To the Graduate Council:
I am submitting herewith a dissertation written by Stephen J. Page entitled "Hidden Traumas: The Experience of Multiple Sclerosis." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Human Performance and Sport Studies.

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HIDDEN TRAUMAS: THE EXPERIENCE OF MULTIPLE SCLEROSIS

A Dissertation

Presented for the

Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Stephen John Page

May, 1998

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ACKNOWLEDGEMENTS

I would like to express my deepest appreciation to a number of individuals who have provided assistance, inspiration, and encouragement thoughout the stages of completion of this project:

Craig Wrisberg has provided me with editorial criticism, encouragement for the development of my ideas, and continuous support throughout my program. These are significant contributions to the growth of any student...yet they only tell a small part of the story. This dissertation is, in part, about the qualitative ways in which things are done - and redone - in time. Perhaps it is fitting, then, that the most important changes in my entire life have come during the past three years under his kind, unassuming, and gentle example. Truly Dr. Wrisberg has mastered the incredible balancing act of providing me with enough freedom to find my own voice and become my own researcher and independent thinker...yet, at the same time, he has somehow managed to gently guide me with his nature and example. With all of my heart I thank you, Dr. Wrisberg.

Wendell Liemohn and Gene Hayes have served as my "experts" concerning people with disabilities, both for this project and during the past three years, and I wish to thank each of them for their accessibility, and for providing me with countless academic and practical experiences with people with disabilities. I also wish to acknowledge, though, the very applied and pragmatic approaches that they take to

working with people with disabilities and the very human ways in which they do it. I deeply respect individuals who do not remain in "an ivory tower," but who are as devoted as each of you are to people with disabilities, and I appreciate the very practical and "hands-on" approach that each of you have instilled in me.

Lastly, I thank Sandra Thomas, who has not only provided helpful critical comments for this project, but who has been a warm, positive, and encouraging colleague influential in my development as a qualitative researcher. Please know, Dr. Thomas, that our exchanges have been stimulating and rewarding for me, and I hope to occasionally return to campus and continue them as a participant in your research group no matter where I am.

I also wish to acknowledge the following people whose words or examples have influenced this project in particular and my work and me in general: Howard Pollio, Pat Beitel, Handel Wright, Valerie Wayda, Keith Beckett, Rod Korba, Walter and Barbar Hauser, John Page, and the members of the Qualitative Interdisciplinary Research Group. To all of you I say with all of my heart that I probably could have gone to other universities and gotten an advanced degree and been productive...but I can not imagine another place where, I, as a person, could have gained so much. Your examples shall be missed but never forgotten.

ABSTRACT

While it is true that individuals with disabilities have made strides in their acceptance in occupational, social, and sportive contexts in the past two decades, disabilities still present both measurable changes in one's negotiation of the world on a superficial level and qualitative changes in the ways one deals with the world. Because of the nature of these changes, the experience of becoming disabled is not always quantifiable or measurable. Hence, the purpose of this study was to examine the experience of multiple sclerosis, and, secondarily, to qualitatively examine the phenomenon of disability using a pheneomenological approach. Six participants with multiple sclerosis were queried regarding their experiences of the loss or compromise in movement and in vitality as a result of the onset of their disease. Thematic analysis of the transcribed interviews revealed that participants were concerned with the notions of certainty and uncertainty in time, becoming or changing in time, the perceptions of others about their disability, and the alienation from others that their disability caused. Implications for caregivers and family members of individuals with multiple sclerosis are discussed.

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PREFACE

A Unified Journey

Prior to studying at The University of Tennessee I was exposed to research methodologies at schools with strong but very quantitative research traditions. Although this was in many ways beneficial, consistent exposure to such a view also necessarily causes one's view of research and of the world to each become very Western, conservative, and outcome-oriented.

An interesting thing happened to me as I progressed through my education and through the preparation for this project, however. Through life and death and through my educational and life experiences while here at UT, I was exposed to the "alternative" viewpoints espoused by Post-Modernism, social constructionism, and so on. Through all of this I learned the rather non-Western notion that outcomes are uncertain and often unimportant, and that it is often beter to look instead for meaning in the unstructured journey that one experiences.

Movement can be defined literally or figurally as the action of negotiating a medium towards a goal. As I finished the discussion section of this paper I realized that, although it was originally intended to address the notion of movement, this dissertation experience and its topic were more about progression and about "getting there" - both for me and for the participants - and less about physical movement. Specifically, this

dissertation is a reflection of a change in life and in personal orientation which resulted in me learning and employing a new methodology to my research and to my work, and wondering how or where it would all end; perhaps it is fitting that, in my culminating work at UT, learning, re-learning, uncertainty, and adjusting to change were each themes which emerged from the conveyed experiences of the participants of this study.

CHAPTER I

INTRODUCTION

"I want you to realize that there is no color in the natural world and no sound - nothing of this kind; no textures, no patterns, no beauty, no scent...in short, none of the objective facts upon which we usually base our reality is fundamentally valid without perception and experience"

British neurologist Sir John Eccles

In April of 1996 I received a memorable telephone call from my father. After the usual pleasantries and discussion of the goings-on of my sisters and brother he paused, finally blurting out, "I had a few tests done at the doctor...I have cancer in my lymph nodes and salivary glands on the left side of my face." He then paused again and, after a moment, began with a number of confusing disclaimers: "Don't worry, I can still hear; there's just a hole on the side of my head with a patch over it; I can still walk." These were confounding admissions to me until he subsequently whispered in an explaining manner, "They had to remove my left ear and graft skin from my leg to cover the missing skin on my head."

As you can imagine, following that conversation, my relationship with my father changed in a substantial, qualitative way until he passed

away the following April. Keep in mind that, if a physician were to administer any quantitative test or battery to my father measuring his hearing, his movement, or his cognitive abilities, my father would have appeared "healthy" from a third person perspective. Yet, during the final year of his life, as he lived with cancer, my father also exhibited a qualitative change in the ways in which he viewed and negotiated his world. Of course we became closer; most family members become more intimate when a relative is terminally ill. Yet, whereas before he was usually not concerned about the opinions of others, he became extremely vigilant of others and concerned about others' perceptions of him when he would accompany me to lunch or to school functions with a large, white patch on his head and a cane to assist his walking. Additionally, although my father could still hear perfectly and had this patch covering the area where his ear was removed, he was nonetheless ademate about getting a prosthetic replacement for his ear, confiding that he was "just not the same person that he used to be."

The Lived Experience of Disability

Of course, what my father was expressing was a first-person, qualitative shift in the ways in which he was experiencing his body, his illness, and, consequently, his world. These differences are each ultimately linked to what Pollio, Henley, and Thompson (1997) termed

the first and third person conceptualizations of "the lived body." In illness, the lived body becomes transformed and, at the level of consciousness and immediate experience at which we all live, bodily dysfunction necessarily causes a disturbance in the interactions between consciousness and the world. As a result, illness represents a dis-ability; an "inability to" engage the world in habitual ways. In short, the ways in which one typically negotiates the world and becomes a person in the world, such as through work, school, and activities, is compromised and a disturbance between everyday consciousness and the world occurs. For my grandfather, for example, arthritis represented not so much a disturbance in the limbs as it did the "inability to" button a shirt, swing a golf club, or run. In the event that the disability relates to death or is chronic, such as with chronic-progressive multiple sclerosis, the experience of disability not only relates to one's immediate engagement in the world, but also to his/her "inability to" carry out future goals.

In an illness like multiple sclerosis, body intentionality is also disturbed (Pollio, et al., 1997). Objects which were once grasped and able to be used now present themselves as problems to the body. Things such as stairs, doorways, and the like which were once traversible now take considerable effort with rests in between attempts and, perhaps, represent obstacles rather than entries. The relationship between the lived body and the environment is also changed in that the world is experienced

differently; with MS, what was once a sunny and warm day during which one could go outside, exercise, and sunbathe is now to be avoided because of the deleterious effects of heat; the touch of certain materials on the skin might be unpleasant or elicit an allergic reaction; a short walk to the restroom might cause hours of fatigue. As a result, body image changes, not only in terms of things like posture and gait, but in the sense that one no longer has available an open system because the alternatives once available in health are no longer available.

Illness also affects the body's gestural display, thereby affecting one's interactions with others. This change may be perceived by others as merely a "look" of sickness, or as a brooding glance which discourages them from interaction. In addition, gestural displays such as weeping, laughing, crying, or falling may be experienced as uncontrollable and inappropriate by the patient, but may be misunderstood and disparaged by others (this is especially common to multiple sclerosis patients). These displays can be especially frustrating to patients, not only because they represent a signifier of locus of control to themselves, but also because they can also represent poor self-presentation to others.

I have also seen examples in which an individual's social world has been changed by disability. Indeed, the onset of a disability can result in an individual becoming relegated to a lesser role in social environments such as the workplace, sporting environments, or even in

relationships because of the stigma that is often associated with the term, "disabled." Not surprisingly, a number of authors have likewise considered disability to be a limitation to the psychosocial interactions which a person can have with his/her environment, suggesting that variables such as an individual's impaired body experience and the stigmatizing attitudes of society explain these limitations. Typical psychological phenomena can thus be observed in individuals with disabilities, resulting from the interplay between their individual personality structures and the unique environmental and social problems confronting them (Melvin & Nagi, 1970; Schontz, 1978). In his article, "Breaking Barriers and Changing Attitudes," wheelchair athlete Duncan Wyeth (1989) terms this figural (but very real) location as the "disability ghetto;" a "shared experience rather than an actual place" characterized by "poverty, unemployment, and lack of socialization," and mediated by the social and economic circumstances in which many individuals with disabilities find themselves.

It is believed that societal conceptions of what comprises a "healthy" and "unhealthy" human body, and the limited quantity and quality of opportunities available to individuals with disabilities compared to nondisabled individuals in the workforce, in participatory contexts such as sports, and in terms of accessibility to public facilities have each proliferated and maintained the "disability ghetto." Dunn &

Fait (1989) suggested that the disability ghetto may be caused by "a general tendency for the public, educators, and even some medical personnel to equate the terms 'disability' and 'sickness.'" (p. 520). Likewise, sociologists have commented that, although the development of a disability is typically the result of a trauma or a change in an individual's biology, historically the connection between aging and/or the development of a disability and movement is a socially embedded dialogue that occurs and that it:

> depends on the meaning given to those changes...People with most forms of physical or mental disability during (recent historical) time were either denied the opportunity to participate or actively discouraged from engaging in most activity... (Coakley, 1994, p. 72)

Science and the differential meanings of "illness" for the physician and patient

In addition to the social meaning that being disabled often carries, in discussing both my own illness of hemophilia with physicians and my father's illness with physicians, it has often seemed to me that we were talking about seemingly different topics, never quite reaching one another, so that there is also a referential or meaning difference that is associated with becoming disabled. This inability to communicate did not

result from inattentiveness or insensitvity on either person's part, but from a fundamental disagreement about the nature of illness. In particular, rather than representing a shared reality between us, I realized that illness represented two fundamentally different realities for the physician, myself, and my father. This difference is best described as a difference between the scientific, positivist view that posits that a body is like a machine that can be "fixed," and is common (and, perhaps, even necessary) for physicians, and the experiential view that is common to the "rest of us" who subjectively feel and experience the phenomenon of being ill or in pain. Interestingly, though, despite the need to be empathetic and patient-centered, it is more often the former which pervades most medical journals rather than the latter, which would seemingly provide more meaningful ways of working with patients.

In explicating the differential views that physicians and patients seem to often exhibit, Schultz (1962a) noted that what one attends to depends on the endeavors in which one is engaged and the "system of relevances" that are a function of one' life plan. In particular, Schultz (1962a) noted that one's everyday life, and the experiences in that life, are governed by what he termed the "pragmatic motive;" the individual selects as being of primary importance those objects which actually are or will become in the future possible ends or means for the realization of endeavors, or which are or will become dangerous or enjoyable or

otherwise relevant. While engaging in a scientific project, the scientist adopts a system of relevances which are governed by "stating the problem at hand" (Schultz, 1962b, 37). In being trained to consider what is "at hand," scientists are taught a reality that influences all that they do; this reality defines what is considered relevant and guides the process of inquiry for the scientist. In attending to the experience of illness, then, the physician does so in light of scientific training and its ideologies. In so doing, he or she focuses on the disease process itself. Consequently, the clinical data are of highest relevance. In contrast to this viewpoint is the viewpoint of the patient, who is less concerned with the objective clinical data and more concerned with the effect that the illness will have on daily life.

Leo Tolstoy, in his book The Death of Ivan Ilych, captured this difference in orientation:

> To Ivan Ilych only one question was important: Was his case serious or not? But the doctor ignored that inappropriate question. From his point of view it was not the one under consideration, the real question was to decide between a floating kidney, chronic catarrh, or appendicitis...All the way home (Illych) was going over what the doctor had said, trying to translate those complicated, obscure, scientific phrases into plain language and find in them an

answer to the question: "Is my condition bad? Is it very bad? Or is there as yet nothing wrong?" (Tolstoy, 1978, pp. 520-521).

Since "the problem at hand" is defined differentially and, as a result, reacted to differently by physician and patient, we must remember that the physician and patient do not share a system of relevances. It is clear, for example, that the experience of illness is such that one comes face to face with one's own vulnerability and mortality. One reacts to the "news" of illness, such as terminal cancer, accordingly. The physician, on the other hand, is attending to the patient's experience of illness according to the system of relevances which are a function of scientific training. In this respect, the physician focuses on the clinical data as "knowledge" rather than"news," in order to determine what actions or medical interventions may be possible.

Multiple Sclerosis

One type of illness that requires a great deal of interaction with physicians and other individuals with a scientific perspective, and that confounds the experience of the lived body for the patient, is multiple sclerosis. Multiple sclerosis (MS) is a progressive demyelinating disease that produces lesions in the white matter of the central nervous system (CNS). Some of the manifestations of MS include speech difficulties,

sensory disturbances, motor disturbances, and partial paralysis (Auxter, Pyfer, & Huettig, 1993). Slowness of thought and, more specifically, of information processing capabilities has been listed as a concomitant of MS since the writings of Charcot in 1877, in which he described patients as exhibiting "conceptions (which) formed slowly;" a symptom later termed "subcortical dementia" by Albert, Feldman, and Willis (1974). Albert et al. (1974) theorized that, although the subcortical structures involved may differ, lesions in these areas produce impaired timing and activation and a slowing down of normal intellectual processes. Cortical systems responsible for perceiving, storing, and manipulating knowledge may be intact, but they may be abnormally activated. Moreover, once activated, they may take an excessive amount of time to carry out intellectual processing. This means that the observable results of subcortical dementia include slowing of mental processes and impaired ability to manipulate acquired knowledge, although learning processes remain intact. Hence, knowledge gained prior to the onset of the disease, such as the ability to execute a motor skill, is generally still existent in individuals with MS, but spontaneous use of this stored information is compromised (Benson, 1983; Cummings & Benson, 1983).

A more thorough review of MS, its cognitive and physical concomitants, and the qualitative accounts germane to MS is provided in Appendix A.

Statement of the Problem

"That which can be counted does not always count; that which counts can not always be counted."

Albert Einstein

One may wonder why I have chosen to conduct a qualitative study and, specifically, why I have chosen to conduct a qualitative study concerning the experience of individuals with MS. I would submit that, as stated previously, MS is an experience rather than a singular event and that, for reasons already discussed, it is an experience that is embedded socially, personally, and spatially.

As was mentioned earlier, dis-ability may present a change in one's negotiation of the world on a superficial level, but, on a deeper level, simple things once taken for granted, such as a sunny day, can cause substantial changes in the ways one deals with the world. Hence, in the experience of an illness that affects one's movement such as MS, one phenomenon that occurs is that the character of lived spatiality also changes. For instance, if I am in a wheelchair or I can not move, I experience a concrete shrinking of my world to the confines of my wheelchair, my bed, my room, and, perhaps, my house. There is a heightened sense of distance between myself and surrounding things so that I find that objects that were formally regarded as "near" are now

regarded as "far;" the bathroom which appeared "near" when I was ambulatory is suddenly experienced as far. More importantly, friends and colleagues recede into the distance, and the workplace seems a world away. Spatiality also constricts my range of possible actions. That is, rather than representing the arena of possible action, space is encountered as the restriction of possibilities. The "in order to" character of bodily doing in the world must be explicitly attended to so that motions are no longer automatic and product-oriented, but deliberate so that the simplest motion, such as lifting a spoon, is now a drawn-out, compound, painstaking series of movements and adjustments.

In the mix of these interactions which occur between the social meaning of disability, of differences in viewpoints between patient and physician, of spatiality, and so on, are the patients themselves. The importance of understanding the patient's lived experience through disability is not something that can be quantified, and is a capability that should not be underestimated. Indeed, therapy with such patients by neurologists, physical therapists, or by family members is less likely to be successful if the individual "in charge" fails to take into account what the illness means to the patient (Kleinman, 1988). Conversely, practitioners who focus explicitly on the meaning of the patient's experience find that they are better able to care for their patients (Cassell, 1982; Leigh & Reiser, 1980). All of this made me wonder, what is the experience of movement,

or, more specifically, a compromise in or lack of movement for individuals with a particular disability? That is, what does it mean to be "disabled" for these individuals, if it means anything? What are the affective concomitants of not being able "to do?" What experiences are common to individuals who are less able or unable to move, and what kind of assumptions do we, as therapists, as practitioners, and/or as citizens, make about an individual with a disability when he/she comes into the room?

Hence, the purpose of this study was primarily to examine the experience of multiple sclerosis using a pheneomenological approach, and, secondarily, to examine the experience of disability.

CHAPTER II

METHODS

Participants

Participant Selection Rationale

Individuals who assist phenomenological researchers by sharing their experiences are referred to as participants, co-participants, or co-researchers (Polkinghorne, 1989). According to Polkinghorne (1989), individuals must meet two criteria for inclusion as a participant: the individual must have experienced the phenomenon under investigation, and must be capable of providing descriptions of that experience that are "full and sensitive" (p. 47). Likewise, Colaizzi (1978) also emphaszied these participant requirements, stating that "experience with the investigated topic and articulateness suffice as criteria" for selecting participants (p. 58). It was these two principles which guided the selection of participants in this study.

Phenomenological research seeks to understand and describe human experience. The purpose of participant selection, then, is to obtain a wealth of descriptive experiences which will reveal the possible elements and relationships that can be used in determining the essential structure of the phenomenon (Polkinghorne, 1989). The richness and

complexity of a given description expands with additional dimensions of experiences reported by participants. Thus, one goal of existential-phenomenological research, and of this study, was to seek participants with varied experiential worlds and backgrounds so that their particular experiences of the phenomenon would provide greater nuance to the final description. In phenomenological research, the number of participants varies widely, from a single dyad (Bradley, 1993) to over 300 individuals (van Kaam, 1969, in Polkinghorne, 1989). The number of interviews to be used is guided by noting the point at which no new themes emerge from existent participants, and by not enlisting new participants at the point at which the commitment to a rigorous and exhaustive description of the phenomenon is obtained and at which any new participants would contribute no new contribution to the emerging description of the structure of the experience. This procedure was followed in the present study.

Description of Participants

The sample for this study consisted of six patients with relapsing-remitting multiple sclerosis (1 male, 5 females) who were members of a local Multiple Sclerosis Society in the Southeastern United States (a brief description of each participant is provided in Table 1). Participants volunteered to participate in this investigation after responding to an

advertisement in a local M.S. Society newsletter. Any individuals with MS who volunteered for the study were excluded if their degree of impairment was severe enough to interfere with the interview process, or if they were taking prescribed psychoactive medications at the time of evaluation.

Table 1. Descriptions of Participants.

Pseudonym	Age at Onset of MS	Age at Time of Interview	Occupation/ Interests at Time of Interview
"A"	19	26	A former scholarship soccer player, "A" is a Physical Therapy Assistant.
"B"	29	57	"B" teaches violin lessons out of her home and is active in the church.
"C"	58	71	"C" is a former Educational Psychologist who now is homebound. "C" enjoys reading.
"D"	32	41	"D" is active in the community, works at a local hospital, and enjoys her kids.

Table 1 (cont'd.)

"E"	32	40	A former runner and hiker, "E" enjoys gardening and works at a local university.
"F"	38	50	Prior to MS "F" worked at a local office; "F" is now homebound and active in her church and spends time with her family.

Interview Procedures

Formation of the Interview Question

The primary aim of the study was to determine the experience of being disabled for individuals with MS. A dialogic process was used to tap into this experience. Interview questions for this dialogue were initially developed over the course of two meetings with members of an interdisciplinary research group (decribed later in this section). In these meetings, after identifying and describing how the researcher came to be interested in the research question, members attempted to arrive at an appropriate and comprehensible initial question to tap the phenomenon under investigation.

Two individuals who eventually became participants in this study were the first participants to be interviewed and, based on discussion of these interviews with these participants and thematic analyses of these interviews by the research group, it was determined that the questions were both sensible and meaningful to participants, and were couched in language facilitative of a description of participants' full experiences.

Interview Protocol

At the beginning of the interview, each participant was given informed consent forms (see Appendix B). Each participant was given time to read the form, and then one was signed and returned to the researcher, while the other copy was kept by the participant.

It should be noted that the original intention of this study was to investigate the experience of loss of movement for people with MS. However, as is often the case for phenomenological studies, participants instead discussed phenomena which were not just particular to movement and to mtor control, but to the entire experience of becoming and being disabled. In this way, the initial question asked served as a window, or entry into the experiential worlds of people with MS.

Because of the original purpose of the study (to explore movement and MS), each participant was asked the following open-ended interview question at the beginning of the phenomenological interview: "Since you

have had M.S., can you describe a particular situation or experience in which you were not able to do something that you used to be able to do?" The focus of the ensuing interview was on a detailed description of that occasion and of others which the participant offered. Throughout the interview, the researcher sought to maintain the focus on the lived experience of the participant, and away from speculations or theoretical conjecture about the topic (Kvale, 1983). Typically, several occasions were recounted and explored, as the participant recalled her or his experience of each and discussed how she or he experienced the occasion.

Interviews were unstructured and assumed the dialogical nature of phenomenological research where researcher and participant converse, guided by descriptions of the lived experience of the participant (Kvale, 1983). The length of each interview was determined by the number of occasions which the participant shared, and the depth of the reflection employed. In this study each interview lasted approximately 40 minutes, ranging from 30 minutes to 1 and a half hours. All interviews were audiotaped.

Data Analysis

Preparatory Steps

Protection of participants

To insure confidentiality of all participants, several steps were instituted. Informed consent forms were obtained from all participants (see Appendix B). Audiotapes were coded by number before being given to the transcriber, and only the researcher had knowledge of who was interviewed on each tape. Additionally, the transcriber signed a pledge of confidentiality (see Appendix C), as did members of analysis teams (see Appendix D). Also, all identifying information was removed or transformed in protocols before being reproduced for analysis.

Bracketing

Bracketing helps establish rigor in the analysis process (Hycner, 1985). Typically, bias or slant is thought of as a confounding variable in data analysis. However, when clearly identified and made distinct, the slant of a researcher can actually enhance a study, as it grants another facet of the experience being explored. Thus, the significance of bracketing is to make explicit the perspective and slant of the researcher, and to hold that perspective to the side when analyzing the experiences of participants. This allows the researcher's slant to inform the analysis without determining it.

I participated in a bracketing interview in which I described my personal background, rationale for performing this study, and my belief system concerning individuals with disabilities. This interview was similar to those in which participants engaged. The protocol of the bracketing interview was analyzed by the bracketer, and the themes of my experiences with disabilities were analyzed and identified.

Interpretation of the Data

The purpose of the analysis was to develop, from the interview data, a set of structural invariants or basic categories which, considered as a whole and in relation to one another, would describe the experience of being disabled. For all of the transcripts, then, data interpretation was informed by the work of phenomenological researchers and was modeled on phenomenological procedures (Colaizzi, 1978; Pollio, et al., 1997). Specifically, after reading the transcriptions from audiotape, through reducing and clustering the verbatim data, similar representations of experiences (called "meaning units") from participants were organized into larger core meanings (called "themes"), each representing a specific aspect of the described experience, and descriptive labels were applied to the groupings. Following the explication of major themes, a general description of each theme with examples of quotes from participants pertaining to each theme was prepared. It is important to note in this

final phase that claims of universality were avoided in the preparation of the results, since the stability of essential referents may vary as a result of cultural and social differences. Indeed, in this sample, each participant communicated a slightly different pattern. Consequently, while this final phase involved synthesizing participants' patterns of themes, it is not presented as a universally essential description, but rather as a portrait of the possible experiences of human beings sharing a common problem.

The present analysis followed four steps:

Step 1: Review and digest the data in the protocols. The aim of this step is for the researcher to become well acquainted with each interview so that a sense of the whole interview, and of the person being interviewed, is retained throughout subsequent steps when the interviews are broken into smaller pieces. This was accomplished by listening to the tape(s) of each interview in its entirety while reading the resultant transcript and by jotting down major topics discussed. Despite frequent stops and starts, I had the experience of "reliving" the interview through this experience.

Step 2: Establish natural meaning units. The task of this step is to divide each interview transcript into "chunks" of meaning units small enough to be manageable without eliminating or distorting essential aspects of the participant's message. The nature of a meaning unit as defined by others (Colaizzi, 1978; Polkinghorne, 1989; Pollio, et al., 1997), is a

cohesive phrase or group of words whose meaning is centered around one theme or idea. In some cases, a natural meaning unit consisted of a vignette in which a participant described a particular experience of his/her family. In others, a meaning unit consisted of several vignettes. Not all data, of course, were anecdotal; some participants spoke in more general terms about the experience of being disabled.

A necessary sub-task in discerning essential meaning units is reducing the amount of raw data. Hence, repetition, irrelevant comments, and elaboration not critical to establishing meanings are eliminated. Participants' words and phrasing are retained as much as possible, although minor changes in punctuation and the use of conjunctions is sometimes necessary.

Step 3: Note categories and patterns and thematize the categories and the overall structure. Throughout the first and second steps, in the course of immersion in the transcribed data, certain themes or types of experiences were mentioned often enough or in such a compelling way as to stand out as possible fundamental categories of the experience of being disabled. Therefore, I kept a growing list of these categories. Patterns of tentative categories with reference to other tentative categories also began to emerge.

Based on these categories, a set of tentative summary descriptions or themes was developed and maintained during the process of transcription and analysis.

Use of a research group for thematizing

Unidentified researcher slant and the boundaries of one's own perspective are often limitations in any phenomenological study when conducting hermeneutic interpretations. For these reasons, research groups are recommended (Hill, 1981) as a method of controlling for such limitations. In the present study, a research group was utilized in the thematization process of two of the transcripts. Specifically, two protocols were analyzed with an interdisciplinary phenomenological research group at The University of Tennessee-Knoxville. As previously mentioned, each research group member signed a pledge of confidentiality before participating.

Step 4: Arrange themes into a structure. Steps 1, 2, and 3 involve a continuing process of immersion in the data while basic categories and their relations to one another are noted. This process culminates in the emergence in the researcher's mind of a visual, metaphoric representation of a tentative overall structure called a thematic structure which, in this case, represents the experience of being disabled. In the

present study, each theme and its concomitant subthemes was discussed with a committee member and then written, with examples from participants' protocols serving to illustrate the theme (see Chapter Three).

CHAPTER III

RESULTS

Core Themes

Analysis of the data revealed that, grounded in the bodily and cognitive changes that accompany MS (see Appendix A), a change and, in most cases, compromise in many of the personal, relational, and/or physical attributes that made each participant who he or she was. Specifically, participants discussed a.) a qualitative and dialectical change in their relations with others and with others' perceptions of them; and b.) a qualitative change in time and tempo and, specifically, in the notions of identity and certainty. Themes and their subthemes which emerged from the interview protocols are presented in Figure 1. In the following sections descriptions or meanings of themes and subthemes associated with the experience of MS for the six participants in this study are discussed.

Figure 1. List of Themes and Sub-Themes

I. Relations With and Perceptions of Others

A. Alienation Versus Unity/Support

B. Others' Perceptions - Competence and Hiddenness

II. Time

A. Certainty and Uncertainty

B. Identity and Change in Time

i. Discontinuity of Self Versus Continuity of Self

ii. Thrownness: Positive Aspects of Becoming an Individual with Multiple Sclerosis

iii. Dependence/Depending upon Others Versus Independence/Being Depended upon

Theme One: Relations with and Perceptions of Others

When discussing their experiences with multiple sclerosis, all individuals who were interviewed spoke of others, and/or of the role that their disability played in either alienating them from others or bringing them to others, and in mediating others' perceptions of them in an either positive or negative way. Some of the participants also spoke about the legitimacy or scrutiny with which others judged them, their capabilities, and their use of certain services (a handicapped parking tag)

based on the extent to which they "appeared" disabled (i.e. using a wheelchair).

Others subtheme 1A: Alienation versus unity/support

A basic human need is contact with others, and, as mentioned in the introduction, there is a great deal of research attesting to the often deleterious psychosocial effects that a disability can have on individuals with disabilities. Indeed, whether it is a matter of simple appearance or a judgment that others make based on the disabled individual's physical or cognitive competence, it seems that having a disability can be an isolating experience.

Some participants in this study likewise related a sense of isolation and alienation which, they felt, was a result of their disability. Interestingly, this sentiment was especially prevalent with respect to those who were supposed to act as a source of structure and support for the "others" in their lives; indeed, it was when they recounted experiences with family and friends that participants mostly discussed experiences of isolation and alienation:

> My family reminds me 24 hours a day that I'm ill. They are not - they don't handle sickness very well. Let's just leave it at that. Being sick is being a loser in this family, and dealt with accordingly.

'You're a loser, get over in a corner and get out of my way.' I've run into other people like that and I've run into other families, situations where they treat people - its not just sickness, it's emotional problems too. They want to shove these people out of the way...And, believe it or not, watching X-men (the cartoon) - I know that sounds ridiculous, but its what you call a quick fix. It (is about) social injustice against people who are not - don't look like everybody else. I identify with the mutants (the mutants, or X-men are the protagonists on the cartoon); and I'd like to rip something up too...but the injustice of it. They don't know so they put us in a corner, if they talk to us at all - I would like to go make a big speech and have them all sitting there with their mouths hanging open saying, 'Oh, I didn't know that; now I won't feel that way anymore.' They have to reach a broader perception or understanding of what sick people have to put up with.

"C"

Interestingly, almost all participants spoke not of the normal alienation/being with others continuum that we would expect, but of an alienation/support continuum, suggesting, perhaps, that, since others can not ever be on the same level as those with a disability, all they can really

ever do is provide a means of metaphorical (and sometimes literal) support:

> One thing that I have found out is that some people that I thought were really close friends were not. I mean, it's like they're almost afraid to be around me and if I can't jump and go and do what they want to do then I'm, you know, it's just different...Well, a girl that I had been friends with for years, and she and her husband and my husband and I always went out to eat and did lots of things together. And when I got to where I couldn't go out and go like they did - I mean I could go but I don't know if she was embarrassed because I was on my three-wheeler or what it was, but we just totally lost contact, and it kind of hurts - it hurts. I can think of two instances where - I mean I just don't see these people. They'll call me occasionally, you know, and then its always, 'Well, I gotta go do this,' or 'I gotta go do that,' you know, 'I'll talk to you later.' And they may call me back the next week and they may not. And that's - that's a hard part of it. But I have tremendous support, tremendous support. Our church has bent over backwards for us and I have my own special place where I pull in, and there's a family that brings us a meal because my husband is - I mean he has to do everything. So they bring us a meal every week and it's just

really great support here. And I go - I'm in a support group here, and that's a wonderful thing...

"F"

Others subtheme 1B: Other's perceptions - competence and hiddenness

Most of the people knew me and knew that I didn't drink. So they knew that I wasn't drunk. But it sure did look like it because I would just stumble. I'd walk right into things, just, you know, just stumble - and fall.

"A"

I get that when I see people who I haven't seen for a long time, 'You are sick? You don't look sick. I can't imagine you being sick. How in the world did you get sick?' They come here and see me and say, 'You don't look sick.' Then how am I supposed to look?

"C"

Perhaps the most prevalent subtheme that emerged in the interviews was the notion of competence, which typically refers to the extent to which an individual is judged to be able to do something with efficacy. In most circumstances, being judged as "incompetent," or unable "to do" is negative in this society. We also recognize, however, that

certain individuals, such as people in wheelchairs or people with certain illnesses, can not "do" with as much proficience, and so we attempt (and, in fact, it is typically deemed socially desirable) to help these individuals. Perhaps this is accomplished by providing them with differential privileges, such as special parking places, or help is provided financially and/or with specialized equipment and services by social service organizations whose sole responsibility is to help them (such as the MS Society).

"Hiddenness" refers to a specialized judgment of competence made by others in which one is disabled or has his/her capabilities compromised in some way, but does not appear disabled or "broken" to others (i.e. not being in a wheelchair). As one can imagine, others' estimations of an individual's competence and the opinions of others can be a frustrating problem for someone, for example, with relapsing-remitting MS who suffers from fatigue and vertigo; on the one hand, these ailments will cause them to stumble and/or fall, and will compromise their ability "to do" (i.e. their competence). Yet, without a wheelchair or some evidence of being "broken," because of the often hidden nature of multiple sclerosis, participants in this study conveyed a concern that others may simply think that they are drunk or faking illness, and they related many circumstances in which this has happened. As "E," a participant in this study, related:

> One thing that's frustrating to me I haven't mentioned is the fact that MS, most of the time, seems like its 100% subjective. Because people always tell me when I tell them that I have MS that I look so normal. And it bothers me a lot when people say that - it's flattering at times, but then when I'm having an attack, they're like yeah, you're just using that as an excuse. And that's not something I use as an excuse; when I am having a problem, and I say that I am having a problem, I really am. And unless - people can't see that I'm having visual difficulties, they can't actually tell that my sensation is not there; they just see me being clumsy and don't know that, if I move my head, I get really dizzy, or if I move my head this way it takes my eyes a while to catch up. They just - they just don't understand a lot of the times...A lot of the times when I complain - there'll be a day here when I just don't feel right. Something's going on and I don't know what it is yet, and people think I'm just making an excuse. But I wish, a lot of times, I guess, that when an attack comes on, I would turn blue or something, you know. So they could tell, yes, this is real.

"F," another participant in this study, expressed a similar story about what others termed as "faking:"

> It's like getting handicapped tags, cause I can still walk. I think I read an article on the flu or something, and it was on a lady that had parked in a handicapped spot, and had handicapped tags. And she got out and walked in - and you look perfectly normal, you know, and she came back and there was a man getting his wife out of a wheelchair, and she described how she felt. She had to lie and tell them that she had MS, and the lady in the wheelchair looked back at her and said, 'Me too,' and I thought, 'Oh!' You know, I think with MS there are so many different levels of it that you just don't know what to expect every day.

Handicapped parking tags, and the whole notion of taking a specialized spot so that one walks less distance, was a topic that produced ambivalent reactions from a number of participants:

> It's like, I'm soon going to be there and I don't want to go there (a handicapped parking spot) any sooner than I have to...It's like, yeah, I can park at the curb, but I don't want to have to explain every time I get out of the car or put a bumper sticker on my truck that says, 'I have MS, okay?!' And it's sad because there's too many diseases out there, even if it's chronic fatigue that, hey, walking 20 feet for some of us is hard as hell. We look real good when we walk

but it's - we're really thinking about how good we look when we walk and we don't want to look foolish.

"E"

A number of participants related that the hiddenness of their MS was, in some ways, advantageous given the negative societal conceptions (and misconceptions) of a person with a disability. Participant "E" discussed her efforts to try and keep her disability hidden:

> Yeah, I kinda figure if it happens, it happens, if they find out. And every now and then I'm tempted (to tell others) but I don't want them to know, cause I don't want them to go easy on me or think, 'Oh well, she can't carry her load.'

Another participant was actually able to maintain her "hiddenness" until:

> I fell down, and the second time, it was more visible to the community. Sons were playing ball and I had to be out, so I had to have a patch on my eye. I had to tell the community, so that was a little different. And I know that people looked at me like - I just knew people looked at me differently, as somebody who's sick rather than somebody that was healthy and fit.

"D"

It is interesting to note that participants expressed a definite concern about others' judgments of competence, yet no participant related an experience in which they were told that they were less competent or in which they were actually treated differently. Instead, they related experiences of struggling with hiddenness in which either they felt that they had to legitimize their disability because it was not readily apparent, or they made attempts to keep the MS hidden; in both cases they were concerned about others' estimations of their competence, yet in neither situation were they ever actually told that they were less competent.

Theme Two: Time

Subtheme 2A: Certainty and uncertainty

"The waiting is the hardest part"

Tom Petty and the Heartbreakers

Time and the things that one does in time are often themes of importance to participants in phenomenological studies. In this investigation, participants expressed a definite concern over certainty and uncertainty, which can be defined as a knowledge that a particular event will or will not happen within a particular amount or frame of time. In general, it was not the certainty or uncertainty of an MS attack or the diagnosis of MS that bothered participants, but, rather, the waiting for the

diagnosis or for the next MS attack, each of which elicited anxiety and concern.

Participants spoke of the temporal notions of certainty and uncertainty in a number of instances, one of which was in regard to their diagnosis of multiple sclerosis. As mentioned in the introduction, because of the myriad of symptoms that can occur, MS is a difficult disease to diagnose. Most participants in this study related at least one instance in which there was uncertainty and concomitant stress or anxiety concerning waiting for the diagnosis of MS, and relief after the diagnosis:

> I was very scared, cause, like I said, I was in athletics, and to have something like that come along and totally screw you up and not know what it is just not good. The fact that the doctors didn't seem to know what it was made it really scary; I went through a whole battery of tests, several times - a few MRI's and CAT scans, and, of course, an angiography and all sorts of stuff. They finally diagnosed me, and the whole episode passed.
>
> "A"

> It was scary and most frustrating before - when I didn't know what was going on - when I didn't know I wish I hadn't known. But it was...a sense of relief to finally know what's going on, because, I

mean, I saw seven different doctors and none of them could really tell me what was going on, which, to this day, amazes me, 'cause I had some classic signs. This is such a tough condition to diagnose. It was just frustrating.

"B"

As mentioned earlier, MS is a disease in which there is no cure, which makes the only option symptom management. This, however, can be difficult for physicians because of the tremendous amount of inter-individual differences in the type and location of lesions that occur in MS. Participants overwhelmingly referred to uncertainty in terms of MS symptom management, and in reference to the uncertainty associated with the possibility of an MS attack at any time:

A lot of diseases like arthritis or even lupus, you say, 'OK, this is probably what is going to happen to me,' how you're going to, you know, deal with it - this is the medicine you take for it. With MS you're a constant guinea pig...It's a real catch 22. It's (the medicines) supposed to slow down the progression, but the side effects are so - that you say, 'I'll wait until it gets worse,' which then, you know, you're beyond.

"E"

But I think even AIDS and I think lupus, and even arthritis follow a certain path, and they try to treat each step. But with MS - I mean you could have this massive attack and then for five years be fine. And then - you know - I have yet to figure out where I am. Relapsing-remitting, secondary progressive, you know - when I read my symptoms I don't seem to fit in a niche.

"D"

And that's - with MS it must be as frustrating to doctors as it is patients, because everybody's totally different on their symptoms. I mean, you know, it can be cognitive, it can be aches and pains, it can be your bladder, you know. I mean you're walking...your eyesight. And it is all usually not permanent so you ease back but sometimes you never get back to full strength after an attack, so you tend to fear those; 'I'm not going to rock the boat' type of thing.

"A"

A few participants also related instances of physical uncertainty, in which they were not sure if their bodies would "hold-up" in particular instances:

But I have walked past her (a friend with arthritis) and she - we kind of compare aches and pains, how the weather is affecting them. And she said my name - and I turned and fell. And she looked at me and said, 'That good, huh?' And I said that I knew better. There's certain things I know I can't do; I cannot bend over - I'll fall over. Turning without moving the right foot, it's just because it reacts slower...I took a nutrition and fitness class...and we played games. One of them was a soccer game in the gym and you had to kick the soccer ball. And I have played soccer; I love soccer. The ball would go past me before I could get my foot to react, and, oh, talk about mad! You just never know what it will do.

"E"

Subtheme 2B: Identity and change in time

When discussing the experience of multiple sclerosis, all participants spoke of contrasting identities consisting of who they were and/or what they did prior to the onset of MS compared with after the onset of the disease. For some individuals, their identity remained unchanged or was only slightly altered after the onset of multiple sclerosis; for other participants, their identity and the activities or proficiencies which defined who they were had to change entirely because of the physical or cognitive concomitants associated with MS. All of the

participants also identified and discussed the positive aspects of their new or altered personas and, interestingly, although participants mentioned that they would rather not have the disease, nearly all of the participants were able to recount meaningful experiences or positive aspects of their new identities as people with MS.

Change/identity subtheme 2Bi: Discontinuity of self versus continuity of self

"I think the MS for me, it has just totally changed who I was, which was a very athletic, independent, single person, work on my house, to not being able to do."

"E"

One of the most prevalent subthemes that emerged in the interviews was the opposing notions of discontinuity versus continuity of one's own identity as one begins to live with multiple sclerosis. Not surprisingly, since an individual's activities, likes, and/or dislikes become an important part of who one is, after MS occurred, many participants expressed a very real (and sometimes fearful and/or frustrating) place where they did not know who they were.

One participant remarked on how his forced secession from participation in sport, formerly a huge portion of his identity, because of the onset of multiple sclerosis affected him:

> Having sports back in my life and not just being a spectator, just playing - that was my life for a long time. My first 17 years that was obsessed by sports, succeeding, excelling at sports. And then it happened. And soon as I got to that point (where I had MS), it was taken away. And it was - I feel like a huge chunk - about half of me - is taken away with it.
>
> "A"

Another participant, "C," was highly educated and was a counselor prior to the onset of MS articulated a frustration and anger at not being able to counsel clients anymore, an important component of who she was prior to the onset of MS:

> You lose your accountability. Even though my feelings and the expertise that I had have not left me, I'm unable to help the client...That's the hardest part of all for me to face. I used to think that I was in control; talking about ideals and my anger, I could put it aside. I could when I was well. But it (anger) almost takes me

over, I'm sick and I have a terrible time dealing with anger now. I have terrible rage; I'd like to hit something and just tear it to pieces...and, as far as frustration is concerned, the negative type of frustration is, with me personally, losing my identity. As a sick person who is disabled, I am no longer the person I was before. I had to find new behaviors. Behavioral psychologists will know what I was talking about in order to function. Not being able to speak correctly - the way I used to - I took a lot of things for granted - I don't do that anymore. You either learn new behaviors and develop a new identity - as a disabled individual or as a dysfunctional individual - or you don't survive.

Many participants related that there was a definite affective component to this loss of self. Like the preceding participant, most expressed affect in terms of the frustration that comes with the limitations that MS places upon them and their ability to do the activities that they really enjoy. Indeed, it seemed that MS created a metaphorical and, in some cases, literal obstacle between who participants once were and what they wanted to do with what they were actually capable of doing, which resulted in this frustration. "A," a younger participant who was a college athlete on scholarship until the onset of the disease related the following experience:

> Probably the hardest thing I had to deal with with MS was the limitations it's put on me. Before I thought the (loss of the ability to play) soccer was bad enough; and then it took away recreational basketball, took away jogging - I mean, when I would get frustrated the way that I would vent is I would go out and run five miles. And I can't do that anymore. It (running) messes my vision up, it messes my legs up. And the fact that I can't exercise vigorously anymore - I can't really work-up a good sweat, still is extremely frustrating to this day. I think that I've brought on attacks because of that frustration. Then I was like, 'forget it, I'm not going to do it anymore.' And I'd not work out anymore and feel great for a few days and keep doing it and then, a couple of weeks later, bang, you know.

Where there was once athleticism and vigor, some participants expressed frustration over the compromises which they had to make and the fear and uncertainty that they experienced in attempting to perform the same activities as before, but with different considerations because of their multiple sclerosis:

> I've never really been afraid of anything. I mean, I was always the one that just, 'Hey, come one, let's try this or do that.'...And where

this takes place is when I hike, cause I love to hike, and it's like, 'Okay, I've got to sit down. What pollen am I exposed to? Am I having an asthma attack? Do I have my inhaler with me?' I mean, where you're used to just strapping on your tennis shoes and grabbing a flannel shirt, and all of a sudden you have to take a medical kit with you...Whereas I didn't before, now its the doctor saying that you can't go alone, what if you lose your balance and fall down a ravine?...It can be very frustrating but also very scary.

"E"

On a more positive note, nearly all of the participants were not at the point where they had to relinquish activity completely. As a result, although the onset of MS did result in a discontinuity of identity, many participants mentioned that, although they were not able to do what they loved any more, they were able to substitute an activity that gave them pleasure for one which they could no longer perform because of the MS. As one participant related:

I did hurdles in high school and now my knees are really skinned up because I am falling more now than I did when I was first diagnosed...When we were at Dunford Hall (a dormitory on a college campus) three years ago, I ran-up six flights of stairs; that

was part of my exercise. I'm just obsessive-compulsive about exercising. And now I'm not; I can't be, I mean. So that has taken a lot of adjusting, but then I have substituted. For instance, I garden - things I can sit down and do with flowers and stuff. It's not the same, but I like it.

"E"

Change/identity subtheme 2Bii: Thrownness: Positive aspects of becoming an individual with multiple sclerosis

"Maybe I can't hike or even run the way that I used to; but I can still be useful to others."

"E"

The preceding quote provides an excellent segue into the second related but different subtheme which emerged under the theme of identity: the positive aspects that the condition of multiple sclerosis provides to an individual. Specifically, implicit in the preceding notion of substituting one activity for another is the notion of "making do;" of, as the saying goes, "taking life's lemons and making lemonade." Heidegger (1927/1962) labeled this condition as "thrownness," or what one does with the circumstances into which he/she is thrown. Within this investigation, in the face of living with a disease that mandates that an

individual redefines his/her identity, all of the participants related some positive experiences that resulted from these changes in their identities. These experiences made their new identity as an individual with multiple sclerosis one which was, at the very least palatable, and, at the most, meaningful to them and useful to others.

For example, most participants conveyed that their multiple sclerosis has provided them with an opportunity to educate others about individuals with disabilities in general and, specifically, about MS. One participant described how a change in her persona has provided a positive experience for her grandchildren:

> There is nothing like grandchildren, and, like I said, I think that mine are learning, you know, to see that all people are not able to jump and go and do what other people do. And I think it's going to be good for them. They're going to learn to be compassionate and so helpful...They're learning some things that maybe other children won't learn. I mean, there are other children with, I'm sure, handicapped people around, but I think that it is a valuable lesson...and the grandchildren, they just love - they think I'm neat that I've got a Harley. You know, I've got my three-wheeler and they - I think they're learning, they're learning something different than most grandchildren will ever learn; they're learning that not

> all people are alike...You just have to change your life and just make the most of it.
>
> "F"

Another participant, who sometimes goes into the community to speak about having MS, also related how she was able to use her multiple sclerosis to educate another individual:

> I have several people who know that I have MS who have asked me when they find out that a friend has MS, 'Would you mind talking to that person?' And this has been something that I have liked doing; to talk to someone who has just learned that they have MS, because I remember how frightened I was and how extreme my reaction was, being certain I would be in a wheelchair...and I know how frightened people are when they first hear those words, 'MS,' and so I like to be able to help people and just tell them.
>
> "B"

One participant discussed using her new identity as an individual with multiple sclerosis as a means of political activism for others and as a means of affirming her own viability as an individual to herself:

> We were talking about identity and about positive identity and how my illness has affected those. In spite of the fact that my family thinks I'm a loser, I have found ways to win. I write letters to congressmen, protesting or else giving them compliments for things. Senator X , I like, I think he's a nice person. I feel like rewarding him occasionally, and that helps a little bit. If there was an outlet for disabled people to have a voice in the goings on, everyday goings on of things - for instance, if you could write to the legislature...I don't call that a voice; I call that just a mere offering of what you feel is important...So I write letters, and talk to people when I have the occasion - give them a new slant on things.
>
> "C"

Interestingly, almost all of the participants had been to an MS support group on at least one occasion, and all of them seemed to come away with the same impression: "It just makes you realize that there is always someone worse off than you." Indeed, regardless of type of MS, relapsing-remitting or chronic progressive, and regardless of severity of their respective disabilities, almost all of the participants conveyed a sense that all one can really do is, as one participant said to me, "be happy that some things still work and make the best of things." Following are excerpts from two protocols that speak to this sentiment:

And I've just tried to make the most of it. And I'm - it's not that I'm anything - anything I'm happy about. I'm sorry I have It. But I feel like I can - I feel like I'm a better person in a lot of ways...That sounds crazy, but I feel like I can understand handicapped people better. Maybe I wouldn't have ever done that. And I've come into a lot of peoples' lives that I wouldn't have if I didn't have it...I've met a lot of nice people and I've had a lot of people tell me that I'm an inspiration to them. Not that I'm anything special, but the Lord has just blessed me with the peace that has no understanding, is what I'm happy for every day...and I'm not hurt, I mean, I don't have any pain and I'm thankful for that; I'm just very slow and I have to have help with a lot of the things that I do. But I think I just make the most of it.

"F"

But it's not complaining cause you're thankful that you're still up and walking...it really hit me hard at the first teleconference that I went to right after I was diagnosed - seeing those motorized wheelchairs, the adults with - people my age with their parents taking them to the bathroom and feeding them...But I think when you're diagnosed its bad - maybe cancer is the same way. But then it's like, 'Okay, what's the worst that can happen?' and you move

on and make the most of every day the best you can...and thank God that it's not worse.

"B"

Change/identity subtheme 2Biii: Dependence/depending upon others versus Independence/being depended upon

"I would like to be the caregiver that (my husband) is for me...Because he, you know, he's lost part of his life too. I mean, I feel like, you know, I keep him from doing a lot of the things that he would like to be doing."

"F"

A continuum that is of interest typically at the beginning and end of human life is being able to do, and being able to do efficiently for oneself and for others versus having to allow others to do for one. Indeed, by definition, a decrease in one's independence means one is more dependent on others, which, at the very least, can make one sometimes feel like an inconvenience to others and, at the most, can be humiliating to the individual and/or to the caregiver.

When one is disabled, the notions of independence and dependence as they relate to illness are packaged with ideals such as competence, efficacy, and freedom, as well as questions, such as "How does it feel when you have to depend upon someone else to feed you? To

bathe you? To help you go use the restroom?" Three participants readily expressed appreciation for their caregiver(s), but also expressed concern and frustration, both over what the caregiver had to do to take care of them, and, more prevalently, over the loss of identity that takes place when they, as disabled individuals, are unable to perform simple tasks of daily living without assistance, such as washing oneself and bathing, as well as larger tasks, such as working and earning money for the family. As one participant commented:

> I don't think that I have changed much in the last three years, probably I've been about the same. But I hate being dependent on people. But I've also learned that I hope, and I really feel like I would try and do the same thing for somebody else, for any of my family members. But I hate losing my independence, although I have gotten used to it now.
>
> "F"

Many participants described contexts in which they felt independent in terms of being depended on, such as going to work and having co-workers depend on them. Two described how these feelings were compromised by MS in the workplace:

You just lose your balance completely, and, when you fall, you can't get up. When I would fall at work, I would feel like I was a turtle on my back and it embarrassed me to death. And it happened twice. But then everybody, everytime would get up and say, 'What can we do?' you know, 'Let us get it.' And that gave me a feeling of - I wasn't carrying the load at the office - I really didn't feel like I was doing my job. That's what convinced me to leave when I did, because I just wasn't doing my part.

"E"

I just lost my ability to do my job, which I loved to work...I just knew that I was a danger to other people, and I didn't want to run the risk of hurting somebody else.

"F"

Participants also described loss of independence, also known as dependence, in terms of feeling like a burden on others and depending on others in recreational or home settings:

I just try to go wherever everyone else goes. I can't - the one thing our Sunday school class has a hayride...that was before my three-wheeler. And I know that they had to lug me up in that truck and I

hated that. I hated that worse than anything...And then two years ago my husband and his friend tried get me into the pool. They got me in there fine; it was getting me out that was the problem. I want to be independent. I want to do things by myself. I don't care how long it takes me. I want to do it. I am just like a two-year old: 'I'll do it myself!'

"F"

Summary

In this chapter the themes and subthemes which emerged from the interviews were presented, and exerpts from the protocols of the interviews were provided as support for the emergence of the themes. The emergent themes presented in this chapter were: a) the perceptions of the participants which others appeared to hold and the relationships with others that the participants were able to maintain; and b) changing or becoming in time.

In the next chapter, the themes and subthemes presented will be discussed and grounded in a psychological framework.

CHAPTER IV

DISCUSSION

In this study the experience of MS was explored. From the results of this qualitative study two themes emerged, each of which, in turn, came packaged with a number of subthemes. The themes described - others and time - were found to be adequate to capture participant responses to the initial question. In general, participants tended to describe experiences at work, in relationships, and by themselves in terms of a constant interplay of themes. It is assumed that the interview method did not constrain them to discuss isolated aspects of their experiences but rather allowed - and, perhaps even invited - them to discuss the experience of multiple sclerosis comprehensively. Discussion of MS was often interwoven with discussion of personally meaningful topics such as death, depression, and triumphs in life and in specific contexts (i.e. work). As a result, each theme seems to capture an element of the experience of multiple sclerosis and of disability as well as something significant about life in general for the participants.

In this chapter, psychosocial issues regarding each theme are discussed, and implications of the findings are presented.

Relationship of Emergent Themes to Psychological Literature

Kerby (1991) commented that the nature of human existence, and of the sense of self that an individual experiences is created by the activity of language usage and expression. That is, people "story" their lives and their sense of identity, and self emerges out of this narrative enterprise. Consistent with the hypotheses of Carr (1986) and Kerby (1991), participants in this study shared particular stories and experiences to identify, relate, and describe and, perhaps, define their own life stories. These stories were important for two reasons: a) they were common events that somehow stood out from other occasions; and b) the stories were ones which were used to construct their personal histories and were, therefore, figural for the experience of being disabled, a significant chunk of their personal histories.

However, there are no figures by themselves; all figural aspects - of perception, of experience, and so on - "always emerge against some ground that serves to delineate its specific experiential form" (Pollio, et al., 1997, p. 13). The purpose of this section is to "ground" these collective figural experiences which comprised the themes into psychological theory. It is hoped that by structuring the experience of MS into a patterned event, others will be able to gain insight into the experience of MS.

Others

In the phenomenon of having multiple sclerosis, there were instances for participants where the figural person in the experience was another person, or persons. For the purposes of this study, an "other" can be categorized as any individual other than the participant who is being interviewed. Interestingly, participants revealed that an individual does not have to be a significant other (i.e., a family member of friend) or even be someone who the participant knows to have an impact on the individual. In fact, in reviewing the protocols, I found that virtually any sentient individual, just by being in the presence of a participant and being capable of forming opinions, was a significant other in the eyes of the participants.

Perhaps the most interesting and telling result of participants' discussions of others was the continuum between alienation and support that emerged. When one thinks of an antonym for alientation, phrases such as "friends," "unity," or "being with others" usually come to mind. Yet, in reviewing the protocols of this study, the term that seemed to stand in opposition of alienation for participants was "support," rather than "unity" or another word that suggests being with others in an egalitarian and relational manner. Alienation and support are both experienced in terms of others, and it appears that disability is also experienced largely in terms of relations with others. Indeed, a

hermeneutic and experiential analysis of the protocols in which alienation was cited suggests that disability is truly a unique experience so that the closest participants in this study could come to counteracting the experience of alienation is having others around who provide support, either in a metaphorical or very literal sense.

Participants also described the experience of hiddenness. In this experience, participants, many of whom did not appear "broken" or disabled to others (i.e., using a wheelchair or a cane), attempted behaviors that would not normally be associated with being disabled, such as walking. Because of the effects of their disease symptoms, though, they would stumble or fall. This, in turn, caused those around them who could not otherwise tell that they were disabled to assume that participants were drunk or, in general, to make negative judgments about them:

> I've never been arrested for drunk driving...carrying a medic bracelet...because if I'm stopped by the police and they say get out and take the test (for drunk driving), I've got to say, 'Hey I haven't had a drink, but I can't do that.'...I told somebody I'm going to get a shirt that says, 'I'm not drunk; I have MS...'
>
> "E"

This result is consistent with two accounts that I found in other first-hand descriptions of MS:

> The question of legitimacy with a disease such as M.S. is never completely resolved. One's condition is not usually or necessarily reflected in one's appearance. And I found that receiving a diagnosis catapulted me from one world of judgments and perceptions to another-the world of being 'sick.' A different world now that my 'sickness' was legitimate; nonetheless, another world and the central issue of maintaining my integrity remained...Another example: I have trouble walking on a moving bus and tend to lurch around and bounce off people and seats and, of course, like everything else with MS, my difficulty varies from day to day. Over a period of several weeks I had engaged in a normal conversation with a man who always took a seat near the rear of the bus, as I did. One afternoon, when my difficulty moving was extreme, I fell getting off and he looked away. After that day that man, who had been friendly, changed his seat and never even acknowledged a hello from me (Webster, 1989, p. 63).

> Now others insist that there is nothing wrong with me. Even the well-intentioned persist in denying that I am ill at all. Those close to me feel an uncomfortable need to defend the diagnosis, to repeat

details over and over again. It is a period of excruciating uncertainty, exacerbated by doubts and by hope, because no one can say how long remission may last (Birrer, 1979, p. 43).

Although the experiences of hiddenness and of alienation/support were common to both participants in this study and to other individuals with MS with whom I have spoken, these themes do not appear in any studies that I could find. This is somewhat surprising given the enormous number of studies concerning multiple sclerosis that have been performed in the last half-century alone. I feel, however, that the omission of these themes says something about the incomplete nature of quantitative information and it illustrates the need for and utility of qualitative methodologies in providing unique and useful information that is not easily gained using quantitative methodologies.

Difference from others

Some participants related experiences of discrimination which, by definition, is an experience of others and, more specifically, of others perceiving oneself as a different other from them and subsequently treating them differently. In other studies and presentations, I (Page & Peterson, 1998; Wayda and Page, in press) and other researchers (Sherrill, 1998) have refuted the notion that there are disability-specific personality

types. Cratty (1980) states, though, that nondisabled individuals do respond in some similar and specific ways to individuals with disabilities. In fact, Richardson and Green (1971) reported that the major factor influencing children against their peers was neither race nor intelligence but a visible disability. Mills (1960) offered this description of the plight of individuals with disabilities in many parts of the world: "There they sit, fed and housed by more or perhaps less sympathetic relations, but regarded by all as useless and unproductive" (p. 3). More recently, a number of authors have likewise suggested that disability is a major limitation to an individual's psychosocial interactions with his or her environment, suggesting that variables such as an individual's impaired body experience as well as the stigmatizing attitudes of others combine to explain these limitations (Jason, 1972; Schontz, 1978).

Cultural or religiously/morally-influenced definitions of illness can also be a source of suffering for the individual with MS since such definitions influence the behavior of others towards the person with a disability. Cultural norms often dictate whether or not a disabled individual will be considered acceptable and whether or not they should be isolated (Dunn & Fait, 1989). Webster (1989) provides the following example:

> There is a clear relationship between the view of the disease as a moral issue and religion...Contemporary American religions do

continue to support and legitimate what it is that people want to do and to give an underpinning and a rationale to their fears (for example, the religiousfundamentalist's response to AIDS)...Religion both keeps alive and supports that notion that disease is a moral issue...There is a not very subtle thread in Christianity...to the effect that disease and suffering are deserved. They are also viewed as good in and of themselves in that they promote a desired moral outcome...A relative of mine, on hearing that I had MS, referred me to Romans 5:3, where St. Paul writes that suffering produces endurance, endurance promotes character, and character, in turn, promotes hope. The implication, hard to ignore, was two-fold: First, my character needed improving, and I don't think it is far-fetched to see an element of punishment here. After all, were I not in need of improvement, did I not lack character, or were it not deficient, I would not be in need of suffering ultimately to improve it... The notion that disease indicates a flawed relationship with God and is to be accepted as a consequence thereof is also common. If one's nature is flawed, then disease is a reflection of that...For society at large, there is both the idea the illness is deserved and the God's-will theory (p. 76).

Summary

Disability is an interesting process; while it is the individual who comes to know that he or she is disabled, such knowing comes about by virtue of observing the reactions of others to oneself, and by contrasting oneself with others. Awareness of the limits and possibilities attendant to being disabled first emerges in the context of relating: 'I am different from nondisabled people, and this limits me; I am the same as nondisabled people, and this opens possibilities.' Additionally, one of the most essential aspects of becoming disabled that participants discussed was beginning to take advantage of supporting relationships with others and utilizing relationships with others, both disabled and nondisabled, to gain a sense of belonging: 'The difficulties disability brings are ameliorated by family and church members who love me, by friends who love me, or by acquaintances in support groups and the like with whom I can communicate easily and work towards community goals.' Even the stage at which individuals accept their disability, which would seem on first thought to be a more privately reflected phase than the others that Kubler-Ross (1970) and Dunn and Fait (1989) mention (see Identity section of the Discussion section), is also grounded in the world of others: 'I feel less different from others.' In all of these ways, then, although the experience of being disabled is, on the superficial level, a bodily experience about not feeling well and the recognition of qualitative

changes in one's own health, ascertaining a disability is also a comparative process and, therefore, a process in which the perceptions and existence of others are very important factors.

Time

Identity and change in time

The human capacity for change and the psychosocial changes associated with disability are each themes that are described in the psychological literature and that were articulated by participants in this study. Dapkus (1985) explains that change and continuity:

> refers to the fact that things (people, nature, etc.) are constantly changing and yet have continuity in time...This is essentially a category of 'becoming in time' (p. 411).

For the participants, figural changes in work activities or hobbies and personal changes in identity were each grounded in the physical and cognitive changes associated with MS. Specifically, because of the restrictive nature of their multiple sclerosis symptoms, most participants related that they had to significantly alter or stop altogether participation in sporting activities (such as hiking or soccer), work activities, and/or hobbies. In most cases these secessions from life activities meant that

participants had to reconsider who they were because they were relinquishing activities and jobs which were defining aspects of their identities; an athlete, a counselor, or, in some cases, a parent or spouse. Again, although there were no studies or reports attesting to this phenomenon, there were several qualitative accounts of MS with which the accounts of time in the current study were consistent:

> The implication that physical adjustment was all that was necessary to live with MS...was secondary. The physical fact of walking with difficulty is not nearly so important as the psychological and social consequences...Over the course of the next year...I began to see myself as an otherwise healthy person with an underlying but, for the most part, inactive disease. The primary task was learning to live with day to day uncertainty (Webster, 1989, p. 39).

> ...before I became multiple sclerotic, I lived in the future, and in the past only in so far as it affected my future. Apart from a few special moments, I never really lived now...but incurable disease denies me escape: multiple sclerosis focuses and crystallizes the eternal present. All of existence is immediate now... (Birrer, 1979, p. 19)

MS as a Process

Although all participants cited specific instances during which they were more aware of their MS, it is worth noting that they described disability as an individualized dialectic process between themselves and the multiple sclerosis rather than an instantaneous event requiring instant adjustment:

> So you're going along like normal...and then you feel a twinge and you're uncoordinated or your leg can't move. So you say, 'Okay, I can do this,' and you adjust. Then later, if it (the condition) don't stay - or even if it does - you have to adjust again. Either way all of your activities, the way you do things...it's a constant give and take - except the MS is doing all the taking, so you have to do all the giving and be ready to say, 'Okay, this or that happened,' and adjust to the changes that it puts on you, while still keeping all of what you were doing or who you were intact.
>
> "E"

This dialectic process of life change and identity, in which life "takes" and the individual adjusts, attempting to preserve aspects of his/her identity, is consistent with Erikson's (1968) conception of human existence as the continuous process of maintaining one's "continuity of identity." Erikson

(1968) posited that deleterious psychosocial effects correlate with changes or "discontinuities of the self," including anger, depression, or other psychological adjustment disorders. He further hypothesized that the compromise or termination of defining activities (those activities which significantly contribute to an individual's identity), such as no longer being able to participate in a sport, go to work, or even walk across the street (all of which were experiences recounted by participants) can elicit a discontinuity of identity and subsequent psychosocial disorders .

Consistent with Erikson's (1968) conception, there was a definite affective component to the process of change; such compromises or losses of identity mandated by the onset of an uncontrollable disease - the notion of "what they were" compared to "what they now are" - led many participants to feelings of frustration or anger. As one participant reported:

> I still don't have a sort of, I guess the word is distant - it's not vague - it's a distant notion of the person I was. I try to hold on to it a little bit. And I have to hesitate because I really haven't developed a way that I can still observe that person and feel that person is still in some control. It makes me very angry and very frustrated.
>
> "C"

Related to the procedural loss or change in identity, participants also expressed a significant decrease in their feelings of independence and, in some cases, increases in their feelings of dependence. By definition, dependence means depending upon others, whereas if one is independent, one can be depended upon by others. As a result, those who were parents or spouses, roles in which one is depended upon, spoke a great deal about changes in their relationships with their family, and the affective components associated with these role changes. According to Scheinberg and Holland (1987) and to Cook and Dowling (1980) such feelings are common in relationships in which a spouse has MS:

> As transitions occur, the MS person may experience feelings of frustration and a loss or reduction of the sense of self-worth...whereas physical dependence may result because of specific MS impairments, psychological factors include depression, 'putting off' efforts...special problems arising when role reversal is encountered. This entails one or both spouses assuming tasks or responsibilities previously within the other partner's domain (Scheinberg & Holland, 1987, pp. 224-225).

In general, the examples presented in Chapter Three and those presented above appear to be consistent with Rokeach's (1979) findings of

personal change being accompanied with feelings of loss, frustration, and distress. Specifically, Rokeach (1979) found that the threat to self-image associated with change and with periods of change evoked periods of distress in clients' lives (Scheinberg 1987). While I am in no way accusing any of the participants in this study of exhibiting pathological tendencies, there was a great deal of evidence suggesting that there was a definite affective component to the process of losing identity and experiencing a compromise in one's level of independence.

On the basis of the experiences of participants in this study and on preexisting literature it might be concluded that the development and maintenance of self and of one's identity is a reassuring but lifelong project that is radically altered by the incidence of a disability. This was seen in the testimony of one participant who discussed the periods through which she went before finally reaching acceptance of her disability:

> I went through all different feelings of it...first of all I was 'why me?' And then I was mad. I mean really mad - and I thought, 'Why would the Lord pick me to go through this?' And then I got depressed and had depression. And then I came to where I accepted it.
>
> "F"

It is interesting to note that these periods strongly resemble Kubler-Ross's (1970) description of the stages that an individual goes through in attempting to deal with death, another large-scale life change: denial, anger, bargaining, depression, and acceptance. It has been hypothesized by other authors (e.g. DeLoach & Greer, 1981; Dunn & Fait, 1989) that this is, in fact, what goes on when an individual becomes disabled and, metaphorically, the old "self" dies, and a new identity must be "born" and accepted by the individual.

Adjustment to disability

This section is about changes that occur in time which are figural to the experience of becoming disabled. Grounding such changes which individuals experience as a result of disability are the adjustments to disability that individuals must make. Wright (1983) discussed acceptance of physical disability, describing fundamental value changes entailed in the process of coming to accept a suddenly imposed disability like MS. In her discussion she posits that "loss" is the major variable which needs to be accepted in the experience of become disabled. That is, what is lost in physical disability is what she terms a set of "personal and social satisfactions that are now felt to be denied" (Wright, 1983, p. 164). Wright decribes a crisis period immediately following the realization that one is disabled:

> during a crisis period, one's resources are mustered to fight the physical and psychological assault to one's integrity. As part of the shock reaction, there occurs a narrowing of the person's world and a preoccupation with the loss itself (p. 163).

Mourning the loss is a natural and necessary step toward the acceptance stage mentioned earlier in Kubler-Ross's (1970) taxonomy. Dembo, et al. (1956) describe intense phases of mourning following physical injury:

> the loss seems to pervade all areas of a person's life. Whatever he thinks about, whatever he does, he is troubled, pained, and distressed. There is no differentiation between areas of the person which are and are not injury-connected. All that matters are the values affected by the injury and they are lost (p. 36).

As mourning subsides, acceptance begins as a function of a variety of experiences. One realizes that all is not lost and the value of life slowly becomes reaffirmed, albeit sometimes in the wake of the contemplation of suicide. Recognition ofthe contrast between the individual's own condition and that of others perceived to be even less fortunate, as mentioned in the others section of this discussion, also contributes to an afflicted person's re-entry into life. Finally, according to Wright (1983), the

individual finally reaches a "satiation" point; an emotional state where he/she is tired of being tired, the mourning ebbs, and the person is ready for something new and different.

The overlap between the experiences of persons with suddenly imposed disability and those with multiple sclerosis is relatively small. Although MS is a physical disability, it is often not visible to others, and having MS from relatively early in one's life and having it progress slowly or relapse and remit rather than having it immediately imposed later virtually eliminates the acute loss experience described by Wright (1983). Perhaps, then, in this way, the taxonomy proposed by Kubler-Ross (1970) is appropriate and useful. One experience that is shared by both groups is the acceptance-facilitating effect of comparing oneself to people perceived to be less fortunate; participants in this study were grateful that their condition was not worse than it was, and some were glad that they were not blind, and that their mental capacities were still intact.

Thrownness: A positive change

Of course, change does not always have to be negative. As mentioned in the above section, temporarily tumultuous periods of instability and/or change can result in positive and long-term periods of stability, such as those which occur following the acquisition of a skill. In this study, although participants bemoaned the changes associated with

disability, most were also able to find positive aspects associated with the end state of being disabled, and/or felt that, since MS was an incurable disease, they had to "make do" with what life had given them.

In his work Heidegger (1927/1962) conceptualized an organism's personal existence as "Geworfen," or always thrown or cast into the world beyond its own willing. Because this "thrownness" is a condition that humans do not choose, and because human existence is replete with examples of "thrown" conditions (i.e. racial, temporal, place, and familial conditions into which one is born) he concluded that one of the essential elements of human existence is found in the ways in which an individual attempts to ameliorate his/her particular condition(s) of thrownness through the activities of his/her life. Participants related that disability was a thrown condition in so much that, although none of them chose it, they were all trying to "make the best of it," and, in most cases, their disability enabled them to help others in some way, thereby making their disability positive or useful in some lights. Specifically, using Heidegger's (1927/1962) conceptualization of the condition, most participants related a sense of recognizing that the world into which they were "thrown" is the one in which they are going to have to exist and that they must accept and be responsible for their existence as uniquely theirs; indeed, each participant seemed to recognize the finality of his/her

condition, and recognized that he/she must accept this project that is his/her life.

Ways of making this "thrown" project more palatable and/or meaningful for participants included giving talks or educating others, participating in advocacy movements for people with MS, and/or giving money or time to local volunteer organizations.

Temporality and the ill/disabled body

With regard to the lived experience of illness, it is important to recall the distinction between lived (or subjective) time and objective time. The patient experiences his or her illness and its immediacy in terms of the ongoing flow of "lived" time. If one is in pain, for example, each moment of pain does not represent discrete measurable instants, but, rather, a continuum of discomfort in which past and future coalesce. For participants in this study, illness as it is "lived through" is experienced as an ever-present, enduring consciousness which often resists measurement in terms of objective time. In the preoccupation with here and now obstacles like negotiating the room in a wheelchair or pain and fatigue, many participants expressed paying little attention to clock time. Just as the student immersed in his/her exam has no concept of time and may be surprised to learn that each timed exam takes as much time as the

other, so the person living through the illness may have no concept of clock time.

The physician, on the other hand, uses the objective time scale to measure the physical events and biological processes which define the patient's illness as a disease state. Consequently, as mentioned in the introduction, the patient and the physician are operating in two separate and often incompatible temporalities.

Implications of This Study

When one sees an iceberg, typically only its tip is visible floating above the dark ocean, yet it is assumed that there are massive amounts of ice which underlie this immense structure but are invisible since they are under the water. Truly it appears that the compromises in time and one's relations with others that are associated with MS are but the "tip of the iceberg; " they are mere indicators that something that is massive and embedded socially, temporally, and bodily lies underneath this relatively small portion that is visible to us. As a result, this dissertation has significant implications for the practitioner who is working with a person with a disability and especially with someone with MS.

First of all, because it is an incurable disease, MS, much like the cancer with which my father dealt, is a dynamic and experienced process that the patient must negotiate on a daily basis. In the case of my father

and other cancer patients, this meant that counselors were available to discuss psychosocial issues with the patient and the patient's family, social workers were available to discuss financial and legal arrangements (such as living wills), and specialists, such as physical and rehabilitation therapists, were available to discuss adaptive options such as prosthetic devices. Indeed, one could say that an entire care "team" is usually made available to most cancer patients, because there is a realization that the negotiation of the cancer disease goes beyond simply attending chemotherapy treatments or taking prescribed drugs.

In the case of MS, though, this is not typically the case; although there is some literature that is available concerning the impact of MS on familial relationships, or financial burdens that can be anticipated when a loved one has MS, by and large there is little published material that treats MS as the process that it is, and few health care centers which treat MS as a process (i.e. incorporating a team approach to the care of each MS patient). Hence, one suggestion/implication of the results of this study would be the proliferation of holistic MS care teams rather than maintaining the current "piece-meal approach" of managing MS by dispatching the patient to a neurologist or, perhaps, a physical therapist. Indeed, health care professionals "in the field " should be making available to MS patients the diverse collection of social workers,

community agencies, and physicians who are available in their respective regions.

Some of the problems of people with MS are generated to some degree by a lack of understanding by others. Hence, an additional application of the present findings is the education of individuals in contact with people with MS such as physicians, physical therapists, parents and friends, teachers and administrators of schools, and mental health professionals. Specifically, it is evident that illness is fundamentally experienced by the patient as a disruption of the lived body. Illness, then, must be understood not simply as the physical dysfunction of the mechanistic, biological body but as a disorder of body, self, and world (and of one's being in the world). Unlike the conception of body as a scientific object, the biological body represents the patient's particular embodiment and, as such, represents and comprises the patient's relationship to the world, to the past, to the future, and to a unique self. The patient does not simply possess this body; he or she <u>is</u> this body so that patients do not have an illness but <u>exist</u> as ill. People with multiple sclerosis, or with any other disorder, then, are people living a disordered existence in a very specific way and, hence, their body must be perceived as a body - and the individual in the body - in situation.

Besides the implications of this study for the modality and humanity of interventions, there are also implications for the type of treatment that physicians or therapeutic practitioners should be providing to the patient. The goal of medicine is primarily to relieve the body's physical state of disruption. Therefore, treatment is typically conceived by the physician to encompass relief of organic or bodily dysfunction. However, the patient with MS comes to the physical therapist, neurologist, or whomever because of a perceived disruption of everyday life. Indeed, in order to address the patient's experience attention must be paid not only to the physical manifestation of a disease state but also to the changing relations of the body and self to the world. Again, this would seem to suggest that a holistic approach that utilizes a "team" of experts would be the most appropriate way of caring foran MS patient.

Because MS does cause such a constriction in the lived spatiality of the patient, Merlou-Ponty (1962) notes that, in normal tasks of daily life, the embodied individual incorporates objects into space. For example, as I type this, I experience the keys of my computer not as objective locations at which I must aim. To get used to typing on a computer is to extend my body and incorporate it into my lived body. Likewise, the incorporation of objects provides a means to expand the constricted lived spatiality of the patient. The physician or practitioner can assist the patient with MS in

increasing the range of bodily space by encouraging, where necessary, the use of a cane, a walker, a wheelchair, and so forth, and can encourage patients with MS to get out and utilize these devices rather than merely negotiating the space in their home. Although some patients may initially view such adaptations as demeaning or demoralizing or as "giving in," with encouragement they may eventually learn to see these tools as extensions and extendors of their bodily spaces, enabling them to expand the range of possible actions.

Future Research

The results of this study provide some insight into the ways in which MS affect individuals experientially, psychologically, and physically. Such initial results, in turn, provide impetus for additional phenomenological studies examining some of the processes described in this study in more detail. For example, several participants indicated that disability is a psychosocial process in which there are definite stages of grieving similar to those proposed by Kubler-Ross (1970) in her stages of dealing with death. Hence, one study of interest would be the experience of becoming disabled; themes derived from such a study would be helpful to case workers and/or rehabilitation psychologists working with individuals with MS and other disabilities. Other possible studies would

include the relational experiences of people with disabilities, or further exploration into the experience of hiddenness.

Psychological questionnaires are also a useful way of measuring the extent to which dispositions exist concerning a particular phenomenon such as becoming disabled. One way to identify those experiences or dispositions that are common to a particular type of person or to a person with a certain trait (i.e. someone who is disabled, anxious, motivated, or optimistic) would be to conduct a phenomenological study. A study such as this one would be a useful first step in determining the scales which should comprise a questionnaire to be administered to people with disabilities, or the items to which an individual responds on such a questionnaire (i.e. "Having MS makes me look less competent in the eyes of others").

Possible Threats to Reliability and Validity

The limitations of this study can be addressed by discussing the methodology of qualitative research and, specifically, several issues surrounding phenomenological research. Reliability and validity, the two most critical concerns in any study, are addressed differently in qualitative research than in quantitative research.

Reliability

Phenomenological research seeks a participant's experience of the phenomenon under investigation. The goal of this research is to impose no a priori suppositions or structures on the study, thereby allowing for themes to emerge from the participants themselves through the narratives. Because of the hermeneutic nature of data analysis in such studies, reliability coefficients such as those typically used in quantitative research are inadequate and have no meaning in phenomenological research. Instead, other methods for ensuring reliability are used (Kvale, 1983).

One method is participation in a bracketing interview which, in this study, was conducted and subsequently thematized. As mentioned before, this procedure enabled the authorto become aware of any biases he held with regard to the topic under investigation, and to be able to set aside these biases during interviews.

A second method of increasing reliability used in this study was the search for discrepancies in the data. These discrepancies augmented the varied nuances of the experience of disability, making the thematic structure more comprehensive and complex. This occurred in two ways. First of all, the meaning of the texts was continually revised and modified as new data were analyzed. And second, after the analysis of four protocols, no new themes were found to emerge from the data, indicating

that the number of interviews conducted was adequate and that the structure as it existed had presented itself.

A third reliability check was employed through the use of research groups and the collaboration of colleagues. Meaning units and structural themes and subthemes were repeatedly checked against protocols to insure that they were accurate reflections of the original data. These were then shared with colleagues to assure that what I was "getting from" the protocols were the same themes that others were getting.

This study may be limited because of the restricted area from which participants were sought (East TN, Western NC). However, the participants represented different cultures, races, ages, genders, and levels of socioeconomic status. The addition of additional participants may have provided different insights into the phenomenon of MS, but the basic structure would have, in all likelihood, not have changed.

Validity

There are three factors which need to be considered when assessing whether a phenomenological study is valid: a) participant selection; b) data collection; and c) actual data validity (Wertz, 1986). The criteria used in this study to ensure that participant selection was valid were that participants had experienced the phenomenon under investigation and that they were willing to share their experiences. Given the self-selection

process in recruiting volunteers for this study and the narratives produced, participant selection for this study can be considered valid.

Data collection can also be considered valid because the narratives presented were rich in details, varied in stories and life events shared, and textured with nuances and with complexity. Additionally, a thematic structure emerged from these diverse and varied narratives, suggesting that the question posed was detailed and meaningful enough to provide the researcher with valid data on the experience of having multiple sclerosis.

Unlike the other two issues of validity, the issue of data validity is of some concern as it is always reasonable to speculate whether participants, knowingly or unknowingly, deleted or altered material or whether the portrayal of their experiences, because of their sensitive nature, was less or differentially candid. It must also be asked whether it is possible that the researcher/interviewer unintentionally affected the responses of the participants as a result of unfavorable personal dynamics, or perhaps by guiding or not guiding them with certain questions, or perhaps by confusing participants with unhelpful inquiries. Review of the data collection and analysis procedures suggest that none of tese possibilities existed; precise taped transcripts were used, multiple reviewers and participants in the data analysis did not identify explicit or

implicit directing by the interviewer, and material presented by the participants seems to indicate a great deal of candor and disclosure.

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Appendices

APPENDIX A

REVIEW OF LITERATURE

As earlier intimated, my goal in writing this dissertation was to inform the reader about multiple sclerosis and about the experiential world of individuals with multiple sclerosis (MS). When discussing the experiential world of patients who are ill and/or have multiple sclerosis, though, it is important to recognize and understand the symptoms and etiologies of the disorder. Indeed, it is often exacerbations, such as the inability to walk or to feed oneself, and the meanings of these symptoms, such as loss of control or independence, which constitute the ground for the lived experiences of such individuals. In keeping with one of the themes of qualitative research, which is to make real for the reader the experiences of others, I will attempt to explain these processes in this review of literature using plain language and concrete examples whenever possible.

The Physical Basis for Multiple Sclerosis

Although knowledge about the factors influencing the development of multiple sclerosis (MS) has increased appreciably, its cause remains essentially unknown. Demyelination, which can be

demonstrated in MS patients by neuroimaging techniques (such as PET scans) or by clinical electrophysiological methods (such as the use of auditory, visual, or motor evoked response potentials), and the lesions that occur in individuals with multiple sclerosis, which typically occur in the cerebellar white matter, the subcortical white matter, the optic nerves, the optic chasm, and/or on the spinal cord (Waxman, 1981), constitute the hallmark of the disorder. In order to identify the pathological changes that characterize the symptoms of patients with MS, it is first necessary to understand some of the anatomy of the central nervous system (CNS), and why demyelination produces the clinical deficits to be described.

The Nondisabled Nervous System

The human nervous system is a complex system of cells that receive, transfer, interpret, and transmit information. Actions and reactions to a stimulus by an individual's body depend on "news" of the stimulus being transmitted to the brain, the brain's reaction, and the subsequent "instructions" sent from the brain to the effectors concerning how to react to the stimulus. The coordinated transmission of a nerve impulse from one nerve cell to the next that underlies this entire process is dependent on the connections among the nerve cells, called nerve fibers. The coordination that these nerve cells exhibit in relaying "news" from the sensing organ(s) to the brain and then back to the effector(s) to

carry out a reaction is a result of the integrity and the speed of conduction of an impulse along the nerve fiber to the synapse (or connection point) and then on to the next nerve cell. The insulation around the connecting fiber is as vital to the transmission of information-carrying signals as is the fiber itself. In the brain, the spinal cord, and nerves, this insulation is called myelin.

Myelin (a fatty substance that surrounds the nerve fiber forming a sheath) is made and maintained by a cell called an oligodendrocyte. Myelin is literally wrapped around nerve fibers by these cells which produce it. Hundreds or thousands of these myelin-producing cells line-up along the nerve fiber to produce sufficient insulation for signal transmission along the fiber. Each oligiodendrocyte produces a small patch of myelin for each of several, adjacent nerve fibers. This process results in small patches of myelin along the entire length of the nerve fiber that touch, but do not fuse with, the myelin produced by other oligodendrocytes. One oligodendrocyte produces myelin sheaths around a family of axons in its vicinity, with estimates ranging from four or five to several hundred axons per family. The oligodendrocyte cell body is connected to its myelin sheaths by thin cytoplasmic bridges. Oligodendrocytes and, more specifically, the myelin sheaths which they produce, enhance the velocity with which nerve impulses are conducted along the fibers in a process called saltatory conduction, in which

impulses travel along the sheath of myelin, "jumping" from one nerve cell to the next via this sheath. The advantage of the insulation is that it allows faster conduction of impulses along the nerve fiber, as well as better handling of closely-spaced impulses.

The conduction of an impulse along an axon is similar to the movement of an electrical current in an electrical wire. Myelin produces the insulation around nerve fibers and allows only a small portion of the nerve fiber membrane to become depolarized and the impulse to subsequently be transmitted. The presence of the myelin sheath markedly reduces any leakage of "current."

In MS, this sheath is damaged, so that the "insulation" can no longer prevent "leakage;" hence, MS is called a demyelinating disease. As a result of such demyelination, transmission may be either delayed, or may cease completely. In either event, a nervous system activity (such as vision or coordination) is diminished or lost because of the delay or block in impulse transmission that follows demyelination (Carlson, 1994; Poser, 1987).

Symptoms and Treatment of Multiple Sclerosis

When an individual has cancer, it is not only the cancer disease that typically governs much of what he/she can do but also the regimented and restrictive treatments (i.e. chemotherapy) and their

effects on the patient's activities of daily life, each of which can dictate a patient's diet, activity level, ability to work and recreate and, in short, his/her experience of daily living. The same can be said for multiple sclerosis; it is the symptoms of and treatments for multiple sclerosis which provide much of the grounding for the figural themes that participants in this study discussed. The purpose of this section, then, is to identify and discuss the symptoms and treatments of MS.

General

Multiple sclerosis (MS), or disseminated sclerosis (Frith, 1988), is a progressive demyelinating disorder that produces lesions in the white matter of the central nervous system, and specifically in the white matter of the cerebral hemisphere, brain stem, optic nerves, cerebellum, and spinal cord. The appearance of these lesions is typically followed by the overgrowth of glial cells which form sclerotic plaques creating focal lesions on the CNS. It is the most common neurological disease among young adults, affecting 50 to 60 young adults per 100,000, and has an average age of onset of between 25 and 33 years (Adams & Victor, 1989; Baum & Rothschild, 1981; Hopkins, 1993). In fact, it is so common that MS has been called "the great crippler of young adults," (Scheinberg, 1987, 2) and has been associated with an estimated health care cost in excess of $18,000,000 per year in the United States (Feigenson, et al., 1981).

Multiple sclerosis involves a spectrum of symptoms (discussed in detail later in this section) that afflict patients differentially. Most often, MS is associated with symptoms of motor and sensory dysfunction, including vertigo, paraesthesia, numbness and impaired sensation, ataxia, weakness and paresis, bladder dysfunction, pain, loss of vision in one or both eyes, diplopia (i.e., double vision), and spasticity, the latter occurring in 90% of all cases of MS (Sibley, 1990). An especially striking feature of the disease is that symptom manifestations vary markedly across MS patients, and fluctuate over time within an individual. Accordingly, subtypes of multiple sclerosis have been established on the basis of clinical course, the most common of which are relapsing-remitting multiple sclerosis and chronic-progressive multiple sclerosis. Most MS patients exhibit the relapsing-remitting form of MS, which is characterized by periods of clear-cut exacerbation of symptoms followed by recovery or partial recovery in functioning (Paty & Poser, 1984; Sibley, 1990). The frequency of exacerbation varies considerably across patients and appears to be related to severity of disability. Furthermore, since recovery is frequently incomplete following a relapse, the majority of relapsing-remitting patients display a slow progression in disability (Sibley, 1990). Frequently, patients progress from relapsing-remitting MS to chronic-progressive MS over time (Paty & Poser, 1984). This time

course involves a steady progression of symptoms from onset without periods of exacerbation and remission (Paty & Poser, 1984; Sibley, 1990).

The etiology of MS is believed to be multi-factorial. Several studies have been conducted which correlate specific laboratory and clinical findings with the presence of MS. Although the cause and pathogenesis of multiple sclerosis are unknown (Oger, Roos, & Antel 1983), there are a number of existent theories which have been proposed to explain the cause of MS, including activation of a latent viral infection (Cook & Dowling, 1980), genetic predisposition (Hader, Irvine, & Scheifer, 1990; Murray, 1976), and autoimmune disease (Pomales, 1990). The one that currently receives the most credence involves an autoimmunity basis for multiple sclerosis. This explanation has long been considered likely because the pathologic features of MS are similar to those in the encephalomyelitis that occurs after the administration of the Semple rabies-virus vaccine. The theory posits that MS could be a rare sequel of a childhood viral infection, because patients with multiple sclerosis have a high antibody to measles and herpes viruses (Scott, 1982). Specifically, it is suspected that a virus in childhood with a long latency period is activated by a secondary factor later in life and that multiple sclerosis is a resulting autoimmune reaction which attacks the myelin (Adams & Scott, 1977; Polman & Hartung, 1995).

Hundreds of studies of the geographic distribution of multiple sclerosis indicate that multiple sclerosis is more prevalent in Canada, Northern Europe, and the northern United States. Additionally, researchers (Adams & Victor, 1977; Scott, 1982) report that, within these areas, there is a familial tendency to develop the disease, but the explanation for this appears to be common exposure to an environmental factor rather than heredity. Some precipitating factors of MS include influenza and upper respiratory tract infections, pregnancy, surgery, tooth extraction, and electric shock. Again, though, there is still not enough evidence to confirm either a viral cause of multiple sclerosis, or that MS is an autoimmune reaction.

The Nature and Course of the Disease

While the precise etiology of MS is unknown, both genetic susceptibility as evidenced by concordance rate data (Ebers, Bulman, & Sadovnick, 1986) and environmental factors in the form of exposure to a viral agent (Poser, 1993; Raine, 1990) predispose an individual to developing MS. MS is still often conceptualized as a systemic "trait" carried by genetically predisposed individuals (Poser, 1993).

Pathologically, MS is characterized by the presence of sclerotic plaques distributed primarily in the white matter of the central nervous system, and by a state of hyperactive responsiveness, which, as mentioned

earlier, possibly results from an antigen challenge by a viral protein, from a viral infection, or from a vaccination. MS begins to affect the central nervous system only when the blood-brain barrier has been altered; with the permeability of the blood-brain barrier, edema and inflammation occurs within the CNS, leading possibly to demyelination of axons. It is this demyelinating process that is important in understanding the cognitive deficits that are commonly found in patients with MS (discussed later in this review).

As mentioned previously, myelin is the cell membrane of the oligodendroglia, which, during neuronal development, wraps around axons. In surrounding the axon, the myelin acts as an insulator for nerve conduction. While the exact etiology of the demyelinating process is unknown, it is estimated that it only requires 1 mm to 3 mm of the myelin sheath around the axon to become inflamed, then, at times, to harden, in order to be deemed sclerotic. Although it does not have to, such edema or inflammation typically does lead to destruction of the myelin (for a review see Lumsden, 1970; Raine, 1990).

When plaques develop in functionally important parts of the central nervous system, neurological and cognitive deficits can occur. Acute deficits resolve as the inflammation subsides, but with demyelination and repeated attacks, more and more plaques begin to accumulate. While the myelin is being stripped, the cell body and axon

are initially intact (Poser, 1993). Thus, the demylination tends to interrupt or slow signal conduction, rather than causing it to cease firing (Hopkins, 1993). Not surprisingly, then, neurologic dysfunction attributable to MS results from partial, complete, or intermittent nerve conduction block caused by myelin dissolution (Pomales, 1990).

Relation between demyelination and clinical deficits

MS affects the myelin sheaths throughout the CNS and, thus, causes many sensory, motor, and autonomic impairments. These impairments, then, give rise to various symptoms which vary in intensity in different patients, presumably according to the site and extent of the lesions. Some of these symptoms impair daily living activity. For example, because of demyelination in cerebellar and vestibular pathways people with MS may lose their balance even during sitting and more commonly during standing and transferring. Subsequently, they compensate for the loss of balance by changing the body posture by flexing the hip joints or fixing of the lumbar vertebrae in a lordotic position. In time, this leads to fixed postural abnormalities, making transfer more difficult.

It is well-established that demyelinated plaques can be present and produce conduction abnormalities without necessarily leading to clinical

deficit. Recovery from optic neuritis, for example, is usually characterized by parallel improvement in visual acuity and amplitude of the visual evoked potential response, but it is not associated with a recovery of the prolonged latency of the evoked response (Halliday, 1981; Halliday, McDonald, & Mushin, 1973, 1976). Serial evoked response studies of MS patients demonstrate that electrophysiological recovery, in terms of latency, lags behind clinical improvement (Namerow, 1968b). In a recent study of evoked response potentials in MS suspects who subsequently developed definite MS, Hume and Waxman (1987) demonstrated that nearly one-half of visual evoked response potential abnormalities were clinically unexpected. That is, they occurred in the context of history and physical examination that did not suggest pathology in the pathway under study. Asymptomatic plaques are thus not uncommon in MS patients. Moreover, changes in conduction latency are not necessarily closely connected with production of clinical abnormalities (i.e., a lesion on an effector pathway would not necessarily result in a latent response).

In contrast to conduction delay, conduction block does not appear to produce significant clinical deficits. Namerow (1968b), for example, used somatosensory evoked potentials to demonstrate impaired frequency-following in MS patients that was qualitatively correlated with the degree of clinical involvement. A number of researchers have demonstrated that neural information can be coded by the pattern of

impulses transmitted along CNS axons (Waxman, 1972). These observations suggest that the capability of axons to carry impulses (possibly at specific frequencies or in specific patterns) is significant with respect to clinical outcome; loss of even a fraction of impulses can lead to degradation of neural messages.

Summary

Because there are a variety of symptoms that can occur, and because there is only theory regarding its etiology, MS is a disease that is both hard to identify and, once prognosed, difficult to cure (treatments are discussed later in this section). In general, MS is typified by sclerotic plaques or lesions which occur in various sensory and motor tissues in the white matter of the brain and in the central nervous system.

The resultant cognitive and physical/structural deficits from these lesions are discussed in detail in the next section.

Cognitive Disturbances Common to Individuals with MS

Cognitive deficits in individuals with multiple sclerosis have been clearly documented over the past two decades (Beatty & Gange, 1977; DeLuca & Johnson, 1993; Grigsby, Ayarbe, Kravisin, & Busenbark, 1994; Klonoff, Clark, Oger, Paty, & Li, 1991; Rao, 1990). Many investigators have attempted to determine the frequency, as well as the exact nature of these

deficits, and have attempted to identify how they are related to disease variables, such as age at first symptom, age at diagnosis, specific course of the disease process, and degree of physical disability at time of testing.

Depending on the type of exam (e.g. brief mental status exam versus a comprehensive neuropsychological exam), estimates of cognitive dysfunction have ranged from 30% to 65% in the patient cases that have been reported (Beatty, Paul, Wilbanks, Hames, Blanco, & Goodkin, 1995; Fennell & Smith, 1990; Rao, Leo, Bernardin, & Unverzagt, 1991). Heaton, et al. (1985) reported that, in both relapsing/remitting cases and in cases in which patients exhibited chronic progressive multiple sclerosis, cognitive impairment on a neuropsychological test battery was poorly predicted by the results of other clinical mental status exams which could be administered. A decade later, Beatty, et al. (1995) echoed these sentiments, commenting that the occurrence of a cognitive deficit could not and should not be predicted from knowledge of the patient's age, level of physical disability, duration of the disease, disease type, and/or performance on mental status examinations. Degree of cognitive impairment has also been found to be highly variable from one individual to another, although high rates of deficits are typically reported for patients with a chronic/progressive form of the disease (Beatty, et al., 1994; Heaton, et al., 1985).

Severe dementia is unusual in MS, but more subtle abnormalities of cognitive function are common. These are often unnoticed by parents, families, or physicians, but they may be detected using more formal neuropsychiatric evaluation techniques. The most frequently encountered difficulties are with memory (Rao, 1995; Rao, et al., 1984) and with abstract/conceptual reasoning (Peyser, Edwards, Poser, & Filskov, 1980). Although cognitive impairments, much like motor disturbances, are variable, they most typically follow patterns usually associated with subcortical pathologies. MS can also affect cognitive function to various degrees, and in many different fashions (Rao, 1986). Studies assessing cognitive functioning in MS patients consistently reveal deficits of memory, speed of information processing, and problem solving or conceptual/abstract reasoning (Anzola, et al., 1990; Beatty & Gange, 1977; Beatty, et al., 1988; Carroll Gates, & Roldan, 1984; Grigsby, Ayarbe, Kravcisin, & Busenbark, 1994; Jambor, 1969; Litvan, et al., 1988; Peyser, Edwards, Poser, & Filskov, 1980; Rao, 1995; Rosche, Mauch, & Kornhuber, 1994).

The literature is replete with studies examining different aspects of mental life common to individuals with MS, and how MS compromises the speed or efficacy of these processes. However, the majority of these quantitative studies merely reaffirm how slowly or to what extent these processes occur within individuals with MS, and do not typically describe

the factors which contribute to the genesis of such cognitive symptoms. In the next sections, three of the most common cognitive maladies associated with multiple sclerosis are discussed.

Memory

The frontal lobes are of considerable importance in a number of aspects of memory and cognition. Specifically, frontal regions play an important role in conducting strategic and organizational memory search, and in monitoring temporal and spatial dimensions of memory. Evidence also suggests that the frontal lobes may mediate the organization of material during encoding. Furthermore, these regions are involved in monitoring and recalling sequential events which may be essential to developing and executing motor plans (Carlson, 1994; Petrides, 1989). These "executive " functions may give rise to deficits in memory performance that rely on such functions when the integrity of the frontal lobes has been compromised. Indeed, evidence generated from tasks assessing memory and other cognitive functions are consistent with Moscovitch's (1994) theoretical contention that the frontal lobes are involved in effortful working-with-memory processes. The role of the frontal lobes proposed by Moscovitch encompasses both aspects of memory per se, as well as deficits in other cognitive domains. Moscovitch (1992) suggested that the prefrontal brain region selects and implements

encoding operations that organize information flow to and from the hippocampus, provides temporal and spatial context to events, and uses the information that results from its operations to further guide cognitive and mnemonic processes and future actions.

Since evidence suggests that the frontal lobes are a primary site of pathology in MS (Brownwell & Hughes, 1962; Omerod, et al. 1987), deficits in executive or working-with-memory processes may play a key role in the long-term memory (LTM) impairments observed in MS patients (Foong, et al., 1997). Furthermore, the cognitive resources that are essential for these processes may exceed those which are available to MS patients. Thus, available cognitive resources may serve as a boundary or limiting condition that defines memory failures in MS patients (Mitchell & Hunt, 1989). Within this framework, memory impairment in MS patients should be associated with both retrieval and encoding processes and can be dependent on the particular processing requirements of the task.

Whether memory dysfunction in MS patients reflects an amnesic disorder or results from more diffuse cognitive difficulties is not clearly established. Litvan et al. (1988) did not find a relationship between tests of general intelligence and memory measures. Moreover, cognitive dysfunction, such as conceptual reasoning, has been demonstrated to occur independent of memory disturbances (Rao & Hammeke, 1984).

While Rao and colleagues (1984) have suggested that the distinction between generalized cognitive disturbance and memory impairment is not straightforward, they conclude that the degree of cognitive impairment in MS patients is relatively mild compared to the memory disturbances which they experience. Based on a cluster analysis, Rao et al. found that only those patients with severe memory dysfunction were likely to exhibit cognitive impairment. The findings of Minden et al. (1990) support those of Rao et al. (1984); although the former noted a dissociation between generalized cognitive impairment and memory impairments for some patients, they reported some degree of relationship between the severity of memory deficits and that of other cognitive impairments, such as arousal and attention, motor speed, mental flexibility, and the ability to maintain and shift sets.

These results highlight the notion that an MS patient's performance on memory measures and cognitive tests can vary.

Memory deficits in MS.

Numerous studies have demonstrated a memory impairment in MS patients (Beatty & Monson, 1990; Grigsby, et al., 1994; Litvan, Grafman, Vendrell, & Martinez, 1988; Rao, et al., 1989). In fact, neuropsychological studies suggest that 40% to 60% of MS patients suffer significant cognitive deficits with the most prominent deficits being in

memory, attention, and conceptual reasoning (Beatty & Monson, 1990; Peyser, Edwards, Poser, & Filskov, 1980; Rao, 1986; Rao, Leo, Bernardin, & Unverzagt, 1991). Memory deficit isthe most commonly reported ailment (DeLuca & Johnson, 1993) and memory impairment has been commonly observed in samples drawn from clinical settings (Carroll, Gates, & Roldan, 1984; Rao & Hammeke, 1984) as well as in more representative samples drawn from community registries (McIntosh-Michaelis, et al., 1991; Rao, et al., 1991). Furthermore, MS patients have been found to exhibit substantially more memory impairment than patients with psychiatric and neuromuscular disease (Jambor, 1969), spinal cord injury and disease (Caltagirone, Carlesimo, Fadda, & Roncacci, 1991), chronic pain (Rao, et al., 1984), and rhematoid arthritis (McIntosh-Michaelis, et al., 1991). This suggests that the deficits observed in MS patients are related to specific features of each disease rather than to general illness factors.

In MS, certain aspects of memory seem to be more affected than others (Grafman, et al., 1990). Although the exact nature of the memory deficit may vary from one MS patient to another, retrieval deficits (as opposed to encoding deficits) have been the most common type of deficit reported in the literature (Armstrong, et al., 1996; Fennel & Smith, 1990; Grafman, et al., 1990). In fact, retrieval deficit in MS patients appears to differentiate their pattern of cognitive dysfunction from that of other patients with Alzheimer's Disease who experience "cortical dementia," in

which an encoding or "initial acquisition" memory deficit is reported. It has recently been contended that memory impairment noted in MS patients primarily reflects *effortful* retrieval of information from long-term memory (LTM), while encoding and storage processes are relatively preserved (Grafman, Rao, & Litvan, 1990; Rao, 1986; Rao, et al., 1993). Impairment on measures of verbal and category fluency also suggests a breakdown in retrieval processes in MS patients (Grafman, et al., 1990; Rao, et al., 1989). Verbal fluency involves the generation of as many words as possible that begin with a certain letter, while category fluency requires the generation of exemplars of certain categories. Both category and verbal fluency are thought to require the retrieval of semantic and lexical information from memory. Thus, decreased fluency is thought to reflect deficits in retrieval of stored information. Recently, 13 independent samples were used to derive an effect size estimate for verbal fluency performance in MS patients (Thornton, unpublished manuscript). The results indicated that, compared to non-MS controls, MS patients were moderately impaired in lexical and semantic access and retrieval (effect size = 0.65). While this evidence suggests the prevalence of retrieval deficits in MS patients, encoding processes were not examined and therefore their contribution to memory deficit remains unclear. Additional evidence for a retrieval-based deficit in MS comes from a recent study by Armstrong, et al. (1996), in which participants with MS

and controls attempted to learn a list of words and were given post-encoding retrieval and recognition trials. The results indicated that, although MS patients exhibited normal encoding capabilities, they displayed impaired word recall performance.

Support for the existence of retrieval-based memory deficits among MS patients has also arisen from studies examining participants' performances on a selective reminder task (Buscke, 1973; Buschke & Field, 1974). For this task, participants were read a list of unrelated words over multiple trials, and were reminded only of words which they failed to recall on the preceding trial; items recalled without reminders were presumed to have entered long-term storage. Findings indicated that MS patients recalled the words in a considerably less consistent manner than did non-MS participants (Rao, et al., 1989; Rao, et al., 1993). This pattern of inconsistent recall following apparently successful encoding suggests a failure in memory access and retrieval for MS patients. However, the findings also indicated that MS patients initially learned items less effectively than did control participants (Rao, et al., 1989).

Although there is ample evidence indicating that this retrieval-based memory deficit exists in MS patients, the belief that memory deficits in individuals with MS are retrieval-based is not universally held. Several researchers have provided evidence for an encoding-based rather than a retrieval-based memory deficit in MS patients. For example, Van

der Berg (1987) found an encoding-based or initial learning memory deficit in a group of relapsing/remitting MS patients. More recently, DeLuca, Barbieri-Berger, and Johnson (1994) attempted to evaluate the contribution of acquisition versus retrieval processes in MS patients by controlling for the amount of initial information that was given to participants. The researchers postulated that, once acquisition was complete, subsequent deficits in recall would reflect impaired retrieval processes. The results indicated that, once all information was acquired, participants with MS and controls did not exhibit a significant difference in either delayed recall or recognition, and the authors concluded that memory deficits in MS are associated with information acquisition rather than information retrieval. Based on these results, DeLuca et al. (1994) suggested that the nature of memory disturbances in MS is a consequence of inadequate encoding of novel verbal information, and not of impaired retrieval.

Many factors may contribute to the apparent memory difficulties observed in patients with MS. Factors such as attention or the individual's ability to concentrate on the material to be encoded, and speed of information processing may be but a few of the mitigating factors in the memory deficits that MS patients exhibit. For example, Grigsby, et al. (1994) examined short-term memory (STM) among a group of 23 chronic/progressive MS patients, and a control group matched closely on

age and on education. Administering the Brown-Peterson Test, the logical memory scale on the Revised Wechsler Memory Scale, and the Mini-Mental Status Exam, Grigsby, et al. (1994) reported significant differences between groups, with the group of MS patients performing significantly more poorly on each of the three tests than the control group, suggesting significant working memory impairment in the MS patients. Grigsby, et al. (1994) concluded that an impairment of central information processing capability was a fundamental aspect of the memory deficits that MS patients exhibited.

In summary, although considerable support exists for a retrieval-based memory deficit in MS patients, the support is not universal. While studies examining verbal and category fluency, and free recall versus recognition have provided evidence of retrieval-based deficits, these findings do not preclude concurrent deficits in encoding. In fact, evidence suggests that MS patients suffer impaired recognition deficits in memory acquisition. Furthermore, the evidence cited has not *directly* examined encoding and retrieval processes in MS patients, but instead the integrity of the processes are inferred based on assumptions regarding the processes that underlie indices of memory performance. That is, it is assumed that recognition provides a measure of encoding and storage while free recall provides a measure of encoding plus retrieval processes. However, it is possible that recall failure in the context of intact recognition may also

arise because items have been stored in memory in a degraded or weakened form.

The connection between memory and attention is an especially important one, and one that is often not considered by researchers. Nissen (1986) stated that "before concluding that an individual has a memory disorder, it is necessary to consider the possibility that the difficulty stems instead from a failure of attention" (pp. 13-14). In the next section, attention deficits common to individuals with multiple sclerosis are discussed.

Attention

The basic cognitive skills that enable the execution of complex functions measured in memory tests include attention and speed of information processing (Leininger & Kreutzer, 1992). Attention impairment is reported to be characteristic of many disorders, including schizophrenia and head injury (Stuss, Stethem, & Poirier, 1987), and has been demonstrated to be a prevalent deficit in MS patients (Filley, Heaton, Nelson, Burks, & Franklin, 1989; Jansen & Cimprich, 1994; Litvan, Grafman, Vendrell, & Martinez, 1988).

Despite the prevalence of reported attentional impairment in clinical populations, no common consensus exists in the literature as to what "attention" means (Glass & Holyoak, 1986; Gronwall, 1987). It is

generally well accepted that attention is not a unitary construct but instead comprises a variety of interacting processes (Halperin, 1991; Parasuraman, Mutter, & Molloy, 1991). Sustained attention and selective attention are the two types of attention most commonly discussed in the literature. Sustained attention, the maintenance of attention for sustained periods of time (Parasuraman, et al., 1991), has also been called "concentration," "freedom from distractibility," and "vigilance." Selective attention, which can be further partitioned into focused and divided types (Halperin, 1991), involves selection of higher levels of conscious processing, while preventing access of other signals to those same high levels of processing (Posner, 1986). A third aspect of attention, termed "attentional capacity allocation," involves the ability to vary the amount of attention in response to information processing demands (Parasuraman, et al., 1991). While the term attention has been subdivided into different types or processes, such as selective attention or "focus," "sustained," and "shift" (Mirsky, Anthony, Duncan, Ahearn, & Kellam, 1991), this does not remediate the uncertainty surrounding the definition and measurement of attention. There is also a lack of consensus among clinicians as to the individual and specific processes of attention which are measured by most purported attention tasks. For example, the WAIS-R Digit Symbol subtest has not only been considered to be a measure of

concentration and sustained attentionbut also of distractibility (Shum, McFarland, & Bain, 1990).

Few studies have systematically examined attention in an MS population and those that have have done so in concert with tests examining speed of information processing, and have reported decrements in performance in both clinic-referred and community-based samples of individuals with MS (Jansen & Cimprich, 1994). Rao (1988) specifically examined attentional performance in a group of MS patients through the administration of an auditory vigilance task. Results of this study revealed that MS participants, relative to control participants, made significantly more errors of commission over four consecutive 3 minute blocks of time. Filley, et al. (1989) compared the performance of 42 chronic/progressive MS patients with that of 42 patients diagnosed with senile dementia of the Alzheimer's Type on a comprehensive battery of neuropsychological measures which included tasks of visual and auditory attention. Results indicated that the MS group displayed greater relative impairment on tests of visual and auditory attention, incidental memory, and fine motor speed and coordination than did the senile dementia group. Compared to the Alzheimer's population, the MS patients also exhibited greater motor deficits and a tendency toward more impairment in sustained attentional abilities. Filley, et al. (1989) concluded that underlying attentional disturbances were the fundamental cognitive

abnormality that differentiated patients with MS from patients with senile dementia in Alzheimer's disease. Ron, et al. (1991) also investigated attentional disturbance in MS patients, examining the cognitive performance of 55 MS patients, 48 patients who exhibited some clinical symptoms of MS (e.g. optic neuritis) but were not diagnosed with MS, and 46 control participants. Results indicated that the MS group performed significantly poorer on measures of auditory and visual vigilance, and that the overall performance of the MS participants correlated significantly with the degree of physical disability and with the duration of illness. Poorer performance was also exhibited by the MS sample on measures of verbal and visual memory, naming ability, and auditory attention, all of which correlated significantly with higher MRI lesion scores. Such was not the case for visual attention skills and abstracting abilities, however. Ron, et al. (1991) concluded that clear relationships between individual psychometric functions and the presence of MRI abnormalities in specific anatomical areas were not established. They also postulated that, with advancing disease, early attentional deficits may extend to involve memory and abstracting ability. More recently, Kujala, et al. (1995) assessed the attentional abilities of two clinically and demographically matched groups of MS patients who differed in cognitive status. Using a variety of attention tasks, they reported that the cognitively mildly deteriorated group was slower than

the cognitively preserved group and the controls on all tests of attention, and suggested that certain kinds of processing slowness were the source of the deficits that participants exhibited on the two attention tests that were administered.

Perhaps the paucity of research on attentional functioning in certain disorders, such as MS, is due to this aforementioned difficulty in clarifying the individual components or types of attention and how to measure them. Shum et al. (1990) clearly capture the heart of this difficulty when they state, "a problem arises from the amorphous nature of the concept of attention and the fact that most of the attention tests were not developed or constructed with reference to a generally accepted theory or model of attention" (p. 152). An additional problem with the detection of attentional impairment, is that such deficits are unrelated to depressive symptoms, or to physical symptoms (Jansen & Cimprich, 1994).

In an attempt to better understand and identify the individual components of attention, several investigators have examined the construct validity of purported measures of attention used commonly in clinical practice. Several of these studies have used head-injured individuals as participants since disorders of attention are reported frequently after closed head injury (Parasuraman, et al., 1991). Based on the findings of Shum, et al. (1990) and others, Mirsky et al. (1991)

presented a neuropsychological model for studying attention by identifying a set of processes or elements involved in attention. Analyses of data from 203 neuropsychiatric patients and from 435 elementary school children indicated that four distinct components of performance conformed to the multi-element model proposed by the researchers. That is, the results supported Mirsky et al.'s hypothesis that attention can be viewed as a process involving four independent elements: focus-execute, sustain, encode, and shift. Based on their results, and on anatomical data from human clinical cases and animal lesion studies, Mirsky et al. (1991) identified anatomical localizations for each of the elements in their model; they proposed that the inferior-parietal, superior temporal, and striated regions played a special role in their focus-execute element of attention, that the mesencephalic brainstem structures were critical for the maintenance of sustained attention, that the prefrontal cortex was the locus of control for the capacity for attention, and that both the hippocampus and the amygdala were involved in the encoding element.

Although attention has been studied to some degree in individuals with closed head injuries, as mentioned before, the examination of attention in both clinic-referred and community-based MS populations is recent and has not been as thorough. However, the results of the few studies that *have* examined attentional performance in MS patients (Ron, Callahan, & Warrington, 1991) have suggested slowed information

processing and auditory and visual attention deficits. In fact, although the number of studies examining attention is small, the number of researchers suggesting a causal linkage between decrements in information processing and subsequent decrements in attentional performance in MS patients is considerable (DeLuca & Johnson, 1993; DeLuca, Johnson, & Natelson, 1993; Litvan, et al., 1988).

Information Processing

Information processing is one of the most widely researched topics in the area of multiple sclerosis. This is because, as mentioned earlier, information processing and attention are two processes that underlie many of the events of mental life, and that mediate the speed with which events such as memory occur. Slowness of thought and, more specifically, of information processing capabilities, has been listed as a concomitant of MS for over a decade. Charcot (1877) described patients as exhibiting "conceptions (which) formed slowly;" a symptom later termed "subcortical dementia" by Albert, Feldman, and Willis (1974). Albert et al. (1974) theorized that, although the subcortical structures involved may differ, lesions in these areas produce impaired timing and activation and a slowing down of normal intellectual processes. Cortical systems responsible for perceiving, storing, and manipulating knowledge may be intact, but they may be abnormally activated. Moreover, once activated,

they may take an excessive amount of time to carry out intellectual processing. This means that the observable results of subcortical dementia include slowing of mental processes and impaired ability to manipulate acquired knowledge, although learning processes remain intact. Hence, knowledge gained prior to the onset of the disease, such as the ability to execute a motor skill, is generally still existent in individuals with MS, but spontaneous use of this stored information is compromised (Benson, 1983; Cummings & Benson, 1983).

It has been reported that anomalies exist in the information processing capabilities of individuals with MS (Peyser & Poser, 1986; Rao, St. Aubin-Faubert, & Leo, 1989). Moreover, there is a great deal of evidence suggesting that this slowing of information processing is attributable to the existence of subcortical dementia in individuals with MS (Mendez & Frey, 1992; Rao, Leo, Bernardin, & Unverzagt, 1991). However, much of this research has been descriptive in nature, merely measuring and reporting any differences that exist between individuals with MS and control participants. For example, Rao, et al. (1989) found that multiple sclerosis patients performed slower than healthy patients on a test measuring cognitive speed in information processing, but no attempt was made to determine at which point in the information processing sequence the impairment existed. Jenneks-Schinkel, Sanders, Lanser, and Van der Velde (1988a; 1988b) similarly found that the reaction

times of MS patients were slower than those of controls. Albert, Feldman, & Willis (1974) found similar differences, and remarked on the slowness of certain patients with MS with subcortical lesions, suggesting that the increased amounts of time that these individuals required to respond to stimuli were due to slowed information processing. Litvan et al. (1988) reported that patients with MS exhibited "slowness of thought," and theorized that slowness of thought "could account for less information processed" (p. 282).

Summary of Cognitive Deficits

It is apparent that cognitive deficits comprise a substantial portion of the experience of MS. However, diagnostic and methodological problems have prohibited clinicians and researchers from determining the precise cause(s) of these deficits. Despite these shortcomings, there are several studies suggesting that deficits do occur in memory, attention and information processing although the precise aspects of these processes that become compromised with MS remains unclear. For example, in memory it is unclear whether MS results in memory loss (similar to amnesia), or simply cognitive deficits in certain processes. Likewise, it is unclear whether the nature of memory deficits are retrieval-based, meaning that patients experience difficulty in recalling facts, or

acquisition based, meaning that individuals with MS experience difficulty in acquiring skills and information.

In addition to the cognitive deficits that can occur, there are also a variety of physical deficits that are common to individuals with MS. These are considered in the following section.

Multiple Sclerosis and Its Structural Effects

Patients with MS may exhibit several symptoms at one time, and no symptoms at another time. Some symptoms, including fatigue and weakness of one or more limbs, can be so extreme that the patient may not want to perform any activities at all. Many patients also have dysequilibrium, which has often been described as a "drunken gait," and spasticity, which is manifested as a nonrigid stiffness of the limbs. Tremor and incoordination are also commo, and can result in the loss of ability to perform fine-motor, well-organized, purposeful movements.

Vision problems in patients with MS can also be problematic, and can consist of blurred or double vision (which can be corrected with an eye patch) or loss or decrease of visual acuity in one or both eyes. Optic neuritis is one of the most common manifestations of MS, occurring in 14-23% of MS cases (McAlpine, 1972). Patients with optic neuritis usually complain of dimming vision unilaterally, generally accompanied by photophobia and pain aggravated by eye movement. Even in the absence

of acute optic neuritis, many patients still exhibit the clinical abnormalities of optic neuropathy. This may be manifested by diminished visual acuity or an afferent pupillary defect. Visual evoked responses will often be abnormal, even in patients that do not exhibit any optic nerve disease (Halliday, 1981; Lowitzsch, 1980).

Sensory deficits, in particular numbness and tingling in all or part of a limb or limbs, may cause difficulties with gait, balance, and coordination, particularly in darkness. For example, a fairly specific sensory symptom of MS is Lhermitte's sign, in which patients complain of sudden electric-like sensations radiating down the spine or extremities for a brief moment, typically when flexing the neck (Kanchandani & Howe, 1982; Sibley, 1992). Urinary urgency and frequency are also common, and can result in incontinence. Patients may need to remain close to a restroom unless medication, pads, or mechanical devices are used to provide temporary freedom from these distressing symptoms (Auxter, Pyfer, & Huettig, 1993; Scott, 1982).

Spasticity

Even when muscles are at rest, a certain amount of resistance to passive stretch usually remains. This persistent degree of contraction in skeletal muscle resulting from nerve impulses transmitted via alpha motoneurons axons is called muscle tone (Guyton, 1991).

Spasticity is a velocity-dependent increase in muscle tone often associated with exaggerated deep-tendon reflexes, decreased muscle strength, decreased movement speed, and decreased range of voluntary movement about the affected joint(s) (Pierrot-Deseilligny & Mazieres, 1985; Wright & Rang, 1990; Wisendanger, 1991). Clonus (regular rhythmic muscle contraction in response to maintained muscle stretch) and flexor spasms might also be observed (Pierrot-Deseilligny, 1990).

Spasticity is a common symptom of many neurological diseases, but is especially prevalent in patients with MS (Sibley, 1992). Most commonly seen in the legs, it may be prevalent in the arms as well. It is, without question, the motor disturbance that has been most frequently associated with multiple sclerosis. In fact, in one extensive study of MS patients' symptoms, as many as 95% of all patients complained of spasticity to some degree (Poser, 1979). The degree of spasticity appears to depend on the extent of corticospinal tract involvement.

Demyelination and plaque formation along the spinal pathways result in partial lesions which are responsible for the development of spasticity. Spasms, both spontaneous and induced by certain stimuli, occur in patients with lesions of the spinal cord. Purposeful movements may still be possible but activity in motor units of opposing muscle groups (i.e. co-contraction) may be brought on by the initiation of an intended action. This creates antagonistic activity, with the result that the

desired movement is not completely achieved. In spastic paraparesis, a purposeful movement may impose reciprocal inhibition on a muscle antagonistic to the prime mover. Additionally, reflex activation of antagonistic muscle groups can interfere with maintenance of desired posture or movement. Extensor spasms of paravertebral muscles can cause difficulty in standing, ambulating, transferring, or even sitting. Painful flexion spasms, increasing in frequency with fatigue, cause discomfort and can interfere with sleep. At times this abnormality actually helps a patient walk (Matthews, 1985; Scheinberg & Geisser, 1987), but sometimes it may cause discomfort or pain, cause flexor or extensor spasm, or interfere with personal hygiene. The spastic paraparetic gait is also associated with an increased incidence of chronic low back pain (Clifford & Trotter,. 1984; Moulin, Foley, & Eberes, 1988).

The amount of spasticity varies from one individual to another because of differences in the size and distribution of areas of demyelination. Therefore, impairments resulting from spasticity may vary from a minor motor deficit to extreme difficulty or incapacity to perform motor activities (Smith, LaRocca, Giesser, & Scheinber, 1991). For example, a small plaque located where nerve tracts are dense will result in greater spasticity and perhaps more widely manifested symptoms than one in a location of less dense pyramidal system fibers. Because of this potential variation and its implications for treatment, Kurtzke (1961,

1983) emphasized the importance of estimating the amount of white matter destroyed by the disease process in order to obtain a reasonable knowledge of the course of the illness and the development of signs and symptoms. Specifically, he suggested that the measure of severity of spasticity in multiple sclerosis by degree of neurologic disability probably reflects the extent of the diseased tissue.

There are two manifestations of spasticity that require treatment. The first is phasic spasms: these spasms can be either flexor or extensor; they occur most commonly in the legs, and are especially frequent at night. Such spasms are very detrimental to the balance of the patient and can also be very painful. The second form of spasticity is the sustained increase in tone that interferes with walking in ambulatory MS patients, and interferes with hygiene and nursing care in bedridden patients.

Pain

Sensory complaints, including pain, are often the earliest symptom of MS (21-55%), and, during the course of MS, occur in 52-70% of patients (Kurtzke, 1970; Muller, 1949). Several distinct pain syndromes may occur in MS patients; some experience severe neuralgic pains in the limbs or elsewhere, while others complain of more persistent, intolerable dysesthesias, frequently with a burning quality (Moulin, Foley, & Ebers, 1988). Three kinds of pain are identified in the literature. First, there is

musculoskeletal pain which is often related to musculoskeletal imbalance. For example, patients with moderate disabilities may have back pain due to incorrect posture and/or poorly designed wheelchairs. Pain due to osteoporosis, compression fractures of vertebrae, arthritis in the hips and neck, contractures, and spasticity are all considered in this category as well (Sibley, 1992). Second, there is paroxysmal pain which is the sharp stabbing pain of the face (attributed to trigemial neuralgia), but other paroxysmal pains can occur, often in the general distribution of the nerve root (Carlson, 1994; Sibley, 1992) (see section on paroxysmal symptoms). Lastly, there is chronic neurogenic pain, which is often described as constant, boring, burning, constricting, or intense tinglings that are present in diffuse distributions, especially in the legs. Often individuals who are not aware that they have MS will attribute such pains to their foot being asleep, or to a pinched nerve (Davis, 1973; Sibley, 1992).

Paroxysmal symptoms.

The familiar symptoms of MS are those due to either impaired axonal conduction, temporary or permanent, or to the release of exaggerated reflex activity. Apparently a different category, not easily attributable to other causes, are brief paroxysmal symptoms.

Many authors have noted that paroxysmal symptoms of every type are frequently precipitated by sensory stimulation or movement. In fact, Shibasaki and Kuroiwa (1974) were able to identify trigger zones in some patients which, when enervated, would elicit paroxysmal symptoms. The similarities between the different kinds of paroxysmal phenomena in MS - the brevity of attacks, the frequency, the eliciting factors, the effect of anticonvulsive treatment - make it tempting to seek a unitary pathogenic hypothesis that could explain all of the different kinds of attacks as arising from the same neurologic disturbance.

It has been suggested that the paroxysmal phenomena in MS are caused by a transversely spreading activation of axons within a partially demyelinatyed lesion in fiber tracts somewhere in the central nervous system (Osterman & Westerberg, 1975). In the following sections the most common paroxysmal symptoms, from which most secondary and tertiary paroxysmal symptoms develop, are identified and described.

Tonic seizures.

Of the paroxysmal symptoms that have been described, tonic seizures have been reported most often (Berger, Sheremata, & Melamed, 1984; Heath & Nightingale, 1986; Osterman & Westerberg, 1975). Patients with tonic seizures suddenly experience dystonic posturing of part of the body, most typically the hand or the arm, lasting for 30 seconds to 2

minutes. An "epileptic" origin of tonic seizures was proposed by Guillain and colleagues in 1928, and then by Storring in 1940. Matthews (1958) suggested that tonic seizures are focal epileptic fits originating in mesencephalic lesions.

Trigeminal neuralgia.

Trigeminal neuralgia (TN) is the most common paroxysmal disturbance (Fromm, 1987), and occurs more frequently in MS patients than in any other population (Brisman, 1987; Katusic, Beard, Bergstalh, & Kurland, 1990). When TN develops in MS patients, the disease is usually well established, but TN can also be the presenting symptom of MS (Mallin, 1961). Typically, MS is present for an average of 11-14 years (Broggi & Franzini, 1982; Hooge & Redekop, 1990; Jenson, Rasmussen, & Reske-Nielsen, 1982) before symptoms of TN occur, with the largest possible range of years of incidence of trigeminal neuralgia reported by Rushton and Olafson (1965) at 1-29 years. There is only a small amount of descriptive data regarding the frequency of occurrence of TN in the general population, and even less information is available concerning its incidence in MS populations. Katusic, Beard, Bergstralh, & Kurland (1990), reported that the rate of incidence of TN per 100,000 among the general population in Rochester, Minnesota was 4.3 for both genders, with women (5.9) reporting a significantly higher incidence than men

(3.4) per 100,000. Hooge and Redekop (1994) reported that TN occurred in 35 patients (1.9%) from a clinical population of 1882 MS patients. However, before their study in 1994, there had been no clinical reports since the Mayo Clinic series in 1965 and 1966, in which Olafson and Rushton (1965, 1966) reported the prevalence of TN among 3880 MS patients.

TN is a highly frustrating condition for both patient and physician (Gale, Prime, & Campbell, 1995; Nielson & Field, 1994). Despite being one of the most painful syndromes for patients, clinical examination often fails to show pain pathway abnormalities, there are striking similarities between TN and other paroxysmal symptoms (Espir, Illingworth, Ceranic, & Luxon, 1997), and theories of its etiology are equivocal. Although neuroimaging techniques do provide objective data on sensory pathways, the results can also be contradictory. For example, electromyographic (EMG) recordings of the blink reflex and jawjerk in such patients are often reported to be normal (Cruccu & Bowsher, 1986; Ongerboer de Visser & Goor, 1974). In contrast, recordings of the scalp potentials evoked by cutaneous stimulation of the gum, lip, and mental nerve sometimes show a significant delay (Drechsler & Neuhauser, 1986; Stoehr & Petruch, 1981), although after surgical removal of lesions affecting these areas, these potentials become normal or, at least, exhibit improvement (Drechsler & Neuhauser, 1986).

The French neurologist Trousseau (1853) was the first to comment on the clinical similarities between TN and other disabilities, including some types of epilepsy. He proposed that the pains associated with TN were due to paroxysmal discharges in the trigeminal nerve similar to those exhibited by epileptic patients, and suggested that cerebral paroxysmal discharges should be called "epileptiform neuralgia." Trousseau's observations were later confirmed by the research of Kugelberg and Lindbloom (1959), who demonstrated the presence of a measurable latent period between the onset of a stimulus to the trigger zone and the onset of an attack of trigeminal neuralgia. They also found that the attack was self-sustained, and that once it had started it was then followed by a refractory period. All these features would suggest that a central mechanism is indeed responsible for the painful paroxysm, as Trousseau had posited.

Disagreement arises when discussing the etiology of trigeminal neuralgia chiefly because comparable data are lacking; reports are often based on varied neurophysiological techniques, which examine different sets of fibers and trigeminal divisions. Conventional opinion in patients with multiple sclerosis is that TN is due to a demyelinating plaque affecting the trigeminal pathway (Brisman, 1987; Wallace, Seland, & Fong, 1992), however it is clear from research in the past three decades that the pathophysiological processes underlying TN, in fact, remain an enigma

(Calvin, Loeser, & Howe, 1977; Fromm, Terrence, & Chattha, 1981; Meaney et al., 1994). It is estimated that about 1-2% of reported cases of TN are caused by demyelinating plaques of multiple sclerosis affecting the trigeminal pathway and the results of many postmortem examinations support this notion (Brisman, 1987), and that 10% of cases are due to cerebellopontine masses compressing or invading the fifth cranial nerve (the trigeminal nerve) (Cheng, Cascino, & Onofrio, 1993). Numerous reports of compression, distortion, or stretching of the trigeminal nerve by lesions involving the trigeminal nuclei are typically attributed as an etiology for this disorder (Fromm, Terrence, & Maroon, 1984; Selby, 1984). In fact, studies suggest that the lesions associated with TN usually affect the trigeminal roots within a few millimeters of the pons (Selby, 1984). In support of this hypothesis, plaques have been found in the pons at the trigeminal root-entry zone in all patients with MS and TN who have been examined at autopsy or surgery (Fromm, 1987). Therefore, the responsible factor in these cases may have been a lesion affecting the trigeminal roots.

An alternative theory that has also gained credence is that some cases of TN may, in fact, be attributable to vascular compression of the trigeminal nerve by a looping blood vessel where the nerve enters the pons (Fromm, Terrance, & Maroon, 1984; Meaney, Miles, Nixon, Whitehouse, Ballentyne, & Eldridge, 1994). This notion of neurovascular

compression has been a widely, but not universally accepted, cause of TN due in large part to the fact that, until recently, demonstration of vascular compression was not possible by imaging means. However, the recent advent of magnetic resonance tomoangiograms (MRTA) has enabled researchers to examine depictions of the intracranial vasculature, in concert with the information provided by magnetic resonance imaging (MRI) readings and by evoked response potentials (ERP). The proliferation of such multiple diagnostic technologies has been an important milestone because it has enabled researchers to detect many more pathological symptoms of TN, which has subsequently led researchers to believe that TN may be a multifactorial condition rather than being attributable a single cause (Meaney et al. 1994).

Weakness and Fatigue

Fatigue, in addition to pain in its various forms and to spasticity, is the most frequent disabling symptom of MS (Krupp, Alvarez, LaRocca, & Scheinberg, 1988; Monks, 1989; Murray, 1985) and, depending on the methods used, fatigue has been observed in as many as 75% to 89% of MS patients in some studies (Cohen & Fisher, 1989; Colosimo, et al., 1995; Freal, Kraft, & Coryell, 1984; Krupp, Alvarez, LaRocca, & Scheinberg, 1988). The definition proposed by Varricho (1985) best describes the fatigue experienced by people with and without chronic diseases:

> An acute or chronic experience characterized by ineffective task performance, self-assured inadequacy, aversion to activity, tiredness or a sense of weakness, feelings of discomfort, and attempts to terminate the feelings of discomfort (p. 128).

Fatigue is a common experience that refers to a slowing and/or worsening of performance, usually brought about after prolonged activity (Berrios, 1990). Muscle weakness, incoordination, and reduced physical endurance are also each symptoms of fatigue, which can profoundly affect the lifestyle of MS patients, including ambulation and their ability to perform other relatively mild physical activities (Schwartz, Coulthard-Morris, & Zeng, 1996). In fact, fatigue is one of the two major reasons for unemployment among MS patients (Edgeley, Sullivan, & Dehoux, 1991; Jackson, Quaal, & Reeves, 1991).

Although considered a motor disturbance, the experience of fatigue in MS patients is not restricted in cause to merely to motor acts, but also to a myriad of other areas, including cognitive activities (Colosimo, et al., 1995; Jennekens-Schenkel, Sanders, Lanser, & Van der Velde, 1988a; 1988b; Schwartz, Coulthard, Morris, & Zeng, 1996). For example, Schwartz, et al. (1996) administered the Multidimensional Assessment of Fatigue Scale and a number of other scales assessing psychological and neuropsychological function to MS patients in the Boston areain order to measure the interrelation among the neuropsychological, psychological,

psychosocial, and motor concomitants of fatigue in patients with MS. They found that having a low sense of environmental mastery (via motor skills) and depression were each strong predictors of the incidence of fatigue and of poor performance on the tests that were administered, suggesting a strong relationship between the neuropsychological, psychological, and psychosocial factors of MS and fatigue. Colosimo, et al. (1995) likewise reported that a number of genetic, demographic, physical, and psychological factors covary with the onset and degree of fatigue that patients with MS exhibited.

Fisk, Pontefract, Ritvo, Archibald, & Murray (1994) administered the Fatigue Impact Scale to 85 MS patients and 20 hypertensive patients while also assessing neurologic impairment, mental health, and general health. In addition to exhibiting significantly higher fatigue impact than the hypertensive patients, Fisk, et al. (1994) reported that fatigue had a significant effect on the mental health and the general status of the MS patients who were surveyed, with the MS patients exhibiting low scores (compared to a criterion of typical scores for MS patients) on many of the general health assessments.

While changes in muscle metabolism can follow prolonged exertion (Lenman, 1989), the experience of fatigue probably has multiple explanations, since it is experienced in a wide range of diseases (e.g. hepatitis, cardiac failure, systematic infection) and, obviously, in normal

people following effortful cognitive and physical functions (Bartley & Chute, 1947). Two types of fatigue can be distinguished in individuals with MS. The first is a persistent sense of tiredness which may prevent the accomplishment of even light tasks. In the other form of fatigue, the patient typically feels well at rest, but is overcome by a generalized sensation fatigue, usually after only a few minutes of physical activity. This latter form of fatigue is termed fatigability, and it often disappears after a short rest. The most common form of fatigability is in the legs, when the strength of the legs deteriorates after walking for a short distance. Some patients will overexert, or try to exceed the limits of their ability by walking with canes when they should be using a motorized wheelchair for traveling longer distances. Fatigability may also affect the sensory system in some patients. For example, with prolonged reading, visual ability and clarity deteriorate, but return after a short rest (Krupp, Alvarez, LaRocca, & Scheinberg, 1988; Sibley, 1992).

In contrast to other accounts, Shapiro and colleagues (1987) identified four specific types of fatigue, only one of which they reported to be specific to MS: (a) Physical exertion, which is experienced by the general population after a "hard day" of physical activity. The prescription for this "normal" type of exertion, according to Shapiro and colleagues (1987) is rest; (b) Depression, which is associated with the clinical signs of depression, such as change in appetite, sleep disturbance, and/or poor

self-esteem. Fatigue from depression is typically treated with a combination of anti-depressant drugs and psychotherapy; (c) Nerve Impulse Fatigue, which occurs when the nervous impulses that control a particular muscle are worked beyond their capacity. This type of fatigue usually dissipates with rest; and (d) Idiopathic Lassitude. The etiology of this type of fatigue is unknown (Cohen & Fisher, 1989; Monks, 1989; Murray, 1985). Some investigators have referred to it as an abnormal sense of tiredness or lack of energy that is disproportional to the amount of energy expended and to the level of disability. Patients describe it in terms of weakness, tiredness, fatigue, and lack of stamina. As mentioned earlier, Krupp, et al. (1988) defined fatigue in MS as a sense of physical tiredness and lack of energy, distinct from sadness or weakness, but none of these terms may differentiate this type from those described previously.

The physical/physiological aspects of fatigue, especially the phenomenon of fatigability, may be related to a marginal ability to conduct nerve impulses through plaques, and should be distinguished from psychological fatigue. Physically, quadriceps voluntary forces are typically weak in relation to patients' body weight, and their muscles can not be activated maximally, despite twitch occlusion measurements which suggest that, if fully activated, the strength of MS patients muscles are not markedly below the lower limit for normal individuals (Rice, Vollmer, & Bigland-Ritchie, 1992). Research has also shown that: a.)

voluntary force of phasic contractions are typically 30-50% weaker in MS patients than in normals (Rice, et al., 1992; van der Kamp, et al., 1991); b.) MS patients exhibit abnormal responses to exercise, including an earlier anaerobic threshold and, more specifically, an abnormal peripheral exercise response having to do with peripheral O2 utilization (McComas, Miller, & Gandevia, 1995; Vaz Fragaso, Wirz, & Mashman, 1995) and abnormal thermoregulation capabilities (Capello, et al., 1995); c.) MS patients exhibit reduced motoneuron firing rates (Rice, et al., 1992); and d.) the muscle contractile properties of individuals with MS are different from those of normal individuals. Specifically, research has reported that the excitation rates required to achieve a given degree of muscle activation is higher than normal among individuals with MS (Rice, et al., 1992; Vroba, 1987). This reported voluntary muscle weakness in MS patients is usually ascribed to impaired conduction in demyelinated CNS pathways (McDonald & Sears, 1970; Rice, et al., 1992; van der Kamp, et al., 1991). This presumably reduces the general level to which the spinal motoneuron pool can be excited, resulting in either reduced motor unit recruitment, or the inability to drive units at sufficient rates to generate full force. This chronic reduction in muscle excitation may also cause deterioration in intrinsic muscle strength per se, similar to disuse atrophy, which may be further exacerbated by the increasing sedentary lifestyle into which individuals with MS are often forced.

There is no consensus regarding the etiology of fatigue in patients with MS, especially in relation to psychological and CNS measurement. Although the mechanisms of fatigue remain unclear (Cooke, Franks, Luciani, & Pate, 1988; Sharma, Kent-Braun, Mynhier, Weiner, & Miller, 1995), central sources of fatigue might well be a factor for MS patients, and could involve at least two mechanisms (Djaldetti, Ziv, Achiron, & Melamed, 1996; Kent-Braun, Sharma, Weiner, & Miller 1994; Oligiati, Jacquet, DiPrampero, 1986; Sandroni, et al., 1992). First, recruitment of alpha motor neurons may be impaired because of lesions in corticospinal pathways (Rice, et al., 1992). The findings of Djaldetti, et al. (1996), in fact, supported a major role of upper motor neuron lesions in the pathophysiology of MS patients, as did the findings of many other studies over the past decade (Hess, Mills, Murray, & Schreifer, 1987; Ingram, Thompson, & Swash, 1988; van der Kamp, et al., 1990). Second, as mentioned earlier, reaction times are delayed, and cognitive activity is abnormal in many patients with MS, suggesting that the processes involved in the preparation for and initiation of motor responses are also affected (Sandroni, et al., 1992). However, there are also those who report that the fatigue exhibited by individuals with MS may have peripheral origins (Miller, Green, Moussavi, Carson, & Weiner, 1990). For example, Miller, Boaska, Moussavi, Carson, & Weiner (1988) investigated tibialis anterior muscle metabolism and fatigability in nine individuals with

spastic paraparesis and six individuals with MS. They claimed that the decline in muscle force during repetitive stimulation was independent of the CNS since it was produced by peripheral nerve stimulation. Lenman, et al. (1989) assessed fatigue of the tibialis anterior muscle by repetitive electrical stimulation and found a decrement in muscle tension and an increase in the half-relaxation time during repeated activity in patients with MS. They suggested that the long-term inactivity of patients with upper motor neuron dysfunction leads to increased fatigability of the muscles, as fatigue-resistant fibers are probably transformed into fatigable ones. More recently, as a follow-up to Lenman et al.'s (1989) study, Sharma, et al. (1995) attempted to determine the relationships between muscle fatigue, clinical status, and perceived fatigue. During exercise, the decline in tetanic force, phosphocreatine, and intracellular pH was greater in MS patients than in controls. Also, the compound muscle action potential amplitude did not decrease during exercise, indicating that there was no failure of neuromuscular transmission during fatigue. Thus, it was concluded that the excessive fatigue, they concluded, developed from sources beyond the muscle membrane. Following exercise, the recovery of tetanic force was delayed in patients (a pattern that suggests abnormal excitation-contraction coupling), whereas the recovery of metabolites was complete in both groups. These results suggest that fatigue in MS has both central and peripheral components.

Other Motor Deficits

Ataxia (Incoordination).

Disturbances resulting from both vermian and hemispheric lesions are common in multiple sclerosis. Gait ataxia, or imbalance when walking, has been a somewhat common initial complaint, reported as the initial symptom in MS in 13% of MS patients in at least one study (McAlpine, 1972). Although common in chronic patients, its incidence is difficult to discern from published reports because many symptoms are included under vague categories such as balance. Examination may show intention tremor on finger-nose-finger tests, or other incoordination problems when the patient tries to perform rapid alternation movements. Limb ataxia has been reported in 45-50% of chronic patients (Kurtzke, 1970).

Researchers have hypothesized that ataxia is due to axonal loss or, at the very least, axonal dysfunction in the efferent pathways of the cerebellum, the superior cerebellar peduncles, and/or the midbrain (Lu & Liu, 1994; Nguyen, Feve, & Keravel, 1996). For example, Davie, et al. (1995) employed proton magnetic resonance spectroscopy (MRS) and MRI techniques on 11 MS patients who exhibited severe cerebellar involvement, 11 matched MS patients who had minimal or no signs of cerebellar involvement, 8 patients who displayed symptoms of ataxia, and 11 healthy controls. The MS patients also underwent MRI to assess

cerebellar volume and lesion volume in the posterior fossa. Results indicated that the MS patients had a greater amount of cerebellar lesions, with the ataxic individuals exhibiting the most considerable lesions in terms of volume. A small group of the MS patients with cerebellar involvement also exhibited smaller lesions in the cerebellar region than expected, suggesting that axonal loss from normal white matter also contributes to their observed deficits.

Exogenous Conditions and MS.

In many neurological disorders the damaged structures show a heightened sensitivity to changes in exogenous conditions. For example, an MS patient who is seemingly in remission may be relatively asymptomatic. However, in the face of a toxic encephalopathy, the former clinical deficits that seem to have disappeared may suddenly reappear (Halliday, McDonald, & Mushin, 1976; Schauf & Davis, 1981). This sensitivity to exogenous conditions, which implies a lability of neural function is, not surprisingly, most common to demyelinating disorders such as MS. This condition most notably occurs in individuals with MS in the areas of metabolic status and body temperature.

The classical clinical literature (Guthrie, 1951; Simons, 1937) called attention to the fact that patients with MS often exhibit degradations in their neurological status. Namerow (1968), for example, provided a

graphic example of a patient who exhibited a circadian rhythm in which neurological deficits varied together with body temperature, worsening in the evening when body temperature was highest. A similar case was reported by Davis and colleagues (1973), who described a patient exhibiting marked worsening of finger-to nose movements and slurring of speech in concert with changes in body temperature. The sensitivity of demyelinated fibers to increase in body temperature may also provide, at least in part, an explanation for what is termed "Uhtrhoff's phenomenon," in which visual acuity decreases following sustained periods of physical activity (Alexander & Costello, 1987; Guthrie, 1951; Halliday, 1981). Rasminsky (1973) made an important contribution in showing in single fibers that increases in temperature of as little as .5 degrees Celsius could lead to reversible conduction block, presumably on the basis of the decrease in the time integral of the action current that occurs with increasing temperature. This finding is consistent with classical formal descriptions of nerve membrane kinetics (e.g. Hodgkin & Huxley, 1952). Since conduction velocity increases with increasing temperature, an important conclusion of this study was that clinical deficits attributable to increasing temperature are the result of conduction block, and not of a worsening of the slowing that accompanies demyelination (Rasminsky, 1973).

In addition to the effect of changes in temperature, changes in metabolic status may also alter the conduction properties of demyelinated fibers (Davis & Schauf, 1981). Davis and his colleagues (Becker, Michael, & Davis, 1974; Davis, Becker, & Michael, 1970) have shown that changes in acidase balance, which can be produced by hyperventilation or the introduction of an oral phosphate, can produce significant changes in neurological status.

In general, new signs and symptoms may appear at any time, but there are circumstances that will predictably worsen a patient's condition. One such setting is extreme heat; a hot bath has an immediate and dramatic effect on a patient's ability to function, although this effect is entirely reversible (Sibley, 1992). Precisely why this occurs is not understood, but, as mentioned previously, it is known that heat interferes with transmission of nerve signals along already impaired fibers. An equally brief worsening of neurologic problems will develop if the affected individual hyperventilates. Hyperventilation changes the chemical composition of the blood only slightly, but the change is substantial enough to be reflected in the chemical composition of the fluid surrounding the brain. This transient chemical change interferes with normal brain and spinal cord activity in individuals with MS (Sibley, 1992; Toyokura, Sakuta, & Nakanishi, 1976).

When combined with the structural lesions that can occur in MS, the increased sensitivity of demyelinated fibers to changes in metabolic status or temperature may account in part for the relatively rapid waxing and waning of symptoms reported by some patients. This may be of importance to practitioners and family members who are dealing with a patient who has experienced a worsening of clinical status, since, in some cases. this worsening may reflect a change in metabolic status or temperature, and not a progression of the disease itself.

Summary

There are a variety of physical deficits that can occur in MS, each of which can have serious implications for the experience of daily living. Moreover, the unpredictability of the disease and the occurrence of these symptoms confounds this experience. Some of these physical deficits, such as visual problems (e.g. optic neuritis), mean that an individual with MS, for no apparent reason, could wake up blind or only able to see out of one eye. Others, such as fatigue and spasticity, can compromise one's ability to move as well as to carry on activities of daily life, which can result in feelings of loss, frustration, and/or depression. For example, the co-contractions of muscles that often occur as a result of spasticity can make movements such as walking difficult if not impossible. Additionally, impaired Hoffman reflex control in patients with spasticity

can result in muscle stiffness and subsequent discomfort. Fatigue also causes problems in the MS patient's negotiation of the world, resulting in decreased muscular endurance and ambulation so that the patient has to rest after simply crossing the room or climbing stairs. Consequently, fatigue severely restricts what an individual with MS can do and where he/she can go, and is one of the primary causes of unemployment among individuals with MS, as well as eliciting feelings of low environmental mastery and competence.

The unpredictable threat of a tonic seizure also presents a serious problem to individuals with MS. Indeed, not only do such seizures confound an individual's motor control, but they require that the individual and those around him/her remain vigilant and ready to assist, since such a seizure can cause substantial fatigue or incontinence. Likewise, ataxia (incoordination) can also be a confounding and embarrassing condition since, unexpectedly, it can cause patients to exhibit a "drunken gait," or lose their balance completely. In addition, individuals with MS also have to remain wary of temperature conditions which are either too hot or too cold, each of which can result in compromised conduction of nerve impulses. This impaired conduction, in turn, can result in impaired motor control, slurring of speech, and sensory loss.

In the next section, some of the treatments commonly employed to control these symptoms are discussed.

The Utility of Qualitative Research in this Paradigm

My interest in employing a qualitative methodology in this study is due to my own experiences with science and medicine, my experiences as a hemophiliac, and the experience of my father, who was a cancer patient for many years. In discussing both my own illness and my father's illness with physicians, it often seemed to me that we were talking about seemingly different topics, never quite communicating with one another. This inability to communicate did not, I feel, result from inattentiveness or insensitivity, but from a fundamental disagreement about the nature of illness. In particular, rather than representing a shared reality between us, I realized that illness represented two fundamentally different realities for each of us. This difference is best described as a difference between the scientific, positivist view that views the body as a machine that can be "fixed," and is common (and, perhaps, even necessary) for physicians, and the experiential view that is common to the "rest of us" who subjectively feel and experience the phenomenon of being ill or in pain. Interestingly, though, despite the need to be empathetic and patient-centered, it is more often the former view which pervades most medical journals.

Interestingly, it is the latter view which would likely provide more meaningful ways for physicians to work with patients.

Themes of Patients with MS and Other Diseases

The purpose of this section is a review of the terms disability, illness, and multiple sclerosis; what effect do they have on individuals with disabilities and their daily lives? What baggage is packaged in the terms, "disability," "M.S.," and "illness?" What are the relationships that are implied or explicitly experienced between physical, emotional, and spiritual well-being and MS?

Despite the very real possibility that the occurrence of a disease or disability may affect each of us in some way, there is a scarcity of qualitative accounts directly describing the feelings associated with the incidence of illness and disability. Instead, the incidence of disability and illness has historically been discussed as a metaphor for something else, such as a form of karma for a poorly lived spiritual life.

Cancer and TB, for example, have each been documented and described throughout history; indeed, the themes that are described in such accounts and the elaborate, but often irrational belief systems that patients construct to explain how they acquired the disease, each provide the reader with insights into how these diseases affect individuals spiritually and emotionally, as well as physically, and serve as strong

backdrops for many of the themes that were anticipated in this study. According to the mythology of cancer, it has actually been suggested that a steady repression of feeling that causes the disease. Norman Mailer, for example, once explained that had he not stabbed his wife (and acted out of a "murderous nest of feeling") he would have gotten cancer and "been dead in a few years himself." William Reich defined cancer as a "disease following emotional resignation-a bioenergetic shrinking, a giving-up of hope." Tolstoy's The Death of Ivan Illyich is also often cited as a case history of the link between cancer and characterological resignation.

An additional theme that prevails in literature and narratives is the romanticizing of illness, and the way in which it isolates and singles out an individual. Indeed, it seems that as one's individual illness is articulated, he/she is made more conscious as death is confronted, and in the images that begin to collect around the disease, the reader sees an emerging sense of loneliness and of individuality in the diseased character.

Illnesses have also always been used as metaphors to enliven charges that a society was morally corrupt or unjust. Disease imagery is used to express concern for social order, and to express a sense of dissatisfaction with the society. With the advent of Christianity, which imposed more moralized notions of disease, a closer fit between disease and "victim" gradually evolved. The idea of disease as punishment, an

idea that is still commonly held today, yielded the idea that disease could be a particularly appropriate and just punishment. The Bible, of course, gives the most widely known example of an immoral society and the subsequent flood. In the 19th century, the notion that the disease fits the patient's character, as the punishment fits the crime, was replaced by the notion that it expresses character and is a product of will. Recovery from the disease, in this case, depended on the healthy will assuming "dictatorial power in order to subsume the rebellious forces" of the sick will. Today, we often see examples of individuals or entire communities who cite the incidence of diseases like AIDS or cancer or the incidence of particular disabilities as evidence of a corrupt will. For example, despite the scientific biological evidence, many still argue that homosexuality and homosexual behaviors are a matter of choice, will, and intention, rather than biology. As a result, the incidence of AIDS and other diseases common to the homosexual community is to some merely a result of karma; a "payback" for impure and weak sexual behaviors exhibited by individuals who are gay.

Qualitative Accounts and Multiple Sclerosis

There are few existent qualitative accounts of the incidence of MS and how its diagnosis and symptoms affect one's lifestyle, family life, and spiritual beliefs. In this portion of the review will focus on three

qualitative accounts of M.S.: Multiple Sclerosis and Me by M.H. Greenblatt (1972), All of a Piece by B.D. Webster (1989), and Multiple Sclerosis - A Personal View by Cynthia Birrer (1979) are briefly discussed. Although a summary of each book is beyond the scope of this review, a citation of common themes and supporting quotes in these three works is warranted given the scope and purpose of the current study. Use of this format will also serve as a primer for the reader, since the results section of this study will consist of themes and quotes that support the existence of the themes. The source of each quote in the following setion will be abbreviated by using the acronyms "GB" for Greenblatt's book, "Web" for quotes from Webster's book, and "Bir" to represent quotes from Birrer's narrative.

Loss of motor/physical skills:

GB: I can no longer walk...As M.S. progresses in such a slow manner that changes are often unnoticeable. The only way I can detect changes is to try to think back to five or ten years ago and imagine what I could do then...My present situation is that the muscles in my arms and legs are apparently just falling away. I cannot walk or stand; I have great difficulty holding onto anything with my hands...In 1959, I started to use a cane...Shortly after that, things had deteriorated to a point where I could not walk with the Canadian

canes at all. I was completely dependent on the wheelchair for locomotion (pp. 210, 211).

Others' estimation of one's physical skills/relationships with nondisabled individuals

GB: People greatly underestimate the physical capabilities of people with M.S. because it is a 'hidden disease.' In one case, the patient with M.S. is in a wheelchair and 'claims' not to be able to pick up a glass. I put that word 'claims' in quotation marks because I am sure that many people, upon seeing a seemingly normal person, will find it inconceivable that he cannot pick up a glass. Yet, this is precisely the case. The person in the wheelchair may not be able to stretch his arms out far enough to reach the glass, or he may be able to stretch it out far enough to reach the glass but his fingers cannot be controlled so that he can pick the glass up (p. 36).

Web: The question of legitimacy with a disease such as M.S. is never completely resolved. One's condition is not usually or necessarily reflected in one's appearance. And I found that receiving a diagnosis catapulted me from one world of judgments and perceptions to another-the world of being 'sick.' A different world now that my 'sickness' was legitimate; nonetheless, another world

and the central issue of maintaining my integrity remained...Another example: I have trouble walking on a moving bus and tend to lurch around and bounce off people and seats and, of course, like everything else with MS, my difficulty varies from day to day. Over a period of several weeks I had engaged in a normal conversation with a man who always took a seat near the rear of the bus, as I did. One afternoon, when my difficulty moving was extreme, I fell getting off and he looked away. After that day that man, who had been friendly, changed his seat and never even acknowledged a hello from me (p. 63).

Bir: Now others insist that there is nothing wrong with me. Even the well-intentioned persist in denying that I am ill at all. Those close to me feel an uncomfortable need to defend the diagnosis, to repeat details over and over again. It is a period of excruciating uncertainty, exacerbated by doubts and by hope, because no one can say how long remission may last (p. 43).

<u>The obscenity of MS</u>

Web: Obscene-illness, disability, disease are often seen as obscene. A friend suggested that the meaning of 'obscene' is to turn away from; etymologically that is incorrect but intuitively it is right on the

mark. What exactly was going on when a co-worker asked, 'What happened to your leg?' and I responded, 'Nothing is wrong with my leg, I have MS.' The response, and there is nothing uncommon about it, was 'Sorry I asked' as he walked away. I can understand that response. Nevertheless, I felt rejected. I felt exactly as though I, in some fashion, affronted him; as though I was a reproach; as though I was, most of all, something that he did not wish to see or acknowledge.

Morality and M.S.

Web: There is a clear relationship between the view of the disease as a moral issue and religion...Contemporary American religions do continue to support and legitimate what it is that people want to do and to give an underpinning and a rationale to their fears (for example, the religiousfundamentalist's response to AIDS)...Religion both keeps alive and supports that notion that disease is a moral issue...There is a not very subtle thread in Christianity...to the effect that disease and suffering are deserved. They are also viewed as good in and of themselves in that they promote a desired moral outcome...A relative of mine, on hearing that I had MS, referred me to Romans 5:3, where St. Paul writes that suffering produces endurance, endurance promotes character,

and character, in turn, promotes hope. The implication, hard to ignore, was two-fold: First, my character needed improving, and I don't think it is far-fetched to see an element of punishment here. After all, were I not in need of improvement, did I not lack character, or were it not deficient, I would not be in need of suffering ultimately to improve it... The notion that disease indicates a flawed relationship with God and is to be accepted as a consequence thereof is also common. If one's nature is flawed, then disease is a reflection of that...For society at large, there is both the idea the illness is deserved and the God's-will theory (pp. 64, 76).

Uncertainty/the future

Web: The implication that physical adjustment was all that was necessary to live with MS...was secondary. The physical fact of walking with difficulty is not nearly so important as the psychological and social consequences...Over the course of the next year...I began to see myself as an otherwise healthy person with an underlying but, for the most part, inactive disease. The primary task was learning to live with day to day uncertainty (p. 94) .

Altered view of personal space

Bir: Today my world is shrunken to the size of my bedroom, or rather my bed. Even going to the bathroom is an unfriendly, slightly surreal excursion...My clothes, hanging from hooks at the back of the bedroom door, are another reminder that the limits of my existence are crushingly circumscribed...The horizon is the edge of my bed. But even this intimate repository is no longer wholly my domain. When I knew the interminable rhythm of work and sleep, of being up and about and being in bed, my bed was an attribute of the night...aired by breezes which daily blew through the open windows, it received me with constant hospitality...Now apart from the exact spot where I lie, my bed is cold and rejecting...sleep is elusive because what is to come tomorrow is only my bed and that is not a promise; it is a permanent consignment (p. 15).

Altered view of time

Bir: ...before I became multiple sclerotic, I lived in the future, and in the past only in so far as it affected my future. Apart from a few special moments, I never really lived now...but incurable disease denies me escape: multiple sclerosis focuses and crystallizes the eternal present. All of existence is immediate now...(p. 19)

Summary of Qualitative Research

As intimated previously, feelings of sadness, loneliness, and/or a feeling of moral impurity, as well as the loss of physical skills may not evoke images of physical pain or compromise one's movement capabilities in the ways in which symptoms such as trigeminal neuralgia or spasticity mentioned earlier can. Nonetheless, these emotional/spiritual symptoms and the life themes that have been identified in this review can be concomitants of the incidence of any disease, and deserve consideration by any practitioner. To this end, Birrer (1989) notes:

> Being multiple sclerotic, I find that my body is something more than an overcoat, the purely material encasement of what I really am. In this state I cannot avoid the reality that I am my body. I am not consoled by the remark that my illness has only to do with my physical shell; I know, as you cannot, that my whole existence is stricken by a calamity (p. 19).

In an earlier section of this review, the beneficial effects that a team approach, incorporating the use of therapeutic practitioners working with physicians and neurologists, was mentioned. Since there is no cure for MS, and since, as mentioned earlier, activities can act as an effective and inexpensive means of symptom management, the services of a

therapeutic recreation specialist can be especially important to an MS patient whose only choice is to adjust to his/her condition. In their book, Therapeutic Recreation Program Design, Peterson and Gunn (1984) emphasized a holistic approach to therapeutic recreation (TR) and to all service fields that work with special populations that facilitates "the development, maintenance, and expression of an appropriate leisure lifestyle" (p. 5) by employing a shared responsibility/client-oriented approach to counseling and designing a program for the client. Given the need to work closely with the needs and limitations of the client, as well as the demands of the rest of the medical team, it is not only important for practitioners to have a strong knowledge of the techniques of their discipline, but it is also important for them to be knowledgeable and to have an appreciation of themes such as those mentioned in this review. In that way, a common language between patient and practitioner that might not otherwise exist.

Relationship Between Heretofore Mentioned Research and this Study: The Necessity for Employing Qualitative Research Techniques

As mentioned earlier, my interest in exploring the experience of movement of patients with MS has grown out of my own experiences with individuals with disabilities and with disease. I submit that, because of the unique aspects of the lifestyle of an individual with MS,

psychological phenomenology provides the means to examine the nature of this unique experience in a rigorous fashion. In particular, psychological phenomenology discloses the manner in which the individual constitutes the meaning of his/her experience. One of the primary aims of an explicitly phenomenological approach is to let what is given appear as pure phenomenon and to work to describe the invariant features of such phenomena. As Casey (1976, pp. 8-9) noted, "the phenomenologist's basic attitude is: no matter how something came to be in the first place, what is of crucial concern is the detailed description of the phenomenon as it now appears."

Maurice Natanson (1968) explains with regard to Edmund Husserl's notion of bracketing or phenomenological reduction, what is thus disclosed in the reduction is the field of intentionality - the conscious processes of experiencing and the objects of experience:

> To bracket the world is neither to deny its reality nor to change its reality in any way; rather, it is to effect a change in my way of regarding the world, a change that turns my glance from the real object to the object as I take it, treat it, interpret it as real. Within the natural attitude I attend to the object; in the phenomenological attitude I attend to the object as known, as meant, as intended...The object continues to be in the real world as I do, but what now interests me, phenomenologically, is my awareness, my sense of its

being in the real world. The object I reflect on in the reduced sphere is the real thing as I've taken it to be real. Thus, 'the' world is replaced by my world...in the sense that 'mine' indicates an intentional realm constituted by my own acts of seeing, hearing, remembering, imagining, and so on (Natanson, 1968, pp. 58-59).

This reflection does not deny the existence of the physical, social, and cultural world but rather reveals the prejudices and taken-for-granted presuppositions which are not explicitly recognized in our spontaneous, mostly unreflective experiences. Indeed, the phenomenological reduction alone discloses the "setting of the world" which is presupposed at every moment of our thought, but rarely disclosed:

> The philosopher, in so far as he is a philosopher, ought not to think like the external man, the psychophysical subject who is *in* time, *in* space, *in* society, as an object in a container. From the mere fact that he desires not only to exist but to exist with an understanding of what he does, it follows that he must suspend the affirmations which are implied in the given facts of his life. But to suspend them is not to deny them and even less to deny the link which binds us to the physical, social, and cultural world. It is on the contrary to *see* this link, to become conscious of it (Merleau-Ponty, 1962, pp. vii-xxi).

With its emphasis on firsthand or direct description, phenomenology provides the means to elucidate the domain of unreflective, taken-for-granted experience, to provide a detailed account of the manner in which we interpret the world of everyday life (termed lifeworld). In particular, phenomenology holds that meaning is constituted in the light of certain invariant intentional structures which characterize consciousness. Such structures should be recognized if one is to give an account of meaning. Furthermore, phenomenology provides an explication of the fundamental and important distinction between lifeworld interpretation and scientific conceptualization. In summary, then, the psychological phenomenological approach includes the following: (a) the effort to elucidate the manner in which meaning is constituted; (b) the commitment to a radical reflection upon lived experience which requires (as a methodological device) the setting aside of theoretical commitments and taken for granted common-sense presuppositions in order to focus on the conscious properties of experiencing; and (c) the attempt to uncover the invariant features of phenomena and thereby to provide a rigorous description of such phenomena.

Qualitative research is, thus, a perfect mechanism for studying the experience of movement and of individuals with MS. This approach provides a powerful means of rendering explicit the unique perspective

of movement and information processing that MS patients share. In particular, such an approach focuses explicitly upon the phenomenon of disability and the manner in which meaning of this illness is constituted by the MS patient.

Earlier it was noted that it is imperative to differentiate between meaning which is grounded in immediate experience and meaning which is not so grounded. As mentioned before, there is a definite distinction which needs to be made between the "natural" attitude which involves the immediate pre-theoretical experiencing of the world of everyday life, and the "naturalistic" attitude which involves an essential abstraction from immediate experiencing in favor of a theoretical, scientific account of the causal structure of such experiencing. The existence of such a difference makes this study all the more necessary, since the latter perspective is well-represented through the considerable number of quantitative studies which examine measurable physical and cognitive aspects of MS, while the former perspective has been relatively underrepresented though at least as important.

Summary

Although there are few qualitative accounts which provide a first-hand description of the experience of MS, those that are avaialable point towards the perceptions and morality of others, time and becoming in

timend identity as major themes with which MS patients must contend. The incurable and experiential nature of the disease necessitate that MS be treated in a more holistic manner by physicians and professionals, and that t be examined using both quantitative and qualitative methods.

APPENDIX B

Moving Testimony: The Experience of Movement for Individuals with Multiple Sclerosis

Informed Consent Form

You have been invited to participate in a study examining the movement experiences of individuals with multiple sclerosis. This study is being conducted by Steve Page in partial fulfillment of the requirements of the Ph.D. degree at The University of Tennessee, Knoxville. Your part in this research will consist of a confidential interview. In this interview, you will describe occasions or instances in which you were particularly aware of the ways in which multiple sclerosis has compromised your movement capabilities. The entire interview will last approximately one to one and a half hours.

During the interview there should be no risk or discomfort on your part. Your participation is completely voluntary. In the event that you experience any distress as a result of recalling these experiences, you may discontinue your participation in the study at any time without penalty or prejudice and, if desired, appropriate referral to a qualified counselor will be made. Your identity will be kept confidential at all times to everyone but the researcher. All interviews will be audiotaped and

numerically coded before they are transcribed to ensure your anonymity. All identifying information given in the interview will be removed or disguised in the transcript. At the completion of the study, the tape will be erased by the researcher.

It is hoped that the results of this study will provide the psychological community and the rehabilitation community with a better understanding of the movement experiences of individuals with multiple sclerosis. It may also offer you an opportunity to clarify and understand this experience for yourself.

This consent form will remain in a locked filing cabinet at 344 HPER Building at The University of Tennessee throughout the study, and for a period of three years thereafter. I would be happy to provide you with an explanation of the findings if you so desire. Any further questions you may have concerning this study may be answered by contacting me, Steve Page, at 974-5111.

****

_____
Name

_____ _____
Signature Date

Stephen J. Page, Ph.D. (cand.)
Cultural Studies Unit
1914 Andy Holt Ave.
Knoxville, TN 37996-2700
(423) 974-5111

Craig Wrisberg, Ph.D.
Cultural Studies Unit
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APPENDIX C

Transcriber's Pledge of Confidentiality

As the transcriber for this research project, I understand that I will be hearing tapes of confidential interviews. The information on these tapes has been shared with the principal investigator (Steve Page), with the understanding that all material remain strictly confidential. Recognizing this confidential aspect of the interviews, I hereby pledge to keep all of the information on these tapes in the strictest of confidence, sharing it with no one other than Steve Page or Dr. Craig Wrisberg, his doctoral advisor. Any violation of this agreement would constitute a breech of the ethical standards to which I herein pledge myself.

_____ _____

Transcribing Typist Date

_____

Stephen J. Page, Ph.D. (cand.)

Principal Researcher

APPENDIX D

Research Team Member's Pledge of Confidentiality

In accepting membership on the research team for Steve Page's dissertation, I understand that I will be reading transcriptions of confidential interviews. The information contained in these transcripts has been shared with the principal investigator (Steve Page), with the understanding that all of the material remain strictly confidential. Recognizing this essential aspect of the transcripts, I hereby pledge to keep all information in these protocols in the strictest of confidence, sharing it with no one other than Steve Page, Dr. Craig Wrisberg, or members of the interdisciplinary research group. Any violation of this agreement would constitute a breech of the ethical standards to which I herein pledge myself.

_____ _____

Research Team Member Date

_____

Stephen J. Page, Ph.D. (cand.)
Principal Researcher

VITA

Steve Page was born in Columbus, Ohio on December 12, 1970. A former intercollegiate swimmer, Steve became interested in research in the area of human performance during his Bachelor's degree work at The College of Wooster in Wooster, Ohio where he was required to perform two theses in order to graduate. Steve subsequently enrolled at Ball State University in 1994 where he began his research in the areas of sport and rehabilitation psychology, and obtained a Master of Science Degree in 1995. That same year Steve enrolled at The University of Tennessee where he completed his Doctor of Philosophy degree with a specialization in Motor Behavior in 1998. At the time of the completion of this dissertation, Steve was the primary author of one book chapter, several articles appearing in journals or research publications, several articles in press, and had presented numerous symposia and research papers at regional and national academic conferences.