [names facility] but I haven't been going ...too much lately because I find I was really kind of staggering around, and I try to go between 1 and 2 [pm].*

Participant One therefore participates in regular, activities in her community, but only in activities where she feels comfortable and included.

Participant Four was also moderately mobile and able to drive. She reported exercising at a private fitness facility, housed at her place of employment. She greatly valued this facility and believed that her exercise regime had positive impact on her physical wellbeing. She also felt that regular exercise helped to mitigate the severity of her MS symptoms:

*I try to get there at least 3 times [per week] ... exercise for me has been the one thing I'm sure if I wasn't doing I would be in a wheelchair right now. [Be]cause my legs, even if I don't go for 2 or 3 days I can feel it.*

Her work facility had once offered a class for persons with disabilities, which she joined. The class however was no longer being offered. Participant Four reported feelings of sadness at the loss of friends she had made within this group, with whom she had formed a special bond:

*In the mornings when I went, there was a group of people there who had some sort of disability. There was a guy with a brain injury, a guy with ALS. There was a guy with COPD; he had the oxygen tank, there was a woman who had been in an accident. It seemed like there was a group of people that went in the mornings that shared some sort of common illness or injury....and when [the facility] closed its doors to those people, I mean I was really sad, because these people had*

*become my friends and we shared something in common which made it that much easier because when you have something in common its easier... I miss that because sometimes I'll go to the gym now and I'll be the only person there. I'll have the whole gym to myself, and it's a little bit lonely.*

Participant Two reported having once attended a fitness facility, for woman only. She had subsequently stopped, due to the expense of membership fees. She described how she missed the 'MS friendly' activities and woman orientated approach offered at the fitness facility, which included preventative healthcare educational sessions:

*[This women's only fitness facility] was accessible, much smaller, less room [than most fitness facilities]. The thing I miss about this [facility] is it was very woman oriented, so you went there, there was things on breast awareness, and that's not the case at this place. But it was very expensive... and you had to pay extra for your Zumba classes, which I find for me, and I've tried many a thing, it's something that I can join.*

In both of these stories, participants stressed the importance of feeling safe, accepted and free from feelings of stigmatization. Programs that included activities designed to include persons of variant abilities were greatly valued. Activities orientated to women were also valued by all three participants.

**In home activities.** Several of the participants shared stories about their preference for engaging in health promotion and leisure activities at home instead of out in the community. Participation in home activities gave them a sense of control and accomplishment, as well as a sense of positive physical and mental health, and emotional safety (e.g., feeling free from stigma, feeling comfortable in their own environment, etc.).

Affordability and access to private fitness facilities also factored in to their decision to exercise at home. As an alternative to community Zumba classes, Participant Two practiced Zumba dance videos at home:

*I have a program my husband bought me for home. So days when I can't get out when it's icy or whatever in the winter, I Zumba at home. I am addicted to Zumba, I find it's made a difference for me mentally and physically, I'm exhausted after, but the mental cleansing I get from it, the endorphins.*

Participant Three also reported practicing exercises in her home. Although the exercises were simple, and sometimes tiring, she found these to be beneficial to her overall physical health:

*There are little physio[therapy] exercises I try to do at home...I do some exercises at the counter... I've called them 'rinky dink' exercises, [be]cause they're just... minor...They're about sitting here and pulling my shoulders back sometimes. What kind of exercise is that? But I know that if I do it regularly, I will feel the benefit of it, the benefit of it is pretty big, but to force yourself to do those little exercises. Sometimes it is tiring.*

Similar to Participants Three and Two, Participant Five preferred to engage in physical activity close to her home, within her neighbourhood subdivision. As a precaution, she preferred to walk around her neighbourhood block several times, so that she would be closer to home if she became too tired to continue:

*I do my own walking at home, again... I tend to walk around, where I used to kind of go out of my own subdivision, I don't do that so much now, I tend to stick around my own subdivision and maybe go around twice.*

Two participants also mentioned practicing yoga at home. Participant Three reported doing a modified yoga routine, while Participant Six sometimes followed yoga classes offered on T.V., and found that breathing techniques, taught in yoga, helped improve her mood.

Participant Three. *I have done yoga for a long time, like 20 years, and so I have little routines that I like to do, now with MS I don't do the routines that I used to do, there are positions that I don't do anymore at all, so I do this modified, five minutes here and five minutes there, sometimes ten minutes.*

Participant Six. *Well, Channel 10 at 7:00 or 6:30 it's just a very, half-hour yoga that concentrates on breathing and stretching. I was into it for quite a while and then again life just takes over and I'd rather sleep than do it, but I found that a lot of breathing really, the breathing was especially great because you might wake up feeling pretty; like a bad sleep, you're feeling kind of achy and stuff. You sit there for half an hour and you breathe and do some stretches and you might not be able to do the two-step but the breathing really just changes your mood.*

Other participants mentioned in-home health promotion activities focused on leisure pursuits. For example, Participant Two noted *"I started making soap with a friend, because I don't like the stuff that's in commercial stuff so I do that once a month, we make our soap, and I'm a hooker. I hook, I knit, I preserve."*

She also described gardening: *"I garden, I have a vegetable garden, and I have an apparatus that I can garden from that, and then I do all my own preserving from my own garden, I do my own herbs, so I'm busy."*

**Supportive services.** Participants Three, Four and Six reported participating in complementary health supportive practices in addition to community activities and at-home activities. These supportive practices included: specialized physiotherapy, massage therapy, chiropractic therapy, occupational therapy and naturopathy. Participant Four greatly valued her experience with a physiotherapist who specialized in neurological conditions:

*He knew the muscles and the way my legs curve in, the exercises that are specific to that, he seemed more, could look at me and pinpoint what was wrong with me than the ones that didn't have specific training in neurology, he seemed a bit... more knowledgeable.*

Similar to Participant Four, Participant Three also utilized a private physiotherapist and went to a massage therapist and a chiropractor on a regular basis. She felt that the physiotherapist took her concerns seriously and helped her to work toward maintaining her abilities, which in turn gave her a sense of independence and some semblance of empowerment and control over her disease course:

*I recently met with a private physiotherapist, and I like her very much, and I like her attitude. I've gone to her just recently over the past Fall... I told her that what I wanted to do was, I wanted to maintain what I have,...rather than getting up and sitting in that wheelchair right away, so that's when I went to her saying I'd like to have some specific exercises that specifically look at, abdominal muscles and how I carry my shoulders, how I stand, all those things I have to do very consciously, otherwise I'd just kind of cave over and give up, and she's kind of willing to take me seriously.*

In addition to complementary services, Participants Four and Six also shared stories about nutritional regimes and special dietary restrictions they have integrated into their daily diets to help reduce MS symptoms. These included: fat, gluten, dairy, sugar and Aspartame restrictions. All three participants felt that diet changes have helped to lessen the severity of their MS symptoms.

As a final example of supportive activities, Participants Five and Six both shared insights about how their overall health is positively impacted by their sense of spiritual wellbeing. Participant Six used prayer and her Christian based beliefs to cope with the uncertainty of the future of her disease course. Participant Five belonged to a self help group for persons with MS. When asked to elaborate on her views about spirituality and health, she recollected an event where a Chaplin came to her MS group, to help the group cope with grief and loss of a member:

*There are times that, our group, particularly, as far as life in general, we've had births, we've had deaths, we've had sickness and illnesses with themselves, or their family members, and we at one point were really down in the dumps... it was springtime, and in springtime, hope is eternal kind of thing, and we were in the dumps. We had lost one of our members and there were things that were happening...it was suggested [we] watch a funny movie together, or whatever, and I said, 'well, that's good at the moment, but as soon as we walk out the door we're still going to be filled with all this emotion that we don't know what to do with'... [a Chaplin came] in and did a talk on change and change that we have no control over, and how to manage that, and how to kind of go with it, and that was*



*helpful...So we didn't do the religious aspect but we definitely looked at the spirituality of things and that really, really helped [us to cope with our grief].*

Participant Five went on to explain the complexities and emotions that come with the death and loss of a fellow member and what this loss meant to her and the group. These emotions were closely related to their own uncertain futures about the disease course of MS. Spirituality and group supports greatly help with their loss and personal fears:

*So it is scary because when you have made relationships with the persons and you watch them deteriorate and the progression of the disease is ongoing, and you think that could be me, it's hard not to take it personally even with your own emotions and dealing with your own loss. But that, that could be you.*

**Peer support.** Participants One, Two and Five all shared stories about friendships they have formed during their participation in health promotion activities. Participant One was first introduced to aquacize by a friend who also had MS:

*My friend she has MS, she's a really good friend, and about 10, 11 years ago she was swimming, and she said ... why don't you come swimming, and I don't like the water. I said, 'no I can't go swimming, I don't like the water, I don't like the pool,' and she said, 'well, come,' and I went once, and I never stopped.*

She also recounted a story about friendships she has formed while participating in this activity that were outside of her usual social circle, which included people of variant abilities and ages. The friendships she had formed within her aquacize class helped her sustain a positive attitude and sense of pride related to trying something new:

*It's really good because all the people there, I'm friends with them all. We've kind of built up a thing and every Thursday we go for a coffee and I've made so many*

*friends, and one stands out, she just turned 95 [years old]. It's just really, really nice.*

Participant Two's descriptions mirrored Participant One's experience as she shared her sense of satisfaction with having the opportunity to be part of a group of her peers. Her feelings of being stigmatized were mitigated when participating with others who have who have similar disabilities:

*I think [health promotion is a] social thing as well... I'm lucky because I have a car, but you need to socialize with people with disabilities and people without disabilities, and you have to be able to have access to that, so that's part of health promotion... You can forget you're not like everyone else. I can do some of the moves, but I just don't do all of them, and there's other people not doing them too, because they're old, they've got knee issues, the focus isn't oh look at her she's disabled because there's other people with issues there too, and that way, you don't feel disabled so much when you go there.*

Similar to Participants One and Two, Participant Five stressed the importance of long-term relationships with peers in her MS group:

*[T]here's friendships, long term friendships, that have come out of [our MS support group]...we meet at self help, we go to massage together, we go to lunch or dinner or whatever...My own friendships, or my network of friends, have certainly changed over the years, there's a lot more persons with MS that are in my circle... there's only a select few that I've kept over the years that are not in my MS circle.*

**Positive feelings derived from health promotion participation.** Overall, when participants felt safe and in control of their health promotion activities, they reported feeling a sense of freedom, 'normality, pride and accomplishment. Participant Two talked about the sense of normality and freedom she experiences while participating in Zumba classes. She shared a story of a positive interaction she had with an instructor, who commented on her happy attitude:

*When I do Zumba, even within the first few minutes when I work through the pain and the stiffness, I get such a feeling of normality, that I look around, and I'm doing OK, when I look around to everybody else, and that feeling, is worth a million dollars to me, because I'm not any different from anybody else, and that makes me feel really good, and I need that, because I struggle with so many other things that that is a time when I'm just like everybody else...[ the instructor said] 'I love watching your face during Zumba, I focus on it, because in a couple of minutes your smile is up to here.' And she [the instructor] doesn't realize it's a freedom, [from MS], because all you can think about is the moves, you have to follow the moves, listen to the music.*

Participant Four also shared a story about her sense of pride and accomplishment through regular visits to a fitness facility within her place of work:

*Going to the gym, it's not something I really look forward to, it's not something I wake up and say, 'ooh, I'm going to the gym today.' But once I go, and even when I'm there I think, 'ugh, get this done and over with,' [be]cause it's not easy. But when I come out, there is a sense that I've done it and completed it. That my muscles have been strengthened and stretched, I can move a little bit better.*

*Mentally it's a good feeling not only physically but mentally, it's good, and I feel good that I'm taking care of myself and that's important to keep my mobility and my strength up. So it's important. [Interviewer asks, so a sense of accomplishment?] Exactly, exactly!*

Participant Four also described her sense of accomplishment when she hit one of her own health promotion goals of using the exercise bike for 45 minutes:

*The first time that I hit the 45 minute mark on the exercise bike I almost cried, because for me that was huge, it was huge, [be]cause the bike starts at 45 minutes. And to work my way down from 45 to zero, and to still be able to do that, and finishing that 45 minutes, and being able... my legs not collapsing, to be able to get off the bike and continue on with something else, that was a huge milestone for me to do that.*

This poignant statement shows how participants gain a sense of accomplishment through health promotion participation, while also navigating the challenges of their MS symptoms. These challenges, as well as participant's ideas for improvements, are described in greater detail in the next section.

**Summary of health promotion participation.** Each participant reported participating in health promotion programs or activities. Programs included aquacize, Zumba dancing and exercise in recreational facilities. Activities included yoga (at home), Zumba (at home) walking, exercise at home and leisure activities. Several participants also utilized complementary, health supportive practices and nutritional and dietary regimes. Self-help groups or participation in peer groups with other women and/or

disabled persons were greatly valued. Participants reported positive feelings and a sense of pride, accomplishment, normality and inclusion, as a result of their participation.

### **Health Promotion Challenges**

In addition experiencing the positive benefits of health promotion participation, each participant shared stories about challenges which hinder their health promotion participation. As discussed in this section, health promotion challenges included: (1) logistical and mobility challenges, (2) the challenge of MS fatigue, (and coping strategies) and (3) systemic and structural challenges. See Figure 2, with health promotion challenges represented by the yellow blocks.

**Logistical and mobility challenges.** Participant Six did not attend a fitness facility or exercise classes as she worked full time and many of the classes that she was interested in occurred during her working hours. She also reported fear of falling as a reason for not utilizing fitness facilities and exercise classes:

*No, the thing is that my attitude in that particular scenario is for me to get the 100%, I mean regardless of anything you are self-conscious, you do have fear, you want to make sure that the situation you're trying to be in is going to be as, nurturing and as safe...so for me to join a gym or to go into a class, for me I probably wouldn't enjoy it because I'd be nervous; If I fell I mean.*

**The challenge of MS fatigue (and coping strategies).** Every participant in this study talked about the challenges of MS-related fatigue. Participant Three described fatigue as a fog, which affects her cognitive function, and also as a physical fatigue, which greatly impacts her energy reserves:

*There's several kinds of fatigue that hits you with MS, there's a fog that fills your brain and you can't think very well, but then there's a physical fatigue where you don't even have the energy to lift a leg.*

Preventative activities to mitigate fatigue symptoms, including dietary changes and drug therapies helped to mitigate her fatigue symptoms:

*Fatigue is an issue, something I've dealt with for a long time, because of the MS, and it's a lot better now than it was, because of diet changes and I'm on a new drug that seems to be dealing with the fatigue.*

Participant Four described her own experience of fatigue as limiting her desire to do anything, which greatly influenced her life satisfaction and her ability to participate in desired health promotion activities:

*When you're tired and you feel this way, you don't want to do anything, there's no enjoyment in life, there's nothing. So that is a huge, huge thing.*

Most participants shared strategies they employ for coping with fatigue. For example, Participant One used a mind-over-matter approach to avoid feeling that her MS will get worse, while Participant Six set limitations for herself and accepted what she could not do:

*Participant One. Say I'm feeling real terrible, and I stay home, it's not going to get any better, it's going to get worse. I find that if I get up, if I can get dressed and get up and get out, I'm better, it's very difficult.*

*Participant Six. ...humility, you just kind of know your limitations and it gives you such a release because you know that there's so many things bigger than you are. So I think it ties in with the therapy, it ties in with that mental state.*

In both of these accounts, each participant struggled with their desire to participate in health promotion activities, while also struggling to accept and adjust to their limitations.

Participant Two overcame some of her fatigue limitations by resting in between her Zumba dance classes, or leaving classes early. She also purposefully selected modified classes, where routines were more manageable:

*Now I rest a lot in between, if I go Mondays and Fridays, I can do the whole class because it's a slower class, if I go Tuesdays and Thursdays I might only do half the class, and leave halfway through, but I still do my 35 minutes. But I do it according to what my ability is...*

Participant Three no longer attended community yoga classes, as her attendance expended too much of her limited energy reserves, to the detriment of her family responsibilities. Instead, she practiced yoga at home and sometimes hired an in-home yoga teacher:

*I stopped going because it was physically tiring for me to get there, do the yoga, and then when I got home I'd have to have the rest of the afternoon to rest, that's very difficult to manage. I couldn't keep up with the rest of the class... I've done yoga long enough to know that I can just do it on my own, I've found a teacher that comes here, so about once a year I give myself a treat and have the teacher come here.*

As described by participants, strategies for overcoming MS fatigue challenges involved time management, pacing or modifying routines and practicing activities at home.

**Structural and systemic challenges.** In addition to logistical, mobility and fatigue challenges, participants also shared stories about structural and systemic challenges they encountered. For example, Participant Four shared a story about a time she went to a movie with a friend and was denied expedited access to the theatre seating:

*I don't know if you'd call it so much health promotion, socially we were going to this show .... and they made you take your ticket and go through the concession stand... I said to the young kid, ' let me see your manager....I just want... to go sit down to see the show.' I said, 'I'm disabled... it's really difficult for me to stand that long in the line up' .... So the manager came over, and I said to him, 'I have a free pass, I don't want ... to stand in that lineup, I'm not able too,' ..... He said, 'I'm sorry, we're short-staffed today.' I said, 'well is it normally your policy that people have to go through the concession stand just to get a ticket?' ... He said no, 'we're short staffed.' I said, 'well, I can't do it, I can't stand that long.' He said, 'I'm sorry that's the way it is today.' He didn't say to me, 'give me your ticket and it's fine I'll look after it, you can go in and have your seat' .....I thought that was really unbelievable, such incredible poor service for one thing, and then to just look at somebody that's handicapped and just be so dismissive with it.*

Later on in the interview this participant stated that she had followed up with a complaint to the movie theatres regional office and was continuing to advocate for a policy and practice change at her local movie theatre. From these two stories it is clear that self-advocacy had become part of this participant's landscape of navigating her leisure and health promoting activities, which would be readily available to those who do not have a disability. Similar to Participant Four, Participant Three also wished to see improved,



integrated access to community facilities, where persons of variant abilities could meet and have access to healthy food and cultural events, such as poetry readings.

Four of the six participants shared stories about their difficulties in accessing health promotion facilities and programs within their communities including yoga classes, community pools and recreational facilities. Swimming was a popular activity amongst participants. Participants Two, Three and Five all had experienced difficulty with accessing public pools in their communities. In each of their stories there was a sense of frustration related to structural barriers they encountered. These barriers included stairs, lack of lifts or ramps to get in and out of the pool safely.

Participant Three. *So at the pool at [this facility] you have to be able bodied to do all those stairs, I don't know if they have an elevator, but I don't want to be stuck in an elevator in that building. So they're assuming you're 20 and able bodied, and have lots of energy.*

Participant Two....*they had the pool here but it's not working anymore...Most of the things that are available in the community [are] for the general public, not for specialized [services].*

Participant Five. *...it was easy to get into the pool but it was very difficult to get us out...but to get them out you had to lift out of the water and we didn't have a lift it was people actually picking the people up; there was no walkout you had to climb the ladder.*

In addition to difficulty with access to the local pool, Participant Three also experienced structural barriers which inhibited her access to yoga classes:

*Five years ago I was going to a class ... and I really liked it, [but] there are stairs all the way up to the class, it was just very, very tiring.*

Participant Four also talked about her frustration with access to a recreational facility in her community. Although the facility had an accessible bathroom and an elevator, the doors within the facility were difficult for her to manipulate:

*[It has] a handicap [bathroom]. I said to them the other day, though, that they need to start propping their doors open, [be]cause when you get off the elevator, to go into the fitness facility, there's two doors that are closed, and they just put a wooden thing in there to open it up. Sometimes they say barrier free but they're not realizing what the barriers are.*

In this example, management had failed to consult their clients to make sure the facility was accessible for all. Some of these reported structural barriers seem to have low cost solutions (e.g. making sure doors are easy to open). Each of the participants articulated how difficult it sometimes is for a person with a 'moderate' disability to navigate health promotion facilities. This was especially true of older facilities.

In some instances participants reported satisfaction with access to recreational facilities within their communities. These participants said they felt comfortable and were able to maintain their desired personal autonomy when moving about the facility. Participant Two for example, valued accessible parking, ground level access, accessible lockers and access to an elevator.

### **Suggestions for Health Promotion Improvements**

In this final theme, participants shared their ideas for health promotion improvements along with whatever topic they felt was important for improvement to

health promotion for women with MS. The four subthemes within this theme include: (1) financial resources, (2) community resources, access to peer support & supportive services, (3) form collaborative partnerships and, (4) promote education. Figure 2 represents suggestions for health promotion improvements in the orange blocks.

**Financial resources.** Participant Four reported greatly valuing holistic, services including massage therapy and chiropractic therapy as part of her health promoting activities. Although she had the means to pay for these services, she suggested that these should be made more readily available to other persons with MS, through the increase of benefits:

*I go to massage regularly, I go to the chiropractor every two weeks, those are things that are important to me too....The majority of it is out of pocket, hopefully they're doing their review on our benefits because so many people are opting; I mean this is [the] stuff that I've been doing for a long time but it seems to be catching on more and more. A lot of people are going that direction, and the health benefits need to catch up with that.*

Participant Two felt that discounts for fitness facilities for disabled persons on fixed incomes should be made available and felt that long-term investments into health promotion activities will help to improve overall health:

*You get no discount if you're joining a fitness facility which you need to do in order to keep mobile, and be less drain on the system. There's no cash incentive for people on a fixed income; you pay the same as anybody else, and that limits the people that have access to it, and you need to exercise in order to keep limber, mentally [and] physically. The healthier you are the less drain you are going to*

*be on the health care system. It's not rocket science...The MS society will give you...\$75 a year... for that, as long as you have, [a doctor's note by] your GP [General Practitioner].*

Participant Two also suggested that more government funding should be made available for persons with disabilities to participate in health promotion activities:

*There's so many things that aren't available to disabled people. If you have the fatigue level, the government should give you a service. Maybe ...somebody could come in and prepare some meals that are healthier...those are all part of health promotion.*

Funding specific for persons with MS should therefore not only include opportunities for health promotion activities, such as yoga or discounted gym memberships, but also for supportive services to help persons with MS complete day-to-day tasks, so that they can reserve energy for health promotion activities. Participant Two also suggested funding should be made available for outreach workers to visit isolated women with MS:

*I think we need outreach workers that go into the home especially in the rural areas. Like a public health nurse, [can] go in and look at things in the person's home, bring something to them...I do think, I think we need an outreach for people with MS.*

**Community resources.** Participant Four felt that her sense of health and wellness was supported by having fair access to such things as farmers markets and leisure facilities within her community. She advocated for fair access when she felt excluded. In one example, she emphasized access to parking:

*I love to go to the market, I love the fresh food and the vegetables and stuff like that, but there was never a parking spot [be]cause it was so busy. So I called one day and ... I spoke to the manager and I said, ' you know what, I'm handicapped and I love to come to your market, but I can never get a parking spot. I have to walk for two miles almost to get in there.' He said, 'well we're getting ready to repave and there will be a handicapped parking spot and, well they probably have to have one anyway.' I felt better for saying that, so there is one now.*

**Access to peer support & supportive services.** In addition to their ideas for improved access for financial resources (e.g., for holistic services, fitness facility and membership discounts) and access to community resources (e.g., markets, leisure and health promotion facilities), most participants also stressed the need for improved access to specialized exercise classes specifically for persons with neurological diseases or disabilities and access to peer support. Participant Two, for example, suggested that specialized exercise groups should include persons with Parkinson's disease, fibromyalgia and MS. Participant Two also stressed that there is a need for peer support groups, for women who have been newly diagnosed with MS:

*I also think it would be a very good idea ... to have somebody with MS talk to somebody who's been newly diagnosed, or who is isolated in the community... even on a telephone ... Volunteers, with the disease. [Be]cause you don't understand how I feel, but I would understand if you had MS... just to have the mental support.... I think, myself, that's something so small that can be done without funding....[Also] trying to match people up according to their*

*socioeconomic as well as their education and backgrounds and you know, a city girl may not talk as much to somebody in a rural setting... like a match.*

As illustrated the previous statement, this participant felt it would be a good idea to group peers as 'MS buddies,' matched to their social economic standing, age and geographic commonalities. Participant Three also felt that women with MS would benefit from having access to a meeting facility for persons with MS. She shared her feelings about how health promotion is linked to social support and her overall mental health:

*You go through so much when you live with a chronic disease, you have to depend; you have to be, mentally and emotionally; you go through so much ups and downs, and it would be really good to have somebody to talk to about all those ups and downs.*

This participant greatly valued her relationship with the MS Clinic nurses who support her mental health, but wished for something more structured:

*The people [at the MS Clinic], the nurses, I've been able to call them up and chat with them when I'm at my lowest. And I have MS buddies. In town a woman who runs an MS support group...she's been great [be]cause I called her, and talked to her... it would be nice to have that in place for the MS clinic.*

Participant Four felt that there should be greater availability of healthcare professionals, specially trained to help people with neurological issues:

*More of, people that offer services whether it's getting physiotherapy or whether it's chiropractors trying to find people that are maybe a little more specialized, [be]cause that's a really difficult thing to do, to find somebody. Whether it be a chiropractor massage therapy or whatever, that actually... specializes in*

*neurological problems...I would love it if there was a list, that said this chiropractor specializes or this is a dietician that specializes in MS ...a list [to]refer to.*

Participant Six shared her thoughts about her participation in Your Way to Wellness, a six week provincial program for persons with ongoing chronic physical and mental health conditions. This participant greatly valued the program for its sense of community and peer support:

*Well you know the course On Your Way to Wellness is really good. And I think one of the things that anybody that has a chronic illness they always think that they're alone. That concept of aloneness [be]cause you know it's me against the world kind of thing, that sense of community and it's important to have it. [Be]cause when you have a sense of community it gives you more courage, it gives you more energy. It's just a different, and I can't define it but that being said, yah I found, I've had many little successes in the different things ....On Your Way to Wellness, there's something really important to that one.*

This participant also offered her suggestions for improving the program. She felt that the program was too rigid, as it is run by volunteers, and that it should be offered as an ongoing support:

*And I don't know if they can tweak it up a little bit. I enjoyed it, I found the conversations were good, if anything I found the delivery wasn't that great. In the sense, they are volunteers and they are doing a great job... but it's almost like, 'you know we have to go through the book,' and that kind of thing. It's almost like you want a little bit of flamboyant, a little more flair to it. But that being said, I*

*think that one was probably one of the most enjoyable because it gave me a sense of community. It gave me a sense that I'm not alone... everybody almost was sad to see it end. It's almost like it would be lovely to have something like that constantly, to have something going on.*

The last two themes within participant's suggestions for health promotion improvements (form collaborative partnerships and promote education) are related to the topic of women's empowerment and reducing stigma. Empowerment for women with MS is achieved through collaborative partnerships and through educating the public and healthcare professionals about MS.

**Form collaborative partnerships.** Participant Six suggested collaborations, initiated and led by women with MS, with the support of the MS society and grassroots organizations within the area:

*I would put something in place that's easy and as that takes force, then there's a lot of creative minds and as that snowballs and that energy happens and that kind of collaboration happens...I would say, 'we are living in this big city, could we do something on a weekly basis...or a bi-weekly basis'.... I mean learning and collaborating is an awesome thing...That's where some of the greatest things happen...In collaboration probably with the MS Society, and maybe some of the branches, some other arms.*

**Promote education.** As illustrated throughout this chapter, most participants shared at least one story about experiencing stigma and dismissive or hostile attitudes in their communities. Most have also experienced structural barriers when attempting to participate in activities. Participant Two stressed the importance of educating people



about MS to help alleviate stigma. She speculated that misconceptions about disability and MS lead to public apathy. She also suggested that MS advertisements should be modeled on more visible campaigns, such as the heart and stroke foundation's campaign:

*Show this young woman, and she's struggling, and she has a walker and she's walking... people don't understand what MS is and how it affects people, like you see heart and stroke, and yeah people are aware of that because it's in their face all the time.*

Participant Five felt that it is important to educate women with MS about their disease and teach them how to communicate more effectively with healthcare providers:

*Train us to be more proactive with our own disease ... not that we have to have MS take over us, and that it's everything, but to be ... aware of certain things that can be happening, and I think the only way we can do that is through education sessions.*

Participant Five shared her thoughts about the need for greater access to valid, evidence based information for women with MS. She felt that information on the local hospital's website was scant and difficult to locate and that information on the internet is not always credible:

*With technology now, it's either still word of mouth, or go on the computer, on the Internet. And thank god for that, that we have that, however not all the information that you have on there is credible, so you have to really make sure that your resources [are] giving you accurate information, and updated stuff.*

Participant Five also felt that persons with less education, or who are more vulnerable may be susceptible to believing information that is not credible:

*So if you don't know that in advance, and it depends on how vulnerable the individual is of the information, that they're going to be sucking' up whether it's good information or whether it's going to do them more harm. So I don't know, there's barriers there... and it depends on how well educated the individual is, as far as, the grades of school. And what they've done, what they're doing in their life currently, I think that it has a lot to do with the steps that they know to take to get the information.*

Participant Five was an activist in her community and was proactive in educating herself and sharing information with other people with MS. She did however feel that women with MS should be taught to be more proactive about seeking out information. She also felt that there was a need for community organizations and MS peer groups to become more active in collaborating with doctors and the local MS clinic:

*There's something that we're missing as far as the education and teamwork, as far as our doctors and us together, of what we should be looking out for, in advance. Because sometimes I feel, and I've done it myself, I've sat on things too long, and I could've done something about it in the meantime, and then knowing I've still got to wait 6 months to a year, to see somebody to talk about it, that's not going to do anything for me right now, because I need the help right now. So, it's almost like to train us to be more proactive with our own disease ...[be] aware of certain things that can be happening, and I think the only way we can do that is to through education sessions, whether it be from the MS clinic or the MS society Atlantic division or publications or things like that. Which are happening now more so than they ever were before, but I think they're still room for improvement,*

*and there's a lot of people out there that are still walking around scared to death of having MS, and regardless of the outcome you shouldn't be afraid of it.*

**Summary of suggestions for improvements.** In this section participants shared their ideas for health promotion improvements including; financial and community resources, the need for greater access to peer support, supportive services and collaborative partnerships and the need to promote education.

### **Chapter Summary**

The participants' accounts provided rich insights into what it means to live with MS. Participants reported struggling with the symptoms of MS. Fatigue was the most common symptom, which was often overwhelming. Participants also reported struggling with family responsibilities and dismissive, sometime patronizing encounters with healthcare providers. Others described positive supportive relationships with healthcare providers. Some reported feeling uncomfortable in their communities due to stigmatizing experiences. They also shared their need for independence and 'normality,' Health promotion participation was viewed as a means for independence. Health promotion activities included participation at home and in community based programs in which participants feel safe, accepted and free from feeling stigmatized. Positive feelings included a sense of accomplishment and independence. Participants' suggestions for improvements included financial resources for supportive services, discounts for fitness facilities, improved access to community resources (such as barrier free, fair access to community and recreational facilities, etc.), access to peer support, collaborative partnerships and the need for enhanced MS education for the public, women with MS and healthcare professionals.

## CHAPTER V. DISCUSSION

The overall purpose of this study was to gain deeper insight into the health promotion experiences of women with MS to add to the growing body of literature pertaining to health promotion for people with chronic disabling conditions. Six women with MS participated in interviews about their experiences of living with MS.

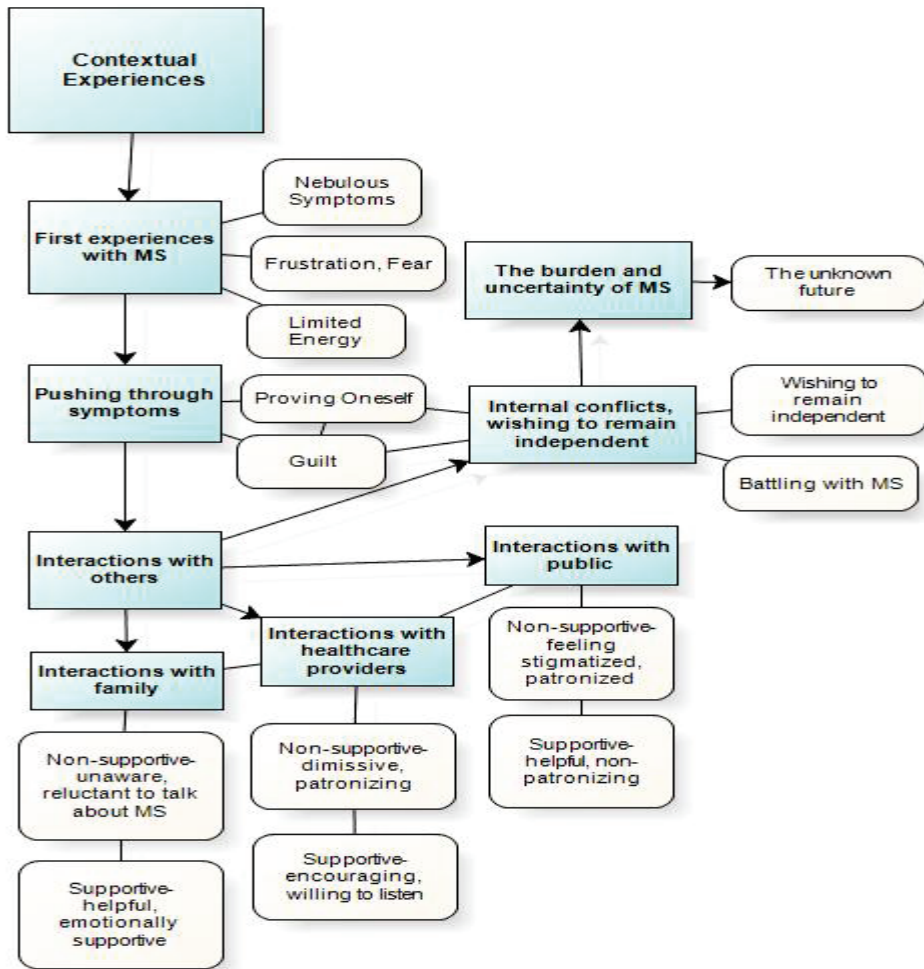
Participants shared stories about their first experiences of MS, as well as interactions with their family, healthcare providers and people in the community. Participants' background experiences then set the context for descriptions of health promotion experiences, preferences and needs, and challenges encountered in health promotion participation. It was in the context of their background and health promotion experiences that the women shared their ideas for improvements to health promotion activities, programs, and opportunities specifically for women with MS.

In this chapter, the research results will be discussed in relation to the constructed themes presented in Chapter Four (see Figure 2). These results were interpreted through the reviewed literature pertaining to health promotion models, interventions, critical feminist and disability rights. Contributions and possible implications for health promotion will also be discussed. The chapter ends with study limitations, ideas for future research and conclusions.

Figure 2, in Chapter Four, illustrates the thematic structure of the research results. This figure is referred to throughout the proceeding discussion. Figures for each theme from this overall thematic model are placed at the beginning of each theme discussion, to provide a visual for how themes are connected and interpreted.

## Discussion of Participants' Contextual Experiences

Figure 5. Contextual experiences



\* Note: in each figure, white blocks represent summaries of the main points from participants' accounts, within themes.

**First experiences of MS.** The findings from this study related to first experiences of MS are consistent with existing literature. As described by Flensner et al. (2003), women with MS often have difficulty coming to terms with their diagnosis and struggle with MS fatigue and the unpredictable disease course of MS. Koopman and Schweitzer (1999) also described this struggle and argued that it is not uncommon for women with MS to feel ignored or belittled by family members, friends and healthcare

providers, due to the inconsistent nature of how MS symptoms occur. Consistent with the literature, the women within this study also reported struggling with limited energy, other MS symptoms and with the uncertainty of initial MS symptoms (Bombardier et al., 2005; Hughes, 2006; Koopman & Schweitzer, 1999; Miller, 1997; Nosek et al., 2004). Their first symptoms occurred in early adulthood, while working in paid labour and/or raising young families. All six women shared stories about their experiences of nebulous, early symptoms, which led to feelings of confusion, frustration and fear (Koopman & Schweitzer, 1999). Several participants described being stuck or saddled with MS, or described MS as an adversary to be battled (Flensner, 2003).

**Pushing through MS.** Most participants felt compelled to push through their MS symptoms, in order to prioritize their family and/ or their career responsibilities. Participants recollected stories about ‘pushing through’ their symptoms to get on with life and overcompensating at work to ‘make-up’ for being disabled. This need to push through symptoms seemed to come from feelings of guilt and wishing to prove oneself. These results support other research related to women’s experiences of disability, including MS. In other studies of women with MS are reports of feeling shame for being unable to fulfill traditional gendered roles, leading to feelings of guilt for neglecting family duties (Asch, Rousso & Jefferies, 2001; Taub, Fanflik & McLorg, 2003). Moreover, disabled women often feel perceived as broken or not ‘normal’ (Gerschik, 2000; Taub et al, 2004). Asch and colleagues (2001) argue that disabled women therefore often feel compelled to negotiate their familial roles to avoid being perceived broken or helpless (Taub et al., 2003). Feelings of guilt and pushing oneself were evident in the

participants' accounts and were linked to internal conflicts and wishing to remain independent.

**Interactions with others (family, healthcare providers and the public).** As evident in the literature reviewed, it can be surmised that stigmatizing attitudes about people with disabilities remain pervasive in society (Becker et al., 1990; Denton, Prus & Walters, 2004; Gerschick, 2000; Schur, 2004; Taub et al., 2003). Kaplan, (1999) argued stigmatizing attitudes toward disabled people remain pervasive because some people (which one can argue, include healthcare providers and health promotion practitioners) continue to view disability within the 'rehabilitation model' or as a defect to be fixed or cured. Furthermore, disability rights and critical feminist scholars argue that women with disabilities, or disabling conditions such as MS, face additional, gendered stigma in life, including unsupportive or patronizing attitudes of non-disabled persons (Garland-Thompson, 2004; Gerschick, 2000; Schur, 2004; Taub, et al. 2004). This is consistent with the current study results.

As consistent with the literature, some women in this study did indeed report feelings of gender and disability stigma (such as guilt for being disabled; Bethune-Davis, et al., 2006). As outlined in Bethune and colleagues (2006), women with chronic disabling conditions continue to face social discrimination and stigmatization. Although all of the participants reported being in emotionally supportive, helpful relationships some felt that family members are unaware of their symptoms or reluctant to talk about MS. Yet, similar to other women's accounts, some of the study participants reported hiding their MS symptoms or refusing to ask for help from family members and friends, to avoid being perceived as needy, or to hide the severity of their MS symptoms

(Bethune-Davis et al., 2006; Kirkpatrick et al., 2009). Participants in this study, in addition to not wanting to be perceived as needy, also shared stories about their need to hide MS symptoms, which were linked to their desire to appear ‘normal’ to others. Appearing ‘normal’ was associated with their ability to complete tasks related to their genderized roles (mothering, household tasks, etc.). Completing these everyday tasks were important in order to maintain their sense of independence and perceived responsibilities within their family. This sometimes led to feelings of isolation, as some did not always feel free to express their true experiences of MS to family members.

Some participants shared accounts of supportive interactions with healthcare providers including encouragement and willingness to listen; however others reported stigmatizing experiences with healthcare providers. For example, Participant Four was told by her doctor that she was complaining and worrying too much, leading to feelings of being dismissed and patronized. These stigmatizing interactions mostly occurred prior to or during initial diagnosis, which are consistent with literature that argues women with disabilities may be patronized by healthcare providers and told that their symptoms are psychological manifestations (Isaksson & Ahlstrom, 2006; Koopman & Schweitzer, 1999). In contrast, interactions with healthcare providers who specialize in MS or neurological conditions were mostly positive.

In relation to interactions in the public, participants shared accounts of supportive interactions (including people offering to help with tasks or open doors), while others shared stories about stigmatizing interactions (e.g., one participant shared accounts of verbal abuse in her community and another felt patronized during a yoga class and leisure activities). According to Schur (2004), women with disabilities are more likely to



experience discriminatory attitudes and verbal abuse in their community when compared to non-disabled women, disabled men and able bodied persons.

**Internal conflicts and wishing to remain independent.** Contextual experiences related to participants first finding out about MS, pushing through MS and stigmatizing interactions with others led to internal conflicts in some participants related to wishing to remain independent and battling with MS. This finding is consistent with other literature related to women's experiences of disability, as women with disabilities often internalized negative messages related to gender and disability stigma (Schur, 2004), which may result in feelings of poor self-image (Bethune-Davies et al., 2006). Negative interactions with family, people in the community and healthcare providers contributed to some of the study participants' feelings of stigmatization (which impacted their health promotion preferences and participation, as discussed later).

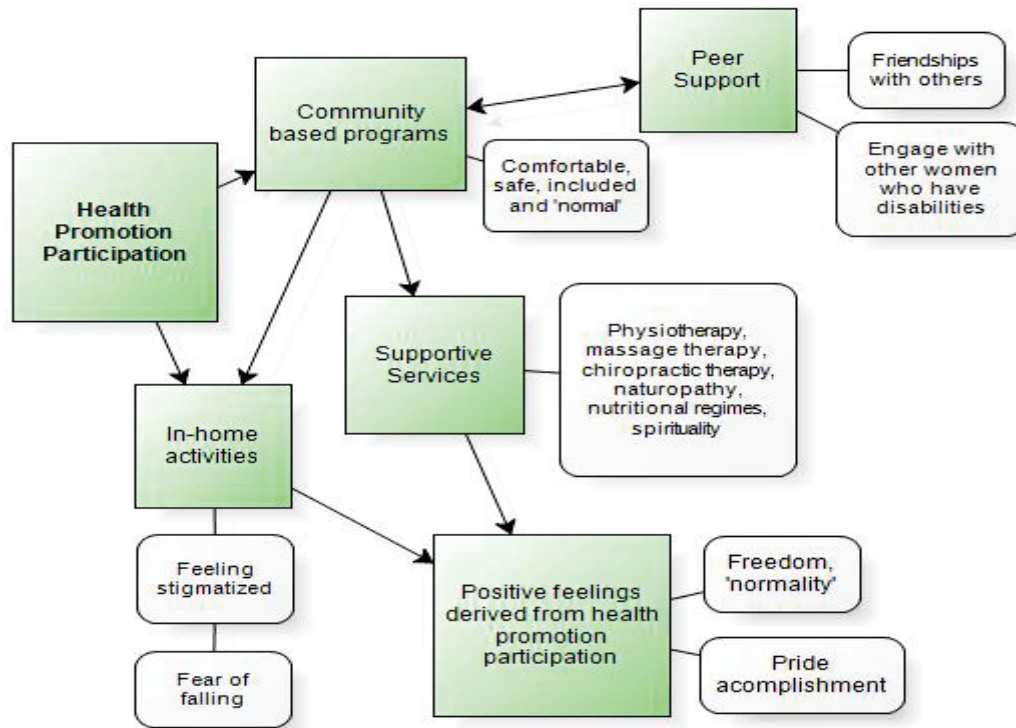
**The burden and uncertainty of MS.** Participants shared accounts of feeling burdened and saddled with MS; these feelings were linked to fear of the unknown future of MS (Flensner et al., 2003). This again is consistent with existing literature. As described by Flensner and colleagues (2003), women with MS may experience profound emotional impacts while living with MS, including fear of the unknown future or feelings of being betrayed by their own body. Overall, the contextual experiences described by the women of what it meant to live with MS and how this impacted interactions with others supported existing research.

### **Discussion of Health Promotion Participation.**

The contextual experiences participants shared then linked to what they subsequently shared about health promotion participation, challenges and practical

implications related to their suggestions for improvements. The figure below represents participants' health promotion participation.

Figure 6. Health promotion participation



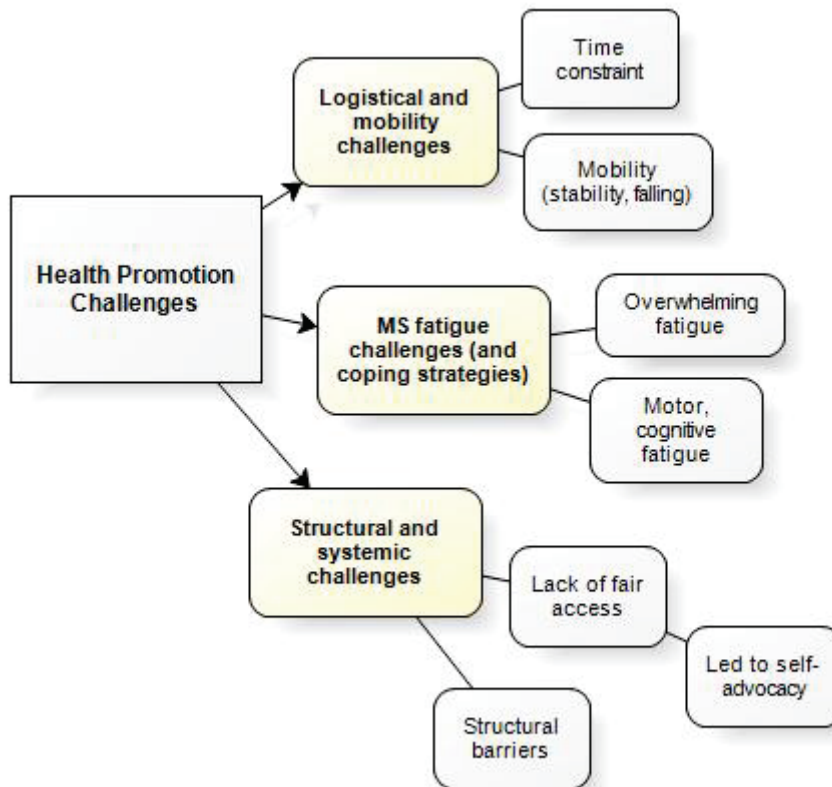
**Participation in home activities versus community.** As outlined in the contextual section, some of the women in this study reported feelings of fear and stigma during their everyday, lived experience of MS. Stigmatizing experiences occurred for some women while participating in community-based programs. Bethune-Davis and colleagues (2006) argue that women with disabilities continue to face stigmatizing attitudes while engaging in their communities. Similarly, and in part as a result of their ongoing, everyday experiences of stigma, some of the participants in this study therefore mostly preferred in-home health promotion activities. In contrast, when participants felt comfortable and included, they viewed health promotion participation in community-

based programs as a means to maintain health, access peer support, make friendships with others and to engage with other women who have similar disabilities. As outlined by Nosek and colleagues (2004), women with disabilities value social support from others when describing their views of health and wellness. A sense of inclusion and relationship development are also important factors influencing other disabled women's decision to participate in health promotion activities (Nosek et al., 2004). Women in this study who participated in community-based activities also stressed their desire to feel 'normal,' during health promotion activities in addition to valuing social support and peer engagement. They shared stories about avoiding drawing attention to themselves during fitness classes. Others felt most comfortable in classes or programs designed for women, older people or persons with disabilities. In addition, they also felt that supportive services for women with MS are important for overall health and wellness. Access to supportive services provided a sense of independence, empowerment and control over their disease course, by helping them to manage physical symptoms in addition to enhancing their feelings of accomplishment. Participation in health promotion activities, regardless of whether in-home or community-based, led to feelings of freedom, normality, pride and accomplishment for all six participants. As corroborated in Hughes (2006), women with disabilities may benefit from tailored health promotion interventions that are customized to suit their needs, which foster this sense of pride, independence and accomplishment. This may also be true for women with MS.

### **Discussion of Health Promotion Challenges.**

Logistical and mobility challenges, MS fatigue and structural/systemic challenges were cited as the most common challenges. Logistical challenges were related to time constraint, convenience, and mobility issues.

Figure 7. Health promotion challenges



Similar to findings reported by Flensner et al. (2003), all six participants in this study experienced fatigue and limited energy, which they found difficult to describe to others. According to Schwid, Covington, Segal and Goodman (2002), health researchers have also had difficulty in defining and measuring MS fatigue. These authors propose the need for improved investigation into the causes of MS fatigue, which include more effective assessment of: (a) motor fatigue (decline in motor function during physical activity), (b) cognitive fatigue (decline in cognitive function during cognitive activity) and, (c)

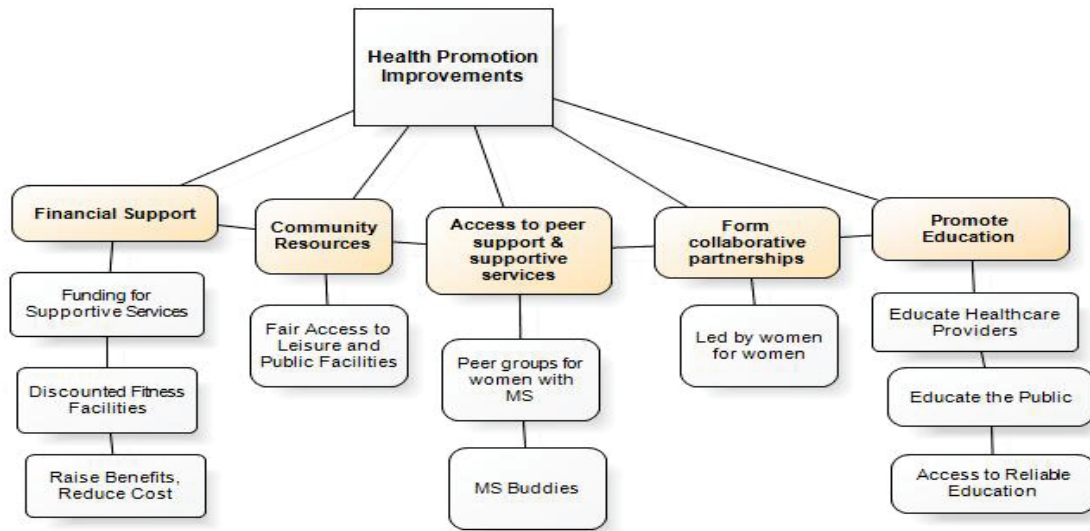
lassitude fatigue (participants perception or rating of their own fatigue experience) (Schwid et al., 2002).

In this study, motor fatigue was as one of the main reasons for not participating in community-based programs and cognitive fatigue as one of the reasons for participating at home. More generally, most participants described their fatigue as a disabling condition that hindered their energy reserves and often prevented them from socializing or engaging in health promotion activities, thus impacting their overall sense of health and wellness. As consistent in the literature, people with MS often describe their experience of fatigue as frustrating, leading to ‘involuntary’ or unwanted isolation (Flensner et al., 2003, p. 712). The experience of isolation may be particularly troubling for women who view social support as a key factor in maintaining health and wellness (Nosek, et al., 2004). Like other women with disabilities, study participants also shared accounts of how their limited energy would sometimes be reserved in favour of family needs over their own health promotion needs (Gerschick, 2000).

### **Discussion of Participants’ Suggestions for Health Promotion Improvements**

Participants’ contextual experiences (e.g., their frustration with MS, their limited energy and family responsibilities, their interactions with others and their desire for independence, etc.) and their health promotion experiences and challenges set the context for their discussions of what improvements are most important and meaningful to the participants. These discussions of participants’ ideas for improvements are followed by implications for health promotion improvements, which includes further reference to the literature and practical implications.

Figure 8. Health promotion improvements



**Financial support.** As argued by Nosek et al. (2004) resources that help support and empower disabled women’s health include access to financial support. Funding for health preventative services for disabled persons however is often not prioritized (Sprague & Hayes, 2000). All but two participants in this study were unemployed and therefore had limited financial resources for fee-based health promotion activities. Themes constructed from the research data in Chapter Four (see Figure 2), show that several of the participants suggested that government funding should be made available for such things as discounted fitness facility memberships and health promotion classes. Others suggested that benefits should be available for supportive services that improve overall health and mobility, including massage therapy and chiropractic services. Participant also felt that funding should be available for outreach workers to assist isolated women who have MS with in-home tasks.

**Community resources and access.** As noted previously empowerment is “the freedom of persons to choose from options available to them and to control decisions that

affect their lives” (Zimmerman, 1995, p. 583). Similarly, Barr et al., (2003) argue for inclusive strategies in population health “to facilitate individual and community empowerment so that all people, both ill and well, are able to achieve a greater sense of control over the many complex factors that affect their health” (p. 75). One of these complex factors is limited health promotion choices for women with MS. Barr and colleagues (2003) suggest ways to facilitate community and individual empowerment, through focusing on the needs of individuals within communities. One way to do this is to help all citizens, including persons with disabilities or chronic conditions, to secure fair access to public space (e.g., public parks, recreation facilities, etc.) and public transportation (Barr et al., 2003).

Although most of the women in this study valued the sense of control, independence and personal achievement they experienced from in-home and community-based health promotion participation, three participants reported limited choices for accessible health promotion and leisure facilities in their communities. For example, several participants shared experiences of inaccessible pools within their communities. Most of the urban areas within the research settings also have accessible bus routes and accessible low floor buses. In the winter, however these routes may be impeded by delayed snow removal. Accessible bus routes in the suburban and rural areas are more limited, or non-existent. In addition to improved access to fitness facilities, several participants also felt that there is room for improvement for access to public facilities in general, including bathrooms and parking lots that are more accessible. This suggestion extended to private facilities such as restaurants and movie theatres.

**Access to peer support and supportive services.** The participants in this study highlighted the importance of having access to peer support. This is consistent with existing literature. For example, Hughes (2006) and Stuifbergen et al. (1999) each emphasize the importance of empowerment of women through peer engagement. Other authors also advocate for peer support that, in part, provides opportunities for disabled women to develop their decision-making, self-efficacy (Hughes, 2006) and leadership skills (Zimmerman, 1995). Heisler (2006) describes peer support groups as an effective way to motivate people to participate, “because of non-hierarchical, reciprocal relationships created through the sharing of experiences and knowledge with others who have faced similar challenges” (p. 8). This author also argues that “the more homogenous the peers are... the more likely it is that the support will lead to understanding, empathy and mutual help” (p. 8).

Most women within this study reported having access to social support within their communities, with an emphasis on the provision of ongoing peer support. As supported by the literature however, some desired greater contact and opportunities to engage with peers, especially with other women who have MS, or similar disabling conditions (Hammel et al., 2008). One suggestion for how this could occur included coupling women with MS as peer buddies. Participants in this current study greatly valued the social support received within MS support group as well as exercise groups for people with disabilities, and strongly advocated for increased peer support.

**Form collaborative partnerships.** Barr and colleagues (2003) developed the ECCM as a model to guide health care transformation related to disease prevention and management. These authors argue for a continuum of care across population health,



health promotion, disease prevention and treatment. In order to achieve optimal functional and population health outcomes, they stress that collaboration between those working in healthcare systems, individuals and community partners is essential. To achieve these outcomes requires enabling both community and individual empowerment (Barr, et al., 2003).

One of the six key principles recommended by Hughes (2006) is to ensure women with disabilities are afforded opportunities to be involved in health promotion planning and implementations. In this current study, participants suggested practical ideas for collaboration initiatives, led by women who have MS. Specifically for women with MS, these initiatives should be easy to attend and should be established with the MS society and other similar partners in the community at a grassroots, local level. It was recommended that the women could meet to discuss their ideas, form a bond and sense of community and then expand collaboration beyond their individual group in a ‘snowball effect,’ to the surrounding communities and with additional partners as ideas arise.

**Promote education.** In the ECCM model people work closely with the community, including workplaces and local organizations, toward developing and enhancing self-management skills (Barr et al., 2003). Self-management skills as contextualized within the ECCM moves beyond traditional health education to include an emphasis on education that recognizes social determinants of health (Barr et al., 2003).

Hughes (2006) argues that health promotion interventions for women with disabilities should also be tailored and customized to suit the needs of women with disabilities. She suggests education in part should include advocacy education, which

discusses: a) poverty, b) violence against women, c) women's sexual and reproductive health and, d) substance abuse and e) employment counseling (Hughes, 2006).

In this current study participants suggested educational components for women's health (e.g., breast health) are useful to include in health promotion activities (e.g. after an exercise class or as a workshop). Participants felt strongly about women with MS becoming more proactive and felt they should be provided with opportunities to learn more about their disease. Other suggestions for education for women with MS, as interpreted through the research results, include: a) fatigue management, b) dietary regimes that are beneficial for women with MS, c) how to access specialized supportive services such as physiotherapists who specialize in neurological conditions, d) how to access reliable MS information, and e) lists of resources available in the communities.

Hughes (2006) suggestions for education focus on education for women with MS. The women in this study however suggested that education be expanded to also include for healthcare providers and health promotion practitioners and should place priority on mitigating potential stigmatizing attitudes of healthcare professionals (Sprague & Hayes (2000). This education should therefore include topics specifically about MS fatigue, gender, disability and stigmatizing language that may impede effective communication with their patients and clients. In addition, was the suggestion that public campaigns should be created to educate people about MS, therefore potentially reducing stigma and public misconceptions about MS.

### **Implications for Health Promotion Improvements**

As discussed above, the women in this study had an array of ideas for what would be most meaningful for them in the context of health promotion improvements.

Implications and examples of how to health promotion practitioners might work with women who have MS toward health promotion improvements are discussed next.

**Health promotion advocacy.** As outlined by participants, public and private spaces are often inaccessible. Lack of accessible space may in part be due to disability stigma, where abled-bodied persons assume that people with disabilities have limited capacity to participate (DAWN, 2008; Hughes, 2006; Neri & Kroll, 2003). Sprague and Hayes (2000) argue that disabled person's access to resources are impacted by the effect of exploitative relationships, "that allow some to accumulate resources and maintain control" (p. 674). Health promotion practitioners should therefore work with women who have MS to lobby the government to demand equal access to health promotion programs for all citizens (Weaver & Olson, 2005).

For example, there are compassionate resources available for drug therapies, for those who have low income in Nova Scotia. However, there are no provincial initiatives that provide funds to women with MS for health promotion and prevention activities. Health promoters and women with MS should work together with community partners to advocate for government funding for: a) discount fitness facility membership, b) benefits for supportive services, and c) funding for outreach workers. For example, alternate funding sources could also be sought through local or regional healthy communities initiatives or through fundraising initiatives in collaboration with the MS society.

**Advocate for improved access to peer group opportunities.** Empowerment is achieved in part through the community's (e.g., healthcare, educational and government institutions) willingness to facilitate disabled women's sense of self through the development of relationships that are mutually beneficial and afford disabled women the

opportunity to freely choose and interact with their peers (Sprague & Hayes, 2000). Health promotion interventions should therefore include the facilitation of relationship development, led by women, for women with MS. As suggested by research participants and as interpreted through the literature, access to peer groups are greatly valued and should: a) be specifically designed for women who have MS, or other similar disabling conditions; b) offer leadership opportunities for group participants and that develop reciprocal relationships; c) pair women within peer groups, with similar backgrounds; d) offer continuous, ongoing peer support, and; e) provide women with supportive resources to form collaborative partnerships.

**Advocate for improved partnerships.** To give voice to their concerns and to foster a sense of self-determination (Sprague & Hayes, 2000). Health promoters should help mitigate gender and disability stigma through helping women with MS engage in shared leadership opportunities that support development of a group identity (Sprague & Hayes, 2000) and that enable women with MS to work with community partners. For example, one person suggested collaborative partnerships, led by women, for women with MS. Potential partners in the research setting could include: a) the MS fatigue clinic, b) the MS Society (Halifax Chapter), c) the MS self-help group, d) the YMCA Abilities in Motion program, e) the Victoria Order of Nurses program for isolated persons, and f) the “*Your Way to Wellness*” chronic disease self-management group. The Abilities in Motion program is run through the local YMCA, and offers participants access to accessible physical fitness equipment and social programs. The *Your Way to Wellness* program is a six-week chronic disease self-management program, offered in strategic locations throughout the province of Nova Scotia. This program is base on the Stanford

Chronic Disease Self Management program (Lorig, González & Laurent, 1999; Lorig et al., 2001).

**Improve health promotion education.** (To include a feminist, disability rights lens). Empowerment messages, embedded in traditional health promotion discourse, that are singularly based on behaviour modification techniques are incomplete, as these techniques overemphasize the individuals' responsibility for controlling their own behaviours. Health promotion education initiatives should provide education to help mitigate gendered and disability stigma through the use of inclusive, non-patronizing language in program planning and interactions with women with MS. Healthcare providers and healthcare promotion partitions should adopt a holistic approach to health, which promotes opportunities to engage with women who have MS, to understand their day-to-day experiences of MS, including their fears, confusion and frustrations and family responsibilities.

**Education that addresses the needs of women with MS.** As fatigue was one of the predominate factors for reduced participation in health promotion activities, wider dissemination and integration of fatigue management strategies into private and public health promotion activities are indicated. Participants reported strategies to help mitigate fatigue symptoms such as: a) drug therapies, b) dietary changes, c) knowing one's own limitations, d) resting in between activities, and e) selecting modified exercise routines and pacing oneself during exercise and leisure activity. For example, the Dalhousie Multiple Sclerosis Research Unit (DMSRU), located in the urban area of the research setting, offers education to MS patient for fatigue management strategies. All of the participants in this study attended the MS Clinic, so therefore may have employed some

of the DMSRU strategies which include: pacing (taking breaks), planning ahead for activities, prioritizing activities, exercising in the morning, trying MS friendly activities (such as yoga and aquasize), and using dietary and medications therapies to mitigate MS symptoms (DMSRU, 2002). These strategies should be more widely disseminated within health promotion education.

### **Contributions**

This research sought to address the following research questions: How do women with MS describe their health promotion experiences, preferences and needs? Sub-questions (that framed the overall research question) included: How are contextual experiences of MS related to health promotion experiences? What barriers or challenges to engaging in health promotion activities do women with MS experience? What ideas are important to women with MS for improvements to health promotion programs and opportunities?

This study offers a unique contribution to the health promotion literature, as it responds to the call for the health promotion researchers to adapt feminist and disability rights definitions when undertaking health promotion research (Hughes, 2005). Several important findings from this study contribute the discussion of health promotion for women with MS. These included adding unique lens related to disability, gender stigma and empowerment. These lens add a deeper understanding how health promotion participation for women with MS is related to a sense of independence, freedom and feeling normal.

Additionally, through exploring the phenomenon of women's' shared accounts of contextual experiences, this research also contributes to a clearer understanding of how

guilt, gender roles and family responsibilities may take precedence over personal needs, including health promotion participation. This may be particularly true for women with MS, who experience limited energy, which manifests not only in physical limitations (loss of mobility, cognitive and motor fatigue) but also to internal conflicts of guilt, which negatively impact their health promotion participation (Becker & Stuifbergen, 2004; Bethune-Davies, et al., 2006).

The study also contributes to understanding how women's experience of MS, gender and disability stigma impacts their health promotion choices, including their decision to participate at home or to participate in the community. Empowerment for this study was defined as, the ability of community partners to work with women who have disabilities, to foster a sense of self-determination (Sprague & Hayes, 2000). Empowerment from a feminist and disability rights perspective is closely linked to giving voice to those who may not otherwise be heard or whose voices are overlooked when planning health promotion programs (Sprague & Hayes, 2000). This research provided a means for participants' voices to be heard through having women share their suggestions for how to improve opportunities in health promotion s for women with MS.

Through engaging with participants, using a feminist/disability rights methodological approach to discover what is most important to them for health promotion improvement, it was discovered that there are important opportunities for health promotion practitioners to work in partnership with women who have MS as advocates and facilitators for fair access (Hughes, 2006). Health promotion practitioners may also help improve opportunities for access to peer groups that move beyond short duration and self-help programs, which are designed by and led by healthcare

professionals, toward more inclusive collaborative models of care and support led by women with MS (Hughes, 2006).

Additionally, health promoters may also work with women who have MS toward improved partnerships and education that integrates topics about gender/disability stigma, not only for program participants, but also for healthcare providers and through facilitating public educational campaigns. Moreover, health promotion education, designed to address the needs of women with MS, should move beyond discussion about diet and exercise, to also include discussion about women's health, MS fatigue and other issues that are important to women with MS (Hughes, 2006)

Finally, the study also contributes a unique lens to the discussion of health promotion models such as the ECCM (Barr et al., 2003); although these models help guide health system reform they do not address systemic, environment, attitudinal barriers (related to gender and disability stigma) encountered by women with MS.

### **Study Limitations and Future Research**

The researcher applied qualitative standards to address rigor and trustworthiness. Data analysis for this study followed rigorous criteria, testing for credibility, transferability, dependability and conformability (Guba 1981; Lincoln & Guba, 1985). In qualitative research, validity is established through credibility. Data collection and analysis within this study was completed until saturation occurred (no new themes were produced). Rich description of the data results and interpretative literature are provided for the reader to assess and compare to their own research setting.

As indicative of qualitative methodology, participants for this study were drawn from a small purposeful sample of six unique participants. Some of the themes that arose



from this study however are be useful in understanding the unique health promotion needs of women with MS and may therefore be useful for other settings.

Participants were recruited from a single centre (the NSRC, MS Clinic). The typical age range for outpatients at the NSRC, MS Clinic does not represent all women with MS. The sample of women for this study ranged in ages 44 to 64, from mostly mobile, moderate and limited mobility, which provide a diverse perspective form this group. The researcher set out to recruit from age ranges of 20 to 65, those who agreed to participate were mostly middle age, married women. Younger and older single or women were therefore not represented in the discussion. Future research may therefore benefit from the inclusion of younger women or women who are not married or living in common-law relationships, to obtain their unique insights. Women with advanced stages of MS were also not included in this study, due to the nature of the study tool (in-depth, semi-structured interviews), so therefore should be included in future studies. As outlined in the literature, social determinants of health are known to impact peoples experiences. Future research should therefore also include the perspectives of older, isolated women, women of colour, women with variant sexual orientations and women who do not attend the MS, NSRC clinic. Topics that were not covered in the research question included women's access to preventative services including, pelvic examination and breast health. Sexual health and fertility were also not addressed within this study. Further research is needed in this area.

Finally, future research may include ideas for health promotion practitioners to develop interventions that consider the unique needs of women with MS. These include topics related to how contextual experiences of gender and disability stigma may impact

health promotion preferences, needs and experiences. In addition there is a need for program development and evaluation that: (a) effectively integrates ongoing peer support into program planning, (b) includes women with MS as partners and leaders, (c) takes into account the unique challenges women with MS encounter when participating in health promotion activities (such as stigmatizing experiences, limited energy, logistical and access challenges) and (d) prioritizes health promotion improvements that matter most to women with MS.

### **Conclusion**

I felt honoured and privileged to listen to the participants' stories and was deeply touched by their honesty, candor and thoughtful insights. Women within this study were proactive and had many ideas for improvements to health promotion in their community. Their determination has inspired me to continue to advocate for the improvement health promotion programs and activities for women with MS.

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## **APPENDIX A: INTERVIEW GUIDE**

### **Introduction**

Hello, My name is Kristine, I'm a graduate student at Dalhousie's School of Health and Human Performance. My thesis research interest is about how women with MS describe health promotion and their experiences in health promotion activities. We have about an hour and a half to talk so feel free to tell me about anything that you think is relevant. In the next half of the interview, I will ask you to share more specific questions about some of the challenges you may have experienced while participating in health promotion activities. I will also ask you to share your suggestions for improving health promotion services for women with MS.

### **First Half (Semi-Structured)**

So let's get started,

- I. First, tell me a little bit about yourself . How old are you, where do you live, are you married, do you have kids, do you work in paid labour or in the home, etc? (Whatever participant felt was important to share).
- II. Also, tell me about your background experiences with MS. What type of MS do you have, when were you diagnosed, what was that experience like for you, what are your symptoms, etc.? (Whatever the participant felt was important to share).
- III. How does MS affect your everyday life, your relationships, etc? (Participant directed the conversation; interviewer prompted for family, community and healthcare provider relationship examples).
- IV. What strategies do you use in everyday life. (Whatever the participant felt was important to share).

### **Second Half (Semi-Structured)**

a) Descriptive

- I. Please describe what health promotion means to you. What do you do to promote your own health?
- II. Please describe some of the challenges you may have faced while participating in health promotion programs? With family, within the community, with healthcare

providers, etc. [Prompt- It's OK for you to describe whatever comes to mind first. If you haven't experienced very many challenges, that's OK also. Instead, tell me a little bit about your successes]. [If participant has experienced challenges]. -I'd like you to think about and describe to me how some of these challenges may have been connected to the negative attitudes of others. [Prompt: even if you do not feel you have 'concrete' proof, it's OK to think outside of the box a bit here and take your time].

- III. Please describe What do you feel has supported the successes you have just described to me?]. For example, does your family support your participation in health promotion activities? [If yes ask the participant to describe how her family supports her, if no, ask the participant to describe why and how she feels her family does not support her participation]. [Prompt-What about healthcare providers or your doctor, do they support and encourage you to participate]?

b) Narrative

- I. Tell me a story about other challenges you may have encountered while participating in health promotion activities? For example, have you ever experienced access challenges?

c) Feelings

- I. How do you feel about these challenges you have described?  
II. How does participating in your health promotion activities make you feel?

d) Direct questions

- I. Does your family support your activities?  
II. Do you feel that your being a woman has affected your participation in health promotion activities and if so, how?  
III. Do you have any suggestions for improving health promotion services for women with MS?

e) Conceptual

- I. What has the whole experience been like for you? Is there anything else you would like to share?

## **APPENDIX B: THE KURTZKE EXPANDED DISABILITY STATUS SCALE**

### **Expanded Disability Status Scale**

#### **a) Mobile**

- normal neurological exam (all \*functional systems (FS) grade 0)
- no disability, minimal signs in one FS (on FS grade 1)
- 1.5 non disability, minimal signs in more than one FS (more than one FS grade 1)

#### **b) Mostly Mobile**

- 2.0 minimal disability in one FS (one FS grade 2, others 0 or 1)
- 2.5 minimal disability in two FS (two FS grade 2, others 0 or 1)
- 3.0 moderate disability in one FS (one FS grade 3, others 0 or 1) though fully ambulatory: or mild disability is three or four FS (three/four FS grade 2, others 0 or 1) though fully ambulatory
- 3.5 fully ambulatory but with moderate disability in one FS (one FS grade 3) and mild disability in one or two FS (one/two FS grade 2) and others 0 or 1; or fully ambulatory with five FS grade 2 (others 0 or 1)

#### **c) Moderate Mobility**

- 4.0 ambulatory without aid or rest for  $\geq 500$  meters; up and about some 12 hours a day despite relatively sever disability consisting of one FS grade 4 (other 0 or 1) or combinations of lesser grades exceeding limits of previous steps
- 4.5 ambulatory without aid or rest for  $\geq 300$  meters; up and about much of the day, characterized by relatively sever disability usually consisting of one FS grade 4 and combination of lesser grades exceeding limits of previous steps
- 5.0 ambulatory without aid or rest for  $\geq 200$  meters (usual FS equivalentents include at least one FS grade 5, or combination of lesser grades usually exceeding specifications for step 4.5)
- 5.5 ambulatory without aid or rest  $\geq 100$  meters

#### **d) Limited Mobility**

- 6.0 unilateral assistance (cane or crutch) required to walk at least 100 meters with or without resting

- 6.5 constant bilateral assistance (cane or crutches) required to walk at least 20 meters without resting
- 7.0 unable to walk 5 meters even with aid, essentially restricted to wheelchair; wheels self and transfers alone; up and about in wheelchair some 12 hours a day
- 7.5 unable to take more than a few steps; restricted to wheelchair; may need some help in transferring and in wheeling self

**e) Not Mobile**

- 8.0 essentially restricted to bed or chair or perambulated in wheelchair, but out of bed most of the day; retains many self-care functions; generally has effective use of arms
- 8.5 essentially restricted to bed much of the day; has some effective use of arm(s); retains some self-care functions
- 9.0 helpless bed patient; can communicate and eat
- 9.5 totally helpless bed patient; unable to communicate effectively or eat/swallow
- 10.0 death due to MS

\*Functional systems include; “Pyramidal (a type of neuron found in the brain), Cerebellar (a region of the brain), Sensory, Bowel and Bladder, Visual, Cerebral or Mental, and Other or Miscellaneous” (Kurtzke, 1983, p.1444)

## APPENDIX C: INFORMED CONSENT

Non-Interventional Study

Consent Form

**STUDY TITLE:** A qualitative study exploring the health promotion experiences of Nova Scotian women with MS

**PRINCIPAL OR QUALIFIED INVESTIGATOR** **Kristine L. Webber, 24 Maple Street, Bedford, Nova Scotia, B4A-2P2**

**SITE** **Dr. Christine Short**

**INVESTIGATOR:** Department of Medicine, Dalhousie University, Division Chief, Physical Medicine and Rehabilitation, Nova Scotia Rehabilitation Centre, Rehabilitation Program, Capital District Health Authority  
1341 Summer Street, Halifax, Nova Scotia, B3H-4K4

**DIRECTOR** **Dr. Susan Hutchinson, Associate Professor, School of Health and Human Performance, Dalhousie University, Halifax, Nova Scotia**

PART A.

### Non-Interventional Studies – General Information

#### 1. Introduction

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide,

you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

We do not know if taking part in this study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. We will always give you the best possible care no matter what happens.

If you decide not to take part or if you leave the study early, your usual health care will not be affected.

## **PART B.**

### EXPLAINING THE STUDY

#### 2. Why Is This Study Being Done?

This research is being undertaken by the Principle Investigator [PI] in partial fulfillment of her Master Thesis, in Health Promotion, through Dalhousie University's School of Health and Human Performance, Halifax, Nova Scotia. The study will begin in July, 2012. The research will explore:

1) How women with Multiple Sclerosis [MS] describe the strengths they find or draw upon from their participation in self-defined health promotion activities.

2) How women with MS describe health promotion participation experiences in relation to attitudinal and social barriers they may encounter with family members, the community and with healthcare providers.

‘Health promotion activities’ may include (but are not limited to) such things as exercise classes, nutritional classes, health education classes or classes designed for people with MS or people with chronic conditions. It might also include services or classes you have paid for in a private gym, recreation facility or physiotherapy clinic. Health promotion activities may also include things that you do on your own time, in or out of your home, that you feel help you to gain a sense of health and wellbeing. As a result of participating in health promotion activities you may feel empowered or more in control of your situation and life.

This study is important as: research has shown the positive benefits of health promotion participation for women with chronic disease/conditions such as MS. Few studies however have asked women with MS to share their actual ‘real life’ health promotion experiences and none have asked them to share attitudinal or social barriers they have experienced while participating in health promotion activities. (E.g., by social or attitudinal barriers we mean the poor attitudes of others and lack of support or help to participate, etc.) In addition, there are very few studies which ask women to share the strengths they find or draw upon from participating in their chosen health promotion activities. The proposed research will address this gap in the literature.

### **3. Why Am I Being Asked To Join This Study?**

You have been asked to join this study because you are a woman with MS between the ages of 20 and 50 years (note- changed to 65 years) who has had MS for at least one year and has participated or has attempted to participate in health promotion activities.



#### **4. How Long Will I Be In The Study?**

This study involves a onetime participation in a 1 and ½ hour interview. This interview will take place before or after one of your regular visits to the MS clinic, at another time (which is most convenient for you) at the MS clinic or in your home, if you prefer.

#### **5. How Many People Will Take Part In This Study?**

This study is taking place in Nova Scotia only. Six to 8 women will be included in the study.

#### **6. How Is The Study Being Done?**

Your doctor [Clinic Lead] or the Clinic Nurse Practitioner at the Nova Scotia Rehabilitation Centre [NSRC] MS Clinic will decide if you qualify for the study, will talk to you about the study and will provide you with the introductory letter. If you are interested in hearing more about the study the Principle Investigator will contact you to tell you more. She will then give you the blank consent form to take home and read. Once you have read this consent form and you agree to participate, your doctor [Clinic Lead] or the Nurse Practitioner will have you sign this consent form. Before you sign the form he or she will first ask you a few questions to make sure you understand the purpose of the study, the type of research tool being used [a audio recorded interview], and what the risk and benefits are for your participating in the study. The Nurse Practitioner or your doctor [Clinic Lead] will also let you know that you are under no obligation to participate and that you may withdraw at anytime.

#### **7. What Will Happen If I Take Part In This Study?**

Your one time interview will last 1 and ½ hours. It will be conducted in a quiet, private room at the NSRC, MS Clinic or in your home if you prefer (the PI will come to you). If you get tired or need a break during the interview or want to stop, you will be free to do so. You are also free at any time to not answer questions you are uncomfortable with or you may withdraw from the research study at any time, without any change to your regular care.

The interview will be recorded with a digital audio recorder (a voice only tape recorder). After your interview, the PI will transcribe (type-out) your interview and will summarize it. The audio recording and the transcription from your interview will not have your name on it and will be stored at the MS Clinic in a locked cabinet and locked office. Your transcript documents will be stored in the same locked cabinet and locked office. Your name will not appear in the thesis report or within future research.

### **8. Are There Risks To The Study?**

There are risks with this, or any study. To give you the most complete information available, we have listed some *possible* risks. We want to make sure that if you decide to try the study, you have had a chance to think about the risks carefully. Please be aware that there may be risks that we don't yet know about.

**Possible risks-**You may find the interview questions upsetting or distressing. You may not like all of the questions that you will be asked. To reduce these possible risks, you do not have to answer questions you find upsetting or distressing.

### **9. What Happens at the End of the Study?**

After your interview is complete and your interview summary will be sent to you for review, by registered mail with a paid return envelope. This envelope will contain a form for you to include your comments and feedback. After all interview are analyzed and participants feedback and comments are received, the Principle Investigator will write her thesis report. This report will be presented to her thesis committee (defended) in the Spring of 2013. The report will also be shared with the MS Clinic.

### **10. What Are My Responsibilities?**

As a study participant you will be expected to:

- Follow the directions of the PI
- Report changes in your health status
- Be willing to participate in a 1 and ½ interview
- Be willing to be audio recorded

- Be willing to participate in the interview without your spouse, significant other or primary care giver present

### **11. Can I Be Taken Out Of The Study Without My Consent?**

Yes. You may be taken out of the study at any time, if:

There is new information that shows that being in this study is not in your best interests. Capital Health Research Ethics Board or the Principal Investigator decides to stop the study.

You will be told about the reasons why you might need to be taken out of the study.

### **12. What About New Information?**

It is possible (but unlikely) that new information may become available while you are in the study that might affect your health, welfare, or willingness to stay in the study. If this happens, you will be informed in a timely manner and will be asked whether you wish to continue taking part in the study or not.

### **13. Will It Cost Me Anything?**

#### Compensation

You will not be paid to be in the study. You will get a small amount of money to cover parking on study visit day and a small amount (up to \$40 for mileage and gas receipt or Access a bus expense) if you need to make a separate visit to the MS Clinic to participate in the study. Please bring your receipts with you.

#### Research Related Injury

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the Principal Investigator, the research staff,

the study sponsor or involved institutions from their legal and professional responsibilities.

#### **14. What About My Right To Privacy?**

Protecting your privacy is an important part of this study. A copy of this consent will be put in your health record.

When you sign this consent form you give us permission to:

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

#### Access to records

The PI and members of the research team will see health and study records that identify you by name.

Other people may need to look at the health and study records that identify you by name. These might include: the CDHA Research Ethics Board and Research Quality Associate

#### Use of records.

The research team will collect and use only the information they need to complete the Study. This information will only be used for the purposes of this study.

This information will include:

your age

- where you live (urban or rural area)
- your marital status
- your parental status (do you have children)
- your work status (paid or unpaid labour)
- the length of time you have had MS symptoms
- when you were first diagnosed with MS

- your type of MS
- your ability to get around your community (i.e. do you drive, do you have access to transportation, etc.)

Your name and contact information will be kept secure by the research team in Nova Scotia. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study. Information collected for this study will be kept as long as required by law. This will be for 7 years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. After your part in this study ends, we may want to check that the information we collected is correct.

Information collected and used by the research team will be stored at the NSRC, MS Clinic, Capital District Health Authority. The PI is the person responsible for keeping it secure. You may also be contacted personally by Research Auditors for quality assurance purposes.

#### Your access to records

You may ask the study PI to see the information that has been collected about you.

#### **15. What if I Want to Quit the Study?**

If you chose to participate and later change your mind, you can say no and stop the research at any time. If you wish to withdraw your consent please inform the PI. All data collected up to the date you withdraw your consent will remain in the study records, to be included in the study related analyses.

#### **16. Declaration Of Financial Interest**

The PI has no financial interests in conducting this research study.

#### **17. What About Questions Or Problems?**

For further information about the study call **Ms. Kristine Webber** who is in charge of this study at this institution (he/she is the “Principal Investigator”). Kristine Webber’s work telephone number is (902) 470-3740. If you can’t reach the Principal Investigator, please refer to the attached Research Team Contact Page for a full list of the people you can contact for further information about the study.

If you experience problems related to your participation in the interview, please let the Principal Investigator know immediately.

The Principal Investigator is **Kristine Webber**

Telephone: (902) 470-3740

### **18. What Are My Rights?**

After you have signed the consent form you will be given a copy.

If you have any questions about your rights as a research participant, contact the **Patient Representative** at **902-470-2133**

*In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.*

### **PART C.**

#### ***19. Consent Form Signature Page***

I have reviewed all of the information in this consent form related to the study called:  
**A Qualitative Study to Explore How Nova Scotian Women with Multiple Sclerosis Describe Their Empowerment Experiences Through Participation in Health Promotion Activities and Social and Attitudinal Barriers Encountered While Doing So.**

*I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction.*

*This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time.*

\_\_\_\_\_  
/ \_\_\_\_ / \_\_\_\_  
Signature of Participant                      Name (Printed)                      Year    Month    Day\*

\_\_\_\_\_  
/ \_\_\_\_ / \_\_\_\_  
Witness to Participant's  
Signature                      Name (Printed)                      Year    Month    Day\*

\_\_\_\_\_  
/ \_\_\_\_ / \_\_\_\_  
Signature of Investigator                      Name (Printed)                      Year    Month    Day\*

\_\_\_\_\_  
/ \_\_\_\_ / \_\_\_\_  
Signature of Person Conducting  
Consent Discussion                      Name (Printed)                      Year    Month    Day\*

**I Will Be Given A Signed Copy Of This Consent Form**

***Thank you for your time and patience!***

## **APPENDIX D: INTRODUCTORY LETTER**

### **Introductory Letter**

September, 30<sup>th</sup>, 2012

#### **Introductory letter for a research study entitled:**

#### **A qualitative study exploring the health promotion experiences of Nova Scotia women with MS**

This thesis research study is being conducted by Kristine Webber, Principal Investigator (PI), in partial fulfillment of her Masters in Health Promotion, through Dalhousie University. The research will be overseen by her Thesis Advisor, Dr. Susan Hutchinson and her Site Investigator, Dr. Christine Short.

**The study will include:** 8 women between the ages of 20 to 50 years, who have had MS for at least one year and who have participated or attempted to participate in health promotion activities here in Nova Scotia. The study will involve your one time participation in a 1 and ½ hr interview at the MS Clinic, Nova Scotia Rehabilitation Centre (NSRC) or at your home, if you prefer. The interview will be audio recorded, however your name will not appear on the recording or study report. To allow for open, frank discussion, we prefer (if applicable) that your significant other, friends, family member, or caretaker not be present during our discussion. Please let us know if this isn't possible and we will do our best to accommodate you in the study.

After hearing more about the study, if you wish to participate outside of your regular visit at the MS Clinic your parking and transportation will be reimbursed (up to \$40).

**Some of the questions the PI will ask include:** a) questions about yourself, MS and how MS affects your everyday life, b) questions about how you define health promotion activities and your experiences in participating in these activities, c) questions about barriers you have encountered including: supportive barriers (i.e. does your family and community support you?), attitude barriers (i.e. have you experienced poor or positive



attitudes from others, while participating?). The PI will also ask you to share your success stories related to internal strengths you draw upon and how others support your health promotion participation.