Engaging in the disablement process over space and time: narratives of persons with multiple sclerosis in Ottawa, Canada

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This article presents an interpretive analysis of the narratives of 15 men and women who have been diagnosed with multiple sclerosis (MS) living in the city of Ottawa, Ontario, Canada. Relatively little is known about how people who are affected by MS cope with the challenges posed by social and physical barriers in their environment. Our research investigates two objectives: (1) to explore how those who have developed MS cope with their disease and resulting impairments, both in terms of the bodily experiences of becoming a chronically ill person and in terms of how they cope with changing relationships, changing identities and challenges in their physical environment; and (2) how they engage in the process of disablement over time and space as a result of these changing social and spatial relationships. We argue that the physical body and its social placings in public and private spaces are intertwined and both affect experiences of health, ability, impairment, disability and chronic illness. We further argue that these relationships are experienced across time and space, and in place, as people who have developed a chronic illness, such as

Cette étude présente une analyse interprétative du cas narratif de quinze hommes et femmes de la ville d'Ottawa, Ontario, Canada diagnostiqués avec la sclérose en plaques. Nous en connaissons relativement peu sur la façon dont les personnes atteintes de cette maladie dégénérative font face aux défis imposés par les barrières sociales et physiques de leur environnement. Notre recherche poursuit deux objectifs: 1) explorer comment ceux qui ont développé la sclérose en plaques font face à cette maladie et les incapacités qui en résultent, en terme de leurs expériences individuelles corporelles et des changements effectués dans leurs identités, leurs relations sociales et leurs environnements physiques; et 2) explorer comment ceux-ci s'engagent dans ce processus d'incapacité de manière temporelle et spatiale, en tenant compte des changements dans leurs relations sociospatiales. Nous argumentons que le corps physique et son emplacement social où le public et le privé sont inter-reliés, vont influencer directement les expériences d'un individu sur le plan de sa santé, de sa capacité, de ses facultés affaiblies, de son incapacité et de sa maladie chronique. Nous

MS, engage in, with and through the process of disablement. This article demonstrates the need for researchers to pay more attention to the role and significance of the simultaneity of space, place and time in shaping the experiences of people with disabilities and chronic illnesses, as it has been shown that these variables played a significant role in regulating the everyday experiences of this study's respondents.

avançons que ces expériences sont vécues sous un axe temporel, spatial et local et de plus, que les gens qui ont développé une maladie chronique, tel la sclérose en plaques, sont profondément engagés dans ce processus d'incapacité. Cette étude démontre qu'il existe un besoin important de poursuivre la recherche sur le rôle et la signification du phénomène de la simultanéité de l'espace, de l'endroit et du temps, puisque ces variables ont joué un rôle prédominant dans la détermination des expériences quotidiennes du groupe ciblé.

Mot clé: Sclérose en plaques, processus d'incapacité, incapacité, construction d'une identité, spatio-temporelle.

Introduction

Multiple sclerosis (MS) is a progressively worsening chronic disease of unknown etiology for which there is as yet no cure. It affects primarily the central nervous system and has varied symptoms ranging from fatigue, balance problems and weakness to visual disturbance, bladder and bowel problems, depression, cognitive impairments and pain (Aronson *et al.* 1996). Diagnosis is difficult, usually being by residual attribution after other possibilities have been excluded, and often occurs years after the onset of initial symptoms (Robinson 1988). MS is bewilderingly diverse in its pace and severity. This encapsulates the biomedical reality, but it reflects none of the possible social outcomes of developing the disease. Many people with MS have to cope with reduced mobility while adapting to changing social, personal and familial roles. Others may have to deal with relatively mild and only slowly worsening consequences. MS often strikes individuals when they are young and at a stage in their lives when they are raising a family, launching a career or both (Dyck 1995). Those who develop a chronic illness such as MS have often already defined an identity, established social relationships and have determined, to a substantial degree, the form and patterns of their life (Brooks and Matson 1982). After a diagnosis of a chronic illness, such as MS, some or all of these conceptions may have to be reconstructed (Fife 1994; Garro 1994). Individuals may experience a loss of self-identity (Charmaz 1983), 'biographical disruption' (Bury 1982) or 'changing lifeworlds' (Dyck 1995), which consequently results in altered 'social

careers' (Robinson 1990). It brings the meaning of the illness to the individual into context, prompting those men and women who have developed MS to deal with the disruption, in place and over time.

We know relatively little about how people who are affected by MS deal with the challenges posed by sociospatial barriers in their environments of daily living. Nor do we know how they seek to alter physical spaces to minimise the impact of these obstacles as the disease progresses and their experiences of this change. We seek to examine how people who develop MS engage in the process of disablement both over time and over space. Using a qualitative interview format, we recorded verbatim the narratives of 15 men and women diagnosed with MS. In interpreting these narratives, we concentrated on the following research objectives: (1) to explore how those who have been diagnosed with MS cope with their disease, both in terms of the bodily experiences of becoming a chronically ill person in society and space and in terms of how they cope with changing relationships, changing identities and challenges in their physical environment; and (2) how they engage in, with and through the process of disablement over time and space as a result of these changing social and spatial relationships.

While not all 15 respondents followed the same disease trajectory (i.e., relapsing–remitting or progressive MS) (Aronson *et al.* 1996) or engaged in the process of disablement in the same way, there were sufficient similarities in the strategies employed by the respondents to illustrate that

our research objectives were indeed relevant. This follows Pollock *et al.*'s (1990, p. 300) finding that people adapt and respond to chronic illnesses in different ways. They view adaptation to chronic illness to be 'a complex process and implies a balance between the demands of the situation and the ability of an individual to respond to the demands'. In this article, we pay particular attention to the abilities of the participants to cope with becoming impaired and the resulting physical, social and economic changes that result as a form of adaptation. Thus, not only will we illustrate the ways in which they engaged in and through the process of disablement both spatially and temporally, but we will also examine their responses to such significant changes in their lives and lifeworlds by looking at their processes of adaptation and the resulting coping strategies.

In this article, we outline our conceptualisation of the disablement process and situate our larger argument of how participants engage in this process over time and space by positioning our research vis-à-vis other research studies. We then describe how we designed and carried out the research, paying particular attention to contextualising the 'body' and 'place' of the study participants—two significant aspects of our analysis. We argue that changing physical and social bodies affect the microspace of participants but that these experiences cannot be divorced from the spatiality of the City of Ottawa at a macro scale, particularly with respect to the housing market. We concentrate our analysis on how engagements with the disablement process over space and time are manifest in adjustments that are made to self-identities and personal relationships with others, as well as to the physical environment of everyday life spaces. We conclude by revisiting the larger process of disablement, demonstrating how time and space are central to an understanding of how the physical body and the subsequent social placings are intertwined in the context of these participants' daily lives.

Conceptualising the Disablement Process

The focus of this article is on the process of disablement and how the participants involved in this study experienced the changes resulting from engaging within it over time and space and in

place. According to Verbrugge and Jette (1994, p. 1), the disablement process describes how chronic and acute conditions affect functioning in specific body systems, generic physical and mental actions and activities of daily life and describes the personal and environmental factors that speed or slow disablement, namely, risk factors, interventions and exacerbators. Furthermore, Guccione (1994) conceptualises the process of disablement as integrating three interrelated variables. He asserts that it is the relationships between disease, impairment and functional limitations that create this process. Forces and factors such as age, sex, education, income level, experiences of health care and rehabilitation, motivation, social support, health habits and environment all affect the process of disablement based on Guccione's understanding of the process. Both of these definitions are useful here, as they integrate physical, social and personal variables as being key components of this process. It is these two definitions of the process of disablement that inform this specific research project and our analysis.

We conceptualise the disablement process as being the process through which men and women who have developed MS become and live as a person with a disability, impairment or illness. It is this process that results in, for example, spatial deprivation and socioeconomic exclusion as a result of the outcomes of the disablement process happening over both space and time and also in place. Time, for example, plays a significant role here because as a person becomes more acquainted with experiencing what it is like to live as a person with MS, he/she can develop strategies to help cope with everyday life. These strategies can range from being as straightforward as learning how to remain mobile while using an assistive device to being as complex as learning how to re-value one's role in the home space and society-at-large after no longer participating in paid labour and facing changes in familial and personal relationships. Space, however, is equally as important as time in this process. Changes can occur in peoples' use of public spaces, in their everyday life spaces, and even in how they arrange their living spaces after becoming chronically ill and engaging in the disablement process. We contend that such changes over space and time, and even in place, converge on the body of the person with MS resulting in the person experiencing

the process of disablement and the resultant outcomes. We examine this specific circumstance in the remainder of this article.

It is also this process of disablement that creates a distinction between a disabling experience happening to an able-bodied person who is temporarily ill or impaired and a disabling experience happening to a person with chronic illness. Moreover, in order to understand the process of disablement, it is important for us to draw a distinction between a person having an impairment, a chronic illness and a disability. We understand that impairment refers to a 'biological dysfunction' (Hughes and Paterson 1997, p. 328). Fatigue, visual disturbances or loss of function of a limb, all symptoms of MS for example, can all be considered impairments by this definition. A chronic illness is an '...ongoing biophysical or psychological condition, which normally involves therapeutic interventions' (Parr and Butler 1999, p. 8). Given this definition, we can see that time or temporality plays a significant role in conceptualising chronic illnesses, as it is the presence of symptoms and the resulting impairments occurring over time that allow us to identify illnesses as being chronic. We also know that it is common for symptoms to vary over time and for some persons with chronic illnesses to experience changes in levels of ability and functioning over time, in addition to the severity of the actual illness. A disability, in comparison, can be considered 'any lack of ability to perform activities to an extent or in a way that is either necessary for survival in an environment or necessary to participate in some major aspect of life in a given society' (Wendell 1996, p. 23). These definitions, based on a social model of disability, inform this study. A social model of disability emphasises the disabling nature of society and space, including ineffective social policies, systemic barriers to inclusion, prejudice and the social construction of illness and disability, among other things. The social model also reinforces that such variables as these result in the creation of a disability, where disability is an outcome of such social, political and economic processes and not simply a physical state of being resulting from a physical or mental impairment (Linton 1998; Wendell 2002).

Given these explanations, we realise that almost any person can have a disabling experience regardless of whether or not they are in fact recognised as being physically or mentally impaired. We are also aware that able-bodied persons can experience periods of temporary impairment that sometimes results in the use of mobility devices, which could potentially render them disabled for a period of time. While an able-bodied person experiencing temporary disablement or a disabling experience may find his/her use of space limited, she/he will not have these experiences continue for an extended period of time. Thus, it is the intersection of changes over space and over time that result in the process of disablement for a person with an impairment and chronic illness. This specific aspect of the process of disablement, the simultaneity of changes across space and over time, is the focus of this article's analysis.

Throughout this article, we will illustrate the changes that have taken place across space and over time in the participants' everyday lives. We reflect on how such changes are related to the larger process of disablement and the social and spatial strategies of adaptation used by the participants.

On Becoming and Being an Individual with MS

Within the last decade, the number of geographic studies of the lives of people with disabilities and of the processes of becoming and being a disabled person has been on the rise (Imrie 1996). An early area of interest for geographic studies in this field was the relationship between persons with disabilities and access to the built environment. According to Park *et al.* (1997), geographers who studied the disabling nature of the built environment were often motivated by a belief that a lack of physical access to space is an infringement upon basic human rights. Imrie and Kumar (1998) study of access to the built environment follows this early tradition of disability-based research in geography: they concluded that persons with physical impairments are oppressed by the inaccessibility of certain spaces and feel powerless in evoking change.

Geographers have started to move beyond producing studies of access in the built environment and have refocused, to a certain extent, on issues of daily life as experienced by persons with disabilities. Much of this shift has been influenced by a more critical gaze emerging from social theorists who have challenged the hegemonic construction of a biomedical discourse that emphasises the

centrality of the physical body and the disease state to the neglect of social context, embodied subjectivities and the significance of place (e.g., among geographers see Smith 1981; Kearns 1993; Dorn and Laws 1994; Brown 1995; Curtis and Taket 1996; Dyck 1998). Just as race and gender are socially constructed, so too are categories of normal/deviant, healthy/diseased, well/ill and abled/disabled. In an uncritical gaze, the latter of these dualisms (e.g., deviant, diseased) are often compared against the standard of the former (e.g., normal, healthy) (i.e., that which defies the norm is deviant). These 'standards' are produced and reproduced through social and cultural practices that impose an interpretive lens on how 'reality' is viewed. Within a Western culture, it is often only through a biomedical diagnosis that previously unlabelled symptoms (i.e., subjective reporting by patient) become legitimised as signs of chronic illness (i.e., objective evidence of illness measured by physicians) (Twaddle 1974). This is compounded when individuals have experienced symptoms that have gone undiagnosed for an extended period of time, or whose symptoms are 'invisible' (e.g., fatigue) (Moss and Dyck 1999a) as is typically the case with MS. Hence, the power to 'name' (Foucault 1980) within biomedicine is significant in how illness experiences move from a subjective state (i.e., in the realm of the individual/patient) to the objective state (i.e., legitimated by a trained physician). The relevance of this 'reality' for our analysis is that a person's experience of illness and symptoms is legitimated only once a physician has provided a diagnosis. However, we contend that this ignores the social, spatial and temporal impact of an illness for the individual prior to the assignment of a biomedical label. The delay between experiencing symptoms and diagnosis is part of the space–time continuum of the disablement process, which we recognise as not 'beginning' with diagnosis. Furthermore, experiences of the chronically ill, when reflected upon, are often representations of the pre- and postsymptomatic self and not merely of diagnosis and subsequent legitimation.

As Cummins and Milligan (2000) argue, these challenges to conventional biomedicine have prompted many social scientists to become increasingly interested in the social and cultural dimensions of health, illness and impairment. This is certainly true of research being conducted by geographers (Dyck 1995, 1998, 1999; Wilton 1996; Butler and Bowlby 1997; Chouinard 1997, 1999; Laws and Radford 1998; Moss and Dyck 2002). Dyck (1995), for example, has studied the 'changing lifeworlds' of women with MS. According to her research (Dyck 1995; p. 307): 'The concept of the lifeworld, with its concentration on the taken-for-granted, mundane experiences and activities of everyday life as carried out in particular spatio-temporal settings, has been important in investigations of the subjective experiences of the chronically ill'. Similarly, while people diagnosed with MS share the same 'disease,' they may experience very different levels and types of disability and impairment due to the unpredictability of MS. Consequently, the ways in which individuals experience 'space' and 'place' will vary both by the disease trajectory itself, 'but also from the social externalities in the context in which the person with MS lives' (Thapar *et al.* 2001, p. 29). For example, in one study, the diagnosis of MS for one participant led to altered social relationships on a number of scales: the marital breakdown led to his separation from his children as he had to move to another state in the United States to avoid being placed in a care home by his parents (Thapar *et al.* 2001).

These studies show that the lives and life spaces of those who become chronically ill with MS and other chronic illnesses change drastically in that social relationships and spaces of everyday life can be altered or completely removed from a person's lifeworld as a result of the disablement process. The two geographic studies cited here are important as they assist with illustrating some of the spatial outcomes of becoming physically impaired. Such changing spatiality is important in the context of this article as well; however, in our analysis, we also address the variable of time and how the intersection of these two major aspects of daily life results in participants engaging in and through the process of disablement. Although time is undoubtedly an aspect of these earlier studies, given that the activities of daily living they report on also have a temporal context, it is not a significant component of their analysis.

By contrast, Charmaz's (1991) account of the importance of placing chronic illness and chronically ill bodies in time, for example, illustrates ways in which chronically ill persons locate themselves in different temporal settings (the past,

present and future) at various times. She contends that people 'place' themselves in these different settings for a number of reasons. As such, we must consider how individuals conceptualise time, and where they place themselves as being located throughout their own time, when attempting to understand how people adjust and adapt to becoming chronically ill. However, her account, while significant, lacks attention to the importance of spatiality and place in addition to the temporality of these people's everyday lives, as the concept of 'place' that she adopts has little to do with actual lived spaces and places and more to do with being 'placed' throughout time. In this article, we merge these two interrelated themes, the spatial and place-specific outcomes of becoming chronically ill as outlined by researchers such as Dyck (1995) and Thapar *et al.* (2001) and the significance of time as outlined by Charmaz (1991), in our analysis.

That said, not only must a chronically ill person learn to renegotiate daily life over time and space and develop a process of adaptation, but his/her friends, coworkers and family must also learn how to maintain social or familial relationships with a person undergoing this process. Such sociospatial changes are related not only to people's processes of adaptation but also to their experiences of undergoing and engaging in the process of disablement. For example, family members may attach feelings of grief and generate questions surrounding the legitimacy of the illness or impairment that then can effect the relationships they hold with the chronically ill person (Moss and Dyck 1999b). Similarly, others may trivialise the illness experiences of those living with hidden illnesses or impairments, which can include MS, due to the commonality of symptoms or disbelief about symptoms that cannot be seen by others such as fatigue or chronic pain. Such trivialisation leads to the delegitimation of the illness experience (Ware 1992), thereby straining the chronically ill or disabled person's social and personal relationships with others due to disbelief and a lack of understanding (see, for example, Crooks 2001).

Finally, we acknowledge that the bodily experience, and the body itself, plays a significant role in becoming and being a person with MS. Hall (2000) calls for an embodied geography of disability and impairment, one that recognises the physicality of the body and the bodily experience while also examining its social, cultural and political placings

in everyday life. It was shown earlier that the disablement process not only refers to social and economic changes to everyday life but also to physical and bodily changes. By using this process as a framework for discussing our data, we acknowledge the significance of the body in a social analysis of impairment and disability as is consistent with Hall (2000). In the context of the discussion presented in this article, the physical body and the social placings are viewed as intertwined, both affecting experiences of health, ability, impairment, disability and chronic illness; thus, we do not view disability as solely physical or social but rather a combination of multiple influences on the individual and the individual's actual physical state. In the case of people living with MS, changes to the body are directly linked to a person's social and economic positioning within Canadian society and space, such that the organisation of space can keep people both 'in their place' and 'out of place' (Kitchin 1998).

For the participants of this study, being kept in one's place generally involves being restricted to the house, or even particular areas within the family house, which greatly affects their everyday geographies. Being kept out of place can occur in any number of public and private settings. Feeling out of place in the paid work force is a reality of everyday life for many of the study's participants. Our research also documents how impaired and ill bodies can also be viewed as out-of-place in the home. While the individual diagnosed with MS may be able to adjust to changes in his/her body, the altered social relationships and redefinitions of self create new-layered 'scripts' (Moss and Dyck 1999a) such that deviant bodies are 'read' by themselves and others as being out-of-place. As Bordo comments (1992, 167 cited in Dyck 1998; pp. 105–6): 'we thus have no "direct", innocent, or unconstructed knowledge of our bodies; rather we are always "reading" our bodies through various interpretive schemes.' Hence, the body is also an important site in the analyses presented throughout this article. As Dyck (1995) and Moss and Dyck (2002) have shown, the body is not static, it is in a state of constant negotiation with multiple social processes and forces at all times. The negotiation of space and bodily experiences are central points of discussion throughout this article and will be outlined in the context of the participants' engagement in and with the disablement process both over space and over time.

Research Design and Method

We used a qualitative semistructured interview approach (McCracken 1988; Burawoy 1991; Reissman 1993; Weiss 1994) to record the narratives of 15 self-identified men and women diagnosed with MS living in the City of Ottawa, Ontario, Canada. All interviews, each lasting approximately 2 hours, were conducted, transcribed verbatim, and analysed by S.M. Driedger to ensure consistency in approach. The topic areas explored in each interview included the daily routine of the respondent, issues surrounding diagnosis, how the respondent relates to her/his physical environment (both inside and outside the home), organisation/ reorganisation of the home and social activities, concerns and fears of coping with MS, MS as a factor in a decision to change residence, employment history and how the respondent sees his/her future. In the majority of cases, respondents themselves introduced the topic areas to be covered.

Interviews were analysed thematically, both deductively (categories and themes generated by the topic areas) and inductively (themes and ideas emerging from the narratives) allowing for a 'thick description' (see Geertz 1973). Following this, 'diagrams' of these narratives were constructed for each individual participant. These diagrams provided visual thematic depictions of the processes and patterns of social and physical barriers that were raised by each participant. As no two experiences are the same, no two diagrams were identical. Regardless, with each subsequent analysis, the linkages that could be seen between categories (e.g., barriers in the home) and subcategories became clearer (e.g., accepting help for cleaning, public [home care] or private [cleaning service] help and accepting help from other family members or friends). The iterative process of moving from the interview texts, the analysis of that text and the diagrams helped to develop themes to be discussed below.

The interviews all took place in the participants' homes. While there are several reasons qualitative researchers often conduct interviews in settings familiar to the participant (e.g., concern of power issues in qualitative interviews, particularly in such a sensitive domain of lived experiences), the primary reason for adopting this approach here is because it was the expressed wish of participants. Several participants were concerned both about

transportation obstacles (OC Transpo [public transit] operators in Ottawa were on strike for a good portion of the interview period and not all respondents had access to, or were able to drive, an automobile) and being in an unfamiliar setting. Only one participant had requested to be interviewed in the investigator's home because it would mean an outing for her. She later rescheduled the interview to be in her home, as she was not feeling as strong as she had earlier in the week. Participants were recruited through the Multiple Sclerosis Clinic at the Ottawa General Hospital after ethics approval was obtained.

Respondents were identified by the research question of a separate, but related project, which used geographic information systems to identify spatial distribution patterns of people with MS in Ottawa-Carleton (see Driedger 1997). Owing to cost constraints, we relied on the MS Clinic's Coordinator's familiarity with the patients to identify who might be willing to participate in such a study and would be cognitively able to sign an informed consent form. Contact was initiated through a mailed out package (sent to 80 individuals), and an identical package was given to MS patients at the time of their appointment with their physician on selected 'Clinic Days' at the hospital (given to 50 people). From the 80 mail-out packages, 13 people volunteered. Only a further two individuals were identified by the Clinic Days strategy. In total, 15 people participated in the study, and all participants were invited to select their own pseudonym to be used in the research report and any subsequent publications.

In addition to the open-ended interviews, participants were asked a series of demographic and socioeconomic questions to generate brief profiles of the study participants. This ensured that the same characteristics were collected for all participants. Most of the participants were between the ages of 40 and 55, which is typical of this disease. The youngest was 31 and the eldest was 68. Eight were married, four were divorced (in two cases because of the MS) and three were never married. Four of the participants lived alone. The others either lived with their spouse, or if divorced, were still living with their school-aged children. Nine participants were homeowners. Home ownership did not necessarily imply security of tenure, as 10 participants had changed their residence in the previous 5 years for a more accessible housing

environment. The MS was largely responsible for this change in residence for many participants, but for others, they felt that even if the MS did not affect them much, they were reaching a stage of their life course that a large family home was no longer required. That said, many commented that housing accessibility should be an important concern for any individual of advancing years because 'you just never know' (Mr Fredal). All of the participants had participated in the paid labour force at some point, and four participants were working at the time of the study. Their occupations were largely 'white-collar' (e.g., civil service, teaching, nursing and management). All but four participants had close family (outside the immediate household members) and friends living locally. Quite fortuitously, the ratio of participants reflects the general demographic ratio of people with MS: two women to each man.

Contextualising the 'Body' and 'Place' of Study Participants

To contextualise the disablement process as these participants experience it, it is important to understand how their symptoms vary. It is necessary to remember at the outset that the disease affects people with MS differently. Some people's symptoms are characterised by the relapsing–remitting style of MS, whereas others may be primary progressive or secondary progressive. Primary progressive MS affects a person gradually with no periods of remission. Secondary progressive MS may show a person gradually worsening, but after a period of time she/he may return almost to the original level of mobility and ability. For example, someone who progresses from using a cane or walker for mobility to using a wheelchair for a period of time before experiencing a remission and no longer needing a mobility aid would be showing signs of secondary progression. Relapsing–remitting MS occurs when a person develops a new symptom for a short period of time, but where the effects linger for several weeks before disappearing. People who have this form of MS may also experience secondary symptoms, such as fatigue, bowel and bladder problems, which are intermittent. It is very possible for a person who has relapsing–remitting to also experience secondary progression (Multiple Sclerosis International Federation).

In this study, some participants experience several health problems in addition to the MS, whereas other participants are only mildly affected by the MS. For example, two respondents face problems with their knees that resulted from earlier injuries but are exacerbated by a tendency to fall due to the MS. One of these two respondents also lives with myriad other impairments and illnesses that includes fibromyalgia (a chronic rheumatic disease), no cap on his right knee, vision problems (double and triple vision) and also has a herniated disc and disc degeneration. In fact, he says that of all the illnesses and medical conditions with which he has been diagnosed, 'the least of it is the MS' (Mason). Another participant developed a heart condition, which was brought on by overexertion and stress due to the MS. Similarly, one participant must permanently use a wheelchair for mobility because of a herniated disc, which her doctors have diagnosed as being non-MS related. With each additional illness or impairment developed, these participants are faced with many more mobility limitations and barriers than if MS was to be the only illness they negotiated on a daily basis.

Moreover, more than half the participants experience some type of limited mobility. Most of their mobility limitations have to do with a loss of control over the functioning of their legs and a reduced ability to 'get around easily'. Many rely on a number of mobility aids such as a cane, a walking stick, a walker, a scooter or a wheelchair for assistance. In addition to these mobility limitations, one participant cannot control the fine motor movement skills in her hands. For yet another, it is her memory and cognitive skills that make it difficult for her to make spatial connections in terms of direction, distance, road networks, paths and routes. For each of these daily limitations, there are associated physical, social and economic barriers to be negotiated, as participants actively engage with the process of disablement over space and time and in place.

People who have developed MS also have to deal with the consequences of developing a chronic illness in place. This varies greatly from place to place, especially in Canada where multiple levels of government make disputes over public responsibilities and jurisdictions almost a defining element of the national character. The material requirements for living in a Canadian city for a person with a mobility impairment are basically

those of the general population: availability, cost of, and access to, medical and support services; and access to appropriate housing, including mobility within and outside the dwelling, including transportation. However, the scale, type and urgency of these needs are linked to the stage reached in the disease progression. Where one lives in Canada, and locally where one lives in the study site of Ottawa, Ontario, will have a significant impact on the resources available outside the household's private capacity.

The first set of resources is related to prediagnosis health care costs. It needs to be said that regardless of the popular or media perception, Canada does not have a national health care system. Health care is and always has been a provincial responsibility. The federal contribution covering health care costs has fallen sharply, leaving the individual provinces to find their own ways of coping with an ever-increasing proportion of their budgets being consumed by health care costs, with no upper limit in sight. Provinces are required by the Canada Health Act to cover the costs of 'medically necessary' services, but the definition of 'medically necessary' is left up to each province. The Ontario Health Insurance Program (OHIP) will pay for the direct medical costs of reaching a diagnosis of MS and the direct costs of the MS Clinic's services. However, mobility aids such as walkers and wheelchairs are not directly covered by OHIP. The Assisted Devices Program of the Ontario Ministry of Health helps offset these costs. Individuals may have private extended health care insurance, but more often than not, this is a fringe benefit of employment. Anyone who, because of their MS, either cannot work or loses their job will not have this means of defraying costs. Any home modifications such as elevators, stair-glides or ramps for example, are the responsibility of the individual, although some assistance may be available through the Ontario March of Dimes or the MS Society. Emotional and social support is entirely dependent on voluntary organisations. As health care in Ontario, as in all of Canada, confronts reform driven by the need to control costs and the demands to serve an increasing elderly population, it is likely that resources will shift to long-term, home-based and chronic management.

The second set of resources relates to housing and transportation. A diagnosis of MS may mean that the dwelling at the time is not going to be suitable for long. Its location, the number and placement of stairs and wheelchair access are some of the issues faced by many participants in this research study. The dynamics of housing in Ottawa throughout the 1990s made mobility expensive and difficult (Goff 2001). Moreover, transportation needs may also change after developing the symptoms typical of MS. Personal transportation in the form of vehicle modifications (e.g., modifying the vehicle such that using the brakes or depressing the gas is hand controlled at the steering wheel) is not a publicly insurable expense. The Regional-Municipality of Ottawa-Carlton, via OC Transpo, provides public transportation. In the fall of 2001, a modest light-rail system was introduced as a pilot project, which may lead to more transportation options, although not all service stops are wheelchair accessible. Some of the buses are 'low-floor,' making them more accessible to people with sticks or walkers. OC Transpo also operates ParaTranspo, a fleet of cars and chairlift-equipped mini-buses, which is available to any person with short-term or permanent mobility impairment who cannot use regular OC Transpo services.

Overall, Ottawa is a typically sprawling low-density Canadian city spilling outwards from an older, compact core and is more car friendly than pedestrian friendly. It is probably neither the best nor the worst of places for someone with MS to reside.

Personal Changes and Adjustments: Self-Identity and Relationships

The way in which the participants redefined themselves after developing MS was evident due to the physical, psychological and social changes that stemmed from the disease. For many, the initial moment of identity crisis occurs when the first symptoms appear, and the person is no longer able to act out his/her expected or adopted roles; this identity crisis can be compounded once an individual's illness experience is legitimised with diagnosis of the disease. First, socially, the diagnosis can lead to a source of stigma, in that people with MS now become what Kate calls 'categorised' (e.g., disabled versus abled; diseased versus healthy) and hence viewed differently by others. Such 'categorisation' was felt more by those participants who showed a visible impairment (e.g., use of a mobility aid), though it was also raised by those whose impairments were hidden (e.g.,

general fatigue and balance problems). While some participants were relieved to finally have a label for their symptoms legitimised by health care practitioners, the way in which some friends, family and coworkers perceived and acted on this label resulted in a loss of social relationships.

Second, at an individual level, the disease assaults the body, primarily in terms of balance, where the legs are affected by the MS which in turn affects their physical mobility, or where they experience memory loss and moments of confusion due to the illness. The latter is only experienced by one study participant, Sarah, who finds it difficult to relate to landmarks, streets and directions when driving. During such times, Sarah rarely leaves the house, except with her husband. Sarah feels very isolated, both socially and spatially, as she has lost her own independence to travel freely outside the home. Many respondents rely on a number of mobility aids. Bob, Mr Collins and Judy all use a wheelchair primarily for longer distances, but whereas Bob and Mr Collins rely mostly on their walking sticks for support, Judy's MS has progressed to the stage where a cane or walker is no longer sufficient. She relies mostly on her scooter and wheelchair. Only Ruth and Mason require the use of their wheelchairs both inside and outside the home. These mobility aids become physical extensions of the body, and a source of freedom, as expressed in Vanessa's narrative in describing her scooter:

> I call my scooter my legs. If you take away that scooter, you might as well chop my legs off because without that, I couldn't go out. I mean, I could go out, but I can't move any distance, therefore (the scooter) gives me the freedom to go where I want to go.

It is in part due to these mobility impairments and changing social relationships that participants are forced to redefine themselves with respect to their former roles as a result of engaging in the process of disablement over time. This becomes manifest in three ways: (1) changes in feelings of self-worth as a 'productive' member of society; (2) changes in the type of social contacts that can be maintained; and (3) changes in expected familial roles (by themselves and by significant others), as a parent, a spouse and as friends.

Respondents define 'productivity' in terms of participation in the paid labour force, a sentiment mirrored in other studies (see Dyck 1995; Kitchin 1998). Marris' (1996) research into the lives of chronically ill women has shown that society places great value on those who are able to 'do,' such as those who can perform paid labour and work outside the home, rather than those who 'don't'. This reflects the unfortunate reality in Canadian society of more value being placed on paid labour than the unpaid labour.

Twelve of the respondents cannot perform paid labour, of whom nine are receiving the Canada Pension Plan (CPP) disability benefit and three are retired. The remaining three participants who can still work outside the home fullfil their (expected) societal responsibility of being productive in a modified manner. Since diagnosis, Bob works three days a week as opposed to the five-day-work-week he participated in prior to acquiring MS. Jamie is currently on contract work, but is seeking full time employment. For Jamie, contract work allows her to set her own flexible schedule that can take into consideration her fluctuating levels of mobility, ability and energy. And, while Mr Collins works a full work week, unlike the other two employed respondents, he finds that it is a struggle to maintain what he considers to be 'normal' work habits. He believes that if he does not work 7.5 hours a day, and gives into the 'limitations of the MS', then his working hours will continuously be reduced until he is no longer able to fulfil his role as a paid employee and productive member of society. For Mr Collins, 'this would represent a personal (as opposed to financial) hardship to not be able to work,' because his view of himself is completely intertwined with his role as a worker.

Similarly, seven of the respondents who are still of working age, but are no longer able to perform paid labour, feel as if they are no longer productive members of society and are quite devastated about the fact that they most likely will not be able to work at any point in the near future. Kate expresses these sentiments that are shared by others:

> When you are not contributing—that is, working—your esteem takes a bit of a beating because you know you aren't really doing a worthwhile thing any-more…something that is earning dollars…I mean, I spend a long time with the children, and I think that is worthwhile, but it is not something that society really values…I think my choice, you know, my ability to work is limited by the MS, and that is sad because I have many valuable skills.

Such removal from the paid labour force over time plays a substantial role in how Kate, Ruth, Vanessa, Bubbles, Judy, David and Mason view themselves and their positions, both literally and metaphorically, within Canadian society and space. Many of the skills and abilities they once used on a daily basis are no longer considered 'good enough' to be done as part of paid labour. Moreover, despite Canadian labour laws that are intended to protect employees from discrimination in the work force, some individuals find themselves in difficult circumstances. Vanessa, who was an employee in the federal public civil service, reflects this most keenly:

> Before I was diagnosed, I guess I was 40, 41, when for example, I would walk down the street to go to work, and it was like I was drunk, you know, I would weave. Even after the diagnosis, at work, I used to use a computer, and it got to the point where I no longer had the dexterity in my fingers. So what would happen was, I would do the mental task of the job, figuring things out, and one of the other supervisors would do the writing or computer work, but unfortunately, my boss did not like that. So, in the end, I worked for three years after I was diagnosed and he made it very hard for me. For example, I had to take the bus to work, and on bad days it used to take me longer to make it in from the bus stop to the office. Well, he could have been a little lenient because I mean I always worked through my coffee breaks and my lunch and everything. But he didn't. He would say, 'you are two minutes late' or 'you are five minutes late' and he would look at the other supervisors doing my writing or my computer work. I finally went in to see him and said that I have MS, uh, and this is why things are the way they are. He told me I was useless, I would never be good to anyone ever again.

Furthermore, being forced out of, or choosing to leave, the paid labour force makes it difficult for these individuals to maintain social relations outside the home, resulting in fewer contacts with a smaller range of people and places. Marris (1996) has argued that the everyday social interactions experienced by a person change drastically after developing a chronic illness (see also Thapar *et al.* 2001), which certainly is the case for these seven participants. For example, someone who has to leave the workplace due to physical or social barriers will no longer be involved in the casual socialisation that occurs in the workplace between co-workers and with clients or customers. Consequently, they feel very isolated. Bailey indicates those aspects she misses the most as a result of longer working, sentiments shared by others:

> …[It's difficult] coping with being home all the time. I missed, miss the going out a lot. I miss the friendship I had with the girls I worked with. Uh, I became, you know, just no longer connected? You know, the only connection I had was my home. So it was a bit of feeling devalued, that I didn't serve much purpose.

These feelings of loss of identity and self-worth are also manifest in the ways in which their 'expected' familial roles have changed due to the limitations brought on by the disease, confirming the findings by those such as Dyck (1995) and Thapar *et al.* (2001). Parents who have developed MS are not always able to meet the same challenges and demands they were once able to, thus resulting in changes being made to the parenting role over time. Kate is one of the few respondents keenly aware of the changes in her expected roles due to her diminishing health, for which she, at times, feels guilty. For example, she comments that her son now handles 'mom's taxi service,' managing all the rides to hockey practice, music lessons and other activities as she is no longer able to handle this duty. Kate believes that it is truly her role to carry out these driving tasks and comments that there was once a time where she was able to drive her children around. Another change in her 'expected' parental role is that she is unable to engage in activities outside the family house with her teenage daughter (e.g., going for lunch, going to the shopping mall, etc.). This change, one that takes place both over space and time, has left her quite frustrated as she believes that participating in such activities helps to strengthen the mother–daughter bond. Similar sentiments are shared by Ruth and Bailey, for whom child rearing is viewed as their primary responsibility due to divorce.

The process of becoming and being impaired, disabled or chronically ill can leave a person feeling 'roleless', because roles such as that of an 'employee', 'parent' or 'spouse' may change or completely disappear (Meyerowitz *et al.* 1988). While these sentiments are expressed only by the married or divorced women (reasons for divorce are

not always related to the MS) who participated in the study, they do signal some of the gender differences in coping. Quite often, they describe their husbands as feeling 'powerless' to help them in situations for which there are no easy answers (e.g., dealing with the emotional stresses and changes in self-identity) as compared with situations where husbands feel they can make a difference (e.g., hiring domestic assistance if their partner can no longer handle such activities). These sentiments are articulated in the next two passages:

> I don't know if anyone else has ever said this, but MS does affect your married life a great deal. For example, I used to walk for miles with my husband. I used to cut down trees with my husband. I, you can no longer participate in what you used to share with your mate…and that is an aspect of MS that I find very hard to handle…where it impacts on your relationships. I can see why the divorce rate is high because it has taken many years of struggle on my behalf to sort of put on the facade on that you can still keep up. But over the last year and a half, I have learned that I can no longer play that game. I say to him 'I'm sorry, I just can't do that' (Vanessa).

> (Sigh)…when he comes home, like last night it was 8:30 at night, he had had a long day with his job, and it doesn't seem fair to burden him with stresses of having MS because he will think 'She doesn't really have that much stress in her life. Why does she have to burden me with the MS when I come home?' He just is not going to be receptive to talking about it, and I get the feeling that he doesn't want to talk about it. He'll deal with it when he has to…like I guess if I needed a cleaning lady or something like that, he would deal with it when it happens (Kate).

To deal with these changing roles and relationships, the participants employed various sociospatial coping strategies. Of those no longer participating in the paid labour force, eight now volunteer in work-related or interest-related organisations. One respondent has just finished her diploma as a legal administrative assistant and is currently seeking full time work. Eight respondents pursue different activities or hobbies, which get them out of their homes and into a more diverse array of places, allowing them to make new social contacts. Similarly, four participants engage in activities to keep up with their former 'paid' identi-

ties or alternatively to compensate for changed roles in their marital relationship. For example, Bubbles comments that she and her husband used to share a great deal together, especially in terms of physical activities in which she can no longer engage. To substitute for these activities they once shared, Bubbles occupies her evenings doing other things (e.g., pottery classes and volunteer work) so that her husband does not feel guilty in taking time after work to exercise, work in the yard or participate in organisations different from his wife. While these coping strategies help to expand the circle of social contacts that respondents are able to make, they are also important in giving respondents a sense of self-worth and personal contribution, which help them to deal with their changing identities and also their engagement in the disablement process over time and across space. In fact, Kate, Bubbles, Sarah and Vanessa comment that these activities help to remove some of their dependence on their spouses as their primary social contact. Others also commented that these activities helped them regain contact with their 'pre-MS' selves, thus helping to mitigate the changes that some of them have experienced over time and across space in their social and familial relationships.

As B.L., Mason, Ruth, Vanessa and Judy become more reliant on mobility aids, they are faced with their own preconceived conceptions of what it means to be a person who is not fully mobile as much as they are faced with how others ascribed meanings to their mobility aids. For example, B.L. (a woman in her late thirties) argues that she loves the freedom her walker affords her, but first 'recoiled in horror…[always imagining] that [walkers] are only for little old ladies and men'. While few respondents commented on reactions they receive from others when using a mobility aid, B.L. did remark that whenever she finds someone looking at her walker questioningly, she attempts to smile or initiate conversation and encourage people to ask questions. She always prefers to deal with people's questions and explain why she uses the walker, rather than have people arrive at preconceived judgements about her situation.

All the respondents work hard to resist the outcomes of developing MS (physical mobility impairments and social isolation). This will be outlined more fully in the next section in terms of how participants respond to these sociospatial barriers by reconstructing their spatial environments.

Relationships with the Physical Environment: Renegotiating Everyday Life Spaces

Respondents employ a number of coping strategies as ways of adapting to their developing chronically ill selves to maintain personal control over their physical spaces, both inside and outside the home. Within the home, these strategies range from making modifications to the layout of the home (internally and externally) to modifying the way in which respondents carry out their tasks. Strategies are also devised for outside the home to minimise the stresses (e.g., energy levels, physical strength, walking effort, etc.) on the physical body. Such strategies are adopted when one 'remaps' (Dyck 1995) his/her everyday life spaces to adjust to living with a chronic illness or disability.

For example, to minimise the impact of physical barriers when entering and exiting her home, Judy has a ramp attached to her front and back doors so that she can ride in and out on her scooter. Similarly, Wilma accesses her widened back door entrance using stairs graded to four inches per stair, thus allowing sufficient room for her walker. Respondents also have a variety of modifications or adaptations inside their homes. Both Mason and Wilma use a stair glide to avoid climbing stairs. Judy lives in a house that has the potential for renovation into three separate apartments. Originally, Judy lived on the second floor, while her ageing mother occupied the main floor apartment. This living arrangement is now switched as the stairs have become too difficult for Judy to negotiate. While these types of modifications are structurally and financially possible for these study participants, it does not reflect the norm. Studies have shown that many individuals affected by chronic illnesses and disabling conditions live below the poverty line (see Fawcett 2000) and lack the political voice to force changes. Furthermore, Chouinard (1999) has demonstrated that persons with disabilities can face significant socio-spatial barriers to the types of political activism (such as rallies and protests) that could potentially result in positive changes for this group of Canadians. Thus, the majority of people with MS who would benefit from such structural modifications to their living environments are unable to afford them due to limited finances, unlike those participants discussed above.

However, for some respondents, it is very difficult to modify the type of activities they can carry out within their homes (e.g., cleaning and laundry). For instance, Kate, Jamie and Sarah frequently minimise the number of trips they make up and down stairs by developing a pile of items to be carried to conserve energy. These women are consciously managing their use of both space and energy to effectively complete their daily tasks. However, laundry poses a much more serious challenge for those with MS. While many will not do all their laundry in a day because it is simply too taxing for them, one respondent forces herself to complete laundry tasks in a single day. Because Vanessa no longer works in the paid labour force, it is considered her 'job' (by both herself and her spouse) to perform all the unpaid household labour.

> ...one day if I do the washing, that is all I will do that day because that is a big job. It means I have to go down the stairs, and that is really hard for me to do because I lose my balance easily. You can't see it from where you're sitting, but my hamper is located at the end of that hallway. I empty the dirty clothes and kick them down the hallway to the railing leading to the stairs where I toss them over. I then have to go to the entrance way to the stairs (10 feet away) and I slide down on my bum. Once I kick the clothes closer to the washing machine, I stay there until it is all done. I have a chair down there, a radio, and everything. I sit there until the washing is completely finished...when I take things out of the dryer, I sit on a stool that is the height of the dryer door and my husband made me a frame, an A-frame, so I sit on the stool and take things from the dryer, and hang shirts on the A-Frame. But, when it comes to bringing the laundry upstairs, I have to leave that to my husband.

While Vanessa's situation reflects the extreme in this study, many study participants have indicated that the MS necessitates a change in housing environments, a finding also shared by other research studies (Dyck 1995; Thapar *et al.* 2001). In all but two cases, study participants have expressed a desire to move into a housing environment where everything, including laundry, is located on one level, or have already made such a move. In most instances, the housing environment of choice is a bungalow. Those six respondents who moved into

a bungalow or similar environment (e.g., adapted single level co-op or condominium) did so in order to better use space given their physical limitations as a result of developing MS. Their reasons for these moves largely reflect the difficulties navigating a multilevel housing environment when using a walker, a wheelchair or when they experience balance problems making it difficult to walk up and down stairs. Seven respondents are still waiting for the finances and opportunity to move to a physically accessible home and are living in a restricted housing environment given their mobility impairments.

Until such a time as when they can make the move to a bungalow, adaptable co-op or condominium, some respondents have modified their existing housing situations. For example, Bailey's living space is primarily limited to her bedroom where she has modified the environment to suit all her needs: her bathroom, her bed, a chair for reading in, a television set and a telephone. She rarely ventures to the main level of the house except to eat. Mason too lives in an isolated and restricted housing environment. He is currently living in a two-storey townhouse but is in the process of looking for a bungalow. Both he and his wife are receiving CPP disability pensions and experience mobility impairments, though his are more severe. Thus, in this case, both he and his wife have become spatially and economically restricted as a result of becoming chronically ill and experiencing the process of disablement. The second floor of the townhouse, for example, contains his bedroom, his bathroom and the family room where the television set is located. He rarely ventures to the main floor despite the stair glide that the MS Society paid to have installed. His stair glide is not used to maximum efficiency because his stairs are L-shaped, forcing Mason to navigate the last four steps on his own, which he cannot easily manage. In the search for housing that is both affordable and accessible, Mason and his wife of 16 years have moved 14 times while together. Each move has represented a compromise (largely due to finances) to find a home that Mason can manage with his wheelchair or walker. The search for a one-level affordable unit, preferably a bungalow, continues. Given the rental market in Ottawa over the last 10 years, a situation that we made reference to earlier, finding accessible and affordable housing is difficult.

Despite the many modifications made to their private home spaces, respondents are still faced with many sociospatial barriers outside the home. For instance, Mr Collins and Judy are reluctant to venture out for a walk alone, because they may fall or experience a blackout, keeping them both in the private home space and out of public spaces. Bob will make arrangements to do things with friends, but always attaches the caveat: 'if my MS is acting up, I won't be going'. Kate, Sarah, Bob, David, Vanessa and Wilma also refuse to go into the very large warehouse style 'big box' stores that are becoming increasingly more common in Canadian cities. These respondents all tend to go to smaller, familiar neighbourhood stores, because the larger stores are too overwhelming and difficult to negotiate. Bob comments:

> I never go to Loblaws [an Ottawa grocery store] anymore because it is too big…just too big. And I'll never go to Price Club. I have gone to Price Club in the past with my wheelchair, but it is just too big. I find now when I go for groceries, I go to smaller stores. There is a little butcher shop in the East end. There is another store that is for fruit and vegetables, and that's also in the East end. I still go there even though I no longer live in the East end because it's familiar, you know? I know where things are…. But the boxes and the cans and stuff, I place an order with someone going to the store, because it is just too difficult to get around some of those stores. And I am trying to walk as much as possible, trying to avoid using the wheelchair because I find that my balance has improved from walking so much.

Many respondents schedule their grocery expedition for a specific day of the week to maintain some sort of routine. However, others must be more 'flexible' in their routine, because they are dependent on friends or family to accompany them and consequently have less control over their use of this space. This emphasis on maintaining a routine, despite their own varying experiences in their own personal disablement process, is very important to some respondents. Maintaining a routine for daily tasks seems to have replaced the routine they once filled with paid labour. Strategies vary for each respondent, but there are similarities that are nicely captured by Kate's narrative:

> I'm quite an outgoing person, but I am almost reluctant to go out because my legs start to give away, and then I have to come home again. My legs just go weak

and like they won't hold me up. I have to find some place to sit down. You are just aware of your legs. That is why I don't go out to do things like browsing around the shops or visiting places because, you know, I will end up having to come home to sit down, so it is very frustrating. So, my daily routine is fairly structured but within a limited environment…I function pretty well around the house. I have an agenda book where I mark down the activities that I will tackle that day, so usually the domestic activities…cleaning, laundry, making beds, meals…but I also schedule in rest periods, or I am done for. The thing I do schedule every day is to take the dog for a half hour walk even though it is difficult for me and my legs don't always want to walk. I kind of force myself to do that because I think that if I have given up on that, I give up on getting out of the house, basically.

Discussion and Conclusion: Process of Disablement Over Time and Space Revisited

This research has examined the lived experiences of 15 people diagnosed with MS to help understand how these men and women who have developed MS become, and live as, a person with a chronic illness over time and space. We particularly explored the aspects of their daily lives such as employment status, personal and familial relationships and their use of public and private spaces. As this research shows, our participants each experience the process of disablement over time and across space differently. However, what they share is a specific spatiality and temporality to each individual lives as a chronically ill person in society and space. These commonalities remain regardless of whether or not they had removed themselves from paid labour or moved to a new residence. Moreover, the coping strategies adopted by the participants have been used as a way to adapt to their newly ill bodies. We believe that it is important to note here that these categories of 'space' and 'time' are somewhat artificially separate as it is difficult to divorce individual experiences in space from time. Though they are discussed separately at times, we realise that it is the simultaneity of these variables that results in people experiencing this process of disablement and not their separation. The

presymptomatic expectations of 'normal'/'abled', for example, are juxtaposed against how these changing performative abilities are experienced and defined through a material body. These changing performative abilities fluctuate over time and space.

In terms of time, those diagnosed with MS who experience a relapsing–remitting course of the disease experience very different levels of impairment and even (dis)ability depending on whether their symptoms are flaring up or not. This concomitantly affects their interaction with and through space as this happens in place. In periods of remission, where few, if any, symptoms are present, some participants were able to (re)experience their 'normal'/presymptomatic selves and abilities. However, this does not allow a return to the previously taken-for-granted experience with space and place, as the person with MS is all too keenly aware of how quickly the material body can change over time. This uncertainty creates a forever-altered construction of reality, albeit tempered by (re)experiences with former self-identities (both of an abled and disabled material body). In other words, different experiences in space blend with the bodily changes experienced by these men and women over time. By contrast, those participants who experience primary or secondary progressive MS do not have these (re)experiences with their former selves, but rather create new experiences with space and place over time depending on the severity of progression.

Being diagnosed with MS, or coping with the months or years of symptoms without a diagnosis, resulted in changes for many participants in terms of their personal and professional relationships. Several respondents indicated that with the acquisition of the 'label' of MS came unexpected reactions from some friends and family. Friends distanced themselves, as experienced by Mason and B.L. The marital relationships of Kate, Bailey, B.L., Ruth and Vanessa were strained. Those women who acquired MS and who also performed the role of 'mother' also had to cope with changes in their relationships with their children as evident through Kate's narrative of turning over the responsibilities of 'mom's taxi service' to her son and not being able to engage in mother–daughter bonding activities. Prediagnosis symptoms and eventual diagnosis also prompted changes in the paid labour force experiences of some respondents. For some,

diagnosis coincided with retirement age. However, seven respondents who are still of working age are unable to participate in the paid labour force. Kate, Ruth, Vanessa, Bubbles, Judy, David and Mason all had to leave the paid work force due to their challenges with the MS. This challenge with MS is also faced by Mr Collins, who while engaged in the paid labour force constantly struggles to avoid reducing his hours of work.

These shifts in time, particularly in the way that expected roles are played out over time, have had corresponding shifts in space. Each respondent faces at least one, if not multiple, sociospatial barrier. Some of these barriers are social in nature due to reduced social contacts, inability or limited ability to participate in the paid labour force and an inability to run daily errands to the full extent they once did prior to becoming impaired. Kate, for example, is keenly aware of how the MS restricts her movement within a 'spatial' world. She lives in a 'limited environment' both socially and spatially. She 'forces' herself to take the dog for a walk every day for fear of losing her ability to 'get out of the house'. Bailey feels very isolated by no longer being involved in paid employment. B.L. responded to her change in paid labour participation by returning to school in the hope of getting a job with sufficiently flexible hours to accommodate her needs with her MS. Bubbles intentionally involves herself in social activities different from her husband so that he will not feel guilty by participating in activities that she can no longer share (e.g., going to the gym).

In terms of physical 'space,' several respondents had to adapt to barriers in their homes due to changes to their bodily experiences. Mr Collins, Vanessa and Bubbles all consciously moved into a bungalow to minimise the internal physical obstacles encountered in their living environment. Both Mr Collins and Vanessa had previously been living in townhouses, whereas Bubbles was living in a three-storey home. These contextual differences demonstrate how each individual operated as an active agent in shaping his/her sociospatial environment in the face of the larger process of disablement. While not all participants are living in a suitable housing environment, they are making whatever adaptations possible to make the space livable, even if that means being restricted to only certain spaces within the home, as is the case of Mason and Bailey. Similarly, other barriers in their personal space required physical modifications or a move to a more accessible housing environment. Some respondents faced additional biophysical barriers, which curtailed their capacity to work within the home in terms of cleaning, laundry and cooking, due to fatigue, balance problems and other mobility limitations. This prompted the participants to either divide the tasks to be done into a manageable series or seek outside help. The need to deal with these changes emotionally resulted in a redefinition of self and a redefinition of their roles within the household.

Moreover, when learning to live with a chronic illness, individuals also engage in daily (re)negotiations of different bodily experiences of symptoms and forms of disablement. Some days, their experiences are acute and severely limit their sociospatial environments, whereas other days, the 'presence' of the illness is almost unfelt, thereby effectively removing previously experienced barriers to and within public and private spaces. For example, Bob makes plans with friends, but also stipulates that if his MS is also causing him problems that day, he will be cancelling their plans. The converse, however, is that if he is feeling 'fine,' then he is able to engage in additional activities. Similarly, while Kate, Jamie and Sarah all adopt strategies of minimising the number of times they use the stairs in their homes, the level in which they enforce this habit varies by their energy levels (Crooks 2001).

In this article, we have demonstrated, through the narratives and experiences of 15 individuals, how intersecting experiences in time and space resulted in the participants living in and through the process of disablement. The bodily experiences of these respondents are intertwined with their sociospatial experiences over time in coping with everyday life through the process of adaptation. Individual context (i.e., illness state, level of disability, social and economic positioning) plays a key role in shaping the particular experiences, but active (re)negotiation of daily living was a common thread shared throughout. This confirms the complex relationship between physical and social experiences, as individual experiences of the illness span the spectrum of the disablement process. This article demonstrates the need for researchers to pay more attention to the role of both time and space in shaping the lived experiences of people with chronic illnesses, as it has

been shown that these variables play a significant role in regulating the everyday experiences of this study's respondents.

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