INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

**COPING WITH MULTIPLE SCLEROSIS:
GEOGRAPHIC SPACE AS CONSTRUCT AND CONSTRAINT**

by

Suzanne Michelle Driedger, B.A. (Hons.)

A thesis submitted to
The Faculty of Graduate Studies and Research
in partial fulfilment of
the requirements for the degree of

Master of Arts

Department of Geography

Carleton University
Ottawa, Ontario
May, 1997

© 1997, S. Michelle Driedger

National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-22074-5

The undersigned recommend to the Faculty of Graduate Studies
and Research acceptance of the thesis

COPING WITH MULTIPLE SCLEROSIS:
GEOGRAPHIC SPACE AS CONSTRUCT AND CONSTRAINT

submitted by Suzanne Michelle Driedger, B.A.(Hons)
in partial fulfilment of the requirements for the degree of Master of Arts

Thesis Supervisor

Chair, Department of Geography

Carleton University
May, 1997

ABSTRACT

Geographers assume the issue of space as pivotal to their studies. In medical geography, researchers have been primarily interested in absolute (geometric) and relative space. Only over the last few years have medical geographers begun to look at issues of relational space. Each conceptualization of space becomes increasingly more abstract. The question is: are these same conceptualizations reflected in everyday people's reality? The way in which we relate to our environment can be affected by the presence of a chronic illness, a mobility limitation, or simply increasing age. This research examines how people with a progressively disabling illness, such as Multiple Sclerosis, are affected in their spatial environments in terms of how space is constructed and constrained. Using grounded theory and in-depth interviews, the research finds that not everyone who participated views their world in spatial terms. Yet, for others, issues of space structure their daily events and lived reality. Space becomes an arena for resistance. Through the interview process it was possible to develop a diagram which looks at the construction and reconstruction of space for these respondents.

ACKNOWLEDGEMENTS

A research project of this magnitude is never completed without the assistance of many people. There are a number of people to whom I am deeply indebted and would like to thank for their contribution in the writing and production of this thesis.

I would like to thank my thesis supervisor, Professor David Bennett, for his direction and support. David was always available to offer me sound and pragmatic advice. He listened patiently to my temporary 'crises of faith' and possessed that invaluable characteristic required in a supervisor: the ability to calm my fears. His faith in my ability to complete this thesis within the constraints of my timetable was unwavering.

I would also like to thank Dr. Nelson, Director of the Multiple Sclerosis Clinic at the Ottawa General Hospital. Without Dr. Nelson's support, this research would never have been completed so smoothly. A special mention must be made to the wonderful staff of the MS Clinic: Lorraine Denis, MS Clinic Coordinator and Louise Laniel, Secretary. Louise was instrumental in helping me put together the postal code data base which was necessary for identifying potential respondents that would receive my information package.

Much appreciation is owed to all the respondents who participated in this study. Without their willingness and genuine interest, this research would not have been possible.

A debt of gratitude is owed to Steve Prashker, Geo-processing Analyst at Carleton University, and Peter Pulsifer, fellow graduate student, who both gave me a crash course in using MapInfo and understanding how to use Postal Code Conversion File programs. Without their help, I would never have been able to submit my research protocol to the Ottawa General Hospital Research Ethics Board on time. Sincere thanks is also owed to Denis Arsenault for having provided me with the French translation of my research proposal.

No university is without their special "guardian angels" — Hazel Anderson, Graduate Secretary for Geography, is such a person. She always made sure that I knew which deadlines were critical to meet and kept me out of trouble. In addition to her invaluable help, she possesses one other unique characteristic: she is a fellow Manitoban. Hazel and I would spend time reminiscing about Winnipeg, which always made me feel less home sick.

A word of thanks must also go to my fellow graduate students, especially those who shared space in the former "rat room". You all made my experience at Carleton that much more memorable.

Lastly, there are a few special people who provided me with never-ending support and encouragement. My parents, were always available for long-distance counseling when I ran into yet another brick wall. You are both my very best friends. A special thanks to my grandmothers, Memère and Oma, who are proud of me no matter what I do. Thanks must also go to all my friends in Winnipeg (the 2 Leannes, Lisa, Doug and Scott) who kept up my spirits with endless jokes and stories. To Caroline, my house mate — thanks for having put up with me these last few months. And to Lorraine, thanks for getting me away from the computer long enough to realize that there is a world out there. You helped to ensure that I continued to have a social life!

This thesis is dedicated in loving memory of my Memère: Jeanne Boivin.

TABLE OF CONTENTS

Acceptance Form	ii
Abstract	iii
Acknowledgements	iv
Table of Contents	vi
List of Illustrations	viii
List of Maps	ix
 Chapter 1: Introduction	
Background to the Problem	1
Research Goal	2
Research Questions	3
Methodology	3
Chapter Synopsis	4
 Chapter 2: Chronic Diseases and the Construction of Space	
Introduction	6
What do we mean by SPACE?	7
Space in Human Geography - An Overview	9
Medical Geography: Then and Now	17
From Medical Geography to the Geography of Health and Health Care	18
The Changing Conceptualizations of Space	19
Space and Place: At the Level of Real People	26
Operationalizing Terms	31
Multiple Sclerosis	34
The Bio-Medical Realities	34
The Social Realities	35
Coping and Chronic Illness: Conceptual Frameworks	37
Coping and Chronic Illness: A Framework with a Spatial Twist	44
Conclusion	46
 Chapter 3: The Research Design	
Introduction	48
The Qualitative vs Quantitative Debate	48
Grounded Theory	53
Deviations From a Strict Interpretation of Grounded Theory	57
Critique of Grounded Theory	58
Grounded Theory as Used in This Research	60
Gaining Access	61
The Study Area	62
Identifying Respondents: The Recruitment Procedure	62
Part 1: The Mail Out	63

Part 2: The Clinic Days	67
Topic Areas Covered in Each Interview	68
Summary	69
 Chapter 4: The Construction of Space	
Introduction	70
Developing the Spatial Environment of Real People	72
Constructing Themes From Narratives: The Process	73
Type of MS	73
Identifying Patterns	75
Constructing Space: Based on the Experiences of 15 People	77
The Fifteen Respondents: Socio-Economic and Demographic Characteristics	81
Identifying Themes, Making Connections	82
MS and Mobility Limitations	82
Barriers	84
Work Related Barriers	84
Social Barriers	85
Cognitive Barriers	90
Physical Barriers	94
Understanding the Links Between the Barriers	103
Managing Environments: Above the Spatial Level	104
Redefinition of Self: The Path to Homeostasis	107
Spatial Constructions: From Themes to Reality	109
Conclusion	111
 Chapter 5: Moving From Spatial Abstractions to Concrete Reality	
Introduction	112
Abstractions of Space	112
Concrete Spaces	113
Making Connections: From Abstract Space to Concrete Reality	116
Review of the Methodology and Research Process	123
Future Directions and Conclusion	126
 Appendices	
Appendix A	128
Appendix B	130
Appendix C	132
Appendix D	136
Appendix E	138
Appendix F	140
 References	 142

LIST OF ILLUSTRATIONS

Figure 2.1 Modes of Adjustment to Chronic Illness	39
Figure 2.2 Areas of Homeostasis	45
Figure 4.1 Relationships and Space: Construction and Reconstruction	110

LIST OF MAPS

Map 1: The Distribution of People with MS in Ottawa-Carleton	65
---	-----------

CHAPTER 1 - INTRODUCTION

BACKGROUND TO THE PROBLEM

Multiple Sclerosis (MS) is a disease of unknown aetiology. It affects the central nervous system and has varied symptoms ranging from fatigue, balance problems, and weakness to visual disturbance, bladder and bowel problems, depression and pain (Aronson, Goldenberg & Cleghorn, 1996). Diagnosis is difficult and often occurs years after the onset of initial symptoms (Robinson, 1988). It is a progressive disease for which there is no known cure. MS often strikes individuals when they are young and at the stage in their lives when they are raising a family, pursuing a career, or both.

People with MS may have to cope with reduced mobility, use a wheelchair, adapt to changing social roles, to name but a few consequences. While some people with MS may encounter some or most of these possibilities, this is not necessarily true for all people with MS. However, texts (documents, books, articles) and advertising portray people with MS in one particular light: as following a "linear progression of increased disability...[where] MS is perceived by many to be classed as hopeless" (Sheridan, 1996, p.4). Within these texts, consideration is not given to those with MS who are not disabled and who lead productive lives. In other words, such texts or advertising do not make explicit that not all people with MS follow the same course. Some do become progressively disabled, but there are many instances where symptoms are stabilized, revert back to lower levels of disability, or the disease simply does not seriously affect their lives.

Moreover, some people with MS have to incorporate accessibility issues within their strategies. Thus, some may have to employ different strategies due to either their location within an urban area or choose locations which are wheelchair accessible. These spatial constraints may have an impact on the type of strategies that are followed. There is a concern within current research on health that there has been insufficient attention given to aspects of space and place (Moon, 1995). What is meant by space and place in current health research is not so much concerned with questions such as how many people in an area have a particular disease. Rather, there is a recent shift that is concerned with how people experience illness within their personal (i.e. home) or institutional (i.e. work, society) space. Specifically, geographers have been proposing different conceptualizations of space. Each new conceptualization represents a greater level of abstraction.

It is in this context that there is a need for research into how people who are affected by a chronic disease deal with the constraints in their spatial environment, and how they in turn reconstruct space in order to minimize the impact of these obstacles. More to the point, there is a need for research to help determine, at a preliminary level, if the abstractions of space developed by geographers have a grounding in real terms — that is, are such conceptualizations of space reflected in the reality of everyday people who are affected by a chronic illness. It may be difficult to find concrete evidence for the more abstract notions. This research uses people with Multiple Sclerosis as the study group.

RESEARCH GOAL

This research is primarily concerned with how people with MS make changes to, or reconstruct, their spatial environment in order to minimize the impact of any barriers or

constraints that have arisen within their environment since the time of their diagnosis. It is recognized that not all people with MS will be expected to have responded to their disease in a similar manner. Moreover, not all participants in the research will have experienced the same level of disability. This research uses the qualitative method of grounded theory¹ to examine how people with MS, regardless of their stage along the disease trajectory, deal with their spatial environment, and how that environment is constructed and constrained. The thesis ends with suggestions for further research rather than starting with specific testable hypotheses. The research program aims to discover and report individual experiences rather than to impose concepts and test for general relationships.

RESEARCH QUESTIONS

The following questions guide the research:

- ▶ Do the theoretical abstractions of space developed by geographers have, at a preliminary level, a grounding in the lives of people who must live with a chronic disease?
- ▶ Do people with a chronic disease, like MS, view their physical environment in spatial terms?
- ▶ What are the types of strategies that people with MS employ as a means for coping with their disease in a spatial environment?
- ▶ Do people with MS have to employ strategies which restructure the space within their physical environment?

METHODOLOGY

These research questions provide the basis for identifying topic areas to be covered in the research. This thesis uses qualitative primary data collected through taped

¹ Grounded theory will be explained in Chapter 3.

interviews. A total of 15 interviews were conducted. Potential respondents were recruited through the Multiple Sclerosis Clinic at the Ottawa General Hospital. Some respondents received a letter by mail, whereas other respondents were recruited through the "Clinic Days" held once a week at the MS Clinic. These potential participants were given a letter of introduction from the principal investigator at the time of their appointment. Respondents interested in participating were invited to call the principal investigator.

CHAPTER SYNOPSIS

The theoretical framework for this research is developed in Chapter 2. In this chapter, the conceptualizations of space, developed by geographers, are examined. Through this examination it is possible to trace how medical geography has evolved to incorporate these different aspects of space into its agenda. This chapter brings in issues and concerns from other disciplines in terms of the bio-medical and social realities of MS, and offers a critique of some of these approaches. As an alternative, the concept of homeostasis is introduced as a way in which it is possible to examine, conceptually, how a person with MS would respond to constraints within his/her environment and how this space may be reconstructed to minimize the impact of these barriers. In addition to this, key terms used in this thesis are operationalized. The chapter concludes with a brief restatement of the main points of the research questions.

Chapter 3 outlines the methodology. This chapter explains why a qualitative method was used over a quantitative one. It also discusses why grounded theory was used over any other qualitative method. This chapter explains the process of grounded theory,

offers a critique of it as a method, and describes the way in which this research deviates from the grounded theory objective. The chapter concludes by describing the recruitment process for gaining access to potential respondents.

Chapter 4 outlines the analytic framework that resulted from the interview data. The first portion of the chapter serves as a brief link tying together many of the concepts and ideas mentioned in the first three chapters. From there it outlines the process involved in constructing the framework which visually shows the process and relationships involved in the construction and reconstruction of space among the fifteen respondents. Explicit examples from the text highlighting these conceptual links follow, and concludes the chapter with an unveiling of the framework.

Chapter 5 serves to make connections between the theoretical and the practical. The conceptualizations of space, developed by geographers, as well as how the individual respondents relate to these conceptualizations, are briefly examined. Through a review of the research questions of Chapter 1, it is shown how respondents have made changes to their spatial environment. The chapter concludes by reviewing the effectiveness of the research method and offers suggestions for future directions for research.

CHAPTER 2 - CHRONIC DISEASES AND THE CONSTRUCTION OF SPACE

INTRODUCTION

It seems that throughout geography's development, first as an amateur enterprise, then as a discipline and later as a department of study, there has been a struggle to define what it is. Even today, academics are still struggling with that question, especially in human geography. As a science, physical geography has had a much easier road to follow. That aspect of geography has not been plagued by the same philosophical and ideological debates that have occurred in the social sciences, particularly in the last quarter century. The single largest shared area of debate has centred around conceptualizations of space; understanding the spatial aspects of the physical and social environments has been pivotal to the integrity of geographical studies.

Geographers tend to assume that everything can be represented in spatial terms, and that because we are surrounded by space, its importance is self-evident. The way in which a drainage basin has a geometry sets the geographer apart from the hydrologist. The decision to locate any human-made physical structure like a hospital, a garbage dump, or a housing development has spatial implications for various levels of government as well as for citizens. These siting decisions can affect the overall ecosystem, can prompt the removal of forested land, and disturb the 'natural' dynamics of an area. While many aspects of human and natural development have spatial implications — many geographers would likely go so far as to say that everything is spatial — is this same reality reflected in people's lives? That is, do non-geographers recognize and conceptualize space in the same

terms that geographers use? Indeed does space play **any** explicit part in their concrete practices?

This chapter outlines some of the developments that have occurred within geography in terms of the different conceptualizations of space. This includes an overview of the geographical tradition, albeit briefly, with a special emphasis on medical geography. Also included is an examination of the kind of role that space may play in the lives of people who are faced with decreasing mobility due to a chronic illness, such as Multiple Sclerosis (MS). Space in this sense involves looking at how individuals faced with a potentially progressively disabling illness are forced to change the nature of their activities and their relationships to their overall environment. Although this chapter will use the example of MS to highlight concepts, other areas in which people are forced to face a reduced or modified spatial environment, such as physical limitations due to other chronic illnesses or disabilities as well as due to aging, will also be touched upon.

WHAT DO WE MEAN BY SPACE?

Whittlesey said that “[s]pace is the basic organizing concept of the geographer” (as cited in Blaut, 1961, p.1). Blaut (1961, p.1) followed this up by saying that “[b]ut space is a treacherous philosophical word, and every empirical and metaphysical notion of pure, timeless space has been discarded by scientific philosophy. Where, then, does geography stand?” These two statements nicely sum up the difficulties in looking at the conceptualization of space. However, space as it will be discussed here is not thought of as a pure, analytical mathematical space, but rather, it is an empirical space which has a spatio-temporal reality.

Taking a very large contextual view, Curry (1996) summarizes the four main notions of space that have been prevalent in Western thought. The first notion is one codified by Aristotle, which views space as static, concrete and hierarchical, where everything has a natural place and possesses its own internal spatial order. The second notion is Newtonian. Space is a 'grid' - that is, arbitrary in its articulation - where objects are located and events occur. Here space is absolute. It is not empty. Rather space consists of relations among extended objects in terms of their extension, height and so on. Once you remove these "inessential features" (Curry, 1996, p.10) what remains, is the same as space. While Newton refers to space in terms of its relations to other objects, it is different from the third notion of space put forward by Leibniz. Leibniz argued that you must look at the relationships among objects and events so that space is defined in terms of those relationships. Here space and matter are not identical. Rather "space is relational but consists just in those relations and nothing else" (Ibid., p.13). The last notion of space is posited by Kant. Space is a form imposed on the world by humans.

Curry (1996) has the greatest problem with this last conceptualization of space, because in essence, it means that a representation of space has to be presumed since we can never get beyond our own perceptions. In other words, space has no essentialist or foundationalist 'existence'. We have to assume quite a few things 'realistically', because they are impossible for us to get outside of them. It has been suggested that space and time are categories intuitively known to **all** human minds. They are basic parameters of consciousness, although 'learning' can change them.

Space in Human Geography: An Overview

These four notions of space are simplified summaries which barely scratch the surface of the lengthy and sophisticated debates which are still going on. Nonetheless, these brief glimpses help us to see how geographers have modified their understanding and conceptualizations of space over the years. As mentioned earlier, geography is essentially divided into two major camps: the physical geographers and the human geographers. Whereas physical geographers have largely remained grounded in logical positivism and its realist and materialist assumptions, human geographers branch off into a myriad of philosophical ways of viewing the world. And, it is to human geography that we will turn our attention.

Human geography has basically been interested in three types of relationships: 1) between the social and the spatial; 2) between the social and the natural and between society and the environment; and 3) between different elements of the world created by humans, like the economy, social structure, politics and so on (Agnew, Livingstone and Rogers, 1996; Massey, 1984). For much of this century prior to the 1960s, human geographers were primarily interested in the study of regions. These geographers were interested in understanding and synthesizing the relationships of, and processes of how localities developed. There was an interest in contemplating the unique, as opposed to tearing apart and dissecting relationships through analysis. This type of geography was grounded in a sense of place, but was unsophisticated by modern standards. This type of study was overtaken in the 1960s with the emergence of a self-consciously scientific geography with a largely unrecognized emphasis of logical positivism. It was argued that

through the application of neutral, objective scientific principles and mathematical models using large scale quantifiable data sets, generalizations could be made, thereby removing any aspect of the unique.

At this time in its development, many in geography did not feel that they had a particular niche of study to call their own, in the way that scholars in economics, political science or sociology did (Agnew, Livingstone and Rogers, 1996). "All it had — or appeared to have — was a dimension: space, distance" (Massey, 1985, p.11).

Consequently, geography set itself up as the science of the spatial. Now this is not to say that up to this point geographers were not incorporating the spatial in their studies. Rather, these earlier geographers were not raising the realm of spatial study to the level of the scientific where it could now compete for legitimacy against other disciplines in the social sciences. In fact, these other disciplines were already considering spatial aspects in their research; it was geography that had to catch up (Johnston, 1983).

Thus, geography took a turn where geographic patterns were explained spatially, in terms of spatial laws through distance, trip distribution, and so on, thereby separating the spatial from any social explanations altogether, and consequently from other social sciences and social theory (Gregory and Urry, 1985). The gravity model is a good example of this which measures distance and interaction decay. Whereas land in the downtown region of a city can command a higher price because travel distance is reduced and transportation costs are lower, land found further away from the city core is cheaper, but travel distance is greater and transportation costs are higher. Similarly, Stewart and Warntz's social physics provides another example of this. Social physics applies

observations from natural science to social data. It looks at relationships of distance to other types of interaction like migration, movement of goods, and flow of capital, to name but a few (Johnston, 1983).

Human geography changed once again with the development of a radical critique in the 1970s. Geographers were beginning to study the built environment and examining large scale inner city decline, particularly in the United States. These geographers were finding out that inner city decline had less to do with cities per se, than with changes in industry, production of capital, the movement of goods and so on. They were beginning to look more at space in terms of it being socially produced. They were realizing that they had to go beyond their discipline to emphasize spatial patterns. Thus, they no longer really had this clear and uncomplicated dimension of space left to hold onto. However, at the same time, other disciplines like economics, political science and sociology, which had established niches, tended to conceptualize the world as though it existed on the “head of a pin, as though it were distanceless and spatially undifferentiated” (Massey, 1985, p.12). Hence, geographers were starting to realize that “space *is* a social construct...but social relations are also constructed over space” (Ibid., emphasis in original). Human geographers were thus trying to bring back the social with the spatial. Some of these geographers of the 1970s adopted neo-Kantian views that people construct their own perceptual worlds. Others were bringing in a critical Marxist approach trying to attach a concept of space-economy to the political level in understanding development (Agnew, Livingstone and Rogers, 1996).

The most important figure here is David Harvey, and his conceptualizations of space, which form part of the basis for looking at how people with physical limitations deal with their spatial environments. Harvey (1973), a logical positivist turned Marxist geographer, developed three conceptualizations of space, which prefigure the four notions outlined by Curry (1996).

Harvey's three conceptualizations of space reflect progressively more abstract views. Harvey felt it important to develop these ideas, because if we are to understand urban phenomena and society in general, we have to demystify the nature of space. The first concept of space is *absolute*. Here space is a container and is independent of matter. Space in this sense is very simply geometric or Euclidian. A useful example is to consider your home and property. Registered at the Land Titles Office, your property is part of a lot, block and plan. It is fixed. Even if the physical home is demolished, the land is still part of that lot, block and plan. It has not changed. Moreover, the address of the home is a registered civic address, which distinguishes your home from another home on the same street. Similarly, another useful example is navigation at "earth" scales. Pilots have to follow a coordinate base system in order to transport passengers from point A to point B.

The second conceptualization of space is *relative*. Relative space examines the relationships between objects. The relationship only exists because the objects exist and relate to each other. Here it is possible to consider both a micro scale and macro scale example. At the micro scale, refer back to the example of your house as a registered civic address. In new suburban developments, mail delivery is no longer directly brought to the civic address - i.e. your home. Rather, your civic address identifies your home for people

wanting to visit it. However, for people wanting to send you something in the mail, that letter or package is addressed to your civic address, but not sent to it. Rather it is sent to your box in the super-mailbox system, often located at the end of the street. As such, this shows a relationship between your civic address and the box number in which you receive your mail. At a more macro level, a useful example of this might be to look at traffic patterns. The urban traffic system is generated by particular land use patterns. If you were to change the land use patterns, then the traffic patterns would also change. Moreover, movement of goods, people and information across the road network takes time, energy, and money, bringing these issues within the relationship between objects, and hence making space relative.

The last conceptualization of space is *relational*. Here space is regarded as “being contained *in* objects in the sense that an object can be said to exist only insofar as it contains and represents within itself relationships to other objects” (Harvey, 1973, p.13, emphasis in original). Harvey argues that this conceptualization of space is fashioned after Leibniz. Leibniz, in turn, argues that we must “attend to the relationships among objects and events to the extent that we come to see space as fundamentally relational and defined entirely in terms of those relationships” (Curry, 1996, p.5). Here, this abstraction of space is looking at the way in which space is socially constructed, and given meaning, by its users. More recently, Harvey clarifies his earlier definition of relational space, although he never really re-defines it other than to say it “produces its own space and time” (Harvey, 1994, p.129). He looks at how we, “in our own contemporary circumstances, are actively constructing and supporting certain notions of space and time rather than others” (Harvey,

1994, p.126). As an example, he looks at how quickly capital flows via computer transfers in nanoseconds. Money is not physically exchanged across time and space, but yet there is a fundamental belief that transnational corporation A in location B transferred \$X billion to a bank in location C.

Harvey, himself, argues that “space is neither absolute, relative or relational *in itself*, but it can become one or all simultaneously depending on the circumstances” (1973, p.13, emphasis in original). In determining the appropriate conceptualization of space, one should not ask, “what is space?” but rather ask “how is it that different human practices create and make use of distinctive conceptualizations of space?” (Ibid). It is important to stress that there is no essential meaning to space — that is, space is not simply one of these three conceptualizations, and not the other two. Rather, depending on the context, space may be conceptualized as one of these and may be coherently discussed from that point of view. This research is trying to examine fifteen concrete cases to see if elements of each conceptualization can be found in any, all, or some of these situations. Its purpose is not to argue that only one of these conceptualizations will be “proven” as “true”.

For this third conceptualization of space, it is much more difficult to provide examples. Again, refer back to the home example. The house and property is located at a fixed address, making this absolute space. The house is located within the urban structure relative to other houses in the same city. It serves as part of the boundary of a particular land use, helping to determine the relationship between this and other land uses, and the road network system, making the space relative. At a macro scale, market forces,

demographics, and surrounding land uses can make some areas more desirable than others in terms of people's perceptions. Hence, some areas can be perceived as being run down, dangerous, unhealthy and dirty compared to other areas of similar composition, thereby viewing space relationally.

Similarly, at a micro scale, within a home and its surrounding neighbourhood, individuals may have different attitudes towards perceived or actual barriers. A "perfectly healthy person" — that is, someone who is not significantly constrained by their environment — may not perceive a home with fourteen stairs, narrow hallways, or a shower located inside the tub as being a barrier to movement. Living in an area where it is more convenient to walk the two blocks to the grocery store, the four blocks to the video store and bank, and the six blocks to their favorite restaurant, than it is to drive, they would also not see anything as a barrier to movement. However, a person who is not in "perfect" health, whether it is due to a physical limitation, a chronic illness, a mental affliction or increasing age, would likely view these same patterns as significant obstacles that must be overcome on a daily basis. Moreover, the frequency and pattern of these trips may be considerably curtailed for those who view these activities as barriers.

One final example of relational space may help us to understand the varied nature of its abstraction. People with diminishing health will likely have made adjustments to their activity patterns within their environment from the time when they were in peak health. It may simply start off with their spatial environment consisting of the rooms within their home, and a few blocks radius around their home. As their health deteriorates, this environment shrinks further. The few blocks radius may be reduced to one, or none. The

home may be their only real environment, where others bring into the home the needed resources and services. The relationship within the home may also change. It may no longer be possible for them to climb stairs, so all the living is restricted to one level. If their health becomes worse, their environment may be simply one or two rooms. If it ends up with them receiving extensive attendant care, or being hospitalized, their environment shrinks to just their bed. These changes in their environment are all relational in terms of how they interact, give and derive meaning from their surroundings.

Now, these various conceptualizations of space have been put forward elsewhere, but in slightly different ways. Lefebvre (1991) tries to look at space more holistically. He uses the terms absolute and relative for space, but also raises concepts of social space, abstract space, spaces of representation and so forth. For Lefebvre, we should not be analyzing things in space, but rather space itself “with a view to uncovering the social relationships embedded in it” (1991, p.89). The dominant tendency, however, is to fragment space into tiny pieces and look at the forces which occupy space as though it were a “passive receptacle” which unnecessarily “fetishizes space” (Ibid., p.90).

Soja (1989; 1985) too expresses space differently. He refers to the absolute and relative spaces as being physical spaces which includes the friction of distance. While Soja never seems to use the term relational space, he refers to a socially-produced space, which he calls ‘spatiality’. This concept of spatiality is developed to counter the dominance of the physical view of space, in which, unless it is explicitly stated, any link to human action or motivation is absent when the term ‘spatial’ is used. Soja argues that the term ‘spatial’ “evokes a physical or geometrical image, something external to the social context and to

social action” such that space is viewed more as a container than “a formative structure created by society” (1989, p.80n). For both Lefebvre and Soja, relational space is more apparent at the macro scale, in terms of what these relationships uncover with respect to the dominant underlying structures, and the dominant power relationships therein.

For geographers in the 1980s, these different conceptualizations of space were important (Urry, 1985). Geographers were becoming interested again in aspects of space and place, especially in terms of difference if not uniqueness. These geographers were partly arguing against the Marxist refusal to examine space in anything other than absolute terms. These other kinds of geographical viewpoints have included feminist, postmodernist, and to a lesser extent, poststructuralist conceptualizations of space (Curry, 1996). Feminist geographers have been looking at concepts of gender and place, integrating elements found within the new cultural geography. Postmodernist constructions of space have been less successful in terms of adopting “an “anything goes” attitude of space” (Curry, 1996, p.18). Poststructuralist approaches to space have largely been among non-geographers involving considerable debate about the use of language and metaphor (e.g. critique of ‘containerism’).

MEDICAL GEOGRAPHY: THEN AND NOW

Medical geography has also been dealing with many of these issues with respect to place, space, and has been asking how do we, as geographers, fit. However, for medical geography, space has been very much centred around the absolute or relative conceptualization of space. Only recently have medical geographers begun to consider

aspects of relational space. In order to appreciate this, one needs to briefly consider the history of medical geographical study.

From Medical Geography to the Geography of Health and Health Care

Curtis and Tacket (1996) outline five main strands in medical geography. In brief, the first views space as a container. It is concerned with the spatial patterning of disease and death. It has strong links with the positivist paradigm and its central concern is to map mortality and disease. This strand holds a strong affinity with bio-medical explanations, especially in tropical environments (i.e. a disease has a specific aetiology which can be traced back to a root pathogen). The disease ecology framework is also predominant in this strand. This framework looks to understand the distinctions between human and cultural determinants of human diseases, where environments are seen as indirect causes of the disease (Jones and Moon, 1987; Eyles and Woods, 1983). The second strand looks at the spatial patterning of service provision in terms of: mapping the distribution of health care facilities; identifying patterns of inequity in the supply and use of services; and examining patient use of services. Space is still viewed as an absolute and the analysis is strongly couched in quantitative terms. The third strand begins to move away from a natural science model of analysis to look at concepts of health and health-related behaviour through the use of qualitative methods. Space here becomes more relative and reflects the shifts made by humanism. Issues of accessibility in terms of distance travelled, travel time, travel cost and time spent waiting from the point of view of the service user, are incorporated into these studies. The fourth strand incorporates ideas from structuralism and critical theory in terms of looking at how health and welfare

services improve the quality of life for people. It examines the inequities within the system in terms of access and resource distribution. The fifth strand represents changing views of space and place for individuals and their health. This strand places an emphasis on differences among people. It seeks to incorporate both structure and agency in the promotion of health as opposed to a concern with the causes of ill health. In other words, it looks to understand how people maintain their health, how they deal with illness, as opposed to a concern with conventional epidemiology.

These five strands of study reflect the shifts that have occurred within medical geography. Medical geographers have been arguing that such shifts in focus have been necessary rather than being discretionary (Jones and Moon, 1993; Kearns and Joseph, 1993; Eyles, 1993; 1990; Moon, 1990; 1995; Dyck 1995; Gesler, 1992; Kearns, 1995). However, not all medical geographers are convinced (e.g. Verhasselt, 1993; Meade and Meyer, 1994).

The Changing Conceptualization of Space

Although Curtis and Taket (1996) divide medical geography into five main strands, research has been primarily located in one of two camps: the geography of disease and ill-health; and the geography of health care (Eyles, 1993). The first looks at associations between environments and disease through ecological analysis, similar to epidemiology. The second looks at use of, and accessibility to, health care services and facilities through spatial analysis (Eyles, 1993; Jones and Moon, 1987). However, these two main approaches emphasize only absolute and relative space. Moreover, when researchers have been looking at issues of geographical differences within these types of studies, they tend

to be only reflective of matters of scale, and are rarely included as part of the explanation. In other words, spatial differences serve as a framework within which to order data and identify patterns (Jones and Moon, 1993). These units of analysis tend to be administrative jurisdictions, where people are reduced to ecological indicators, rather than being concerned with demonstrating how people are influenced by different places (Duncan, Jones and Moon, 1993).

Recently, some medical geographers have been questioning this unreflexive use of space and place (Dyck, 1995). Much health and health care research — one of the more recent labels to replace ‘medical geography’ — has an implicit and sometimes an explicit concern with place (Moon, 1995). Eyles (1993) argues that as geographers, we need to move away from these narrow conceptualizations of space to include how space is influenced by human activity and how people give meaning to their environments relationally. Some have asked if we should concentrate our attention on places or people, failing to see that we must stop overemphasizing the social and undervaluing place, and instead look at them simultaneously (Jones and Moon, 1993).

A few medical geographers have started making moves in such a direction. Eyles (1990) argues that much of the comparative analysis in health care research assumes space as a given, in which its role in shaping what happens has almost little or no effect. Sayer (1985) argues that this view of space is unrealistic. While space can only exist in and through objects, it is nonetheless, independent of the objects present. Consequently, there is a need to consider both the objects and their spatial arrangements. Moon (1990)

indicates that a failure to do so misses out on how human behaviour translates physical space into social space.

This move towards a more social constructionist or relational view of space is evident elsewhere. Gesler (1992), in his examination of therapeutic landscapes, argues that it is important to see how the healing process plays out in specific places. The feelings, or sense of place that people attach to given locations help us to understand the strength and power these meanings have in shaping the conceptualization of our individual lifeworld. Picheral (1994) argues that even with epidemiological studies, it is important to consider the natural or physical conditions of a place. However, this recognition must not come at the expense of how a population manages, organizes, uses and identifies with its space. In other words, how people give meaning to their place and space must not be ignored.

Kearns and Joseph (1993) argue that looking at human experience in place, adds a location-specific dimension necessary to an understanding of the impact of social relations in space. People's lives are shaped over geometric space, but it is in place that people give meaning and understanding to their situation — where they develop themselves. Moon (1995, p.1) supports this when he writes:

the intersection of health and health care research with 'place' must retain a concern with differences between and within locations and with distance, mobility and spread, but it must also concern itself with the structuring of meaning and understanding in the places where people live, experience sickness and use health services.

Dyck (1995) incorporates these positions in her case study of women with Multiple Sclerosis (MS). She looks at how these women have had to restructure the spaces of their lifeworlds. For these women, space has been constrained considerably by

their developing a chronic illness. This study will be reported in detail later. At this point, it is important to recognize that Dyck is raising the issue of difference in how people shape their own health beliefs and practices by developing maps of meaning — that is giving meaning to their environment in light of reduced spatial mobility. This latter point is supported by others who call on medical geographers to make visible in their research issues of difference in groups defined by class, gender and ethnicity (Kearns, 1995; Mechanic, 1995b).

Kearns (1995) argues that medical geographers must also become more concerned with theorizing, albeit only theorizing of a certain kind. Much of medical geography research tends to be grounded in applied work and appears to be largely atheoretical (Craddock, 1995). Litva and Eyles (1995) go a long way to show that this is not the whole truth. They argue that “no social science is atheoretical when theory is understood as a way of understanding the world” (Litva and Eyles, 1995, p.5). Much of the epidemiological and health care research in medical geography has been influenced by a positivist paradigm, at least epistemologically. Nonetheless, they contend that three different social theories influence different types of medical geography: structural functionalism, conflict theory and symbolic interactionism.

Structural functionalism uses a positivist epistemology, making claims to neutrality and objectivity, to obtain facts about the social world. It is primarily interested in how human behaviour influences these social facts as well as their interrelationships in shaping the underlying structure of society. Conflict theory, on the other hand, makes no claims to being neutral or objective. It looks towards critiquing economic and social arrangements

in society through revealing power relations using Marxist and feminist analysis. It incorporates both quantitative and qualitative methods. Symbolic interactionists, like feminists, look at how social reality is constructed by different social actors in terms of their experiences. Qualitative methods and micro scale case studies are primarily employed to capture the individual's view of the world.

Litva and Eyles (1995) do not make a case for the merits of one of these theories over the other. Rather, they argue that medical geographers need to open their minds to these various conceptualizations, and employ those which best fit the research question. Moreover, in doing so, medical geographers can begin to move away from an exclusive reliance on the biomedical model which has been a strong undercurrent in health and health care research (Baum, 1995).

The biomedical model has four major assumptions (after Curtis and Taket, 1996), which will only be outlined here. A disease is viewed as a deviation from the norm. A disease has a particular aetiology which can be traced back to a root pathogen. A disease will always show the same symptoms regardless of time or space. Last, the biomedical model is grounded in "scientific neutrality and [the] rationality of medicine" (Curtis and Taket, 1996, p.27). The emphasis of the biomedical model is on ill-health rather than health, and on searching for cures rather than prevention.

Within the biomedical model, it is science, via the skills and expertise of the doctor, that legitimizes the presence or absence of a disease. A physician attaches greater weight to the "signs" of ill-health that are directly observable (eg. fevers, measurement of blood pressure), than to the "symptoms" that are related to the physician by the patient

(eg. changes in the patient causing him/her concern). Signs are viewed as concrete, "objective evidence", whereas symptoms are viewed as "'softer' forms of evidence" because they are "feeling states" identified by the patient (Twaddle, 1974, p.30).

However, ill-health and disease are not so simple as to be only observed through signs and symptoms. Field writes that "one can have a disease without being ill, and one can be ill without having a disease" (from Field, 1976 in Williams, 1983, p.188). For example, a person can have a presymptomatic disease without knowing it, or similarly a person can believe that they are ill in the "absence of a pathology" (Williams, 1983, p.188).

These dichotomies within the biomedical model (expert physician/lay person; sign/symptom; disease/illness; cure/prevention) have been challenged. For many years, the biomedical definition of health has been the absence of disease (Baum, 1995). The presence of disease is determined by signs, patient identified symptoms, observation, examination and lab tests. While these same diagnostic procedures continue, the definition of health has been broadened considerably.

The World Health Organization (WHO) was the first to define health as a positive state. In its 1946 charter, the WHO defined health as: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (as cited in Meade, Florin and Gesler, 1988, p. 8). Though this definition was important in outlining WHO's philosophy, it has had little practical application in research given its utopian nature. Nonetheless, this definition has prompted public health researchers to expand their medical and behavioural paradigms to incorporate socio-environmental approaches which

look at how health is embedded in social, political and economic factors (Baum, 1995).

This broadened approach has led to other definitions of health.

Dubos (1965, as referenced in Meade, Florin and Gesler, 1988) defines states of health and disease in terms of how organisms adapt to environmental challenges based on their level of success or failure. Meade, Florin and Gesler (1988) argue that this does not adequately define what health is. The definition they adopt was developed by Audy, where “[h]ealth is a continuing property that can be measured by the individual’s ability to rally from a wide range and considerable amplitude of insults, the insults being chemical, physical, infectious, psychological, and social” (as cited in Meade, Florin and Gesler, 1988, p.9). Here, health continues until death, and it is a dynamic process in which there are constant adaptations to one’s social and physical environments.

There have also been social and psychological definitions of health. The social definition of health (or functional model) refers to an individual's capacity to perform the roles and tasks that are expected of them by their surrounding peer group, family and society. The subjective evaluation of health (or psychological model) is based on the individual's perception and evaluation of his or her own overall health (Liang, 1986). These last two definitions of health rely more heavily on a subjective evaluation of symptoms, as opposed to signs. More credence is given to the lay perception which can include cultural variations, as opposed to the expert opinion (Lock and Bibeau, 1993). For example, Cockerham, Sharp and Wilcox (1983, p.349) found in their research on aging, that “the perception of one's health status is an important indicator in how people relate to

their social world.” When elderly adults had positive self-ratings of health, they tended to have a higher level of life satisfaction.

References to the importance of examining how people shape their health beliefs and practices, as well as how they relate to their world when they experience illness or reduced mobility -- that is, moving away from the bio-medical model of health research to incorporate aspects of meaning to place and space in relational terms -- have already been highlighted within medical geography. In order to uncover these social realities, perceptions and beliefs, calls have been made for medical geographers to incorporate a multiplicity of tools, using both qualitative and quantitative methods (Scarpaci, 1993; Baum, 1995). It is important at this stage to turn to some examples of such research as it relates to how people faced with a chronic illness, like Multiple Sclerosis (MS), deal with a reduced spatial environment.

SPACE AND PLACE: AT THE LEVEL OF REAL PEOPLE

Up to this point, much of the commentary has been at an abstract level. Issues surrounding the different conceptualizations of space, problems of incorporating theory, and the difficulties in moving away from existing approaches to research questions have all been raised, but this is not the main intent of this chapter. These issues had to be raised in order to lay the groundwork on which to structure how this thesis approaches its basic question: are similar spatial concerns reflected in the realities of everyday people?

It can not be emphasized enough that this thesis is not looking to answer definitively what, if any, conceptualization of space is favoured in the lives of the fifteen respondents who participated in this study. First, such claims would only essentialize

space. Second, this research is not intended to be representative of the wider population of people with MS. To make the research representative, a completely different approach would have been required. Many issues, in terms of level of disability or mobility impairment, type of MS, and stage along the disease trajectory would have had to have been controlled. Moreover, this would have made it difficult to get at the lived experiences of the respondents. The intent of this research is to look, at a primary level, to see if the conceptualizations of space as forwarded by geographers, are reflected in the lives of people with a chronic disease. Geographers have looked at the importance of space in terms of larger macro issues such as globalization, development, flow of capital, power and so on. Many human geographers have been influenced by the new cultural geography which has looked at spatial issues at a micro scale in terms of how it is perceived and constructed by different people and different cultures. Few, however, have examined how such abstractions of space are reflected in people who must contend with a mobility limitation, a mental disability, age or deteriorating health.

Golledge (1993) has argued that geographers have paid little attention to people with disabilities. He writes that the disabled live in a “transformed space” (Ibid., p.64). He argues that although space is not homogenous, and all people must overcome barriers or obstacles in their spatial environment, the impact this has on the lives of the disabled is much more magnified. Golledge calls on geographers to develop “a geography of and for the disabled” (Ibid., p.81). He argues that geographers are better equipped to examine spatial interactions and distributions than are non-geographers (1996).

Golledge's argument is challenged by Imrie (1996) and Gleeson (1996). Both argue that Golledge reduces disability to a physiological view as opposed to considering its "*social delimitation*" (Gleeson, 1996, p.394, emphasis in original) which is mediated by other social factors such as class, gender, age, and so forth. Gleeson also argues that Golledge does not seem to recognize that geographers are not the most appropriate to examine the nature of "distorted spaces" (Golledge, 1993, p.64). Gleeson (1996, p.394) writes: "[s]urely the inhabitants of these so-called 'distorted spaces', rather than (non-disabled) geographers, are the best authors for an authentic description of their own experiences?" This researcher versus researched dichotomy can be "alienating for people with disabilities because of the belief that the researcher is the purveyor of specialist knowledge and skills, who should be in total control of the research process" (Imrie, 1996, p.400).

This last point is echoed in almost any kind of research which is concerned with individual experiences, differences, the 'other', and so on. For example, some feminists have been criticized, by other feminists, for dealing with differences between women as subjects of knowledge, by simply including the mainstream perspective of marginalised women (Harding, 1992). This type of criticism has been prevalent among researchers who study the situation of Third World women (Parpart, 1991; Mohanty, 1991). Harding (1992) argues that while most feminists acknowledge that differences exist, they never really critically analyze them or consider their implications. In other words, they concentrate on those sources of shared oppression, while ironing out those differences which are not shared (Flax, 1987). Similarly, when addressing the failure among feminist

researchers to critically examine aging studies, some feminists have argued that this is due to several reasons. First, they argue that part of the reason lies in the fact that most researchers only study those issues and questions which interest them. Second, most feminists are not immune to the culture in which they have been socialized (Reinharz, 1986). Regardless of how open minded an individual is, there is always some internal bias or prejudice. This second reason ties in with the third. Feminists do not share the same experiences as the subject of study and consequently, they can not engage in the topic (Harding, 1992).

This last reason is extremely problematic, and is not exclusively developed by feminist researchers. Gleeson (1996) and Imrie (1996) both argue that only the disabled can work towards eliminating the oppression imposed on them by society, and only the disabled can better inform research about what is and is not relevant. And, while both acknowledge that Golledge is himself a disabled person, they do not accept what he says as carrying any weight in terms of the experiences of disabled people. If a disabled geographer is not in the position to make suggestions as to which gaps exist in the study of the disabled and geography, then who is? This raises the whole argument about who can make statements about anyone, and more importantly, who has the power to name — i.e. attach labels (Zola, 1991; 1993). Fortunately for this writer, who is not afflicted with Multiple Sclerosis, there has been an understanding within the academic community that if research is carried out in a manner which treats the group under study as the subjects of knowledge, and learn from their experiences rather than imposing on them the experiences of the researcher, then it is possible for researchers, who may not be in the identical

position as the researched, to be in a position to say something about the matter (Flax, 1987; Harding, 1992, 1987).

In spite of this, it is inevitable that the researcher will have greater influence over the research process than the researched, because it is the researcher who defines the problem, devises the framework, and carries out the analysis. Burawoy (1991a) argues that no matter how faithful a researcher is to the researched, the researched is not able to modify what is written in the final analysis. Dyck, Lynam and Anderson (1995) support this statement in concluding in their reflection on the process in conducting a cross-cultural research project that even though the researcher may not always be present, it is the researcher who ultimately carries the power to frame the study design, implementation and final product. Barrett (1995) tried to avoid this problem by returning to the respondents with their transcripts of what was said and the final report to ask if she captured the essence of what they were saying. Such an approach is clearly the exception. All these ideas of marginalization, speaking, the 'death' of the author and so on are contentious -- they make some good points at the beginning, but eventually they reach a state of paralysed "correctness". We will leave them for now.

At this point in the discussion I want to operationalize the terms that are used throughout my research. Given that I am not a person faced with 'disabilities' due to a chronic disease, and in spite of the problematization of similar definitions within the academic literature, I chose to operationalize terms like disability, ability, environment, normal, and so forth based on how the respondents themselves defined them. In this way, I am not imposing a wider definition. Moreover, I am not discarding their reality simply

because their definitions may be primarily physiological and not mediated by other social delimitations, as outlined by Gleeson (1996).

Operationalizing Terms

The term environment, or spatial environment is used extensively in this thesis. The 'environment' is not referring to our global environment (i.e. air, land, water, ozone). It also is not referring to one single 'reality'. The spatial environment for respondents changes in terms of its size. Some respondents live in a more limited environment, whereas others are less restricted. In general terms, the spatial environment refers to the space within the home, the neighbourhood, and wherever else the respondent tends to go. As one respondent worded it, the environment is "the geography of the sphere within which you comfortably function" (Kate, respondent #1). The ability to move around in one's environment has been referred to in terms of freedom. For those respondents who live in a spatially reduced environment, many have expressed: "I am not asking for a lot of freedom, I am just asking for a little bit" (Vanessa, respondent #8).

Normal is another term which is used in this thesis. For many respondents, their behaviour is not 'normal'. They can not "stretch [their] limits, stay up late, party, meet deadlines and work all out, like normal people" (Kate, respondent #1). Normal means the average, what most people do. Many of the things that the respondents experience are not shared by a 'normal' person. Vanessa worded it best by saying:

...but what I find happens is that things that are your everyday life, you assume is everyone's. You assume that, well, I know that not everybody does what it is I do, but you tend not to think about them. Like I might do something and not even think to myself that "Hey! This is not how a normal person would be doing this" but this is the way I can do it. And while I can still do it, I want to still do it. When

you are doing anything, I find that...afterwards, I sit down and I do think that "Gee, I could never see anyone else do it the way I do it" (respondent #8).

Normal can also refer to symptoms. For Jamie, "everything returns to normal" when her symptoms disappear (respondent #6). Mr. Collins refers to it another way. He explains the difference between how a tired MS person feels compared to a normal person:

...because you don't really know what your stamina is. When you get tired, you get very, very tired. Literally you can't put one foot in front of the other if you get tired enough, which a normal person doesn't have happen. Yes, they get tired and slow down, but I stop (respondent #7).

Lastly, normal can refer to maintaining previous patterns before a diagnosis, or changes in one's health. Judy says that "I am still trying to do all the things I used to do, and I am going to continue to do that as long as I can" (respondent #10).

The term disabled is perhaps the hardest term to define. David was the most articulate in defining disability versus ability.

Well disabled means not able. That you are really, it is sort of like a permanent thing, it is a fixed thing. And uh, I believe that people who have disabilities, just have to work around them, and compensate in some way, but work around them. As opposed to being disabled, you are just not capable. You know, I have a disability, and in fact, I prefer the old term handicap, of having a handicap, being handicapped, than the whole 'disabled' term. I know there are so many terms that have come out through the years. There is physically challenged, and I don't like that either, but you know it is sort of trying to give a softer way of saying that you have a limitation, or a, ...I don't think there is any good way to really do it. But more important than that, it is a person's mental attitude to the words that are used. If someone tells me that I am disabled, well, you know, I just think, well that's not perhaps a very good term, but I don't take it to heart. Whereas I know that with some people who have disabilities, it does...you're disabled, you're incapable. Able is by using what you have got. And, and uh, ...the average person, the average human being is using approximately, it is guessed at, as being between 5 and 10% of their mental potential. That's disabled. That is a disability. If anything, my main goal in life is to see if I can raise my own level of mental

disability to as much as I can. So to me, what is abled, is people who would be using their full potential, full mental, physical and spiritual potential (respondent #5).

As we can see, for David, disability is when you are not able or capable to do things. But he dislikes this connotation. For him, it is just something that he has to work around. It does not define who he is. Another respondent sees disabled as reflecting “a physical impairment” (Bubbles, respondent #9). For Judy, disability refers to her walking and energy level. Her role model is her grandson, because it has put ‘disability’ for her into perspective:

I am certainly not disabled, not mentally...physically I am disabled. My grandson has cerebral palsy and he is a remarkable kid. He is a fighter. He and I have a really good connection...and he is my power of example. When I saw this little thing and the way he struggled...now his disability...he hasn't got any more disability than you do, because I think that as long as you are positive in your mind, but sure he is disabled as far as walking, and he is even walking now. He is a real miracle kid. But to me, it (disabled) only means that as long as you have a good mental outlook, you are only as disabled as far as your brain, as far as your body. If you can't walk, you can't walk (respondent #10).

Again, disabilities seem to be more like mobility limitations. They tend to be something physical rather than anything else. Some respondents even use their mobility aids to serve as a visual tool to others to show that they are disabled and needing assistance in cases of emergency. This is the case for B.L. who uses her walker in any new situation to let others know that in case of a fire or something, she is someone who would need some help in getting out.

These terms have not been defined exactly as they would have been if such definitions were coming from the literature and were being imposed. However, by viewing

these terms through the eyes of the respondents, it makes it easier to contextualize their lived experiences.

It has been written that “lives are lived through time; they are also lived in place and through space” (Pratt and Hanson, 1993, p.30). The role of space and place in shaping the experiences of people is very much a function of circumstance as well as the stage in a person’s life course (Monk and Katz, 1993). With this focus in mind we will turn to the nature of chronic illnesses, and specifically to Multiple Sclerosis.

MULTIPLE SCLEROSIS

Multiple Sclerosis (MS) is a chronic disease that can manifest itself in two forms. The first form is marked by periods of attacks or exacerbations followed by periods of remission. The second form is chronic progressive to which there are no periods of remission. The way in which a person with MS may deal with his/her social and spatial environments is very much dependent on the type of MS, as well as where s/he may be along the disease trajectory. This division of types of MS is very simple. It will be discussed in greater detail in Chapter 4, where specific examples from the respondents will be used to highlight subtle differences.

The Bio-Medical Realities

MS is a disease of the central nervous system which is very unpredictable. Its unpredictability lies in the fact that it can remain relatively benign, become somewhat disabling, or totally devastating. During an MS attack, inflammation occurs in various areas of the central nervous system in random patches called plaques. This process is accompanied by loss of myelin, a fatty covering that insulates nerve cell fibres in the brain

and spinal chord and facilitates the transmission of messages between the central nervous system and the rest of the body. When myelin is damaged, neurological transmission may be slowed or blocked completely, leading to diminished or lost function (Internet: <http://aspin.asu.edu/msnews/ms1.html>).

Symptoms may be mild or severe, and their duration may be long or short. Most MS patients at some point experience numbness, muscle weakness, loss of feeling in their extremities, and difficulty with coordination and their balance. For those with chronic progressive MS, the course of the disease is unrelieved by remissions. MS tends to initially affect people anywhere from age 20 to age 50. Women are more likely to develop MS than men, and Caucasians more than others. Definitive tests for the diagnosis of MS are still unavailable. Physicians use a variety of tools to rule out other possible causes through the use of magnetic resonance imaging (MRI) and computerized axial tomography (CAT) scans before arriving at a diagnosis of MS. Prior to these technologies, diagnosis was much more difficult (Ibid).

These are the bio-medical realities of MS. Physicians do not know what causes MS, and they presently have no cure for the disease.

The Social Realities

MS first affects people often when they are in that stage of their life where they are developing their careers, raising a family or both (Dyck, 1995). These individuals have already defined their identity, established social relationships and have determined, to a certain degree, the pattern of their life course (Brooks and Matson, 1977, 1982). After a diagnosis of a chronic illness, such as MS, all of these earlier conceptions may have to be

reconstructed (Fife, 1994; Garro, 1994). Bury (1982, 1991) refers to this process as biographical disruption, wherein it brings the meaning of the illness to the individual into context, prompting the individual to deal with the disruption, in place. There are three biographical disruptions due to chronic illness. First, there is a disruption of the taken-for-granted assumptions and behaviours of everyday life. Second, there is a period of re-thinking or reconstructing a person's self-concept and biographical course of action. Third, there is a response to the disruption which involves a mobilization of available resources (financial, emotional, and social) to cope with the changed reality. In any and all of these stages, an individual may experience a loss of self and self-identity (Charmaz, 1983).

For many MS sufferers, the period leading up to the diagnosis is fraught with uncertainty and the quest for a diagnosis often leads to a 'medical-merry-go-round' -- that is, the patient goes from specialist to specialist and is subjected to test after test -- (Cunningham, 1977 as cited in Robinson, 1988). This pattern is not uncommon with the diagnosis of any disease. In fact, some have argued that people routinely monitor their physical and emotional health whereby abnormalities or deviations in these areas are compared against past experiences. Only when the deviations are interpreted as serious, will a physician, or physicians be consulted (Mechanic, 1995a; Yates, et al, 1993). It is common for a diagnosis to be met with relief, where ultimately, sufferers "know" what is wrong. There is finally legitimization to their complaints, which in turn removes any negative labels like 'neurotic' or 'hypochondriac'. Grief, anger and fear are also common responses (Robinson, 1988).

In dealing with the diagnosis, people are forced into a period of adjustment and coping. In fact, coping continues throughout the disease trajectory. Individuals develop coping strategies to avert the breakdown of close social relationships, among both family and non-family individuals (Sauerborn, Adams and Hein, 1996). While these same strategies may not be present among individuals or people without family, strategies are still developed to avert the breakdown of social relationships. McColl, Lei, and Skinner (1995) distinguish between social support and coping as mechanisms for dealing with the stress of a new situation. Social support and coping consists of similar behaviour, where the difference lies in the fact that coping is initiated by the individual and social support is initiated by others. They argue that social support helps more to effectively reduce the stress of the situation than does personal coping. Pearlin and Schooler (1978) agree with the importance of social resources and support, but give equal importance to the psychological resources of the individual affected (e.g. personality characteristics, attitude).

COPING AND CHRONIC ILLNESS: CONCEPTUAL FRAMEWORKS

With the exception of Graham (1989), major conceptual frameworks which examine how people with a chronic illness, such as MS, cope with their spatial environment, are largely absent. Graham's framework will be discussed in a moment. First, however, it is necessary to raise two other conceptual frameworks, one which specifically deals with MS, the other which looks at chronic illnesses in general, because they are characteristic of the manner in which such research is approached. The two frameworks are largely the same, although different terminology is used.

The first of these conceptual frameworks is posited by Brooks and Matson (1977, 1982), and looks specifically at MS. There are four stages to this framework: denial; resistance; affirmation; and integration. The denial stage is largely self-explanatory. Individuals conceal symptoms, refuse help and hold onto previous lifestyles and habits. The resistance stage involves a conscious search for cures or treatments. People are still reluctant to accept help, because to do so is an admission that something is wrong. Nonetheless, they do make some changes in their lifestyle to accommodate the illness. This stage also involves a heavy education process where individuals learn as much as possible about the disease and what they can expect. The third stage, affirmation, involves an acceptance of the disease, where individuals grieve for their former self. They begin to re-order the priorities in their life, learn to accept help from others, and start to publicly talk about their disease. The last stage, integration, is where they learn to live with the disease. They know it is present, but try not to focus all their energy on it. They accept help when needed and direct their time and energy to other matters.

The framework by Radley and Green (1987) is slightly different. They too divide their framework into four modes of adjustment, but along an axis, as shown in Figure 2.1.

Figure 2.1: Modes of Adjustment to Chronic Illness

Source: after Radley and Green (1985), in Radley and Green (1987)

Three of these four modalities recur frequently in the description of peoples' adjustment to chronic illnesses, the exception being secondary gain. Secondary gain occurs when people withdraw from social participation due to their illness, but enjoy other benefits from the illness in terms of pursuing other activities. In other words, these individuals can:

- (i) ...spontaneously identify compensations related to their condition (ii) make use of the time which illness (sic) may have thrust upon them (iii) are able to enjoy being in a dependent relationship to others (iv) experience benefit from giving up work or social duties as a result of illness (v) enjoy the relative privacy and decrease in social contact which being ill might necessitate (Radley and Green, 1987, p.190).

The remaining modalities are more straight forward. In brief, active-denial occurs when individuals with an illness continue to pursue the same activities, regardless of their illness. These people are seen as 'resisters'. Resignation occurs when people give into the disease and grieve for their former self. Last, accommodation occurs when individuals integrate the illness into their lives, and pursue modified goals. Here, individuals fight the disease and try to maintain a lifestyle of "expressive of normality" (Ibid., p.188). This form of behaviour is distinguished from active-denial. In both instances, individuals are resisting the disease and trying to maintain as much of their former life as possible. However, accommodation implies that these individuals have accepted the realities of the disease and live within their limitations, whereas when they are in active-denial, this does not occur. For those who experience active-denial, the disease is not part of their reality.

There are several problems with these two frameworks. At a conceptual level, it is difficult to determine that people with a chronic illness follow one particular strategy over another (Russell, 1989). People adopt particular strategies based on the point at which they are along the disease trajectory, and based on whether they are overtly feeling the effects of the disease or not. Robinson (1988) argues that of the four main categories presented by these kinds of frameworks, most tend to follow the resistance strategy, as in Brooks and Matson, or the active-denial modality of Radley and Green. However, Robinson argues that this could be the case because the appearance of fighting the disease is a much more socially accepted form of behaviour.

At a methodological level, these frameworks are questionable. Both employ quantitative techniques using closed questions. Brooks and Matson use statistical analysis

to develop their framework on a sample of 174 respondents. Radley and Green, on the other hand, develop a framework to use in investigating a wide variety of illnesses. They recognize the limitations, and indicate that it is a start in the right direction. However, their framework consists of several closed questions where they present respondents a particular modality. The method allows for 'qualitative' data by encouraging respondents to expand on their answers — which is often difficult when presented with primarily closed questions. It is through this elaboration of responses, that a not-yet-clear scoring method is conducted, determining whether or not the modality that was offered, was accepted or rejected. The questions themselves are very leading, and are not really as conducive to getting at the whole picture as other qualitative techniques.

Fischer (1994) notes that interview questions which try to direct the respondent, as is the case with Radley and Green's model, can lead to the problem of self-censorship. Respondents may choose not to reveal certain aspects of their lives, trying to present themselves in the most positive light, or they will try to answer the question in accordance to what they think the researcher wants to know. Thus, for Radley and Green's model, where they present modalities for acceptance or rejection, the respondents may simply try to give the researchers what they think they want. Moreover, when the research is structured around leading questions, then the researchers are not getting directly at the lived experiences of the researched where meaning and contextualization is created (Weiss, 1994; Jaffe and Miller, 1994; Keith, 1994; Kaufman, 1994; Garro, 1994; McCracken, 1988; Eyles, 1988; Jones, 1985). Eyles and Donovan (1986) note that it is critical for the research methods to get at how people perceive and act in the world.

There is another problem with these two frameworks. There is a methodological weakness in MS related research which has a tendency to treat people with MS as a homogenous group — i.e. that they all follow the same disease patterns and experiences (Evers and Karnilowicz, 1996). This same argument could also be applied to people with other chronic illnesses. Chronic illnesses and disabilities affect people differently, and they do not all progress in the same manner. Moreover, the kind of people who agree to participate in these types of psycho-social studies characteristic of Brooks and Matson, and Radley and Green, are likely not representative of the population affected by whatever chronic illness is under study. Schwartz and Fox (1995) found in their study that women, Caucasians and unemployed people were over-represented in psycho-social study samples of people with headaches, MS, pain, physical disorders and disabilities, other chronic illnesses and so on. They argue that “one of the most important limitations of psychosocial clinical research has been the possibility that people self-select participation in such an intervention” (1995, p.359).

In my own research, respondents did indeed self-select participation. And, due to the modal characteristics of people who are affected by MS (female, Caucasian), the majority of my respondents were women. All but one respondent was Caucasian. The majority of respondents were not working. Self-selection is less of a methodological weakness for my research because this research is not making claims to be representative of the entire MS population.

One final potential methodological weakness of these types of studies needs to be recognized. This lies in the question of who has the power to name. Zola (1991) argues

that over the years, many 'liberation' and 'rights' groups have struggled to change the language used by the dominant group. For minority groups, the power to control what they are named was one of the first battlegrounds, especially in turning a negative label into a positive one. However, for groups with disabilities, this is not as easy. For example, feminist groups can shout "Sisterhood is powerful" but how can negative labels for people with chronic illnesses or disabilities be used positively. It is not as though they would yell "Up with Multiple Sclerosis" or "I'm glad I had polio!" (Zola, 1993, p.168). Moreover, minority groups are part of a recognized subculture and hence, develop certain norms and expectations. People with chronic diseases or disabilities are not similarly prepared and are "socialized into the world of the 'normal' with all its values, prejudices, and vocabulary" (Zola, 1993, p.167). In other words, people with disabilities are not recognized as a subculture like a minority group. Consequently, they must adapt within an environment that has been constructed for the 'healthy' person.

Hence, whoever has the power to name, controls much of the relationship between the researcher versus the researched. Thus the way in which some frameworks can interpret respondents' experiences and actions by labeling them as one category or another, has the power to iron out differences. This can be seen in both Brooks and Matson and Radley and Green's frameworks.

While it is not possible to resolve these methodological difficulties, it is important to be aware of them.

Coping and Chronic Illness: A Framework with a Spatial Twist

Graham (1989) in her research on MS, draws attention to one of the oldest concepts of good health: homeostasis. Homeostasis is the balance, harmony or equilibrium we try to maintain in order to feel comfortable in situations. For people with MS, Graham argues, that prior to MS people could likely: tolerate extreme temperatures with little complaint; handle the stress and work of shopping for major holidays without serious effects; and/or manage working long hours when necessary without feeling like you were 'running on empty'. However, once MS develops, these all change. The "area" in which a 'normal' person feels comfortable and healthy is much larger than the same "area" for most people with MS. Graham (1989, p.198) writes "[i]n other words, what will maintain homeostasis in a healthy person is not what will maintain homeostasis in someone with MS." Figure 2.2 outlines this concept of homeostasis.

Figure 2.2: Areas of Homeostasis

Source: after Graham (1989)

As a consequence, people with MS must prioritize events and activities in order to maintain homeostasis. They have to take MS into account when they determine everything from the type of work they can handle, how they get around, in what kind of place they live and where, down to where they might go on holiday. The majority of people with MS are seriously affected by extreme heat, over-exertion, stressful events, over-tiredness and hunger.

Dyck (1995) in her study on women with MS found that many could no longer handle the stress of remaining in the workforce. These women were also finding that their

capacity to work within the home was curtailed. Some of her participants expressed that they felt the need, or were planning, to move into more accessible housing which would allow them to continue with their 'familial' role as best they could. Within the home, a restructuring process also took place. At the level of physical space, furniture and household equipment was rearranged to facilitate its use by these women. At a social level, many women employed strategies of delegating household tasks to others, or modifying their pattern. This might involve pacing their tasks over days or weeks, relying more on help from family members or bringing in a house-keeper or using government home care.

These same patterns are also expressed among others living with a different chronic illness, or are simply affected by diminishing health through age. Golant (1994) notes in his research on the housing needs of the elderly, that this group of people experience varied levels of decreased abilities. They have difficulty obtaining goods and services, and have greater difficulties accessing their dwellings or the facilities and services in their community. Rowles (1986) argues that as we age, we become more spatially fixed to a geographical life space that is both personal (i.e. the home) and environmental (i.e. the neighbourhood/community).

CONCLUSION

This chapter has outlined many of the issues that are relevant to the manner in which this research is being approached. The conceptualizations of space developed by geographers, and how this has been thus far applied in health related research were discussed at length. Equally important has been the examination of how research has been

approached in terms of dealing specifically with people who are affected by a chronic disease or disability. It has been emphasized that this research is not representative and will not be arriving at any definitive conclusions as to how respondents view their spatial environment. Rather, its intent, as identified in the research questions of Chapter 1, is to look at whether the conceptualizations of space, as developed by geographers, are reflected in the lived experiences of the respondents. Through this examination, it will be possible to identify, at a preliminary level, if such a spatial awareness exists. In addition to this, it will be possible to outline the types of strategies that people use to construct their space in light of any potential barriers or constraints that may be present. The next chapter describes the research process designed to investigate these themes and questions.

CHAPTER 3 - THE RESEARCH DESIGN

INTRODUCTION

The intent of this chapter is to outline the methodology used in this thesis. The data from in-depth interviews with people who have MS have been analyzed using grounded theory. Grounded theory as a method will be reviewed. This will be followed by an examination of how respondents were identified, then contacted, and what procedures ensued. First, however, it is necessary to explain why I chose to use a qualitative method instead of a quantitative one, and why grounded theory was specifically chosen over other qualitative methods.

THE QUALITATIVE V.S. QUANTITATIVE DEBATE

Over the past few decades, many social scientists — human geographers included — have tried to raise their research to a level that is reflective of scientific principles: empirical, rigorous, verifiable, neutral, factual, to name but a few. This was achieved by adopting scientific realism as an epistemology which held a view of the world that is external and independent of the observer. Here, the neutral observer is able to test hypotheses and formulate theory based on numerically measurable evidence that is representative of a wider population (Levy, 1993). This is sometimes described as the-view-from-nowhere. The desire for quantification was especially strong in the 1960s and continues even today, largely out of a hope to raise social science from a ‘soft’ science, to a ‘hard’ science, akin to the natural sciences.

By the 1970s, some social scientists were breaking away from the discourse of quantification as a means of explaining and understanding phenomena. This break

represents what Thomas Kuhn would refer to as a paradigmatic shift. Kuhn is credited for having introduced 'paradigm' in his 1962 work, *The Structure of Scientific Revolutions*, although no clear definition of the term emerges from his work. Essentially, a paradigm is a "conceptual framework that reflects a set of values and beliefs which are recognized by a community (say, scientific) as being common to all individuals in the group" (Levy, 1993, p.236). The paradigm allows the group to ask legitimate questions about the world and helps formulate the appropriate techniques to answer those questions. However, once enough of these principles are called into question, a paradigmatic shift can occur where a new set of values and beliefs are held in common by the challenging group (Johnston, 1983). These shifts are usually inter-generational. In contemporary social science, they may be quite deliberately created as a means of achieving power within an enterprise increasingly obsessed with such a goal.

Consequently, social scientists were dividing themselves into two major groups: followers of quantitative and qualitative 'science'. Social scientists who were arguing for the use of qualitative techniques, were arguing that quantitative techniques were inadequate to explain why certain phenomena behaved as they did. Qualitative social scientists tended to adopt a constructivist epistemology, which holds a world view that knowledge is socially constructed and reconstructed. Such knowledge can not be independent of the observer (Levy, 1993).

Since this split in epistemology, quantitative and qualitative researchers have been arguing the merits of their respective methods as being the only appropriate methods for undertaking analysis. Quantitative researchers argue that their methods are closer to 'hard'

science. These researchers try to recreate the ‘laboratory’ setting of natural science by conducting studies that are representative of a wider population under study. Through the rigors of statistical tests, computer modeling, reliability and validity tests, these researchers are able to make generalizations about the phenomena. Within such studies, there is a clear division between the researcher and the researched which reflects more a fact finding mission than a collaboration.

In contrast, qualitative researchers can not make generalizations about the wider population under study, because they do not regard their “respondents” as being a sample which needs to be representative. Moreover, the relationship between the researcher and the researched represents more a partnership or collaboration than anything else.

Qualitative techniques collect data in primarily three ways:

- (1) *in-depth, open ended interviews* with individuals or groups;
- (2) *direct observations* consisting of detailed descriptions of people’s activities, behaviours, actions and interactions;
- (3) *written data*, usually from documents yielding excerpts, quotations or entire passages from organizational, clinical or program records; personal diaries; official reports or publications; and open-ended written responses to questionnaire surveys (after Paton, in Baum, 1995, p.463-64).

These data are not tested using statistics, regression models, and so forth. Nor do they answer the same kind of questions. Quantitative research questions often seek to answer: how much; how many; how often; for example. Qualitative researchers seek to uncover a different kind of explanation in terms of: why did that happen in that context; how is power exerted; what processes are more effective; and so forth (Baum, 1995).

Common sense should dictate that a researcher should use whatever method, or combination of methods, is appropriate to answer the research questions. This key

point seems to have become lost in this debate. Instead of assessing the merits *of using* qualitative over quantitative techniques, we should be asking when is it more appropriate *to use* qualitative or quantitative techniques. Moreover, epistemology should not be confused with methodology. A scientific realist should be able to ask questions which require the use of qualitative interview techniques in order to properly access data to be used in conjunction with other data that may be statistically analyzable. Similarly, a social constructionist should be able to ask 'how much' and 'how many' type questions, which may require the use of a representative survey of respondents, using closed questions, to be used in addition to their other qualitative data.

However, this understanding seems to be slow in coming. For example, many public health researchers have rejected some approaches to research because particular methods are associated with epistemologies that they philosophically do not accept. Baum (1995, p.460) writes: "[i]t seems that in confusing ideological positions with methodology there is a danger public health researchers may throw the epistemological baby out with the methodological bathwater."

In my research, I am interested in seeing if the conceptualizations of space that are put forward by academics are reflected in the lives of real, everyday people, who must live with a chronic disease. This is not something that can be easily quantified. It might be possible to, one day, raise the level of analysis to a quantifiable level once enough research at the qualitative level has been conducted to fully understand the processes and relationships that exist. To this end, I chose to use the qualitative method of grounded

theory to address my research questions and analyze the data, although any number of other qualitative methods could have been used.

The processes for analyzing data collected from qualitative methods are all very similar. In terms of analyzing interview data, each involves a process of coding the data, developing linkages between categories that arise from the data, integrating the categories and sub-categories in a manner that shows the interrelationships therein, and so forth — i.e. they are essentially empiricist (Weiss, 1994). Some qualitative methods require an interview guide to help structure the interview process, whereas others argue for an itemized list of topic areas that are to be covered. Some qualitative methods seek to use the generated data as a means to help strengthen and rebuild weaknesses in existing theory, whereas others look to generate new theories which arise from the data (Burawoy, 1991b).

This research adopted a modified version of grounded theory for one simple reason. One of the principles of grounded theory is that it does not presuppose an explicit underlying theory to help shape the analysis of the data. Rather, it allows the researcher to analyze the data based on categories that are developed from the data itself, as opposed to categories which stem from a pre-existing theory. I do not have a pre-set theory that I am trying to test or strengthen. Instead, I am interested to see if the conceptualizations of space that geographers put forward in their theoretical arguments are reflected in the lives of real people with a chronic illness. These issues will be discussed at greater length in the next section. Moreover, the next section will outline how my analysis varied from a strict interpretation of grounded theory.

GROUNDING THEORY

Grounding Theory was developed in the early 1960s by Glaser and Strauss (Strauss, 1987). It was developed at a time when formal theory in sociology was becoming too distant from the world of real people (Charmaz, 1990). It was also developed at a time when qualitative methods were not being taken seriously as a means for undertaking legitimate analysis. Glaser and Strauss wanted to devise a system for the purposes of generating theory in order to demonstrate "that theory development was not the prerogative of a few leaders at elite establishments who construct deductive systems of thought based on a priori assumptions and concepts removed from reality" (Burawoy, 1991c, p.275). Grounding theory was to become a method for problem solving using field observations and interviews as data collecting techniques (Strauss, 1987).

Glaser and Strauss wanted to set up a framework which would bring the researcher closer to the process, in the sense that the researcher would enter a collaboration with the researched, without approaching the relationship with a pre-conceived idea of the kind of data s/he wanted to collect. The purpose was to move qualitative research away from simple analytic description, as it had been at that time, to conceptualizing processes and generating new theories with greater scientific rigor. Grounding theory is based on an underlying premise that social phenomena are inherently complex. As such, one needs a methodology that emphasizes the need "for developing many concepts and their linkages in order to capture a great deal of the variation that characterizes the central phenomena studied during any particular research project" (Strauss, 1987, p. 7).

The aim of grounded theory is to develop an understanding of how a person constructs his/her 'world'. By developing analytic and conceptual constructs from the data, a researcher can begin to analyze the resulting categories and relationships between the categories with the aim of generating hypotheses about the data which will form the building blocks (what Strauss refers to as theoretical categories) of the developing theory. With each theoretical category, the researcher reduces the categories further into a series of more distinct or explicit categories, all the while raising questions, hypothesizing and developing linkages (Strauss, 1987). The recursive processes seek to allow the structure of a theory to emerge from the raw data.

Uncovering these 'building blocks' starts from the raw data of every participant to see how each constructs and gives meaning to their world. Developing theory from the ground up, the data itself, through the lived experiences of each participant, is what shapes the researcher's approach to data collection and analysis. This method stands in contrast to the logico-deductive approach which derives hypotheses from pre-existing or established theories, and which structures the research with the intent of verifying or refuting the hypotheses, and by association, strengthening or weakening the theory. Grounded theorists check, refine and affirm their ideas, but are not limited by a pre-existing hypothesis (Charmaz, 1990).

Grounded theory differs from other qualitative methods in that it does not wait until after all the data has been collected to begin analysis. Analysis should begin from day one. This allows a researcher to conduct theoretical sampling to test generated hypotheses. Theoretical sampling refers to a process whereby a researcher seeks to sample

a population, event or activity based on ideas that are emerging from his/her early stage of analysis and theory development. This early stage of theory development may begin with the researcher's own thoughts about how s/he might feel about a particular situation, and then test to see if this occurs in the study group. Similarly, hypotheses may arise from the researcher's own experiential data. For example, if the researcher thinks, 'something like this happened to me and I felt like....I wonder if this is true for the study group?' The intent through theoretical sampling is to make connections by collecting new data (Strauss, 1987). Charmaz (1990) however, raises the point that she delays this process until after she has a better understanding of the situation. Consequently, she uses theoretical sampling much later in the analysis to help shape the data collection rather than simply amassing general data.

Although there are no hard and fast rules governing this type of analysis, there are some guidelines (after Strauss, 1987). The researcher codes the data according to the four aspects of the coding paradigm. The first aspect of the coding paradigm is to identify the *conditions*. Conditions are easy to find. Respondents refer to them specifically, or the researcher may look for word cues such as: "because", "since", "as", "on account of", etc. The second is to identify the *interaction among the actors*. This too, is easily identified in the data, whereby the researcher is looking at the interactions occurring between, and among, the actors. This aspect of the paradigm is not to be confused with the third, *strategies and tactics*. Strategies and tactics are how the participants respond to other people and their situations. The last aspect of the coding paradigm is identifying the *consequences*. The consequences can be found through phrase cues like: "as a result",

“because of that”, “the result was”, “the consequence was”, “in consequence”, and so forth (Strauss, 1987, pp. 27-28).

The data will undergo three sets of coding procedures, although the researcher may subject the data to any one of these coding procedures several times throughout the research process. The first coding procedure is *open coding*. Open coding allows the researcher to engage the data (written, oral or other), line by line, at an early stage in the analysis. It allows the researcher to ‘ask’ the data a series of questions in terms of what study the data are pertinent to, what is the main story being told and what do these incidents indicate. The researcher is to analyze the data minutely, interrupting the coding to write theoretical memos frequently. These theoretical memos are simply the researcher engaging the coded categories, in terms of what is being said, and asking, “to what else could the respondent be referring”. In other words, the researcher is raising questions, hypothesizing and trying to answer questions based on what is contained in the text. This procedure is repeated several times throughout the research process. The second coding procedure is *axial coding*. This level of analysis tends to occur later in the process. It enables the researcher to conduct an intense analysis around a single category at a time in terms of the paradigm items (i.e. conditions, interactions, strategies and tactics, and consequences). This allows the researcher to develop a cumulative knowledge about each category and how it may be linked with other categories. The last coding procedure is *selective coding*. This allows the researcher to code systematically, looking only at those codes which are related to the core codes. The core categories appear frequently

within the data and encompass the maximum variation in the analysis. The coding procedures continue until the categories are saturated. That is, no more linkages can be made.

Charmaz refers to much of this in her 1990 review of grounded theory as a method, and highlights a few key points. She argues that it is important for researchers to take their codes or terms and raise them to the level of a concept. Here, the wording of a conceptual category is important because “the researcher specifies its properties, notes the conditions under which it arises, relates how it changes, describes its consequences, and ultimately, specifies its relationship to the other conceptual categories” (Charmaz, 1990, p.1168). In other words, the conceptual category takes on a more sophisticated level of analysis because it is no longer merely a descriptive topic. She also argues that it is necessary for researchers to compare data with data, which means “comparing different people’s situations, beliefs, behavior or accounts of the same type of event or issue” (Ibid.).¹

Deviations from a Strict Interpretation of Grounded Theory

Not all grounded theorists strictly follow the guidelines as they have been set out above. Nor was it ever Strauss and Glaser’s intent to set up a framework that was so rigid that flexibility was not permitted. For example, Charmaz (1990) argues that grounded theorists often follow a social constructionist approach which acknowledges that people’s experiences are the result of outcomes of social interactions, negotiations and power.

¹ Charmaz expands further on this idea, however, it is in reference to research where more than one interview or period of observation is occurring with the same respondent.

However, not all users of grounded theory follow this approach completely. Charmaz, herself, uses grounded theory following a symbolic interactionist approach, tempered by Marxism and phenomenology. Symbolic interactionists tend to look at how meanings are ascribed to the self like any other object. Phenomenology helps to correct this because it considers the consciousness and emotions of respondents. Marxism looks at underlying structures and the processes at play. While it is not my intent to go into these conceptualizations any further, they had to be mentioned to show that there are other approaches when using grounded theory, and that room exists for different interpretations.

In addition, Strauss and Glaser argue that analysis of the data should begin as soon as some data exist. Weiss (1994) argues that this view is not without its merits but in practice, it is not always possible. External forces beyond the researcher's control can impede the process. Examples of such forces include the time constraints involved in setting up the interview schedule, conducting the interviews themselves, waiting for transcripts, and so forth, that immediate analysis becomes almost impossible. Moreover, the investigators can always take comfort in the knowledge that once the interviews have been completed, there will be uninterrupted weeks or months for the data to be analyzed.

The way in which I modified my use of grounded theory will be discussed in a moment. First, however, it is necessary to look at some of the critiques of grounded theory.

Critique of Grounded Theory

Grounded theory is not without its critics. One of the principles of grounded theory is to delay consulting the existing literature and theories on the topic under study.

The purpose of this is to allow the researcher to approach the data with as few as possible preconceived ideas. Glaser and Strauss argue that this is necessary to assure that emerging categories from the data will not be “contaminated by concepts more suited to different areas” (as cited in Burawoy, 1991b, p.10). Moreover, by looking at the literature after the data has been collected and analyzed helps the researcher to develop other ways of exploring and analyzing the data (Charmaz, 1990). Nevertheless, this does not mean that researchers are completely ignorant of the existing literature — that is, researchers do have some point from which to formulate their research problem, questions, and so forth. For many, this delay in consulting the literature and engaging with theory is unacceptable.

Grounded theory, in making generalizations through induction from the data, seeks to find what respondents have in common in order to generate new theory from the ground up. Thus theories are advanced in a movement towards greater generality that applies across time and space (Burawoy, 1991a). However, this drive for ‘quantity’ runs the risk of excluding the unique, and therefore could miss potential interrelationships with conceptual categories (Burawoy, 1991c).

Critics also argue that grounded theory “treats discovery as a stage prior to verification” (Emerson, 1983 as cited in Charmaz, 1990, p.1164). Charmaz (1990) argues that Glaser and Strauss have done this because they are looking to develop new lines of theoretical thought. Moreover, grounded theory is very different from other qualitative methods in that it does not approach the data with a pre-conceived theoretical position. Consequently, its merits or failings should be judged based on its own internal process, something which Charmaz argues that its critics do not often do.

Charmaz, however, does outline several potential weaknesses with the grounded theory method. For one, it is impossible for anyone to remove all of their preconceived ideas when engaging with research participants and the data. A researcher with a particular background will tend to build in “special data-gathering questions, based on their assumptions and substantive interests” (Charmaz, 1990, p.1165). Researchers can also develop a premature commitment to categories and hence, miss key points raised in the data. Moreover, the process of coding the data and devising categories often produces unnecessary jargon in labeling the conceptual categories. Last, there is often an unclear use of the terms theory, category and saturation.²

Grounded Theory as Used in This Research

These critiques of grounded theory serve as a useful introduction to my own modified use of grounded theory. I will only briefly mention the ways in which I deviated from a strict application of grounded theory. These issues will be raised in greater depth in the next chapter when specific examples from the interviews will be used to highlight the reasons for these deviations.

Interviews were conducted with a total of fifteen respondents who have been diagnosed with Multiple Sclerosis. These interviews were taped and transcribed verbatim. A modified version of line-by-line analysis was conducted. Rather than analyzing every single line, sentences related to the same idea were analyzed as a whole. Moreover, in examining the data from these interviews, I did not exclude relevant examples that were only shared by a few respondents. In other words, the lived experiences of the majority did

² For a more detailed debate on this, refer to Charmaz, 1990.

not form the basis of the generalizations that are made, as they relate to the fifteen respondents, in the next chapter. Last, it has already been mentioned earlier in this chapter that grounded theory was chosen specifically because it allowed for the research to be approached without being framed by a pre-existing theoretical framework.

However, my intent in using grounded theory is not to develop a new theory. Rather, I am using grounded theory as a method to discover if the conceptualizations of space put forward by geographers are reflected in the realities of everyday people. Grounded theory afforded the opportunity to approach the topic in as neutral a manner as possible, allowing the experiences of the fifteen respondents to shape the answers to my research questions. Grounded theory is not being used to test if such conceptualizations play a role in shaping the environment of these respondents because such an 'answer' is not being sought. The 'answer' that is being sought is to determine if geographers, in their conceptualizations of space, have a grounding in real terms. I freely admit that I will not be able to answer this question in a definitive or concrete manner. This research is not intended to be representative of the wider population of people with MS where concrete generalizations could be made. It is simply a beginning from which to engage in a debate that has not yet been resolved.

With these points in mind, it is necessary to turn our attention to how access was gained in order to collect the data for the thesis.

GAINING ACCESS

In order to uncover the meanings that respondents may assign to their situations, qualitative in-depth interviews were conducted. These interviews were taped and

transcribed verbatim. Interviews lasted approximately two hours each. These interviews did not follow a set questionnaire. Rather, topic areas, identified through the research questions, were defined before hand to help start the conversation with each respondent. From these initial beginnings, the interviewer was able to build upon the answers given by respondents in order to cover new ground and follow up upon what was said. Copies of the raw text of the fifteen interviews are available on disk through the Department of Geography and the Library at Carleton University.

The Study Area

The study area for this research is the Regional Municipality of Ottawa-Carleton.

Identifying Respondents: The Recruitment Procedure

Before submitting a thesis protocol to be considered by the Ottawa General Hospital's Research Ethics Board - a necessary step in order to carry out the research on people with MS - I met with the Director of the MS Clinic, Dr. Nelson. The reason for this primary meeting before submitting a proposal for ethics approval was simple: if the Director of the MS Clinic was not supportive of my research, then there was little point in seeking ethics clearance to interview potential respondents who attend the Clinic. Dr. Nelson was extremely supportive of the research. He drafted a letter of support for my application, and provided a cover-letter that was included as a letter of introduction in the information package that was given to all patients who were contacted to participate in the research. Copies of these letters and the information package are found in the Appendices (see Appendices A, B, and C).

In addition to providing a letter of support, Dr. Nelson also gave me permission to gain access to the postal codes from the MS Clinic active patient list through the MS Clinic Coordinator. These postal codes were used to determine if people with MS were spatially concentrated in certain areas of the city. If a concentration was found, the intent was to interview an equal number of people with MS concentrated in an area as well as people who lived in a more randomly distributed pattern. It was through this initial data that a concentration was found. This will be discussed in greater length in a moment. From this data, it was possible to set up a recruitment procedure that would allow me to gain access to potential participants specifically receiving a mailed out package as well as those who were contacted through Clinic Days at the hospital. These too will be explained shortly.

Once ethics clearance had been received by both the Ottawa General Hospital's Research Ethics Board and Carleton University, it was possible to collect the data. Letters from these two ethics boards are also included in the Appendices (please see Appendix D and E).

Part 1: The Mail Out

It was hypothesized that people with MS who live in areas of higher concentration in Ottawa-Carleton may employ different coping strategies than people with MS who live in a more randomly distributed pattern. This hypothesis was formed on the basis of earlier research on people with MS in Ottawa specifically (Bennett et al, 1977) and on the socio-demographic characteristics of people with MS in general (Aronson, Goldenberg and Cleghorn, 1996). In order to test this hypothesis, postal code data for Ottawa-Carleton

was obtained from the MS Clinic active patient list. This list held a total of 1030 postal code references. These postal codes were run through a Postal Code Conversion File for Ontario. Through a matching process, using MapInfo, 499 postal code entries were accepted as falling within the Ottawa-Carleton boundary. Map 1 shows the distribution of these postal codes in the Region.

In order to assess whether or not these 499 postal codes represented a concentration within particular census tracts, a location quotient was calculated. In order to calculate the location quotient, I first had to divide the number of people with MS by the total population within each census tract. This value was multiplied by 100 to create a percentage. This value for each census tract was divided by the ratio of the total number of people in Ottawa-Carleton with MS (as identified through the MS Clinic active patient list) by the total population for the area. This new value represented the location quotient for the census tract. In order to establish significance, the median value from the total of 157 census tracts was found. The median value of 1.18 was used as the minimum concentration level and all values below this were dropped. The new median value from the remaining 78 census tracts was found, at the value of 2.07.

Map 1: The Distribution of People with MS in Ottawa-Carleton

It was originally determined that anything twice this new median value (i.e. 4.14) would be considered as an area of concentration. However, this proved to be problematic. A doubling of the new median value left us with a total of 10 census tracts, of which 6 were found in rural areas of Ottawa-Carleton. In these rural areas, there is only one postal code for each census tract. Within a rural area, the postal code assigned is the postal code for the local post office. Thus, this would not represent a true concentration if, for a large spatial area, all of its residents used the postal code of the post office. In order to remove this false concentration, these areas were excluded from the mailed-out recruitment package. Thus only those non-rural census tracts which had a location quotient greater than or equal to 2.07 were included in the analysis. Of the total 499 possible respondents, 128 were selected for a mailing. This list had been compiled by the MS Clinic to assure confidentiality.

Of the 128 possibilities, the MS Clinic Coordinator narrowed down the list to 80 potential respondents who received an information package in the mail. The reason for this reduced number was twofold. First, the Clinic Coordinator removed all those potential respondents who were not cognitively able to participate in an interview. Only those people who could understand the implications of involvement and sign the informed consent form were eligible for participation. Second, due to financial constraints, an initial mailing of only 80 potential respondents was undertaken. If it was determined that it was not possible to find approximately 10 respondents through this first mailing, a second mailing, with the remaining names, would be sent. This proved unnecessary. From this method, a total of 20 people responded. Due to time constraints, not all could be

interviewed. Only 13, of the total 15 respondents, were interviewed from the mail-out procedure.

Part 2: Clinic Days

In order to test one of the original research questions, I wanted to recruit respondents who lived in areas of concentration, as well as those who may be more randomly distributed within the region. The intent was to determine if these respondents employed different strategies as compared with those who live in areas of concentration. To access this group of people, an information package was given to those who attended a MS Clinic day. These clinic days are held once a week, on a Monday, by appointment, at the Ottawa General Hospital. This method was less successful. To date, approximately 50 information packages have been given out, from which only 2 people have contacted the researcher.

It was originally hoped that anywhere from five to ten respondents would be interviewed using each of the recruitment methods. Given the lack of interest among the Clinic Day potential participants, it was decided that more people who were contacted by the mailing would be interviewed as a way of compensation. This forced a change in focus of the original research questions. However, the topic areas that were derived from these research questions were unaffected.

Topic Areas Covered in each Interview

The following topic areas were covered in each interview:

- ▶ The daily routine of participants;
- ▶ How participants relate to their environment (e.g. if MS has restricted some of their activities and how);
- ▶ Issues surrounding diagnosis;
- ▶ Reorganization/organization of the home (e.g. household tasks, shopping) or social activities (e.g. maintaining contact with friends, outside family members);
- ▶ Concerns, fears, coping with MS;
- ▶ If participants have moved as a result of MS, or if they have contemplated such decisions and why;
- ▶ Employment history;
- ▶ What respondents see for themselves in the future.

It is important to note that the order in which a topic area was covered varied for each interview. In many instances these topic areas were covered without external prompting by the researcher. Only the first and last topic area were routinely asked at the beginning and the end, respectively, of each interview. In addition to these topic areas, all respondents were asked to answer a series of set questions at the end of the interview. Most of these questions had already been covered in the conversation. The purpose of having these standardized questions at the end of the interview was for the ease of the researcher in order to briefly characterize the nature and type of respondents that participated in terms of their socio-economic status. These questions are listed in Appendix F.

Moreover, before an interview was started, the researcher explained how confidentiality would be assured and that the respondent could refuse to answer any question, or opt out of the process entirely, at any time. Respondents were also invited to provide me with the pseudonym by which they wanted to be known in the research report.

SUMMARY

In short, a total of 15 people were interviewed. Thirteen of these interviews were recruited by mail, whereas two were recruited on a Clinic day. Reasons for the lack of response through the Clinic day method can only be speculated on. These respondents were being approached at the time of their appointment. A recruitment package was attached to each patient file and delivered to the patient by the attending physician. Consequently, this approach may have seemed more intimidating and less personal than the mailed out recruitment package. The intimidation may have stemmed from the fact that it was their physician delivering the package. It was less personal because the package was not sent directly to them by name. Moreover, those receiving the package in the mail would have more time to digest the information. By contrast, those who received it during the Clinic appointment had more important issues to digest — that is their current state of health and what treatment or procedure they will follow next.

CHAPTER 4 -THE CONSTRUCTION OF SPACE

INTRODUCTION

It should be evident by this point that geographers' conceptualizations of space are neither simple nor conclusive. Space may be conceived as not merely a container of things. It is not a simple connection between two or more objects. It is not even easily explained by a myriad of interrelationships between objects or events, whether real or socially constructed. Space reflects all of these together, as well as independently, in a variety of possible combinations. Feminist researchers are skeptical of essentialist arguments that are based on biological differences. The same could be said about essentialist arguments that would make claims that everyday people conceptualize their spatial environment in one specific manner over another. Space is not inherently absolute, relative or relational, and we would not expect lay conceptualizations to favour one over the others. It is unlikely that non-geographers explicitly think about space at all. This is why we must deconstruct their activities and statements.

This thesis seeks to learn if the abstractions of space that are developed by geographers are reflected in the everyday lives of fifteen people with Multiple Sclerosis. However, it will not make any claims to the effect that one abstraction of space is favoured over another. Rather, it wants to determine, at a preliminary level, if the theoretical abstractions of space, developed by geographers, have a grounding in real terms. Other sub-disciplines of geography and the social sciences have argued the theoretical importance of examining space in terms of large macro structures which underscore such issues as: economic development; globalization; urban development and

decay; and power relations, to name just a few. It has also been described how people of different ethnic groups and cultures give meaning to their "space" through icons, traditions, mores, and history. Despite these gains, few have looked at how people with a chronic disease or disability construct their space at a more micro scale. We would expect people with a chronic disease or disability to construct their space very differently from how people, without these problems, construct space.

For example, a blind person does not relate to his/her environment in the same manner as a sighted person. A blind person cannot rely on landmarks as locational identifiers to get from point A to point B. By contrast, a sighted person in a wheelchair, can rely on such features, but may not be able to access the space once s/he gets there. For this person, there is a different barrier to overcome that may not exist for the blind person.

At a more complex level, a person may not be able to work because of an illness or disability. This person may be living off a disability pension which may not provide enough income to support house payments and other basic necessities. Similarly, because that person is no longer working, s/he is removed from those social contacts with fellow co-workers. If this person has no other source of support (family or friends), then the way in which s/he constructs and uses space will be different from a person, in an almost identical situation, but who has additional supports. Alternatively, two people with identical disabilities and problems, but who live in different housing environments, may not construct space in the same manner. The barriers that have to be overcome through the physical layout of a house will alter the strategies used.

In other words, people manipulate their environments using a variety of techniques to transcend barriers. There will be similarities among these techniques, but also many differences. We turn now to seeing how the fifteen selected people with Multiple Sclerosis in Ottawa-Carleton construct and use their spaces.

DEVELOPING THE SPATIAL ENVIRONMENT OF REAL PEOPLE

The grounded theory method seeks to develop theory which is generated by the data. While some have argued that by so doing, researchers put the cart before the horse, this is not the intent. Despite the claims made by grounded theory that it is theoretically neutral — i.e. does not impose a meta-narrative or macro theory on the analysis before investigation and testing — it is impossible for researchers to completely remove all bias in terms of the types of questions asked. Moreover, in analyzing the data, grounded theory directs researchers to look at the codes and categories of their line-by-line analysis to determine if there is some core category which is central to the integration of the growing “theory”. This core category would be evident in the majority of interviews, if not all. However, this concern with quantity in terms of the core category(ies) and the sub-categories ignores the unique. This is akin to the quantitative researcher rejecting data which skews the normal distribution of a phenomenon, or filtering out extreme values which spoil the fit of a trend.

These issues have already been raised in Chapter 3 and will not be revisited here in any greater depth than a simple restatement of them. However, it is important to reiterate that while this research followed many of the principles of grounded theory, it has also incorporated analytic techniques found elsewhere in qualitative research. Before it is

possible to engage the narratives of the interviews themselves, it is necessary to briefly look at the process which helped structure the analysis.

CONSTRUCTING THEMES FROM NARRATIVES: THE PROCESS

Type of MS

It is necessary to remember at the outset that people with MS are affected differently by the disease. Some are characterized by the attack/remission style of MS, whereas others are chronic progressive. In fact, the term “chronic progressive” is actually used more as a generic term. In specific terms, people with MS may be primary progressive or secondary progressive. Primary progressive MS affects a person gradually with no remission periods ever. Secondary progressive MS may show a person gradually worsening, but after a period of time, s/he returns almost back to the original state. For example, someone who progresses from needing a cane or walker to needing a wheelchair for a period of time before experiencing a remission and no longer needing the wheelchair, would be showing signs of secondary progression. Attack/remission MS is when a person is struck by a new symptom for a short period of time (days as opposed to weeks), but where the effects linger for several weeks before disappearing. These people may also have secondary type symptoms, such as fatigue, bowel and bladder problems, which are intermittent.¹ It is very possible for an attack/remission MS person to also experience secondary progression (Internet: <http://www.ifmss.org.uk/faqs/contents.htm>).

In this research, it is difficult to identify exactly what type of MS each respondent has unless s/he specifically named it as one form or another. However, individual

¹ This is not to be confused with Secondary Progressive MS.

respondents may indicate they follow a particular MS type, when in fact they show tendencies toward other types. For example, one respondent said that he experiences the attack/remission kind of MS. There are many lingering effects, of which one of them is that he must use a walking stick to balance himself. A discussion with the MS Clinic Coordinator at the Ottawa General Hospital showed that this person (as a generic not specific case) likely experiences the attacks and remissions, but is also affected by secondary progression which leaves him with a mobility limitation. Hypothetically speaking, he may never need more than just his walking stick or cane, although, by the same token, it could progress to a more aggressive level where his mobility is restricted even more (Personal Communication, April 7, 1997).

As further evidence that this “misconception”² exists, among the fifteen interviews, it was respondent number 10 who first specified that she had chronic progressive MS, not the attack/remission style. This leads me to consider several possibilities: 1) she was the first actual case of chronic progressive MS that I had encountered in the research; 2) she was the first to be so explicit, although others had referred to attacks, exacerbations and remissions, but showed unstated characteristics of progression; 3) some of the earlier respondents were not aware that, in spite of the attacks and remissions, they were also progressing — i.e. getting worse; or 4) I did not fully understand, myself, that other tendencies of MS could be present at the same time, and thus did not probe deeply

² “Misconception” here may not necessarily be that the respondent does not understand the exact type of MS s/he has, but that s/he may not have wanted to go into the specifics beyond the general label for two reasons: 1) s/he may not be fully aware that two different MS tendencies can be at play; and 2) s/he may not have wanted to confuse the researcher.

enough. The truth lies in a combination of these observations. In fact, it is not surprising that people with MS may not be aware that they can experience the attacks and the remission, and also be progressive. In the literature itself, most refer to MS as being characterized by attack/remission or chronic progressive. Few actually spell out the various types of progression that can exist, and how something can quickly develop in spite of the person's history with a relatively benign form of MS, which has been hardly noticeable in terms of affecting his/her life.

Hence, in analyzing the narratives of the fifteen respondents, I had to be aware that in spite of what was explicitly stated, or not stated, a respondent could show more than one tendency.

Identifying Patterns

It should be clearly understood by this point that depending on the type of MS that is present, people will relate to their space differently. Moreover, depending on where they are along the disease trajectory — that is, having only a relatively minor mobility limitation in terms of using a cane for support as opposed to being constantly in a wheelchair — they will identify different constraints in their environment. It has already been stated that this research is not intended to be conclusive. It is not representative of the wider population of people with MS. To achieve representativeness, the research would had to have been structured in a completely different manner, controlling for such factors as type of MS, disease trajectory, separating “minor” mobility limitations (e.g. cane) from “medium” (e.g. walker, scooter) and “major” (e.g. wheelchair) limitations, and so forth. However, the point was not to achieve scientifically representative results. Rather, the intent was to test,

at a preliminary level, whether or not real people view space in the same manner as academics when developing theoretical arguments. Through this preliminary level, it would be possible to develop hypotheses for further testing at a later date, where at that point, the aim may or may not be representativeness.

Not every research participant viewed space in the same manner. For example, Mr. Fredal only experienced some minor problems associated with the MS. He had been diagnosed only two and a half years ago, but the neurologists felt that the disease could have been present as far back as 1960. For him, there were no real or perceived barriers. His conceptualization of space was fairly straight-forward, if it consciously existed at all.

By contrast, Jamie has two different conceptualizations of space. When she is in a period of remission, she does not conduct herself any differently than normal, other than watching that she not over-extend herself. However, when she is experiencing an exacerbation, she may limit the number of trips she would take up and down the stairs of her parents' home. For example, to shower on the main floor, she would take all the things she would need (e.g. clothes, toothbrush and toothpaste) from the second floor down to the main bathroom so she would not have to go back upstairs. Moreover, for Jamie, no two exacerbations are identical. She experiences an exacerbation about once a year, and has done so for the last ten years. As a consequence, how she relates to her spatial environment will vary based on the nature of her symptoms at the time and the severity and length of the attack.

Similar examples can be found throughout the research, and it is not my intent at this stage to raise them. Rather, I want to underscore that differences exist among

individual respondents. In spite of these differences, there are enough similarities among the respondents that patterns can be traced regardless of the disease trajectory, type of MS, and so on. Figure 4.1 shows the thematic paths which lead to the different constructions of space for these 15 people. Not every single respondent follows these paths exactly. For some, the identified barriers may be more pronounced and long lasting. Note, however, that Figure 4.1 will not be presented until the end of this chapter. The reason for this is simple. There was a very intensive process which led to the construction of this diagram. It did not present itself immediately, and did not result from only one interview. Thus, in order to better understand the patterns identified in Figure 4.1, it is first necessary to understand how it was constructed.

Constructing Space - Based on the Experiences of 15 Respondents

Following the methods of grounded theory, each interview, lasting approximately two hours, was taped and transcribed verbatim. Specific questions were not asked, rather, several topic areas were covered whereby other paths were explored through the natural course of the conversation. In conducting an initial analysis of this data, I performed a modified version of grounded theory's *open coding*. Instead of always following a line by line analysis, I sometimes would treat a paragraph, or topic, as a whole. This would especially arise if the topic itself was not directly (or even indirectly) related to the issue of spatial conceptualizations. For example, one respondent spent a great deal of time talking about the difficulties she was having with her youngest son. While this was very germane to understanding how she was coping overall, it did not specifically feed into how she was manipulating her environment spatially. This is not to say that this part of our conversation

was not useful in developing the final diagram, but it played a less important role than other events. However, when matters were explicitly related to issues of space, a closer analysis was conducted.

Here is one instance where my method varied from grounded theory. As is the case with the grounded theory method, I was not approaching the research with a specific theoretical perspective. Nonetheless, I was not completely neutral. I was interested in looking at issues of space, in terms of its construction and its constraints in the lives of real people. There are many instances in which the respondents talked about the diagnosis procedure and how the diagnosis was delivered to them by the physician. Following a strict interpretation of grounded theory, this would have to be incorporated into the analysis because it was identified as important to the respondents by the respondents themselves. While this data would be very important to a sociologist, and was very interesting to me personally, it did not belong in the final product. Often, this type of data would arise as I was developing a rapport with the respondent, so that a feeling of mutual trust could be built, enabling me to probe more deeply into other issues.

After I had completed the open coding, I conducted a closer re-examination on my own initial analysis, within which several interview quotations were included, similar to the grounded theory's *selective coding process*. Here, I was interested primarily in spatial issues. I pulled out only those areas and categories which were directly related to conceptualizations of space, in terms of how it was constructed and constrained. For each respondent, I would try to divide patterns into those conducted in the home, and those conducted outside the home. This was not always possible because for some respondents,

such a division did not really exist. In such cases, it was possible to identify barriers, potential barriers, and other features which could be related to their spatial environment. Moreover, indirect spatial references were also extracted at this time.

In addition to this, I constructed a diagram which outlined thematically the processes and patterns that were evident for that respondent. No two schematics were identical, although several elements contained in them were. For example, the schematic for respondent number one was easily divided into spaces inside and outside the house, but this same kind of pattern was less prevalent for respondent number two. Regardless, both respondents identified barriers that were important to them and how they adjusted to changes in their former selves. With each subsequent analysis, the linkages that could be seen between categories and sub-categories were becoming more clear. The process of going back and forth through the analysis of the interviews, the verbatim text, and the diagrams helped to develop the core categories of the research.

It was this process that made the development of Figure 4.1 possible. Figure 4.1 was not conceived independently from the data. Rather, it was through the data itself that the categories were formulated more concretely, which in turn better highlighted the linkages and interrelationships between the categories. In this sense, the development of Figure 4.1 is patterned closely after the grounded theory method. However, I did not exclude an item simply because it was only present for two respondents, as might occur if grounded theory were strictly followed. For example, for two respondents the MS affects primarily their memory or brain, more so for one of these two respondents, rather than manifesting itself physically, which is the case for the other thirteen respondents. In

grounded theory, the uniqueness of these two respondents may get mentioned, but would not necessarily form the basis of the “theory” that would be generated from the majority responses.

However, because I was not aiming for representativeness, I have chosen to include the unique. It would have been misleading to exclude the realities of these two respondents. For the majority of the respondents, the barriers faced are primarily physical. They have difficulty climbing stairs. They do not grocery shop in large stores. Rather they go to smaller stores in which the internal space is easier to navigate. These two respondents also face difficulties with stairs, and one of them relies on his spouse to manage the grocery shopping. However, for the other of these two respondents, she experiences difficulties driving a car because she forgets landmarks, and panics thinking she is lost, when in fact she is on a road that should be familiar to her. When she drives, she always follows the same path. For her, the memory is a significant spatial barrier. To discount its importance because it is not reflected among the majority of the respondents would run the risk of missing a potentially key variable in understanding how many people with MS, or other diseases, relate to their environment. As such, including seemingly unique cases in the final product is not part of the grounded theory method, and hence represents another deviation on my part.

The ‘unveiling’ of Figure 4.1 (which the reader is invited to look at before hand on page 110, if so desired) is approached through an account of the various themes which provided the framework for the diagram. In so doing, specific examples and text from the

interviews will be used to illustrate these patterns. However, first it is necessary to briefly describe the “global” nature of the respondents.

The Fifteen Respondents: Socio-Economic and Demographic Characteristics

Of the fifteen respondents, ten are women and five are male. This distribution reflects the general pattern found in the wider population of MS, although recreating such a distribution was not the intent of this research. It simply worked out that way. The youngest respondent is 31 years old and the oldest respondent is 68 years of age. The majority of respondents are between the ages of 40 and 55. The marital status among these respondents vary slightly: 8 are married; 4 are divorced; and 3 are single. Only four of the respondents live alone. The remaining respondents either live with their spouse, or if divorced, are still living with their children. Nine respondents are owners. In spite of this high number, a total of 10 respondents have changed their residence within the last five years — the majority moving to a different location in Ottawa. All of the respondents have participated in the paid labour force in their working career, whereas only 4 respondents continue to participate in the work force. Their occupations vary from being employed in the federal civil service, teaching, nursing, administration/clerical work and management in the private sector. Seven respondents have a combined monthly family income that is greater than \$2,000. Four respondents bring in between \$1,500 and 1,999 a month. The others are divided equally (two in each category) among the remaining income categories. All but four respondents have close family (outside the immediate household members) and friends to call upon for support should it be needed.

IDENTIFYING THEMES, MAKING CONNECTIONS

MS and Mobility Limitations

The different forms of MS have already been discussed. While at the level of the individual case it is possible to see how the forms may be represented in the construction of that individual's spatial environment, at the group scale there are many similarities in the patterns. These similarities are shown in the strategies that respondents have used to manipulate their spatial environment, given the presence of certain mobility limitations. However, MS is not the only health problem with mobility implications faced by all of these respondents. For most, it is only the MS. But for four respondents, there are also other problems, partly stemming from the MS.

Two respondents face problems with their knees, which resulted from earlier injuries but are exacerbated by a tendency to fall due to the MS. One of these two respondents also faces a myriad of other problems. He has: fiber myalgia which is a chronic form of arthritis; no cap on his right knee; experiences vision problems (double and triple vision); has had an ileostomy (removal of the colon due to its unusually large size); and suffers from a herniated disc and disc degeneration. In fact, he says that of all the things he has been diagnosed with, "the least of it is the MS" (Mason, respondent #14). Another respondent developed a heart condition which was brought on by over-extension and stress due to the MS. One respondent is permanently in a wheelchair because of a herniated disc. This respondent is chronic progressive and was already facing many mobility limitations, but the herniated disc, which the doctors say is not MS related, put her in the chair. With each additional health problem, these respondents are faced

with many more mobility limitations and barriers than if they only were being affected by the MS.

Many of the respondents experience some mobility limitations. Most of the mobility problems have to do with a loss of control of the legs and the ability to get around easily. Many of these respondents rely on a number of mobility aids such as a cane, a walking stick, a walker, a scooter, or a wheelchair. These mobility aids become an extension of their physical bodies. Bob, Mr. Collins and Judy all use a wheelchair primarily for longer distances. But, whereas both Bob and Mr. Collins rely most on their walking sticks for support, Judy's MS has progressed to the stage where a cane or a walker is no longer sufficient. She relies mostly on her scooter and wheelchair. Ruth is the only one permanently needing a wheelchair due to her herniated disc. Mason always needs his electric wheelchair when he leaves the house, but only sometimes needs to use his manual chair inside the house. Vanessa is much more emphatic about her use of her mobility aid: the scooter. For her, the scooter is her freedom.

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 that gives me the freedom to go where I want to go (Vanessa, respondent #8).

In addition to these mobility problems, one respondent cannot control the fine motor movement skills in her hands. For yet another, it is her memory and cognitive skills which make it difficult for her to make spatial connections in terms of direction, distance, road networks, paths and routes. For each of these mobility limitations, there are

associated barriers. Some of these barriers are the direct result of a mobility limitation regardless of cause, whereas the others are more directly MS related.

BARRIERS

There are four primary barriers which constrain the spatial environment of the respondents. I have called these barriers: work, social, cognitive and physical. Within each category, there are sub-categories, and in each there are various strategies used by the respondents to reconstruct their spatial environment. Although these barriers have been distinctly recognized, there are many interrelationships between them.

Work Related Barriers

Work related barriers can initially be divided two-fold: 1) where a respondent is no longer able to work and is on a disability pension; and 2) where the respondent works a limited or reduced work day or work week. Twelve respondents can not work, where nine of them are on CPP Disability, and the other two have retired, receiving their pension. One respondent also can not work, but is not on a disability pension. There are three respondents that work, but in a reduced capacity. One respondent has reduced his work week to three days since his diagnosis. Another respondent is currently on contract work but is currently seeking full time employment. In spite of her desire for full time employment, she comments that:

...doing contract work is great. You know, I plan my days according to my energy levels and it seems to be ideal. If I know that my best time to work is in the morning, I'm more mentally alert, that's when I will do the work. And uh, I find that it has really been good to be able to set my own pace. (Jamie, respondent #6).

In contrast to the other working respondents, Mr. Collins works a full day and a full week.

However, he finds that:

...the day is about an hour too long for me, personally. The last hour is always a struggle. And, my employer is very understanding, and says if it is too much, don't do it. But I feel if you don't stay the full seven and a half hour day, then it will turn into six and a half, and then it will just drop, drop, drop. So I rather lead as normal a life as possible, so I do stay the full day, but I do know that the last hour I'm not very productive because I am tired (respondent #7).

Mr. Collins' comment that "I rather lead as normal a life as possible" is made by all the respondents who participated in the study. However, their strategies to achieve this, vary. Before it is possible to discuss these strategies in terms of how these respondents have had to reconstruct their spatial environment, it is necessary to introduce the social barriers.

Social Barriers

At first glance, the social barriers seem to be less spatial than the others, but this is not the case. The diagnosis of MS often involves a long process. For some respondents, they have had MS for years, but have only recently been diagnosed. Others were diagnosed within the first two years of showing symptoms. Regardless of the length of time involved, the uncertainty of what is wrong with the body plagues the minds of the respondents. In most cases, the diagnosis is met with relief because MS is not as bad as the alternatives: cancer, brain tumor, certain death. In the majority of cases, MS is not immediately life threatening. Most respondents said "at least it isn't cancer" (Judy, respondent #10). Another respondent said "it is something physical. It isn't some psychiatric problem" (Bob, respondent #3).

The type of social barriers that exist involve an identity struggle as well as a stigma. Once a respondent has been diagnosed, they become “categorized” (Kate, respondent #1). MS becomes a label which is not met positively by others. These reactions are largely out of ignorance.

And most people don't know what it is and don't know anybody else who has it, and quite often I try to educate them, because I say “it isn't unusual that you don't know anybody who has it”, I say, “you actually do, but those people, you don't see them anymore, you just are not in the places where these people are living or resting”. And so...the reaction can go, well people can recoil in horror because they are ignorant about it, they don't know if they should shake your hand, because they don't know if you are going to pass something contagious on to them. There are lots of old wives tales about people who are sick and infirm, and people, I think, rather than ask you pointed questions, like prying into your, into it, they prefer to...you know, ignorance is bliss. So they don't want to ask questions, and often times people don't know how to ask a question, how to politely ask someone what is going on (B.L., respondent #15).

You would have thought I had contracted HIV, they just disappeared. We had a number of friends and I don't know if it is so much more involving the illness, that they don't know much about it, that it isn't catchable, isn't transferable...but uh, we look at it as, you know, would try to relate to it, research it, that's what I would do if I were in their shoes, type thing, that is what I would do (Mason, respondent #14).

Some respondents indicate that they have lost their circle of friends as a result of the diagnosis, as is the case for Mason. Similarly, when respondents must leave the paid labour force because of the MS, they are removed from those social contacts with co-workers and simply being outside the home. Bailey nicely words it:

...coping with being at 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 devaluated, I wasn't worth much purpose, I only had a purpose around here, but nobody tells me that I am any good. Uh, just being home all the time, not getting up and going to work. Just all that (respondent #12).

This removal from the paid labour force not only can serve as a source of stigma to the respondents, but can also throw their whole identity into question. Kate comments:

I think my self esteem has suffered...um...because I considered that I was an intelligent person, and uh, I went back to school as a mature student when I was in my thirties and came in top of my class in the courses that I took...um, when you are not contributing, your esteem takes a bit of a beating...because you know you aren't really doing a worthwhile thing anymore..something that is earning dollars...I mean, I spend a long time with the children, talking to them, and I think that is worthwhile, but it is not something that society really values. I think my choice is being entirely limited by the MS, and that is kind of sad...because I have got skills...but I don't use my skills that much anymore (respondent #1).

These barriers, both work and socially related, prompt the respondents to re-evaluate their spatial environment. If they can no longer work, they do not get outside the home as much as before. They subsequently lose many of their social contacts through work. They feel devalued. The diagnosis may alienate them from their friends because these friends do not understand that MS is not contagious. All of these factors constrain the spatial environment. However, many of these participants have responded to these constraints by re-constructing their space. Since they are no longer able to work in the paid workforce, many have volunteered in work-related organizations, or other organizations that suit their interests. Three have responded by going back to school to further their education. For one of these respondents, she is only going to school out of interest sake. One respondent has just finished a diploma as a Legal Administrative Assistant and is currently seeking full time work.³ Other respondents become active in

³ MS is one group that the government targets in its CPP Disability Pension. The respondent in question was able to go to work full time, and still keep her benefits. Moreover, once she successfully gains employment, if she finds that the MS is interfering and can no longer continue working, she can be immediately reinstated with her Disability benefits.

other activities or hobbies. These various strategies help respondents to get out of the house and into a wider spatial environment. It permits them to make new social contacts. These all represent positive adjustments to a respondent's changed role.

In addition to this, respondents will engage in outside activities in order to keep up with their former selves. More specifically, some respondents do this to compensate for changed roles in their marital relationship. Only two respondents referred to this explicitly, and thus, I can only draw on their experiences. Vanessa refers to how the MS has affected her ability to help her husband.

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...we work together an awful lot. Like, let's say we wanted to paint the fence, he would start at one end of the fence and I would start at the other. But over the years, as I progressed, I maybe get five painted and I am tired, whereas before, we would have started at both ends and met at the middle. And that is an aspect of MS that I find very, very hard to handle...where it impacts on your relationships. And that is why, I don't know if you noticed it, that the divorce rate is very high, and I can understand why it is very high. If you don't have a husband that is willing to help you, or say, yes, you can't do that, I can see why the divorce rate is very high. Because it has taken, I will be completely honest, it has taken many years of struggle and on my behalf to sort of to put 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 can't do that... (respondent #8).

For Vanessa, pushing herself to continue with activities that she used to be able to handle, and to put on a "facade...that you can still keep up" was her way of resisting the effects of the MS on her married life. She knows that she can not keep up with her husband the way she used to, but she still tries. By contrast, Bubbles tries to have an activity scheduled everyday. She and her husband used to share a great deal together,

especially in terms of physical activities like field hockey and running. She can no longer do those activities, but he can. She comments that:

I have always been physically active all my life and when you suddenly find you can't do things, it is really...So if he is doing something like that, I should also be trying to do things to keep me interested in doing things (respondent #9).

However, in her efforts to stay active, she has become involved in some activities that she would really prefer not to do, but does not seem to know how to pull herself out of it. The instance that I am referring to is her involvement with a MS self-help group that meets every Thursday. She finds that she would much rather not go because it is "another MS thing, and it is very exhausting and very much a downer." She comments that she continues to go:

...because I have difficulty saying no. They need help because I need help. But I do really have difficulty saying no. It would be lovely to not be there, like maybe I am frightened as well that I would cut myself off. I don't know. It is a good question. I have often thought that...why am I going? ... It is an event, a place to go, something to do. But maybe I shouldn't. Maybe I should say no and think of something else to do (respondent #9).

Bubbles later admits that she goes out of obligation to the other person who helped set up the group. She recognizes over the course of the interview that she would not be cutting herself off if she were to quit that group and begin a different activity to get her out of the house.

These examples serve to show the struggle that respondents must face within themselves in order to deal with the stigma of having a life-time disease as well as how they must adapt to the changes and limitations in their bodies which forces them to

confront themselves. The ability to make these adjustments partially ties in with the third barrier: cognitive.

Cognitive Barriers

There are two divisions for cognitive barriers. The first division is what I called *emotional*. The majority of the respondents fall into this category. Emotional barriers represent the manner in which respondents accept or reject the limitations in themselves and their environment. The second division is called *mental*, which affects primarily one respondent. Mental barriers at one level refer to memory related problems in terms of scheduling, length of time it takes to do certain activities, and so on. At another level, mental barriers refer to the abilities of the respondents in dealing with direction, nodes, paths and routes.

It is best to deal with mental barriers and then move onto emotional barriers. Some respondents referred to having difficulties with their memory as a result of the MS. For Mason, his memory is mostly affected when he is in a period of attack. He tends to fall asleep without warning, and not remember. Alternatively, he comments "I don't know people I have worked with for six years, you can give me a picture and I don't remember them" (respondent #14). For Sarah, it is much more severe. Her memory is affected in different ways. First, Sarah is a nurse by profession, but can no longer continue working. In order to stay on top of what is going on in her field, she reads a lot of medical journals. She also does a lot of crossword puzzles to stimulate her brain into working and thinking. Despite these efforts, she feels that it still takes her a while to verbalize what she wants to say. For example, she says:

I, like my nursing terminology, that is all gone. I can't remember, or wanting to express myself, I cannot, it seems that in my head I can see what I want to say, but the words don't come out. I can't explain what I want to say. That is the same as doing the crossword puzzle because it is so difficult for me to do, it seems like I can see the word I want to put down there, but I cannot verbalize... You know, I am very fortunate in the sense that just by looking at me you wouldn't say that I have MS, but when I open my mouth you can see that I have something wrong because I have difficulty expressing myself, like I am a lot worse than at other times, when I am very rested and I don't have any major preoccupations and I take the time to think out what I want to say... (Sarah, respondent #11).

It is important to note, however, that although Sarah felt she was not expressing herself well during the interview, I did not notice any problems.

Second, Sarah also has difficulties with her memory when she is driving. She says:

I had more or less stopped driving, well not stopped because I have my car. I am driving a lot more now. I lose myself. In Ottawa, there is so much construction and things change so fast, I know I have gone that way before but they aren't familiar things I have seen before and then I panic. And these panic attacks...so now I try to drive more and my husband is with me, so when I feel lost, he tells me to "find something familiar, you have been this way before". I tend to follow the same road as much as possible. A straight line or ninety degree. My brother lives in Uplands, I go Montreal road, Riverside and to his place. My husband takes all the back roads and things, and to this day, I wouldn't be able to go his route. I would be scared. I would panic. I wouldn't be able to do it. I have to take a straight line. That is why I can't describe directions to you on the phone.

For Sarah, her strategy to compensate for this is to practice and force herself to get out there. Although Sarah is the only respondent who experiences these problems to such a degree, it was included nonetheless, because it serves to show how other people in her situation might respond to their environment. Sarah is being pro-active in her responses. She reads in her field to stay current, does crossword puzzles to stimulate her brain, and regularly practices her driving so that she can gain a sense of control over the outside spatial world.

The other cognitive barriers are emotional. The respondents that were interviewed were coping with a number of changes in their lives. Many had to give up their career aspirations because they could no longer physically handle the consistent output of energy. Coping with the loss of work related social contacts is subsequent to this. Many are having to cope with the fact that their bodies are deteriorating, especially those that have progressive MS. They are having to cope with the fact they are now becoming reliant on mobility aids to help them navigate their space; aids that are more usually associated with age. Similarly, some may be temporarily restricted to a wheelchair, but must use all of their power to fight the effects of the MS and get well enough that the chair is no longer necessary. This is not a possibility for all respondents, especially those who are progressive where their bodies have deteriorated to that stage. And, while these barriers are not explicitly spatial, they are implicitly spatial because the manner in which the participants respond to these barriers will in turn help shape the re-construction of their spatial environment in light of these constraints. A few excerpts will highlight this.

I have had ups and downs, and uh, loss of vision, I have been in a wheelchair, I have been about every six months, I was in and out of hospitals but that was when I was in my first stages of the illness...Then I realized that it was up to me to make what I wanted to make of life. Did I want to be sitting at home and being a handicap person, or did I want to function again and go back to work? So I decided I wanted to get back to work, and so I worked in a positive way, got back on my two feet, started exercising, started to go everywhere, so I got back to work. I worked part time at first and then I was able to come back to full time for about a year (Sarah, respondent #11).

My first symptoms, they really controlled me. I didn't really have any control over them at the time. I didn't realize what was happening and I didn't know how to take care of myself at all....I can think of two different conditions that I was actually in a wheelchair in my house using my wheelchair, because I couldn't navigate at all without the chair. And I use a wheelchair, I haven't recently used

one...I find in my walker, I don't have to use a wheelchair at all ever, because it (the walker) has become my legs which I think is wonderful. I can't believe how nice a walker is. At first, when it was suggested that I get a walker, I recoiled in horror thinking "how horrible." I always imagined that it is only for little old ladies and men. But you see, lots of people have walkers and they are not infirm and they are not elderly, you know, anyone with a mobility problem, once they have tried a walker... (B.L., respondent #15).

Even for those who have progressed to the stage where the wheelchair is very much a part of their life, either part time or full time, the emotional coping can have a big effect on their environmental constraints. Ruth comments that her MS has primarily been on her left side. She is unable to send messages to her left leg and foot to get them to move. Her right side has always been considered her "good leg" but since the problem with the herniated disc, she is unable to move either leg and is permanently in a wheelchair. She comments:

...so you just accustom yourself to one thing at a time. Luckily it is only one thing at a time. One or two. I think if it was, if I went through one of those drastic attacks where it took everything, or a lot of things, I would, I think I would go bananas, a little crackers. I don't think I would be able to deal with something like that. For my own self-confidence and ability to cope, this is better for me. A little at a time. Now, my little at a time is becoming a little more than a little, I am waiting to find out about attendant care because I find, I can still dress myself in the morning, I can still transfer, I am just finding it harder and harder to do (Ruth, respondent #13).

Ruth is faced with a progression that is not outwardly caused by the MS, but it is nonetheless a significant limitation that she must deal with. She has only been permanently in a wheelchair for the last couple of years, but in that time she has learned how to do everything while sitting down (e.g. dressing herself, moving around in the bathroom, etc.). Only recently has this been more difficult for her, prompting her to be pro-active in applying for attendant care to assist her with certain tasks.

In all of these instances, respondents are faced with limitations or barriers which are implicitly spatial. The barriers themselves are not spatial, but the way in which the respondents cope with them prompts them to take a pro-active stance to resist the barrier and manipulate and control their environment. To better understand how these come into play, we need to look at the effects of the physical barriers.

Physical Barriers

The label 'physical' barriers can be a bit misleading. At one level, the physical barriers are caused by the body's physical limitations. At another level, the physical barriers refer to the spatial environment in which the body's limitations must interact. While it is almost impossible to separate the two, I am primarily focusing on the physical barriers which relate to the respondents' spatial environment. As such, there is an artificial separation of these two types of physical barriers, although both are highly interrelated. Physical barriers have been divided into internal and external. Internal barriers refer to those within the home; external barriers refer to those outside the home.

External barriers are those which are open to the widest possible interpretation. Such barriers can refer to the inability to exit one's house because of stairs. These barriers can refer to the number of activities that one can handle outside the home, and the distance one is willing to travel to accommodate outside tasks. They can refer to one's inability to access local neighbourhood stores because there are no accessible entrances. They can refer to an inability to walk far from the house because one still has to be able to return to home base, or alternatively, one can not venture out for a walk alone for fear that something might happen.

Several strategies have been developed to minimize the barrier of exiting a home. One respondent has built an attached ramp to her front and back door of the house so that she can ride in and out on her scooter. Another respondent has had the stairs leading to the back door entrance of the house graded to four inches so that she can walk up and down them with her walker. These stairs are also deep enough to accommodate both her walker and herself on each step. These types of modifications are relatively easy to make.

However, being able to minimize the body's limitations when outside the home in terms of knowing how many activities can be tackled, and how far a respondent is willing to travel to access certain services, is much more difficult. For Kate, she carefully organizes and plans all of her activities. She uses an agenda book to itemize those activities that will be carried on outside of the house as well as those that are executed inside the house. She also schedules her time in terms of "activity pockets" where she can control what she does and what time she will go home. Kate never goes out to a store without having a specific list of items to buy. She will buy only those items on the list and return home again. She avoids making unnecessary trips because the consequences are heavy. Every trip outside the house is almost forced. She comments:

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....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 (respondent #1).

These trips are forced on her part. Even grocery shopping and other errands are a chore, but one that she handles with the same kind of precision and control. Kate was in a situation where she was having to stand in a long line-up, but was getting very tired. When told she would have to go to another line-up she disclosed the fact that she had MS in order to speed up the process.

And then I was told "take it over to customer service over there", and I looked at the line up and I said "you mean to say I have to wait again in another long line-up?" I said, "when someone has got MS, standing waiting is kind of a difficult task." And then they were service straight away. I felt a bit like I was stretching it, but I thought, "enough is enough" I am not able to stand up in line-ups forever. Like this is difficult. By this time, I was propping myself up on the counter where the, all the goods are, so you know, sometimes you have to disclose it. I mean if it was a case of a choice of just leaving my goods and leaving the store and not having bought what I intended to buy, or else saying something and getting more immediate service. So you know, I am not 'using' it, but you have to make some certain decisions. And sometimes those decisions mean disclosing that you have got MS. You do what you have to do (respondent #1).

Kate, like eight of the other respondents, will not go out to large grocery stores like a new Loblaws or Price Club. These respondents all tend to go to smaller, familiar neighbourhood stores because the larger places are much too overwhelming. Bob comments that to go into such a large store, he would have to use his wheelchair. But, if he goes to his 'specialty' stores, like the butcher shop, a fish store, and a fruits and vegetables store, then he can handle walking up and down the aisles of these stores because they are considerably smaller. He will place an order with friends to get his larger grocery items, that he, himself, can not manage alone. Many respondents schedule their grocery expedition for a specific day of the week. Some are more flexible in their routine, but largely because they are dependent on friends or family to accompany them. Again,

Kate nicely summarizes why the smaller stores are better in terms of navigating their spatial environment:

...the new Loblaws. It was just so overwhelming. I couldn't do the shopping. I had to tear my shopping list in half and give the kids a piece each and they had to do it because it was just physically overwhelming to walk up and down those aisles. So, even though we have this grand new Loblaws, I go back to the Loeb which is just a couple of minutes away by car. I know the aisles, it is a small store. The people know me and there is one guy that he knows to come and take my trolley out to the car and help me with the groceries. And again, the geography of the sphere within which you comfortably function is limited, because I have gone back to what is familiar and what I know I can cope with and Loblaws can keep their beautiful store (respondent #1).

In spite of a preference among most respondents to go to the smaller neighbourhood grocery stores, not all neighbourhood stores are accessible. Wilma lives in a neighbourhood where there are many unique stores, but she can not access them because her walker or wheelchair can not navigate the stairs. If she wants to buy a children's book from a particular specialty store, she has to phone them in advance, warning them of her arrival so that they will bring out to her the items she is interested in looking at. As a strategy, Wilma vocalizes her complaints anywhere and everywhere. She remarks that the 'wheelchair accessible' signs in many buildings are "a farce". Often there are no push buttons so that people in a wheelchair can access the building. Wilma, herself, has been stuck in a wheelchair accessible bathroom in the World Exchange Plaza, and was instrumental in having that sign removed "because it simply wasn't true" (respondent #2). Wilma has also complained, successfully, to the city councilor in her neighbourhood to have the sidewalks repaired so that they are graded to accommodate wheelchairs.

Through these simple examples, we can see that vocalizing and resisting the status quo are two ways to re-construct the barriers within one's spatial environment.

In fact, Wilma argues that she does not really face any barriers in her environment. She is not limited by the distances that she is willing to travel, and is not limited greatly by the effects of the MS in spite of her use of a walker or wheelchair. This kind of public discourse is present in the texts of other respondents. However, in some instances, one can see the fine lines between the public and private discourse. As one example, Wilma comments that her biggest fear is losing her husband, because he assists her a great deal. This is said long after her comments about not being limited by the MS. Whether or not she explicitly states it, her husband acts as an agent in her life helping her to navigate the constraints and barriers within her spatial environment. As long as he is around, she has no problems. But if he were not, her spatial environment would shrink considerably. Consequently, even when respondents face no immediate barriers, potential barriers exist in the background.

In addition to these types of barriers, some respondents refer more specifically to their spatial environment. For example, both Mr. Collins, in general, and Jamie, when she is in an exacerbation, limit the distance they walk from their house, because "the problem is, if you walk too far, you have got to be able to get back to base" (Mr. Collins, respondent #7). Mr. Collins also uses another strategy to limit external barriers. When he leaves the office to return home, he calls his wife. The travel distance from his office to his home is about 12 minutes. His wife will give him 30 minutes (taking into account traffic, running into co-workers in the hallway, etc.) from the time of that phone call before going

out to see if he has run into any problems. Mr. Collins drives one specific route to and from the office everyday, so his wife can easily trace his steps to see if he needs help. Similarly, Judy likes to go for walks on her scooter, but will not venture out without having someone accompany her in case she runs into problems. Judy has a tendency to get dizzy or fall, and is afraid that if she falls off her scooter, she will not be able to get back up without assistance. This has happened to her in the past.

Many of these strategies are extremely spatial and reflect these respondents abilities to resist any limitations caused by such barriers in order to re-construct their environment into something that is more user-friendly. However, these strategies are not limited to the external spatial environment. Most respondents exert the greatest influence over their spatial environment within the home itself.

Many respondents have made modifications and adaptations within the home so that they can minimize the effects of an internal barrier. For example, both Mason and Wilma have had installed in their respective homes a stair glide so that they do not have to climb the stairs. Judy moved into a house that had the potential for three separate apartments. When her aging mother moved in with her, Judy moved to the second floor apartment. However, climbing the stairs became too difficult for her, so she and her mother switched apartments. Judy is now on the main floor, and her mother is living in the second floor apartment. Kate, Jamie, and Sarah try to minimize the trips they make up and down the stairs by developing a pile of items to be carried up or down the stairs.

In addition to difficulties with the stairs, respondents face other internal barriers. Ruth, who is permanently in a wheelchair, was told that she should have her carpets lifted

from her condominium so that her wheelchair would roll more easily. She has been reluctant to do this because she would not want to have the carpets removed in the bedrooms, and feels that the overall appearance would be peculiar to have carpet in some places and linoleum style flooring in others. So, for Ruth, living with this barrier is a conscious decision. B.L. on the other hand, when she moved into her condominium, she had all the carpets removed and replaced with vinyl flooring so that she could navigate more easily with her scooter, and a wheelchair should the need ever arise.

Laundry is a major barrier for anyone with a moderate to severe case of MS. Many will not do their laundry all in one day. Some are unable to do their own laundry and are dependent on a spouse, a homemaker, or home care worker to do the laundry for them. Others tackle the laundry all in one day. For these people, the laundry task takes on a very spatial role and represents a significant internal barrier. This barrier is most severely felt by Vanessa, although she has made some adjustments in her life to overcome the barrier. Because Vanessa is no longer working, it is considered her "job" that she handles all the housework. To assist her with this, her husband has built-in some modifications to assist her. The laundry hamper is located at one end of the hallway - opposite to where the basement stairs lead down to the laundry machines. Vanessa empties the dirty clothes onto the floor and kicks them down the hallway to the railing leading to the stairs - the actual entrance to the basement is still another 10 feet away. From there, Vanessa tosses the clothes over the railing and then goes herself down the stairs, where she kicks the clothes further into the basement, separates the clothes and washes them. For her:

...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 once I go down the stairs, I stay down the stairs. I have a chair down there, and a radio and everything. I sit down 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 then my husband made me a frame, an A-frame, and so I sit on the stool and take things from the dryer, the hangers are hanging on the A-frame, take the hanger, put the shirt on it, and hang it on the A-frame....but when it comes to brining it up, sometimes my husband will bring a basket of socks, lets say, underwear, and I will sit down here on the floor and he will bring me the basket and I will fold it. And then, when everything is done he carries it into the bedroom and then I put it all away in there (respondent #8).

Often, respondents will have an occupational therapist come into their home and make suggestions for modifying the environment so that it is more conducive to them. The most typical of these suggestions include grab bars in the bathrooms. Some have even had instruction to take note of where furniture and other items are located spatially within the room, so that should they fall, they know what they can hold onto to get themselves back up again.

In spite of the many pro-active strategies respondents have made to control their internal space, some are also greatly restricted by this space. In all but two cases, respondents have either expressed a desire to move into a housing environment where everything is located on one level, or have actually done so. In most instances this refers to a bungalow. Some variations on this theme include Bob who moved into an adaptable co-op, or Ruth and B.L. who own a condominium. Nonetheless, the dream, whether already actualized or a work in progress, is a one-level unit where even laundry is located on the main floor. Those who actually live in a bungalow or similar environment did so as a conscious decision given their limitations with the MS. Others have expressed the desire

to move into such a housing environment in the future so that they do not have to navigate stairs. Of those who are still waiting for such a reality are living in a spatially isolated environment.

Bailey has expressed a desire to move into a smaller house, preferably a bungalow. She feels that she can not make this move until her daughter moves out of the house. She argues that her daughter currently makes use of a tremendous amount of space in their two-story home that she could not possibly duplicate in a bungalow. The daughter's space consists of her bedroom, a computer room, the dining room and the kitchen (for studying) and the family room in the basement. By contrast, Bailey's space is limited to her bedroom and the kitchen. She also uses the living room when she has company, which is not a frequent occurrence. In spite of her reduced space, she has modified her bedroom to be all things. In there she has her bathroom, her bed, a chair for reading in, a television set, and a telephone.

Mason too lives in an isolated and reduced spatial environment. He is currently living in a two-story townhouse but is in the process of looking for a bungalow. Both he and his wife are on disability pensions and are faced with mobility limitations, though his are more severe. The second floor of the townhouse contains his bedroom, the bathroom and the family room, where the television is located. He rarely ventures down to the main floor despite the stair glide. His stair glide is not being used to maximum efficiency because his stairs are not a straight line. Rather they are L-shaped where his stair glide gets his most of the way, but he has to navigate the last 4 stairs on his own. His wish list for the bungalow includes: reasonable rent; make maximum use of the stair glide; laundry

on the main floor; five appliances; and a neighbourhood in the West end of the city, but not further than Kanata. For Mason, he hopes that this next move will be his last. Both he and his wife, in their 16 years together, have moved a total of 14 times. All of their moves have been largely related to Mason's mobility limitations and how he can negotiate his spatial environment.

UNDERSTANDING THE LINKS BETWEEN THE BARRIERS

Regardless of whether the barriers being discussed were related to work, social, cognitive or physical, one pattern should be clear. The participants all responded to these barriers in a pro-active way. Their strategies reflected a form of constructive resistance to the limitations caused by a chronic illness.

However, this resistance is different from the coping strategies of people with MS developed by Brooks and Matson and Radley and Green discussed in chapter 2. In those conceptualizations, resistance was a strategy used by participants who would not admit that they had MS, and were trying to minimize its effects by pretending it did not exist. Here, constructive resistance incorporates some of these aspects, but not in the same context. All the participants in this research accept that they have MS. Some of them are also affected by other health problems. All of these respondents deal with their MS by trying to minimize the impact that it has on their lives. They continue to do things even though they find it difficult. When they can no longer work, they find other activities to get them outside of the house and give them a sense of enjoyment and worth. They go to school. They volunteer. They spend more time with their children. They, at all costs, remain as independent as possible. They minimize the physical limitations brought on by

the disease by removing any potential constraints and barriers, when possible. They reconstruct their environment to reflect, as much as possible, a level of homeostasis: a comfortable sphere within which they are in control of their space. Through this they are able to adapt to the changes within their bodies and their environment.

This resistance attitude was best articulated by Sarah who had been reading a book which said that instead of always asking yourself, "Why me? Why me?", you should say "Try me. Try me". This means that you will not be able to get her down, feeling sorry for herself. She will not allow it. She will fight. She comments:

At first, I was sort of looking for any type of help that someone could come up with. Something new, something different, something...but I realized I just wasn't accepting all I was going through and now that I have accepted it, life is easier. I am not trying to find some solution that might be hidden in a corner somewhere. But that is the fact of what I am going through. Because I realize there are so many people around - not only those with MS - who are ill. So, not "why me" but "try me". You know, I have to cope with my own problems, so that is a big help to realize it. It is for me to fight instead of saying "why me" again (respondent #11).

The way in which they manifest this constructive resistance is seen in how they manipulate and exert control over their environment. Some of the earlier examples have already alluded to this. In addition to dealing with spatial barriers, respondents can manage their environment in other ways.

MANAGING ENVIRONMENTS: ABOVE THE SPATIAL LEVEL

Many of the respondents expressed an attitude towards their body as: if you do not use it, you will lose it. David looks at it as assuming responsibility for your own health. When he was first diagnosed, he was told all of the negative aspects. He was diagnosed in the 1970s, and at that time, doctors were telling people that they should be leading a

retired kind of life. In David's words, "you were supposed to slow your pace down and just basically not expect too much from your life." He fought against that attitude. His personal philosophy is:

...that a lot of our inabilities or restrictions in life are those which we place upon ourselves. Sure you have to deal with the physical, the obvious physical limitations, but it is important that you stay active, and stay positive and do your best and try and achieve your full potential (David, respondent #5).

The respondents deal with the physical limitations by using mobility aids and minimizing the impact of barriers in their spatial world. They stay active by continuing to pursue activities that are of interest to them. In addition to this, they try to "live within [their] means" (Mr. Collins, respondent #7). Mr. Collins argued that just as a person with limited income must live within a budget, so too must he with his MS. He knows he can not push himself to the point of exhaustion, otherwise his body will make him pay. This attitude was evident in all of the respondents. There is an understanding that they have MS, must accept it, but they do not have to like it, and they do not have to be terribly limited by it.

In fact, in order for these respondents to take control over the barriers in their lives, they use these barriers as a form of resistance. Although Judy switched levels in the house with her mother (from the second to the main floor), she still makes it a point to walk up and down those stairs at least twice a day for exercise and to keep the body in the habit. Mr. Collins had not moved his office or family room up from the basement of his bungalow because he wants to continue forcing himself to use the stairs. Kate forces herself to walk the dog everyday so that she does not give up on getting outside of the

home. B.L. who always uses Para Transpo to take her anywhere she has to go, will sometimes walk back, in the summer, from her errands at Billings Bridge Plaza provided that the day is not too hot because it affords her a freedom that she does not usually get. Even though the walking can be tiring, she can go home anytime she wants. She does not have to worry about being at 'Door 5' for any specific time.

In spite of their resistance to the MS, the respondents also recognize that they must make daily adjustments and be flexible. They know they will have good days and bad days. Bob will always accept invitations out with friends, but makes a point of telling them that "if my MS acts up that day, I won't be going" (respondent #3). This same sentiment is also carried over by the respondents in terms of the division of household tasks. Many respondents divide household tasks into big and small jobs. Big jobs consist of cleaning the bathrooms, vacuuming, major cleaning (e.g. cleaning the fridge, the oven), grocery shopping and laundry. When looking at Vanessa's situation when she does her laundry, she makes the comment that laundry is a big job, and the only one she will do that day. Other big jobs include spring cleaning, Christmas shopping and preparations, and getting ready for a trip. These jobs will be carried over several weeks before completion. Small jobs are dusting, tidying, planning meals, organizing lists for shopping. Most respondents will divide their days by tackling one major job and handling a couple of smaller jobs.

However, not all respondents manage all of these tasks on their own. The majority of respondents handle some tasks, but also receive help. Such help is provided by paid and unpaid labour. Unpaid labour consists of help that is received by a spouse or family members. For example, Mason and Wilma are dependent on their spouses for help with

grocery shopping, transportation, and other matters. Nonetheless, their two situations are not identical. Mason receives a small amount of help from home care (public paid labour) whereas Wilma has a housekeeper come in once a week (private paid labour). Because Bailey's MS affects primarily her hands and her fine motor movement skills she can not handle any of the internal and external home maintenance tasks. She pays for someone to clean her house. She also contracts out to have someone mow her lawn, shovel her driveway, and deal with other outside maintenance work. Similar examples can be found for all the respondents.

In their efforts to maintain their independence, they resist the barriers within their environments, make adjustments to their lives and adapt to their changing bodies. This all culminates in a redefinition of self which is discussed in the next section.

REDEFINITION OF SELF: THE PATH TO HOMEOSTASIS

The whole process of examining the constructs and constraints in the spatial environments of people with MS has shown that respondents are faced with a constant struggle. Their bodies are changing. They are no longer able to manage all the same tasks that they once did. They can no longer "cope with all the pressures of modern day life" (Kate, respondent #1) without making some modifications to their lives. This leads to a self-examination and a redefinition of self. Such a redefinition is seen at three levels: physical, cognitive and social.

In physical terms, respondents must deal with the physical limitations that have become a part of their everyday life. They must re-construct their environment into something that they can exert control and independence. At the cognitive level, they must

deal with two sub-levels. Mentally, they must adjust to the fact that they can no longer participate in the paid work force, or if they do continue to work, that it may have to be modified into something their body can manage. Having to withdraw from their career aspirations is a very difficult adjustment to make. They can respond to it negatively, by giving in, or positively, by accepting their changed role and engaging in activities where they can make a difference. Emotionally, respondents often have to accept a certain change in their level of independence. They have to start drawing on other people's resources by accepting help from a spouse or friend. Socially, they must deal with their own identity struggles as well as the reactions of others to their disease.

All of these changes within their roles are evident in the strategies that have already been discussed earlier in this chapter. There may be barriers in their paths, but they work towards a management of their environment that reduces the impact of these barriers. In the end, they develop a spatial environment that gives them a sense of homeostasis, a sense of control.

During my interview with David, he asked me how many of the people that I had interviewed were severely affected by MS. He commented that:

...I have this theory, which is mine...I'm being silly now...that a lot of the people who do this type of thing, who are open to be interviewed and whatever, are those who are generally people who are assuming some responsibility for their own lives...who are not completely overshadowed by having the disease, and um, I believe that there is maybe you know 10% or 15% of people who are, uh, just feel that the disease has taken over their lives, completely. And again, coming back to my psychology, if you believe that, then you are going to predispose yourself to being that case, as well as whatever other physical things happen. And so, probably the people that come for these interviews are those who are going to stay active as long as they can. And uh, it is wonderful. And, there is going to be also probably a large portion of people who have MS, who are just affected maybe once in a while.

Or they have an attack and it isn't even diagnosed as MS, because the doctor, doctors really have a hard time and um, and those people, you won't see them at all.

This theory of David nicely ties in with a comment that Mr. Collins made, which is shared by all the respondents. Very early in this chapter, Mr. Collins was quoted as saying "I rather lead as normal a life as possible." Through the resistance that respondents have shown in manipulating their spatial world into an environment where they control the outcome as much as possible is the evidence of this desire to keep their lives normal. The MS plays a part of their lives, but it is not the whole story, nor is it really the main character.

SPATIAL CONSTRUCTIONS: FROM THEMES TO REALITY

At this point it is possible to unveil Figure 4.1 which shows visually everything that the preceding pages have done in textual form.

From the initial diagnosis of MS, the path leads to mobility and other limitations. These limitations become more noticeable when trying to navigate through an environment that was initially designed for someone who did not face these problems. People begin to be confronted by barriers in their work life, their social life, their everyday pattern and routine, and their emotional ability to cope with all of these changes. Suddenly, many aspects of personal security are thrown into question. Finances change. The relationship with their spouse changes. For some, people who were once considered friends, are no longer a part of their lives. Most important, they themselves change. Their bodies are no longer capable of doing everything they once did. They find that their spouse is now managing tasks that were once considered their domain. To compensate for these changes, respondents resist the potentially negative impacts stemming from these barriers. They take it on themselves to manipulate their environment into something where they can exert a bit of control. They come to terms with the changes to their former selves. They re-construct their environment to minimize the effects of any constraints.

They cope. They fight. They resist. They continue to control their lives, instead of being controlled by life's circumstances.

CONCLUSION

Tracing these themes throughout the narratives of fifteen people with Multiple Sclerosis has led to the development of a simple representation of their conceptualization of space. In the next chapter I compare these conceptualizations with the spatial abstractions developed by geographers.

CHAPTER 5 - FROM SPATIAL ABSTRACTIONS TO CONCRETE REALITY

INTRODUCTION

Pratt and Hansen (1993, p.30) wrote that lives are “lived in place and through space.” This is certainly the case with the fifteen respondents of this research, although to varying degrees. Before it is possible to revisit the research questions of Chapter 1, it is necessary to recap briefly the main themes developed in the previous chapters.

ABSTRACTIONS OF SPACE

Chapter 2 outlined Harvey’s three conceptualizations of space, and showed how some medical geographers have begun incorporating these views of space into their research. Absolute space is the first conceptualization. Here space is viewed as a container and it is simply geometric. Relative space examines the relationships between objects, wherein relationships only exist because the objects exist and relate to each other. These two conceptualizations have largely dominated medical geography both through epidemiological studies and research on health care delivery systems and utilization.

In contrast, Harvey’s relational space is only beginning to be noticed in the ‘new’ medical geography: the geography of health and health care. Relational space raises the conceptualization of space to a greater degree of abstraction. Space is not a container. Nor is it simply a relationship to another object. Rather, it is a conceptualization that requires greater sophistication in its description. Relational space refers to how space is socially constructed and given meaning by its users. In health related research, this view of space is starting to gain some support. The unreflexive use of space and place in the first two conceptualizations, which ‘explain’ space only in terms of geographic locations

or artificial administrative units, is being questioned. It is argued that as geographers, we need to move away from narrow conceptualizations of space to include how space is influenced by human activity and how people give meaning to their environments relationally. However, are such views reflected in the lives of ordinary people?

It was clearly stated earlier in this thesis that this research will not be providing definitive conclusions as to which conceptualizations of space are more favoured. Even if it was shown that respondents did view space in primarily one way, it does not make that conceptualization more “true”. There is no essential meaning to space. All three conceptualizations can be present at any one time. Space is not inherently one of these abstractions and not the other two. It all depends on context. What this research is trying to do is to examine fifteen concrete cases to see if elements of each conceptualization can be found in any, all or some of these situations.

CONCRETE SPACES

Chapter 4 provided a detailed analysis of how fifteen people reconstructed their spatial environment — primarily in the home — in order to minimize the constraints or barriers that were present in that space. It was emphasized that the spatial framework, as shown by Figure 4.1, was not reality for all fifteen respondents. Rather, based on the statements, experiences and evidence presented by each individual respondent, a compilation of these were organized to visually outline some of the steps or processes involved for a person with MS to make their spatial environment more user-friendly. Not all respondents followed these paths exactly as shown.

For example, Mr. Fredal did not really view his environment spatially. For him, there were no real identified spatial or non-spatial constraints that needed to be reconstructed. Any changes he made in his life were a function of both the MS and the stage at which he was in the life cycle. The physical effects of the MS were minimal. His diagnosis coincided with the timing of his retirement. MS played a part in his decision to retire at that point, but so too did the “golden-handshake” he received from the Ontario government. Which one played a greater role is unknown. He sold his house and moved into an apartment. This was not a MS decision, but rather, he and his wife felt that the house was too large for their needs and they wanted to downsize. Neither the MS or any other health related problems prevented Mr. Fredal from doing anything and everything that he wanted. There were limitations. He knew that he could not over-extend himself too much, otherwise he would feel the physical effects. But the kind of modifications that he had to make in his environment were minimal.

For Kate, Mr. Collins, Vanessa, Bubbles, Judy and Mason, greater modifications were required. Kate views everything in spatial terms. She lives in a “limited environment”. She “forces” herself to take the dog for a walk everyday because if she gives up on that, she gives up “on getting out of the house basically”. Mr. Collins, Vanessa and Bubbles all consciously moved to a bungalow in order to minimize the internal obstacles of their living environment. Both Mr. Collins and Vanessa were living in a townhouse, whereas Bubbles was living in a three-story home. Vanessa faced one of the most constrained internal environments when she lived in her three-story townhouse. Her bedroom was on the third floor. When she would wake up in the morning, she would

wash, get dressed, and do whatever cleaning she had to do on that floor, before going down to the second floor. Once on the second floor, she would do whatever cleaning or tidying was necessary before going down to the main floor where the kitchen and family room were located. Once on the main floor, she would stay there until it was time for her to go upstairs to bed. Judy faced a similar situation until she switched apartments in her house with her mother — i.e. her mother moved from the main floor apartment to the second floor apartment. Mason, who is in the process of looking for a bungalow to rent, lives upstairs almost exclusively. He only goes down to the main floor when absolutely necessary.

What these examples show is the varied nature of the steps outlined in Figure 4.1. Most of the respondents, once diagnosed with MS, end up experiencing some form of limitation, whether it is a mobility limitation or other (e.g. memory, hands). For each respondent, these limitations manifest themselves in one, two or several barriers. Some of these barriers are external to their personal space in the home, through reduced social contacts, inability or limited ability to participate in the paid labour force, and so forth. Other barriers are internal where either physical modifications need to be made to the space, or a move to a different household space is required. In addition to these physical barriers, there are additional internal constraints which curtail their capacity to work within the home in terms of cleaning, laundry and cooking, for example. Such constraints require respondents either to divide the tasks into more manageable levels so that they can continue to handle them, or seek outside help. The ability of respondents to deal with

these changes emotionally forced them to re-examine themselves in order to adjust to the change in their former selves.

All of the adaptations and modifications initiated by respondents are in a form of constructive resistance. Respondents are resisting the changes by not giving in to the disease. Rather, they are looking for ways that they can make adjustments and still continue to follow their normal routine. This resistance is constructive because many of their strategies are positive ones which seek to minimize the impact of the constraints. The final outcome is a level of homeostasis where the respondents have reconstructed their spatial environment, as well as their lives, into something in which they can still exert an element of control. All of the respondents accepted the fact that they had MS. None of them pretended that it was not a problem. Nevertheless, they were not going to give in to the disease passively. They were going to do everything in their power to manage the disease, instead of having the disease manage them. This was not only true for those respondents who were only affected by MS, but also by others who were experiencing other health related problems, some of which were more serious than the MS.

MAKING CONNECTIONS: FROM ABSTRACT SPACE TO CONCRETE REALITY

It is necessary at this stage to revisit the research questions of Chapter 1. These will be treated in order.

Do the theoretical abstractions of space developed by geographers have, at a preliminary level, a grounding in the lives of fifteen people who must live with a chronic disease?

The answer to this question is a qualified yes, although to what degree depends on the respondent (i.e. the context). It is probably safe to say that all people view aspects of their space geometrically, even though it is not explicitly stated. It is also safe to argue that most respondents relate to their environment in a relative way. They tend to shop at stores that are familiar to them in their present neighbourhood, or former neighbourhood. Such a pattern is not uncommon for any person, whether they are afflicted by a chronic illness or not. For items like groceries, fruits and vegetables, dry cleaning, banking, and so forth, people tend to use the shops that are closest to them, or that are familiar to them — i.e. part of their routine. The distances traveled for these are relative.

In terms of relational space, the situation is less clear. Respondents who are greatly affected by the MS alone or in combination with other health related problems tend to influence their space the most. Stairs no longer become a means to transport the individual between levels. Instead, they become obstacles. To minimize the impact of this obstacle, respondents employed a number of strategies. Judy built a ramp attached to her front and back door entrances so that she could ride her scooter or wheelchair into and out of the house. Wilma had the back steps graded to four inches so that she could walk them in order to get to the car using her walker. Both Wilma and Mason have had a stair glide installed so that they can access the different levels within their homes. Bob moved into a adaptable co-op specifically because everything was on one level. It has stairs that go into the basement, but he does not have to climb them. He primarily stores boxes and other less

needed items in the basement, so there is no need to go downstairs frequently. Kate, Sarah, Bailey and Jamie (when she is in a period of exacerbation) minimize and plan their trips up and down the stairs.

Similarly, some respondents have become isolated in their space while they are awaiting a chance to move into a more suitable environment. Mason spends the majority of his time on the second floor of his townhouse. That is where his bedroom, the bathroom and t.v. room are located. He only goes downstairs when necessary — i.e. he has to go to an appointment. He even eats his meals upstairs. He does not cook often. His wife handles that task as well as all the cleaning and laundry with the assistance of a home care worker for 2 hours once a week. Bailey will not move from her two-story home until her daughter moves out. Her daughter uses the greatest amount of space in the house. Bailey's space is her bedroom and kitchen. She spends about 70% of her time in the bedroom which has been modified so that it is equipped with a bathroom, television area, reading area and so forth. Other respondents, like Vanessa, Ruth, Mr. Collins and B.L., reflected similar patterns before they moved to a bungalow, or a housing environment on one floor (e.g. condominium).

Space for some of these respondents is also affected relationally in terms of their reduced outside contacts. Those respondents who could no longer work expressed that they have lost contact with co-workers. Their outside environment has shrunk because they no longer go out on a daily basis, like they used to when they went to work. They have compensated for this by volunteering and becoming involved in other activities that are of interest to them. Both Mr. Fredal and Wilma have retired, although Mr. Fredal

continues to volunteer extensively for a federal department, and Wilma, a teacher and artist by profession, continues to paint and lecture. Bob, Mr. Collins and Jamie all work, although Bob works only three days a week and Jamie is currently looking for full time work. Kate, Bailey, Ruth and Sarah all volunteer in order to stay active, and supplement these activities with other hobbies. Many of the respondents, like Bubbles, Judy, Ruth, Kate and B.L. try to have an activity scheduled for every day of the week. These strategies all vary the contacts they have outside the home, although for some, these outings are more frequent.

Space is relational in terms of how these people live and experience their illness in place. Physical modifications are made to the internal structure of the home. When such modifications are insufficient, a move is planned or made to a more suitable housing environment where everything is preferably on one floor. While such relationships to space can be argued at a relative scale, it is also relational in the sense that these respondents perceive these spaces differently from someone who does not experience the same kind of health limitations. Space becomes even more relational in terms of how much of their time is spent within that space compared to other people who participate in the paid labour force or who make frequent trips outside their home. In many respects, for some of these respondents, their relationship to their home is very similar to that of a housewife or house-husband (though to a lesser degree) — their lives become very much a part of what is contained within those walls. Space is also relational in terms of how some respondents only travel to certain stores that are within close proximity to the home because they can not physically handle being in larger or less familiar environments.

Thus, for each respondent, one can see how the conceptualizations of space developed by geographers are reflected in their lives. It was only for Mr. Fredal, David, Wilma and Jamie that space did not seem to enter their consciousness in any significant way. Jamie is only affected by space when she is in a period of attack which only lasts for a few weeks out of the year. For the rest of the time, she is not really restricted. David has some difficulty with his stairs, but is not really constrained by them. He still travels regularly for speaking engagements. He spends the majority of his time managing his illness through medication and other physiological techniques. He tends to shop at the local grocery store a few blocks from his home for both the exercise and because he does not have a car. But none of these activities really change how he relates to his environment.

Wilma argues that her space is not constrained at all. Her walker and wheelchair help her get around. The physical modifications she has made to her house (e.g. the stair glide, graded steps) have been sufficient that she does not notice any real difference. Wilma also has her husband to assist her, and he acts as an agent for her helping to remove any spatial barriers. He drives her where she needs to go. She accompanies him when they go shopping, or else, he does the shopping on his own. However, if his assistance was removed, her spatial environment would be significantly curtailed. She has not learned how to drive with hand controls. She needs assistance getting in and out of a car.

It has already been stated that Mr. Fredal does not really view his environment spatially. He is not constrained by the internal space of his home, and is not affected by his outside space. He still cycles, walks, volunteers and shares the household maintenance

tasks with his wife. He is not ‘working’ for pay because he retired from his career. His volunteer work in the government is very much like work, but can not be paid for it because it would be nepotism — that is, he is related to one of the members of Cabinet.

Thus, through these illustrations, it is possible to gain some insight into how space is reflected in the lives of the respondents and to what extent it plays a role.

Do people with a chronic disease, like MS, view their physical environment in spatial terms?

As is evident from the response to the first research question, most view their environment in spatial terms, although to varying degrees. The physical environment refers largely to their space in which they live as well as spaces they visit (e.g. stores, movie theatres, restaurants, etc.). Within their home space, many respondents have made modifications. For most respondents, they do not attempt getting in and out of a bathtub or shower without special grab bars, rubber mats, or bath stools. Doorways have been widened to accommodate a wheelchair. Ramps have been installed as have stair glides. Wilma was the most vocal in identifying spatial constraints in terms of outside spaces. Wheelchair accessible bathrooms are not always wheelchair accessible. Small specialty stores are not equipped with ramps or have sufficiently wide doorways. Sidewalk curbs are not always graded properly. These are all examples in which respondents view their physical environment in spatial terms.

What are the types of strategies that people with MS employ as a means for coping with their disease in a spatial environment?

Many of these strategies have already been discussed in answers to previous research questions. As such, they will only be briefly restated. Respondents make

necessary modifications to the home environment so that it is manageable. If such modifications are not sufficient, they move, or are planning to move, into a housing environment where things are accessible on one level. They minimize their steps. They plan activities before going out. In order to maintain social contacts, they volunteer, return to school or become involved in other activities. They divide tasks into manageable loads. For those tasks that they are unable to manage, they accept the help of others. In assuming a responsibility for their health, they create an environment in which they can exert the maximum control.

Do people with MS have to employ strategies which restructure the space within their physical environment?

Again, many of the respondents employed strategies to restructure the space within their physical environment. Home adaptations have been made. Moves to a more suitable home environment have been planned or executed. Tasks are divided into big and small jobs, wherein only one big job is tackled in a day. Some respondents are limited as to the number of rooms they access. Many require help to manage laundry tasks because the exertion required to go into the basement — the primary location for the washer and dryer for many of the fifteen respondents — is too extensive. Furniture is either set up to accommodate a wheelchair, or there is a visual idea as to how such items would be moved if a wheelchair became necessary. This last point has not yet been referred to in any great detail.

Ruth, who is wheelchair dependent has her condominium set up so that she can access all of the spaces with her chair. She has had her bedroom door removed and the

entrance widened. She has added a double door to the bathroom so that she can now get in with her chair. B.L. who has spent some time in a wheelchair before, recognizes that her condominium has too much furniture, but already knows how things would have to be moved if she ever had to spend time in a wheelchair again. Mr. Collins currently has his office and family room in the basement of his bungalow, but knows that when he is no longer able to navigate the stairs, he will be able to move these to the upstairs level.

In addition to this, Mr. Collins and his wife have modified their bungalow slightly so that he can manoeuver with his walking stick with minimal damage to himself or to the contents of the house. Mr. Collins has a tendency to lose his balance and fall. As a result, Mrs. Collins has made sure that nothing breakable is within his regularly traveled paths. The main dining room light fixture has been moved from the centre of the room towards the side so that there is a clear path from the kitchen to the back door so that Mr. Collins can easily access the back deck. There is also a visual plan in mind as to how the physical layout of the house would be modified should he ever be in a wheelchair.

REVIEW OF THE METHODOLOGY AND RESEARCH PROCESS

This research used a combination of qualitative and quantitative techniques, although the primary emphasis was qualitative. Quantitative techniques were used in order to identify potential respondents that would be contacted by mail to participate in this research. One of the original research questions, when the research was still in its infancy stage, was to see if people employed different strategies to deal with their space — at a preliminary level because the research was not intended to be representative — if they lived in areas that had a concentration of people with MS, from those people who were

more randomly distributed throughout the Region of Ottawa-Carleton. Using a location quotient, some census tracts were identified as showing a concentration of people with MS. From the 80 potential respondents that were contacted by mail to participate, a total of 20 people responded, from which 13 were interviewed. This recruitment method was much more successful than the strategy of giving potential respondents an information package at the time of their doctor's appointment during the MS Clinic's Clinic Days. From the 55 potential respondents contacted in this manner, only 2 agreed to participate. Given this lower rate of response, it was decided that even at a preliminary level, 2 respondents were insufficient to make even the most minimal comparisons. In spite of this, during the course of the interview process, it was determined that many other factors were more important in devising strategies than simply where the respondents happened to live.

In terms of its qualitative analysis, grounded theory was chosen over others — and here, I am only referring to those methods which rely on interviews. Interview styles vary in approach. Some use a structured interview guide where there is a sequence that must be followed. Others use a guide simply to help direct the research topics and questions as opposed to following any particular sequence. The responses given by participants can either be taped or notes are made during the interview. A taped interview can either be transcribed verbatim, or rather it is paraphrased by the researcher who only pays attention to capturing verbatim text for the purposes of quoting. The resulting data can be analyzed in a variety of ways using either an issue-focused approach or a case-focused approach. Issue-focused approaches deal with issues as they are learned through the experiences of

respondents. Case-focused approaches which deal with respondents as individual cases, or a case study approach.

Chapter 3 outlined why grounded theory was chosen over other qualitative techniques. One of grounded theory's requirements is that you do not approach the data with a pre-existing theory, of which I had none. I only had some conceptualizations of space; I was interested in seeing if they were reflected in the reality of real people as opposed to the intellectual creations of academics. Although I was approaching the data with these conceptualizations in mind, it did not make any difference to me if these fifteen respondents viewed their environment spatially or not. That was the whole point. Regardless of whether or not these respondents showed some tendencies to view their environment spatially, which most did, it would signal, at a preliminary level, that geographers would have to go back to the drawing board. If such spatial abstractions were absent from the realities of these people, then clearly the conceptualizations would have to be re-examined in that light, in terms of how geographers can characterize issues of space at the level of people who must deal with ongoing changes in their environment whether it be due to a chronic disease, disability, or age. Similarly, if spatial abstractions were present in their everyday lives, then geographers could learn from this in order to potentially strengthen their conceptualizations and definitions.

Relational space is still a relatively amorphous conceptualization. Scholars at all levels struggle with its definition and application. This research has done nothing to "solve" this problem. Rather, it has used this endeavour as a means to engage in the debate. Through the study of fifteen people who are affected by a chronic illness, it has

been possible to gain some insight into how they conceptualize their spatial environment. It was not possible in the interview process to ask these respondents explicitly spatial questions. Such an approach would have been confusing and unnecessarily full of jargon. Moreover, the full analytic capacities of grounded theory were not applied in terms of developing new theory. In fact, because it can be said that at a preliminary level geographers may be on the right track, then additional research at a more representative scale should be undertaken in order to determine how the existing conceptualizations can be theoretically strengthened as opposed to reinventing the wheel as grounded theory would have you do.

FUTURE DIRECTIONS AND CONCLUSION

The application of grounded theory has allowed this research to approach the lived experiences of fifteen people to see if geographical conceptualizations of space are reflected in their realities. At a preliminary level, it has been found that for these fifteen people, most view their world spatially in terms of how they are having to make adjustments to their previous attitudes and routines before they were affected by the onset of Multiple Sclerosis. Such adjustments must be made almost on a daily basis. However, this research, although it uses the example of people with MS, is relevant to other people affected by different chronic diseases, disabilities, or simply age. Only through a much wider study including participants from a variety of these different circumstances could this be fully understood. Such a task, in order to be done properly, would likely have to incorporate both quantitative and qualitative techniques to assure both reliability and validity.

This research has shown that people do relate to their environment spatially, especially when that environment is challenged on a daily basis due to a deterioration in health and mobility whether it is caused by a disease, a disability, or age. Although this finding is not representative, it does highlight a positive direction in which greater research is needed. Through similar studies, it will be possible to generate hypotheses that can be tested at a more representative scale. By relying on qualitative techniques to allow the respondents themselves identify what issues are important, and then implementing these experiences through questions using a much larger sample based on quantitative techniques, it may be possible to raise these initial insights into something concrete and theoretically sound.

APPENDIX A
LETTER OF SUPPORT TO ETHICS COMMITTEE

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

October 8, 1996.

*Clinique
de la sclérose
en plaques*

*Multiple
Sclerosis Clinic*

Pièce/Room 6371

Mike Tierney
Acting Chairman
Review Ethics Board
Ottawa General Hospital
Ottawa, Ontario

**RE PROTOCOL: Coping with Multiple Sclerosis:
Geographic Space as Construct and Constraint**

Dr. R.F. Nelson
Directeur/Director

Neurologues/
Neurologists

Dr. S. Christie
Dr. M.S. Freedman
Dr. H.E. Rabinovitch

Coordinatrices/
Coordinators

Lorraine Denis
Marie Benavente

The above-named protocol is being submitted to the Ethics Committee for review by Michelle Driedger for your consideration. Miss Driedger who is a student in the faculty of Geography at Carleton University will be carrying on this study through the Multiple Sclerosis Clinic at the Ottawa General Hospital. She will be assessing the relationship between environmental factors and the needs of patients with multiple sclerosis. In order to carry out this study, we will be providing her with access to the postal codes of our multiple sclerosis clinic population but she will not have access to their names or addresses. This will allow her to locate areas in which multiple sclerosis patients live so that she will be able to assess for clustering of these residents and this will help her determine the factors which may influence the localization of patients with disabilities. As a second part of her study, she will be interviewing 25 to 30 patients individually. Patients attending our Multiple Sclerosis Clinic will be made aware of the study and we will ask for volunteers from our Clinic population who may be interested in participating in this study.

I do not believe that there are any ethical problems associated with carrying out this study and I think that it will provide a lot of useful information which will be helpful to the MS population in the end. If you have any specific concerns not addressed in her submission please do not hesitate to contact me.

Yours sincerely,

Tel: (613) 737-8532
Fax: (613) 737-8857

Robert F. Nelson, M.D., F.R.C.P. (C).
Director,
Multiple Sclerosis Clinic.

/11

APPENDIX B

LETTER OF INTRODUCTION TO MS PATIENTS BY MS CLINIC

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

November 21, 1996

Dear Patient:

*Clinique
de la sclérose
en plaques*

*Multiple
Sclerosis Clinic*

Pièce/Room 6371

Dr. R.F. Nelson
Directeur/Director

Neurologues/
Neurologists

Dr. S. Christie
Dr. M.S. Freedman
Dr. H.E. Rabinovitch

Coordinatrices/
Coordinators

Lorraine Denis
Ute Webb

Travailleuse
sociale
Social Worker

Rina Eyre

Tel: (613) 737-8532
Fax: (613) 737-8857

RE PROTOCOL: Coping with Multiple Sclerosis: Geographic Space as Construct and Constraint

We are writing to you today on behalf of Michelle Driedger, a Masters student in Geography at Carleton University. Miss Driedger has submitted the above-named protocol to the Ethics Committee of the Ottawa General Hospital. This protocol has recently been approved by the Committee.

Miss Driedger will be carrying out this study through the Multiple Sclerosis Clinic. She will be assessing the relationship between environmental factors and the needs of patients with Multiple Sclerosis through interviews with consenting patients. I think that her research will provide a lot of useful information which will be helpful to the MS population in the end.

I am asking that you read the enclosed Patient Information Package. If you wish to participate in the study, please contact Miss Driedger at 613-231-7811. She will be able to answer all your questions and tell you more about what your participation will involve. If after this conversation you still want to participate, please sign the enclosed consent form and mail it to Miss Driedger in the envelope provided.

Please be assured that your confidentiality has been respected throughout this mailing. Regardless of your decision, the quality of care you receive at the Clinic will not be affected.

Thank you for your time.

Yours Sincerely

Dr. R. Nelson, M.D., F.R.C.P.(c),
Director
Multiple Sclerosis Clinic

Enclosure

APPENDIX C

INFORMATION PACKAGE GIVEN TO ALL POTENTIAL RESPONDENTS

Michelle Driedger
3rd Floor, Loeb Building
Department of Geography
Carleton University
1125 Colonel By Drive
Ottawa, Ontario
K1S 5B6

November 21, 1996

Dear Patient:

I am conducting a study on the coping strategies of people with Multiple Sclerosis. Specifically, I am interested in examining how people with MS make adjustments within their environments (eg. home, work, neighbourhood). This study has received approval by the Research Ethics Board of Ottawa General Hospital.

I would appreciate it if you would consider participating in this study by agreeing to be interviewed. The interview will take approximately 1.5 hours to 2 hours. We could meet in one or more sessions to complete the interview, whatever is most convenient for you. I would also conduct the interview at your home or at the hospital based solely on your preference.

I feel that by your participation, you will be able to help other researchers better understand the nature of how people with MS cope with their illness.

I would appreciate it if you would take a moment to read the patient information sheet. If you want to participate, please sign the attached consent form and return it in the self-addressed stamped envelope.

If you have any questions or concerns, please do not hesitate to contact me at 231-7811. Thank you for your time.

Yours Sincerely,

Michelle Driedger
M.A. Student, Carleton University

PATIENT INFORMATION SHEET

PURPOSE OF STUDY

The purpose of this study is to look at the various strategies that people with Multiple Sclerosis (MS) use to cope with their illness. Specifically, I am interested in examining how people with MS make adjustments within their environments (eg. home, work, neighbourhood).

ISSUES OF CONFIDENTIALITY

1. You are not identified within the study without your consent. In the actual write up of the research, a fictitious name will be used.
2. Any information revealed by you to the primary investigator will not be disclosed to any third party without your consent. Only the primary investigator will have full access to the data.
3. You can withdraw consent and stop participation in the study at any time and for any reason, and such action will not affect the quality of ongoing and future care.

WHAT KIND OF INCONVENIENCE YOU CAN EXPECT AS A RESULT OF PARTICIPATING IN THE STUDY?

- The means of data collection will be through interviews. With your permission, I will be taping the interviews.
- The interview will last anywhere from 1.5 hours to 2 hours. The interview can be divided into as many sessions as needed to accommodate your wishes.
- Interviews can be conducted at either your home or at the Ottawa General Hospital, depending on which is the most convenient for you.

BENEFITS OF PARTICIPATION

Your participation will help other researchers understand the complex nature of MS and the types of strategies that are used by people with MS to cope with the disease. To some extent it may indicate where greater support and assistance is needed.

FURTHER QUESTIONS OR CONCERNS

If you should have any further questions or concerns about this research project, please do not hesitate to contact either:

- The Principal Investigator, Michelle Driedger, at 231-7811; or
- The Chairperson of the Ottawa General Hospital Research Ethics Board at 737-8930.

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

135

PATIENT CONSENT FOR MEDICAL RESEARCH

Name of Research Project:

Coping With Multiple Sclerosis: Geographic Space as Construct and Constraint

I confirm that I have explained the nature of and known complications of the research project to the patient.

(Researcher)

I consent to the participation of:

Patient's Name

Research No.

in the above study and I hereby authorize the investigator to proceed with the interviews.

I have read the detailed information sheet approved by the Research Ethics Board and am aware of the time involved and any inconveniences.

I have been given an opportunity to ask questions concerning the interviews and the questions which I have asked have been adequately answered.

I have been told that I can withdraw consent and stop participation in the study at any time and for any reason, and such action will not affect the quality of ongoing and future care.

This protocol has been approved by the Research Ethics Board of the Ottawa General Hospital. The Board considers the ethical aspects of all hospital research projects using human subjects. If I wish, I may contact the Chairperson of the Board with questions at 737-8930.

Name (Print)

Signature

Date (D/M/Y)

APPENDIX D

OTTAWA GENERAL HOSPITAL RESEARCH ETHIC BOARD APPROVAL

Conseil d'éthique en recherches
737-8930

Research Ethics Board
APPROVAL 1996

HÔPITAL GÉNÉRAL D'OTTAWA OTTAWA GENERAL HOSPITAL

November 19, 1996

Dr. R. Nelson
Department of Neurology
Ottawa General Hospital

Dear Dr. Nelson:

RE: OGH-96-103 Coping with Multiple Sclerosis: Geographic Space as Construct and Constraint

The Research Ethics Board has reviewed your response to a letter of concerns that you submitted on the above protocol.

I am pleased to inform you that the REB finds these revisions and the revised Patient Information Sheets dated November 18, 1996 to be acceptable with respect to the ethics of research with human subjects and has therefore approved this protocol from November 1996 to November 1997.

The new guidelines of the Medical Research Council require a greater involvement of the REB in studies over the course of their execution. You must maintain, as part of your records, copies of the signed consent form. As well, you must inform the REB of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the REB review, either of which may impinge on the ethics of continuing the study. The REB will review the new information to determine if the protocol would be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Mike Tierney, M.Sc.
Chairman
Research Ethics Board

MT/ram

cc: Michelle Driedger

Ottawa General Hospital Research Institute

501 Smyth, Ottawa, Ontario K1H 8L6 (613) 737-7777

APPENDIX E
CARLETON UNIVERSITY ETHICS APPROVAL

memorandum

Office of Research Services
Faculty of Graduate Studies and Research
Dunton Tower, Room 1501
Tel.: 520-2516; Fax: 520-2521

DATE: November 19, 1996

TO: Professors David Bennett
Department of Geography

FROM: Anne Burgess
Director of Research Services

RE: Ethics Clearance

I am writing to confirm that S. Michelle Driedger's research proposal ("Coping with Multiple Sclerosis: Geographic Space as Construct and Constraint") has been reviewed by the University Ethics Committee, and has been found to be ethically acceptable.

A.B.
MM

c.c. ✓ S. Michelle Driedger, Dept. of Geography

APPENDIX F

LIST OF PREPARED QUESTIONS USED IN INTERVIEWS

INTERVIEW # _____

Do you live alone? Y N

Do you own or rent? OWN RENT

How long have you lived at the present address? _____

Have you had to move within the last 5 years? Y N

From within Ottawa? Y N

From outside Ottawa? Y N

What is your marital status? _____

What is your year of birth? _____

Have you ever participated in the paid work force? Y N

If so, in what type of employment? _____

How long were you employed (if not currently employed)? _____

OR Are you currently employed? Y N

In what type of employment? _____

Would you say your average monthly income (including all sources) is:

- less than \$1,000?

- between \$1,000 and \$1,499?

- between \$1,500 and \$1,999?

- more than \$2,000?

Do you have any children? Y N

If so, how many? _____ Male? _____ Female? _____

Do these children still live with you? Y N

Do they live in the same city? Y N

Do you have close family that you can call upon for help? _____

REFERENCES

- Agnew, John and David Livingstone and Alisdair Rogers, eds. 1996. "General Introduction" in *Human Geography: An Essential Anthology*. Oxford: Blackwell Publishers, pp.1-16.
- Aronson, Kristan, Ellie Goldenberg and Graham Cleghorn. 1996. "Socio-Demographic Characteristics and Health Status of Persons with Multiple Sclerosis and their Care Givers" in *MS Management* Vol.3, No.1, pp.1,6-15.
- Baum, Frances. 1995. "Researching Public Health: Behind the Qualitative-Quantitative Methodological Debate" in *Social Science and Medicine*. Vol.40, No.4, pp.459-468.
- Barrett, Jackie. 1995. "Multiple Sclerosis: The Experience of a Disease" in *Women's Studies International Forum*. Vol.18, No.2, pp.159-171.
- Bennett, Louise, Ruth Hamilton, Ineke Neutel, John Pearson, and Bernard Talbot. 1977. "Survey of Persons with Multiple Sclerosis in Ottawa, 1974-75" in *Canadian Journal of Public Health*, Vol.68, No.2, pp.141-147.
- Blaut, J.M. 1961. "Space and Process" in *Professional Geographer*. Vol.13, No.4, pp.1-7.
- Brooks, Nancy and Ronald Matson. 1982. "Social-Psychological Adjustment to Multiple Sclerosis" in *Social Science and Medicine*. Vol.16, No.24, pp.2129-2135.
- . 1977. "Adjusting to Multiple Sclerosis: An Exploratory Study" in *Social Science and Medicine*. Vol. 11, No. 4, pp.245-250.
- Burawoy, Michael. 1991a. "Introduction" in *Ethnography Unbound: Power and Resistance in the Modern Metropolis*. Michael Burawoy, et al. Berkley: University of California Press, pp.1-7.
- . 1991b. "Reconstructing Social Theories" in *Ethnography Unbound: Power and Resistance in the Modern Metropolis*. Michael Burawoy, et al. Berkley: University of California Press, pp.8-27.
- . 1991c. "The Extended Case Method" in *Ethnography Unbound: Power and Resistance in the Modern Metropolis*. Michael Burawoy, et al. Berkley: University of California Press, pp. 271-287.
- Bury, Michael. 1991. "The Sociology of Chronic Illness: A Review of Research and Prospects" in *Sociology of Health and Illness*. Vol.13, No.4, pp.451-468.

- . 1982. "Chronic Illness as Biographical Disruption" in *Sociology of Health and Illness*. Vol.4, No.2, pp.167-182.
- Charmaz, Kathy. 1991. *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick: Rutgers University Press.
- . 1990. "'Discovering' Chronic Illness: Using Grounded Theory" in *Social Science and Medicine*. Vol.30, No.1, pp.1161-1172.
- . 1983. "Loss of Self: A Fundamental Form of Suffering in the Chronically Ill" in *Sociology of Health and Illness*. Vol.5, No.2, pp.168-195.
- Cockerham, William, Kimberly Sharp and Julia Wilcox. 1983. "Aging and Perceived Health Status" in *Journal of Gerontology*. Vol.38, No.3, pp.349-355.
- Craddock, Susan. 1995. "Sewers and Scapegoats: Spatial Metaphors of Smallpox in nineteenth Century San Francisco" in *Social Science and Medicine*. Vol.41, No.7, pp.957-968.
- Curry, Michael. 1996. "On Space and Spatial Practice in Contemporary Geography" in *Concepts in Human Geography*. Carville Earle, Kent Mathewson and Martin Kenzer, eds. USA: Rowman and Littlefield Publishers Inc., pp.3-32.
- Curtis, Sarah and Ann Taket. 1996. *Health and Societies: Changing Perspectives*. London: Arnold.
- Denis, Lorraine. MS Clinic Coordinator. Personal Communication, April 7, 1997.
- Duncan, Craig, Kelvyn Jones and Graham Moon. 1993. "Do Places Matter? A Multi-Level Analysis of Regional Variations in Health-Related Behaviour in Britain" in *Social Science and Medicine*. Vol.37, No.6, pp.725-733.
- Dyck, Isabel. 1995. "Hidden Geographies: The Changing Lifeworlds of Women with Multiple Sclerosis" in *Social Science and Medicine*. Vol.40, No.3, pp.307-320.
- Dyck, Isabel, Judith Lynam and Joan Anderson. 1995. "Women Talking: Creating Knowledge Through Difference in Cross-Cultural Research" in *Women's Studies International Forum*. Vol. 18, No. 5-6, pp.611-626.
- Evers, Kaylene and Wally Karnilowicz. 1996. "Patient Attitude as a Function of Disease State in Multiple Sclerosis" in *Social Science and Medicine*. Vol.43, No.8, pp.1245-1251.
- Eyles, John. 1993. "From Disease Ecology and Spatial Analysis to...? The Challenges of Medical Geography in Canada" in *Health and Canadian Society*. Vol.1, No.1, pp.113-145.

- . 1990. "How Significant are the Spatial Configurations of Health Care Systems" in *Social Science and Medicine*. Vol.30, No.1, pp.157-164.
- . 1988. "Interpreting the Geographical World: Qualitative Approaches in Geographical Research" in *Qualitative Methods in Human Geography*. John Eyles and David Smith eds. Cambridge: Polity Press.
- Eyles, John and Kevin Woods. 1983. *The Social Geography of Medicine and Health*. London: Croom Helm.
- Fischer, Lucy Rose. 1994. "Qualitative Research as Art and Science" in *Qualitative Methods in Aging Research*, Jaber Gubrium and Andrea Sankar eds. Thousand Oaks, California: Sage Publications.
- Fife, Betsy. 1994. "The Conceptualization of Meaning in Illness" in *Social Science and Medicine*. Vol.38, No.2, pp.309-316.
- Flax, Jane. 1987. "Postmodernism and Gender Relations in Feminist Theory" in *Signs*. Vol. 12, No.4, pp.621-643.
- Garro, Linda. 1994. "Narrative Representations of Chronic Illness Experience: Cultural Models of Illness, Mind and Body in Stories Concerning the Temporomandibular Joint (TMJ)" in *Social Science and Medicine*. Vol.38, No.6, pp.775-788.
- Gesler, Wilbert. 1992. "Therapeutic Landscapes: Medical Issues in Light of the New Cultural Geography" in *Social Science and Medicine*. Vol.34, No.7, pp.735-746.
- . 1986. "The Uses of Spatial Analysis in Medical Geography: A Review" in *Social Science and Medicine*. Vol.23, No.10, pp.963-973.
- Gleeson, B.J. 1996. "A Geography for Disabled People?" in *Transactions of Institute of British Geographers*. Vol. 21, No.2, pp.387-396.
- Golledge, Reginald. 1996. "A Response to Gleeson and Imrie" in *Transactions of Institute of British Geographers*. Vol. 21, No.2, pp.404-411.
- . 1993. "Geography and the Disabled: A Survey With Special Reference to Vision Impaired and Blind Populations" in *Transactions of Institute of British Geographers*. Vol. 18, No.1, pp.63-85.
- Graham, Judy. 1989. *Multiple Sclerosis: A Self Help Guide to its Management*. Rochester: Healing Arts Press.

- Gregory, Derek and John Urry. 1985. "Introduction" in *Social Relations and Spatial Structures*, Derek Gregory and John Urry eds. London: Macmillan Publishers Ltd., pp.1-8.
- Harding, Sandra. 1992. "Subjectivity, Experience and Knowledge: An Epistemology from/for Rainbow Coalition Politics" in *Development and Change*. Vol. 3, pp.175-193.
- . 1987. "Introduction: Is There a Feminist Method?" in *Feminism and Methodology*, S. Harding, ed. Bloomington: Indiana University Press.
- Harvey, David. 1994. "The Social Construction of Space and Time: A Relational Theory" in *Geographical Review of Japan*. Vol.67, No.2, pp.126-135.
- . 1973. *Social Justice and the City*. Baltimore: John Hopkins University Press.
- Imrie, Rob. 1996. "Ableist Geographies, Disablist Spaces: Towards a Reconstruction of Gollidge's 'Geography and the Disabled'" in *Transactions of Institute of British Geographers*. Vol. 21, No.2, pp. 397-403
- Internet: <http://aspin.asu.edu/msnews/ms1.htm>
- Internet: <http://www.ifmss.org.uk/faqs/contents.htm>
- Jaffe, Dale and Eleanor Miller. 1994. "Problematizing Meaning" in *Qualitative Methods In Aging Research*. Jaber Gubrium and Andrea Sankar, eds. Thousand Oaks, California: Sage Publications Inc.
- Johnston, R.J. 1983. *Geography and Geographers: Anglo-American Human Geography since 1945* 2nd Edition. London: Edward Arnold (Publishers) Ltd.
- Jones, Kelvyn and Graham Moon. 1993. "Medical Geography: Taking Space Seriously" in *Progress in Human Geography*. Vol.17, No.4, pp.515-524.
- . 1987. *Health Disease and Society: A Critical Medical Geography*. London: Routledge & Kegan Paul.
- Jones, Sue. 1985. "The Analysis of Depth Interviews" in *Applied Qualitative Research*, Robert Walker ed. Aldershot: Gower Publishing, pp.56-70.
- Kaufman, Sharon. 1994. "In-Depth Interviewing" in *Qualitative Methods In Aging Research*. Jaber Gubrium and Andrea Sankar, eds. Thousand Oaks, California: Sage Publications Inc.

- Kearns, Robin. 1995. "Medical Geography: Making Sense for Difference" in *Progress in Human Geography*. Vol. 19, No.2, pp.251-259.
- Kearns, Robin and Alun Joseph. 1993. "Space in its Place: Developing the Link in Medical Geography" in *Social Science and Medicine*. Vol.37, No.6, pp.711-717.
- Keith, Jennie. 1994. "Consequences for Research Procedure" in *Qualitative Methods In Aging Research*. Jaber Gubrium and Andrea Sankar, eds. Thousand Oaks, California: Sage Publications Inc.
- Lefebvre, Henri. 1991. *The Production of Space*. Oxford: Blackwell Publishers.
- Levy, Ron. 1993. "Believability and Doubtfulness: A Paradigmatic View of Qualitative Methods" in *Canadian Journal on Aging*. Vol.12, No.2, pp.233-243.
- Liang, Jersey. 1986. "Self-Reported Physical Health Among Aged Adults" in *Journal of Gerontology*. Vol.41, No.2, pp.248-260.
- Litva, Andrea and John Eyles. 1995. "Coming Out: Exposing Social Theory in Medical Geography" in *Health and Place*. Vol. 1, No.1, pp.5-14.
- Lock, Margaret and Gilles Bibeau. 1993. "Healthy Disputes: Some Reflections on the Practice of Medical Anthropology in Canada" in *Health and Canadian Society*. Vol.1, No.1, pp.147-175.
- Massey, Doreen. 1985. "New Directions in Space" in *Social Relations and Spatial Structures*, Derek Gregory and John Urry eds. London: Macmillan Publishers Ltd., pp. 9-19.
- 1984. "Introduction: Geography Matters" in *Geography Matters! A Reader*. Doreen Massey and John Allen, eds. Cambridge: Cambridge University Press, pp.1-11.
- McColl, Mary-Ann, Hau Lei and Harvey Skinner. 1995. "Structural Relationships Between Social Support and Coping" in *Social Science and Medicine*. Vol. 41, No.3, pp.395-407.
- McCracken, Grant. 1988. *The Long Interview*. Newbury Park, California: Sage Publications
- McLaughlin, Judith and Ib Zeeberg. 1993. "Self Care and Multiple Sclerosis: A View From Two Cultures" in *Social Science and Medicine*. Vol.37, No.3, pp.315-329.
- Meade, Melinda, John Florin and Wilbert Gesler. 1988. *Medical Geography*. New York: The Guilford Press.

- Mechanic, David. 1995a. "Sociological Dimensions of Illness Behaviour" in *Social Science and Medicine*. Vol.41, No.9, pp.1207-1216.
- . 1995b. "Emerging Trends in the Application of the Social Sciences to Health and Medicine" in *Social Science and Medicine*. Vol.40, No.11, pp.1491-1496.
- Mohanty, Chandra. 1991. "Under Western Eyes: Feminist Scholarship and Colonial Discourses" in *Third World Women and the Politics of Feminism*, C. Mohanty, A. Russo and L. Torres, eds. Bloomington: Indiana University Press.
- Monk, Janice and Cindi Katz. 1993. "When in the World are Women?" in *Full Circles: Geographies of Women over the Life Course*. Cindi Katz and Janice Monk eds. London and New York: Routledge. pp.1-26.
- Moon, Graham. 1995. "(Re)Placing Research on Health and Health Care" in *Health and Place*. Vol.1, No.1, pp. 1-4.
- . 1990. "Conceptions of Space and Community in British Health Policy" in *Social Science and Medicine*. Vol.30, No.1, pp.165-171.
- Parpart, Jane. 1991. "Who is the "Other"?: A Postmodern Critique of Development Theory and Practice" in *Development and Change*. Vol. 24, pp.439-464.
- Pearlin, Leonard and Carmi Schooler. 1978. "The Structure of Coping" in *Journal of Health and Social Behaviour*. Vol. 19 (March) pp.2-21.
- Picheral, Henri. 1994. "Editorial: Place, Space and Health" in *Social Science and Medicine*. Vol.39, No.12, pp.1589-1590.
- Pratt, Geraldine and Susan Hanson. 1993. "Women and Work Across the Life Course: Moving Beyond Essentialism" in *Full Circles: Geographies of Women over the Life Course*. Cindi Katz and Janice Monk eds. London and New York: Routledge. pp. 27-54.
- Radley, Alan and Ruth Green. 1987. "Illness as Adjustment: A Methodology and Conceptual Framework" in *Sociology of Health and Illness*. Vol.9, No.2, pp.179-207.
- Reinharz, Shulamit. 1986. "Friends or Foes: Gerontological and Feminist Theory" in *Women's Studies International Forum*. Vol. 4, No. 5, pp.503-514.
- Robinson, Ian. 1988. *Multiple Sclerosis*. London: Routledge.

- Russell, Susan. 1989. "From Disability to Handicap: An Inevitable Response to Social Constraints?" in *Canadian Review of Sociology and Anthropology*. Vol. 26, No. 2, pp.276-293.
- Sauerborn, R., A. Adams and M. Hein. 1996. "Household Strategies to Cope With the Economic Costs of Illness" in *Social Science and Medicine*. Vol.43, No.3, pp.291-301.
- Sayer, Andrew. 1985. "The Difference that Space Makes" in *Social Relations and Spatial Structures*, Derek Gregory and John Urry eds. London: Macmillan Publishers Ltd., pp. 49-66.
- Scarpaci, Joseph. 1993. "On the Validity of Language: Speaking, Knowing, and Understanding in Medical Geography" in *Social Science and Medicine*. Vol.37, No.6, pp.719-724.
- Schwartz, Carolyn and Bernard Fox. 1995. "Who Says Yes? Identifying Selection Bias in a Psychosocial Intervention Study of Multiple Sclerosis" in *Social Science and Medicine*. Vol.40, No.3, pp.359-370.
- Sheridan, Peter. 1996. "Classification and Categories in MS" in *MS Management*, Vol.3, No.1, pp.3-5.
- Soja, Edward. 1989. *Postmodern Geographies: The Reassertion of Space in Critical Social Theory*. New York: Verso.
- . 1985. "The Spatiality of Social Life: Towards a Transformative Retheorisation" in *Social Relations and Spatial Structures*, Derek Gregory and John Urry eds. London: Macmillan Publishers Ltd., pp. 90-127.
- Strauss, Anselm. 1987. *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.
- Twaddle, Andrew. 1974. "The Concept of Health Status" in *Social Science and Medicine*. Vol.8, No.1, pp.29-38.
- Urry, John. 1985. "Social Relations, Space and Time" in *Social Relations and Spatial Structures*, Derek Gregory and John Urry eds. London: Macmillan Publishers Ltd., pp. 20-48.
- Verhasselt, Yola. 1993. "Geography of Health: Some Trends and Perspectives" in *Social Science and Medicine*. Vol.36, No.2, pp.119-123.
- Weiss, Robert. 1994. *Learning From Strangers: The Art and Method of Qualitative Interview Studies*. New York: The Free Press, a Division of Macmillan, Inc.

- Williams, Rory. 1983. "Concepts of Health: An Analysis of Lay Logic" in *Sociology*. Vol.17, No.2, pp.185-205.
- Yates, Patsy et al. 1993. "Patients with Terminal Cancer who use Alternative Therapies: Their Beliefs and Practices" in *Sociology of Health and Illness*. Vol.15, No.2, pp.199-216.
- Zola, Irving. 1993. "Self, Identity and the Naming Question: Reflections on the Language of Disability" in *Social Science and Medicine*. Vol.36, No.2, pp.167-173.
- . 1991. "Bringing Our Bodies and Ourselves Back In: Reflections on a Past, Present and Future 'Medical Sociology'" in *Journal of Health and Social Behaviour*. Vol.32, No.1, pp.1-16.