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**Embodying Multiple Sclerosis:
A Phenomenological Study**

by

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requirements for the degree of**

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**Embodying Multiple Sclerosis:
A Phenomenological Study**

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by

Christine Stella Larsen

Dedication

To my father and mother, Theodor and Elin Gartner,
and to my husband and daughter, John and Kirsten
Larsen.

"For what matters finally
is how the human spirit is spent"
John Stone
"Gaudeamus Igitur"

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INTRODUCTION

Thus each of us had to be content to live only for the day, alone under the vast indifference of the sky...If, by some chance, one of us tried to unburden himself or to say something about his feelings, the reply he got, whatever it might be, usually wounded him. And then it dawned on him that he and the man with him weren't talking about the same thing. For while he himself spoke from the depths of long days of brooding upon his personal distress, and the image he had tried to impart had been slowly shaped and proved in the fires of passion and regret, this meant nothing to the man to whom he was speaking, who pictured a conventional emotion, a grief that is traded on the market-place, mass-produced. Whether friendly or hostile, the reply always missed fire, and the attempt to communicate had to be given up.

The evil that is in the world always comes of ignorance, and good intentions may do as much harm as malevolence, if they lack understanding.

Albert Camus
"The Plague"

The first year of medical school is generally spent learning about the "normal" human body, that is, the body without disease. In anatomy we memorize organs, bones, muscles, joints, tendons, arteries, and nerves to, in the words of the instructor, "know everything there is to know about the human body." In one of the first rites of passage for the doctor-to-be, we dissect a cadaver, exploring what were once private spaces, never before seen by another person. We begin neutrally, with the back. The faces are at first invisible to us, wrapped in cloth. Gradually we move on to other areas - the chest, the abdomen, the pelvis, the face, the brain, the legs and arms, feet and hands. Before long,

body parts are being carried across the room: Hearts and lungs eventually come to rest in separate containers under the sinks; intestines are stretched out in curiosity; limbs are sawed off, and brains removed. Piece by piece, the structures within the body become more and more visible, more and more real.

During the second year, the "abnormal" body is our focus. In pathology, we memorize names of diseases and their manifestations in the body. In what is arguably another rite of passage, we observe autopsies, where the entire body is revealed at once, leaving the viewer no time to "adjust" to being in the presence of death. The first autopsy I observed was of a man who had taken his own life by putting a gun to his heart. We were told that he had written a note in which he had expressed concern about his declining health due to emphysema and lung cancer, and fear that he would soon be unable to take care of himself. There would be no funeral, as he had had no family. As the pathologist performed the autopsy, we were invited to don gloves and to touch the organs - the tumorous lung, the fragmented stomach, the shattered heart. An assistant sawed the brain out of the cranium and noted, "Cerebellum, cerebral hemispheres - looks fine to me. Think so?" The brain looked fine, I agreed: We would never see his sadness in that mass of neural tissue.

That autopsy seemed to portray in stark relief what Ernest Becker in The Denial of Death calls our "existential

dualism" - the condition of being symbolic selves with life histories, and at the same time, material beings gasping for breath (p. 26). Two days before, the man on the stainless steel table had been living - perhaps reflecting upon his life, perhaps coughing with every few breaths. Through pulling the trigger, his materiality became all that was apparent to us. We had heard about the note, of course, but our real purpose was to explore what was left - the body. In pathology, as in biomedicine in general, "Reality is directly proportional to materiality" (Gordon 1988:24). The cause of death would most likely have been recorded in terms of bullet trajectories and organ damage, not in terms of the suffering that preceded the visible wounds.

This is a thesis about the experience of a particular chronic illness, multiple sclerosis. I could have chosen any affliction; what I have attempted to do is to explore the experience of illness from the perspective that we are integrated beings: body-selves who both constitute and are constituted by our worlds.

Perhaps more than anything else, this thesis evolved out of my conviction that there is a kind of knowledge that is essential to being a healer. My undergraduate Shakespeare professor once said, as closely as I can recall, "Some day, after you have studied and studied, you will reach a point in your life when you know everything you need to know." The

other knowledge will always be attainable from books and other sources.

Having extensive medical knowledge is crucial to being a physician. But beyond that, how can one respond to illness, suffering, and death? To respond compassionately requires a certain presence, a being-with, a "flaring grasp" (Broyard 1990b) of human situations, the cultivation of which is often tragically neglected in American medical education and practice.

Schwartz and Wiggins (1985) discuss the distinction between explanation and understanding as they pertain to medical practice. Medical explanation, the abstract, disembodied way of knowing, tends to dominate over understanding, the more concrete, experiential way of knowing, which is grounded in the patient's everyday lifeworld. Science is based on evidence, the authors point out. Medicine as a practical science can be more scientific by considering more evidence from the lifeworld through human understanding, they argue.

In the brief time I had to work on this thesis, I studied some philosophy, medical anthropology, and historiography of medicine as a background to the study. I take a phenomenological approach, viewing "reality not simply as material or mental but as experiential" (Kestenbaum 1982). My goal has been to describe and interpret - and in the process to perhaps understand - what it is like to live every day,

every moment, with a disease which can be very mild or very disabling, for which there currently is no cure.

In the first chapter, I explore the issue of "reality" in biomedicine, including the reality of the object body as opposed to human experience, the questioning in recent years of empiricism's epistemological authority, and the inseparability of knowing from being. Against this background, I discuss in the second chapter the phenomenological approach to understanding illness as a lived experience. In the remaining chapters, I provide background and methods of the study, six case studies of the experience of MS and, finally, a summarizing discussion.

It has been at times difficult to involve myself in the anthropological task of "making the familiar strange" - to engage in a sort of meta-analysis of the very profession for which I am in training. And in the end I am left with at least as many questions as answers; this writing thus marks both an end and a beginning.

CHAPTER 1

BIOMEDICINE AND THE REAL

The Object Body

One of the participants of this study, a man disabled with multiple sclerosis, wrote in his journal:

Once I suggested that MS was just a name for a collection of symptoms since no one knew what caused it. He [the doctor] replied in an offended tone of voice that it certainly was the name for a disease, "If you laid out on a table the spinal cord of an MS cadaver next to the spinal cord of a normal cadaver the differences would be obvious." Not only did this seem irrelevant to my point, but I didn't like the idea of being a cadaver or of having my spinal cord laid out on a table.

This view of disease - as localizable within the individual body - marked a major shift in medical explanation. In The Birth of the Clinic, Foucault discusses the emergence of the "clinico-pathological" model of disease led by Xavier Bichat (1771-1802), Rudolph Virchow (1821-1902), and the microbiologists of the nineteenth century. The result was a "conceptual move away from clinical observations of disorders (e.g. jaundice) to characterizations in terms of underlying pathological findings (e.g. hepatitis)" (Englehardt and Erde 1980:384). This shift was possible through the objectification of the individual by the "empirical gaze":

By acquiring the status of object, its particular quality, its impalpable colour, its unique, transitory form took on weight and solidity...The object of discourse may equally well be a subject...one could at last hold a scientifically structured discourse about an individual (Foucault 1975:xiii-xiv).

Biomedicine came to view the "space of origin and

distribution of disease" as ultimately visible upon autopsy of the objectified individual body (p. 3). "Disease is an autopsy in the darkness of the body, dissection alive," writes Foucault (p. 131). We take as "natural" that disease takes shape "in accordance with a now familiar geometry, by the anatomical atlas" (p. 3). This view, Foucault shows, is not more natural or more fundamental than other views, but emerged out of particular social, political, and scientific milieu ("There have been, and will be, other distributions of illness" [p. 3]).

Scheper-Hughes and Lock (1987:9) point out that a version of the natural/supernatural or real/unreal dichotomy can be found in the Hippocratic corpus (ca. 400 B.C.), but that it was Rene Descartes (1596-1650) who "most clearly formulated the ideas that are the immediate precursors of contemporary biomedical conceptions of the human organism." Descartes' conceptualization of the mind as an entity distinct from the body reconciled the conflicting domains of religion and science at a time when scientific explanations, such as theories about the solar system and planetary motion developed by Copernicus and Galileo, were replacing metaphysical explanations.

Descartes considered the physical body to be of a different substance or essence than the mind-soul, and attributed to each kind of substance a principal property. For mental, spiritual substance, the principal attribute is

thinking, and it is therefore conscious. Physical substance is defined by its principal attribute of being extended in space, and is measurable by geometry. Mental substance lacks any spacial extension, and physical substance has no consciousness and cannot think (Lavine 1984:122-4).

The Cartesian mind-body separation underlies the modern separation of the disciplines of biology and psychology to study the person. In both disciplines, the dominant approach to obtaining knowledge is empiricism - the doctrine that the source and foundation of knowledge is in the experience of objects of the external world, through the senses (Lovell 1980:10). Through empiricism, it is traditionally argued, science progresses ever closer to the fundamental truths of nature.

Medicine and Science as Social Practices

A primary assumption of empiricism is the existence of "a real world which is independent of consciousness and theory" (Lovell 1980:10). But this assumption has been challenged, most notably, by Thomas Kuhn in The Structure of Scientific Revolutions, who questions whether natural scientists possess "firmer or more permanent answers to [questions] than their colleagues in social science." He developed the concept of the paradigm - "universally recognized scientific achievements that for a time provide model problems and solutions to a community of practitioners."

A paradigm change - such as Einstein's relativity theory in physics - does not necessarily lead to greater "truth", and so the history of science is not the cumulative progression to more and more objective knowledge about the world. Our perceptions of the world depend upon the presuppositions we bring to it; it is impossible to know the world in a conceptless way. Even the very questions we ask depend upon the paradigm in which we work.

Post-Kuhnian writers have gone even further, write Ten Have and Spicker (1990:9). Researchers now analyze science in the making, delving into the "social, dynamic, and practical aspects of modern science." The result of many years of these studies is that "[t]oday we view scientific facts as constructs; they are, so to speak, negotiable." Although debates continue about whether or not science progresses and how to determine such "progress" if indeed it occurs, it is generally understood that science occurs in a social context. Whether something is considered "true" or not, for example, may have more to do with moral appeal and relations of power than any correspondence to "objective" reality. As Fleck (1979:42) writes: "Cognition is the most socially-conditioned activity of man, and knowledge is the paramount social creation."

And so, as Ten Have and Spicker (1990:6) write: "Disease...is not a fact of nature but the result of socially and historically determined interpretive processes."

Furthermore, they argue, "[m]edicine is not the universal science or art it pretends to be."

But, as Deborah Gordon (1988:19) writes:

Although biomedicine both constitutes and is constituted by society, this interdependency is nevertheless denied by biomedical theory and ideology which claim neutrality and universality...[M]uch as scientific facts have recently lost some of their status as absolute, universal truths...so too is western medicine increasingly being understood as one of many medicines - 'biomedicine' - culturally and historically specific and far from universal.

Just as the universality of science and medicine has been undermined by modern scholars, the epistemological superiority of empiricism has come unravelled. Not only are science and medicine social practices, any knowledge obtained by human beings cannot be separated from "what sort of beings we are" (Dreyfus 1991:3).

Knowing and Being

Drawing upon the work of Charles Taylor, Gordon criticizes the traditional view of Western philosophy and science that "detachment provides the purest window to truth," meaning that true knowledge is attainable only by "alter[ing] ourselves - mov[ing] back, distanc[ing] ourselves from values, local bias, and particular interest by taking a universal standpoint, one which is disengaged from everyday life." Traditionally, she argues, knowing is distinct from being: "In philosophical terms, ontology is distinct from epistemology." Gordon contends that the belief that such a

distinction can be made is a "tenacious assumption" in Western medicine based on "naturalism," which Taylor (1985a:2) describes as "the view that humans are not only a part of nature but that this nature should be understood according to the canons of the Enlightenment."

Taylor argues that naturalism holds a certain moral appeal because behind it lies "an attachment to a certain picture of the agent...This picture is deeply attractive to moderns. It shows us as capable of achieving a kind of disengagement from our world by objectifying it." Such objectification allows us to see our situation and function in it "as a neutral environment, within which we can effect the purposes which we determine out of ourselves" (p. 4). Naturalism's "epistemological weaknesses are more than made up for by its moral appeal" in perpetuating an "underlying image of the self...[which] exercises its hold on us because of the ideal of disengagement and the images of freedom, dignity, and power which attach to it" (p. 6). This view gives the subject a sense of control over nature which arises from a sense of freedom:

To understand things in the absolute perspective is to understand them in abstraction from their significance for you. To be able to look on everything, world and society, in this perspective would be to neutralize its significance, and this would be a kind of freedom - the freedom of the self-defining subject, who determines his own purposes, or finds them in his own natural desires.

But even more than a sense of control, Taylor argues, the attractions of freedom

are also of a spiritual origin, in a sense which is understandable from our Western religious tradition...[which] has included an aspiration to rise above the merely human, to step outside the prison of the peculiarly human emotions and to be free of the cares and the demands they make on us (p. 112).

In the naturalist view, Gordon argues, nature is considered to be autonomous from human consciousness - "a thing-in-itself - neutral, indifferent to human purpose and to human relationships," and distinct from culture, morality, and society. The inert body is objectified and split off from the rational mind. Contained in this Cartesian naturalist view of the person is a representational model of knowing. The assumption is that we apprehend the world indirectly through representation in our minds, rather than directly with our entire being as a mind-body unity, with the result that

The meaning of the particular is not in the particular itself, but in its representation of a class, as a symbol. The meaning of symptoms, for example, is not in the symptoms per se, but in the underlying disease process they may indicate. Truth is behind things, not in them (Gordon, p. 31)

Similarly, Toombs (1987:222) writes of the problems this representational model creates for the patient seeking help from a doctor:

[W]hereas the physician sees the patient's illness as a typical example of disease, the patient attends to the illness for its own sake. This is an explicitly different focus. Whenever one considers something as an example, it is not considered for its own sake, but only insofar as it exemplifies something other than the affair itself.

In the subsequent chapter, I explore more fully the connection between knowing and being, with a discussion of

philosophers who understand the person as an engaged knower of the world, apprehending the world directly as a mind-body unity, in contrast to the traditional naturalistic view of the person as a detached knower, forming mental impressions of the "objective" world. For now, I turn briefly to the problems with psychosomatic medicine and the "biopsychosocial model" (Engels 1977) - attempts to reform medicine by acknowledging relationships between body, mind, and society.

Ostensible Reforms

Attempts have arisen within western medicine to "humanize" it by integrating knowledge about the connections between body, self, and society into the dominant paradigm. Gordon (1988) mentions several such "ostensible reforms": psychosomatic medicine, holism, the "biopsychosocial model", bioethics, and the patient autonomy movement. She argues that these "reforms" "often retain the basic values and assumptions of biomedicine and unwittingly perpetuate the 'status quo.'"

A closer look at some of the problems with psychosomatic medicine and the biopsychosocial model will clarify Gordon's assertion. Psychosomatic medicine has attempted to bridge the mind-body chasm, but persists in using the mind-body distinction, as if these were two separate realities. Research in psychosomatic medicine has led to increasing acceptance within medicine that the mind can "cause" illness in the body and that "stress" can affect the

body through its effect on the knowing mind, not that the self is a mind-body unity. Philosopher Gerlof Verwey (1990) discusses the origins of German psychosomatic medicine, beginning around 1910, whose founders attempted to reconcile the mind-body problem. They did not succeed, Verwey argues, because their psychosomatic medicine still remained essentially dualistic. The "psychosomatic paradox is still with us," he writes (p. 134), and is considered by Verwey to be an "unsolvable mystery" (p. 155). According to Verwey:

[Psychosomatic medicine is] constitutionally doomed to dwell in the area of conflict [between the] practice and theory of medicine...as the tension between two conflicting tendencies or motives in medicine past and present, namely the motive of somatological reduction (reduction of the human being to its somatological aspect) and the 'psychosomatic' (or anthropological) motive (rehabilitation of the point of view of the 'psychosomatic' dual unity, or of the anthropological totality)" (p. 133).

Aside from the problem of perpetuating Cartesian dualism by continuing to conceptualize mind and body as separate entities, moral problems also emerge in viewing certain illnesses as physical and others as psychological. In Illness as Metaphor, Susan Sontag explores the cultural meanings attached to tuberculosis in the nineteenth century and cancer today. She asserts:

A "physical" illness becomes in a way less real - but, in compensation - more interesting - so far as it can be considered a "mental" one...Psychological theories of illness are a powerful means of placing blame on the ill. Patients who are instructed that they have, unwittingly, caused their disease are also being made to feel that they deserve it (pp. 56-7).

Similarly, Kirmayer (1988) writes:

[P]sychosomatic medicine has had little noticeable impact on the organization of biomedicine. For the most part, psychosomatic disorders have been incorporated into biomedicine as a class of not quite legitimate illnesses best handled by mental health practitioners (p. 64).

Mind-body dualism is so basic to Western culture that holistic or psychosomatic medical approaches are assimilated to it rather than resulting in any reform of practice. Distress is dichotomized into physical and mental, real and imaginary, accident and moral choice (p. 83).

Like Sontag, Kirmayer argues that labeling an illness "psychosomatic" places the responsibility for the illness on the individual, with the underlying assumption that we are free to choose our behaviors, rational enough to eliminate disease-causing stress from our lives. Citing Lakoff and Johnson (1980), Kirmayer notes that the mind is considered rational, up, active, voluntary, controlled, strong, masculine, form (immaterial), immortal. The body is irrational, down, passive, involuntary, uncontrolled, weak, feminine, matter, mortal (p. 76). "Real" illness in the body is a type of misfortune that "just happens to us." But psychogenic explanation of illness "shifts responsibility for the unexplained and uncontrollable to the patient" (p. 75). Thus values are hidden in metaphors of mind and body in biomedicine. Similar to Taylor's argument that the naturalistic understanding of the person has moral appeal, Kirmayer contends that the mind-body dualism inherent in the naturalistic approach is perpetuated in Western culture (and

hence, in Western medicine) through the moral appeal of the mind as rational and in control and the body as "fragile, mortal, clumsily navigating the material world, a constant reminder of the limits of reason" (p. 76).

The "biopsychosocial model" would give equal consideration in diagnosis and treatment to biological, psychological, and social factors (Engel 1977). This model, widely taught in medical school "behavior science" and psychiatry courses, does not necessarily challenge the status quo. Kirmayer writes:

[I]t is not simply the lack of a comprehensive theoretical model that prevents physicians from integrating psychosocial information into clinical practice. Psychosocial 'data' have affective and moral implications that pose significant problems for physicians (p. 64).

Another serious problem with the biopsychosocial model is the danger of medicalization of social problems which, in the words of Scheper-Hughes and Lock (1987:10), entails a "tendency to transform the social into the biological." Social and political problems can become individualized and considered treatable by medicine rather than necessitating political or social change.

Finally, Kirmayer warns of the challenge posed by the radical materialism predominant in biomedicine today:

Without consistent attention to the experience of illness and the sociomoral dimensions of sickness, the "biopsychosocial approach"...will become just another technique for rationalizing the patient as a system of medical facts. Personality and social stress will be variables duly noted and entered into the equation of the patient's distress, while

disease remains the one solid fact about the person before which emotional reactions and personal values fade to insignificance (p. 84; emphasis added).

These "ostensible reforms" are thus problematic not only in their perpetuation of the status quo, but also in their opening up of new territory - the psychological and the social - for medicalization and moral judgment.

The Reality of Experience

Erwin Strauss (1966a:vii) writes of the widespread search for the "neurophysiological basis of mind:"

A distinction has been made between two ontological levels - a genuine and a spurious one. Full reality is granted to the nervous system and its function, while experience is interpreted as a kind of phantasma...Cartesian dualism has been replaced by the one-and-a-half-ism of the real thing and its shadow. Unfortunately, these shadows are all that we immediately possess.

Because these "shadows" of human experience are all that we immediately possess, they deserve serious attention. For this to be possible in medicine, experience must be considered as real - and as important - as the material. In the next chapter, I discuss the phenomenological approach to the study of lived experience and provide a selective review of phenomenologically oriented writings on the illness experience.

CHAPTER 2

PHENOMENOLOGICAL MEDICAL ANTHROPOLOGY:
AN APPROACH TO UNDERSTANDING ILLNESS AS A LIVED EXPERIENCEPhilosophical Phenomenology

Philosophical phenomenology has its origins in pre-World War I Germany in the work of Edmund Husserl (1859-1938), who was particularly interested in the manner in which the individual experiences the world (Husserl 1931, 1970; Lavine 1984:393). According to Husserl, things cannot be known independently of our way of perceiving them. He developed the phenomenological method of "reduction" or "bracketing," in which the individual suspends the "natural attitude" of taking the "objectivity" of the familiar world for granted and makes explicit the activity of experiencing itself. In this manner, he argued, we can know the essential structures of our conscious acts, such as thinking and remembering, and the essential structures of the objects to which these acts refer. Thus it becomes possible to know the world as it is constituted by individual consciousness, in contrast to "knowing" the world objectively, as positivistic science presupposes: "His concern is no longer with the object-as-such, but rather with the object-as-it-is-perceived or as-it-is-experienced" (Toombs 1987:221). Husserl used the term "lifeworld" (Lebenswelt) - the self-evident, prereflective world of everyday affairs, which he considered to be the foundation of philosophy and all of the humanities and

sciences.

Husserl's phenomenology considers human experience not merely worthy of study, but an essential realm of study if one hopes to know anything at all. Dreyfus (1991:2-3), however, argues that Husserl fails to overcome the subject-object distinction which lies at the core of Cartesian naturalism, the very approach Husserl criticized. In Husserl's view, writes Dreyfus, the human sciences failed because "they did not take into account intentionality - the way the individual mind is directed at objects by virtue of some mental content that represents them." Husserl considered man to be "essentially a consciousness with self-contained meanings, which he called intentional content. According to Husserl, this mental content gives intelligibility to everything people encounter." This is a cognitive, representational view of the mind (Benner and Wrubel 1989:42). The person (subject) assigns meanings to objects perceived in the world.

Martin Heidegger (1889-1976), a student of Husserl's, questions the "traditional claim that the basic relation of the mind to the world is a relation of a subject to objects by way of mental meanings" (Dreyfus 1991:3):

Heidegger breaks with Husserl and the Cartesian tradition by substituting for epistemological questions concerning the relation of the knower and the known ontological questions concerning what sort of beings we are and how our being is bound up with the intelligibility of the world. Following Kierkegaard, he holds that Descartes's famous starting point should be reversed, becoming "I am therefore I think."

Heidegger held that the most basic and most common way in which we encounter the world is by grasping meaning directly while engaged in meaningful situations. This engaged knowing is possible because "the very act of apprehension is based on taken-for-granted meanings embedded in skills, practices, and language" (Benner and Wrubel 1989:42). These "background meanings" surround us from birth as members of a particular culture, subculture, and family with particular ways of paying attention to things, moving about, speaking, etc. These skills and practices to which Heidegger refers are embodied in that they do not require our conscious awareness. Our "embodied intelligence" gives us the capacity for nonreflective being in meaningful contexts (Benner and Wrubel 1989:42). Benner and Wrubel provide the example of bowing in Japan: "It would be a strain to have to think reflectively and decide each time one bowed that this was the appropriate situation in which to bow." Instead, bowing is an embodied practice, no longer requiring conscious thought.

"When embodied intelligence works well, it is rapid, nonconscious, and nonreflective. When embodied intelligence does not work well or when it breaks down altogether, it loses its essential embodied, taken-for-granted quality and becomes something one reflects on consciously" (Benner and Wrubel 1989:43). Illness is a situation in which some degree of breakdown of the smoothly functioning body-self often occurs. In illness, we become more self-aware: of pain, nausea,

fatigue, or any other discomfort as getting in the way of our ability to move as before, impeding our plans, disrupting our sense of well being. In the case of multiple sclerosis, for example, one might become aware that one's taken-for-granted ability to smoothly walk across the room has become instead a feeling of heaviness or awkwardness when one's feet do not land where one feels they should. Instead of simply moving forward as a mind-body unity, the body enters conscious awareness as the first sign that something may be wrong.

According to Heidegger, then, we know the world through grasping meaning in the immediacy of being absorbed in active coping (Dreyfus 1991:162). We are formed by shared practices which over time become embodied. We are capable of detached, analytical thought, but this is a less common way for any person to be in the world. All of us - athletes, carpenters, scientists, dancers, etc. - are most often involved in simply coping in a nonreflective way.

An important point about such a view of the person is that we are not simply going about our lives in an empty way, but are moved to do things on the basis of what Heidegger calls concern (Besorgen). We become involved in the world because things (including other people) matter to us (Benner and Wrubel 1989:47). Heidegger (1962:238) considers the person to be "defined as 'care.'" Our way of being in the world is that we are "occupied with things" or "inhabiting" (Dreyfus 1991:43):

When we inhabit something, it is no longer an object for us but becomes part of us and pervades our relation to other objects in the world...Dwelling is Dasein's [the person's] basic way of being-in-the-world. The relation between me and what I inhabit cannot be understood on the model of the relation between subject and object.

This understanding of the person as involved in meaningful contexts forms the basis for Taylor's description of humans as "self-interpreting animals," as opposed to the naturalistic view of the person as rational and in control of one's aims and purposes, discussed in the previous chapter. "[T]he person does not come into the world predefined but becomes defined in the course of living a life" (Benner and Wrubel 1989:41). "We are brought up in meanings and understand the world in terms of these meanings, which Heidegger calls 'the meaning of being'" (p. 42). Because we are involved in situations which have meaning for us which we grasp prereflectively, "situations have the capacity to engage us and to constitute us" (p. 42). Taylor writes:

[The conception of the person as self-interpreting] resists the reduction of experience to a merely subjective view on reality, or an epiphenomenon, or a muddled description. On the contrary, the claim is that our interpretation of ourselves and our experience is constitutive of what we are, and therefore cannot be considered as merely a view on reality, separable from reality, nor as an epiphenomenon, which can be by-passed in our understanding of reality (p. 47).

In a very real way, then, we are our interpretations of our experience, which includes our experience of our bodies, our families, our cultures, our political systems, and everything that constitutes our world.

Illness has the capacity to dramatically change us, and therefore, to change our world. An understanding of the person as self-interpreting, involved in shared practices, and possessing embodied intelligence brings us beyond the naturalistic view of the person that dominates Western medicine.

In his writings, Heidegger did not directly address the role of the body in shaping the world, but his philosophy has influenced others such as Maurice Merleau-Ponty who, in Phenomenology of Perception, writes of the mind and body as unified in an ambiguous way in our lived experience:

The experience of our own body reveals to us an ambiguous mode of existing. If I try to think of it as a cluster of third person processes - "sight," "mobility," "sexuality" - I observe that these "functions" cannot be interrelated, and related to the external world, by causal connections, they are all obscurely drawn together and mutually implied in a unique drama. Therefore, the body is not an object. For the same reason, my awareness of it is not a thought...Its unity is always implicit and vague...The experience of one's own body runs counter to the reflective procedure which detaches subject and object from each other, and which gives us only the thought about the body, or the body as an idea, and not the experience of the body or the body in reality (p. 198).

Merleau-Ponty distinguishes the "lived body" from the objective or physiological body. Gallagher (1986:140) notes that it might appear at first glance that there are two distinct bodies under consideration, but this is not the case: "A human being neither 'has' nor 'is' two bodies; the body as it is lived and the body as it appears in objective observation are one and the same body. The objective body is

a perceived body; it is the objectification of a body that is also lived." As Merleau-Ponty explains it: "the objective body is not the true version of the phenomenal body, that is, the true version of the body that we live; it is indeed no more than the latter's impoverished image" (p. 431).

The object body studied in medicine is thus an impoverished image, a particular way of perceiving the body. This image of the body has served a useful purpose for medical science in allowing for advances in areas such as infectious diseases, surgery, and many others. But Merleau-Ponty is clear that the "lived body" is a mind-body unity, and that our lived experience, however ambiguously, confirms this unity: "In [bodily experience] we learn to know that union of essence and existence which we shall find again in perception generally" (p. 147).

And like Heidegger, Merleau-Ponty asserts that our perceptions, which we get through our bodies, constitute the world as we know it:

The world is not an object such that I have in my possession the law of its making; it is the natural setting of, and field for, all my thoughts and all my explicit perceptions (p. xi).

We shall need to reawaken our experience of the world as it appears to us in so far as we are in the world through our body, and in so far as we perceive the world with our body (p. 206).

In so far as I reflect on the essence of subjectivity, I find it bound up with that of the body and that of the world, this is because my existence as subjectivity is merely one with my existence as a body and with the existence of the world, and because the subject that I am...is

inseparable from this body and this world (p. 408).

Merleau-Ponty uses the terms "lived body," "bodily experience," and "phenomenal body" to capture the self-body-world inseparability that is our way of being in the world. This understanding of the person is what Verwey (1990) calls the "anthropological point of view" and what has also been referred to as "embodiment" or the "embodied self" (Csordas 1990; Frank 1986; Gordon 1990; Kesserling 1990; Kestenbaum 1982; Leder 1984; Lifton 1986; O'Neil 1985; Young 1984), and "Leib," a German term denoting simultaneously "life," "person," and "body" (Ots, 1990). These terms are attempts to more accurately describe our way of being in the world than our impoverished language and images so far have allowed. Kesserling (1990:83) says it beautifully:

In his paintings, Cezanne searched to attain a synthesis between the unique and the general, between the whole and its parts. He aimed to unite the motif so tightly that there would be 'no hole through which the truth could escape' (Bocala 1989). Embodiment might be the master work containing the whole truth graspable by humans...theories or cultural constructions are, at best, comparable to outlines. Outlines, by definition, stand out because of the emptiness around them. They allow, in Cezanne's terms, plenty of space for the truth to escape.

Some form of this understanding of the person, as an embodied interpreter of self and world, underlies numerous phenomenologically-oriented writings in the philosophy of medicine (Gadow 1982; Kestenbaum 1982; Leder 1984; Schwartz and Wiggins 1985; Toombs 1987; Young 1984), medicine and nursing (Baron 1985; Benner and Wrubel 1989; Kesselring 1990;

Sacks 1985), and medical anthropology (Csordas 1990; Frank 1986; Gordon 1990; Kaufman 1988; Ots 1990; Scheper-Hughes and Lock 1987), in addition to areas not addressed in this paper such as education, psychology, sociology, linguistics, and others.

In the remaining sections of this chapter I take a brief look at anthropological perspectives on body/self/world relationships, and provide a selective review of the literature on the experience of illness from a phenomenological perspective.

The Body and Society

In Natural Symbols, Mary Douglas asserts that "natural expression is culturally determined," and that "there can be no natural way of considering the body that does not involve at the same time a social dimension" (1970:70). She describes the relationship between body and society:

The social body constrains the way the physical body is perceived. The physical experience of the body, always modified by the social categories through which it is known, sustains a particular view of society. There is a continual exchange of meanings between the two kinds of bodily experiences so that each reinforces the categories of the other. As a result of this interaction the body itself is a highly restricted medium of expression (p. 65).

Douglas provides an alternative to the biomedical body, arguing that the body is not merely the utterly physical thing as portrayed in anatomy atlases and operated on surgically; the experienced body is constituted by more than organs,

muscles, and bones. Because the social body varies from place to place, so too will the experience of the physical body vary.

John O'Neill begins Five Bodies by distinguishing between two bodies - the physical and the communicative, or lived body, which we never experience except as a mind-body unity. This is essentially the same distinction made by Merleau-Ponty between the objective body and the lived body "where we learn to know that union of essence and existence" (p. 147). O'Neil's aim is to "deepen the connections between biology and culture" (1985:17). He criticizes the tendency of social scientists to study "disembodied persons," (p. 20) and elaborates a description of embodiment:

[A]t many points, sociological descriptions of institutional settings are essentially and irreparably abstract because they fail to provide for social agents as embodied persons, engaged in embodied inquiries. In everyday life, however, we have - and must have - society in our bones...The work of institutions is finely grained into our physical, mental, nervous, and moral constitution and this is what accomplishes the daily marvel of social order with its pleasures and pains, its rewards and punishments (p. 24).

O'Neil discusses the unity of his two bodies - the physical and the communicative - in terms of five images of the body: The World's Body, Social Bodies, The Body Politic, Consumer Bodies, and Medical Bodies. In the "World's Body," for example, he laments the decline of anthropomorphism and the abstraction of modern experience "based on the removal of the human shape in favor of the measured - number, line, sign,

code, index" (p. 26). Throughout Five Bodies, his arguments revolve around the embodied person, the very existence of which he believes is "threatened with the prospect of an eternal darkness" because of the widening gap between nature and humankind (pp. 147, 158). He warns of the danger of a disembodied world, and of the continuing process of dehumanizing, industrializing, and medicalizing life at the expense of the person.

Scheper-Hughes and Lock (1987) offer a tripartite conceptualization of the body. The "individual body" is understood phenomenologically as the "lived experience of the body-self." The "social body" is as described by Douglas (1970), referring to the "representational uses of the body as a natural symbol with which to think about nature, society, and culture." The "political body" refers to the "regulation, surveillance, and control of bodies...in reproduction and sexuality, in work and in leisure, in sickness and other forms of deviance and human difference" (pp. 7-8). The authors suggest that the analysis of these three levels of the "mindful body" can be used as a heuristic concept for understanding culturally constructed sources and meanings of health and illness.

Body/Self/World Relationships in Illness

According to Merleau-Ponty (1962), our lived experience ambiguously unites body, mind, and world. The boundaries are

indistinct, permeable, fluid. Most of the time our body escapes our awareness as we engage in activities as a mind-body unity, involving ourselves in the world.

The literature contains many cases of body-self disconnectedness, such as autoscopy (the observation of a phantom self, usually as a torso or bust), out-of-body experiences, and hypnosis. Paul Schilder (1935/1950:158-9), an early psychoanalytic writer on body-image, documents numerous examples of unusual body-self relationships, such as the case of Helen, a woman in her forties with some sort of "neurosis," who experiences an extraordinary loss of unity in her body-image as is often seen in schizophrenia: She "complains that she has terrible states of anxiety, especially when walking in the street." In her words:

When I get this anxiety state I cannot walk further. I run into myself. It breaks me into pieces. I am like a spray. I lose my centre of gravity. I have no weight. I am quite mechanical. I have gone to pieces. I am like a marionette. I lack something to hold me together. I am not on the earth; I am somewhere else; I am in between...I felt already as a child that I am not a whole being...The skin is the only possible means of keeping the different pieces together. There is no connection between the different parts of my body. Sometimes the roof of my skull flies away...

The important conclusion we may draw, writes Schilder, is that "feeling our body intact is not a matter of course" (p. 166). "When destructive tendencies go on, the body is spread over the world," he writes. He tells of another patient who, while suffering from a gonorrhoeal infection, felt "that his bladder was lying in the street and a streetcar was crushing

it" (p. 166). In The Body in Pain, Elaine Scarry writes: "It is the intense pain that destroys a person's self and world, a destruction experienced spatially as either the contraction of the universe down to the immediate vicinity of the body or as the body swelling to fill the entire universe" (p. 35). These comments suggest that in actual experience, as Merleau-Ponty indeed states, mind, body, and world are ambiguously unified, leaving open endless possibilities for experiential variations in these relationships.

Illness can move one to a different understanding of the body's place in the constitution of self and world. Illness can be a threat to the self, shaking the foundations of one's existence and revealing with a clarity perhaps never before experienced that self and body are inseparable, as the following excerpt reveals:

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...[M]y whole existence is shaken by my calamity (Birrer 1979:19).

Philosopher Sally Gadow (1982) provides an analysis of what she calls the dialectic between body and self. She suggests four levels of relation between the self and body and describes a dialectical progression from one to the other. In "primary immediacy" (the lived body), there is no distinction between the lived body and the self: "[T]he immediacy of the lived body is the immediacy of being in the world, of feeling

able to affect one's world and be affected by it" (p. 88).

In "disrupted immediacy" (the object body) self and body are distinct and opposed, a situation that arises from the self feeling constrained by the body. The body is the source of impediment, "the force that must be governed, the too meager strength, the pain that destroys purpose" (pp. 89-90). This objectification of the body is not the theoretical object body of anatomy, but the "existential otherness of the self," or the self feeling encumbered by the "heaviness and recalcitrance within itself" (p. 90).

In the third level, "cultivated immediacy" (harmony of lived body and object body) self and body are still distinct but are now mutually enabling, as exemplified in the acquisition of a skill. This is a kind of "unity achieved by the self living more articulately in and through the body" (p. 90). A period of body mastery is initially required to overcome the feeling of being encumbered by one's body, as in the case of the singer who wants to extend the range of her voice beyond its current capacity.

Gadow calls the fourth level of relation "aesthetic immediacy" (subject body) where the body-self dialectic can be completed in experiences such as illness and aging, "phenomena which trouble us because of their apparent destruction of self-body unity" (p. 92). On this level mastery can no longer reunite body and self: "[B]reakdown is inevitable when the unity has been achieved only through mastery of the object

body" (p. 93). Attempts at mastery in illness or aging produce disengagement.

The way out of this conflict is to move beyond the notion of body as object (as instrument or encumbrance) toward the recognition of the subject body as part of the self, able to "formulate aims, purposes, value, meaning" (p. 94). Gadow provides the example of how one might experience the phenomenon of shortness of breath - not as a "limitation upon activity which might be alleviated by proper conditioning," but as an "expression - a symbol of the body's own perspective on the value of activity, speed, endurance." (p. 94)

Gadow's analysis emphasizes the fluidity of the body-self relationship and the possibility of accepting the body as a part of the self, and as capable of expressing its own wisdom. In certain situations, then, body-self unity is incomplete, but something that can be achieved. Illness and aging are opportunities for dialectical completion of the self-body unity, as one can learn to live in "aesthetic relation to the body" (p. 99). Although it is possible to imagine many scenarios in which such an aesthetic relation might seem a hopelessly romantic ideal given the brutal reality of much illness and death (e.g. a lonely death in a nursing home; illness due to poverty or violence), Gadow's analysis is heuristically useful as an approach to understanding the multi-layered reality - the pain and possibility - inherent in bodily experience.

Gadow's analysis is an attempt to get beyond the Western dualistic view of mind and body, and in a way parallels Yuasa's (1987) discussion of Japanese mind-body philosophy. He contends that mind and body are inseparable, but that only through cultivation in such practices as meditation and yoga can the essential state of mind-body unity actually be realized. Ordinarily, according to Yuasa, mind and body function separately. The mind-body relationship is on a continuum, varying from the psychotic to the yogi or Zen Master, from the beginner to the athlete or master musician. Yuasa and Gadow offer similar messages: We can and often do experience ourselves dualistically, but unity between the body and self can be attained. Gadow claims that unity can be attained through the acceptance of the body as subject, as a knowing part of the self, whereas Yuasa holds that engaging the body in certain practices can connect the self to the "dark consciousness" of the body. An essential point about the body-self dialectic, writes Gadow, is that "the truth is in the whole"; one cannot understand the relationship fully by focusing only on one part of it (p. 87). Similarly, Zen Buddhist Shunryu Suzuki says there is a "oneness of duality":

Our body and mind are not two and not one. If you think your body and mind are two, that is wrong; if you think they are one, that is also wrong. Our body and mind are both two and one. We usually think that if something is not one, it is more than one; if it is not singular, it is plural. But in actual experience, our life is not only plural, but also singular (p. 25).

In the next section, I provide a selective review of

studies on the experience or embodiment of illness and disability in Western and non-Western cultures.

Embodying Illness: A Selective Review

Studies of the experience of illness and disability in Western and non-Western cultures can shed more light on the relationships between body, self, and world. In this section I discuss several phenomenologically-oriented studies of the lived body in illness and (in one case) congenital limb deficiency. Through these studies, I explore the changing sense of body-self unity in illness, and social and cultural shaping of the embodiment of illness.

Western Cultures

"The Disembodied Lady" is a case study by Oliver Sacks (1985) of a woman named Christina who has lost her proprioceptive nerve fibers, which provide us with a sense of body awareness. Without proprioception, Christina receives no lived information about where her body is in space; she has lost her sense of embodiment. She must learn to use vision and conscious thought to do everything that she used to do with embodied intelligence. It seems that it would be especially difficult for her to achieve the kind of self-body integration of Gadamer's "aesthetic immediacy," the recognition of body as subject, as part of the self with its own intelligence. Christina's body must always remain at some

level an object; she is encumbered by her body and must constantly master it with conscious effort to simply move around in the world.

Gelya Frank (1986) studied a 35-year-old woman named Diane who was born with a congenital limb deficiency; she lives without legs and has stumps for arms. Diane's life history is filled with trials and eventual rejection of artificial limbs. She gradually comes to the awareness that such devices are not for her; they encumber and cause pain more than they help. She developed a sense of wholeness and bodily integration without limbs - real or artificial. Frank notes that Diane even identifies with the Venus de Milo, the armless statue of the Roman goddess of love and beauty. Diane's story shows that the self can be more complete than the body seems.

Frank notes that Diane's embodiment - "her view of her body and her use of it - came into conflict...with the special culture of rehabilitation," which tends to utilize the "adjustment" approach to physical handicap. The problem, writes Frank, is that this theory "glosses over some areas of her experience, such as the cultural problem of interpreting when adjustment was indeed taking place" (p. 190). Rehabilitation specialists failed Diane, not because they did not provide her with prostheses, but because they did not understand that her rejection of the devices, along with her active participation in American culture, may have represented

her "adjustment" to living without arms and legs.

In a study of the experience of cancer in Northern Italy, Deborah Gordon (1990) finds that Northern Italian women commonly prefer not to be told their diagnosis, even though they may have an embodied sense that they have cancer. Cancer is often experienced as "other" - "as an 'it,' or an animal or beast - evil itself -rarely considered part of the very person" (p. 288). Gordon asks, "What is the relationship between social naming, cognitive knowing, and embodied knowledge?" (p. 276) and argues:

[T]he tremendously strong association of cancer with death, suffering, and hopelessness that still exists in much of Italy, coupled with the tremendous power attributed to naming and 'sentencing' makes nondisclosure a major mechanism for keeping the 'condemned' in this social world, and keeping death, decay, and suffering in the 'other.' It is the social reality that is dominant here, such that informing a patient of cancer can be tantamount to social death (p. 276).

In a culture in which social relationships are so fundamental, "social truth may have more power than biological truth" (p. 290). Gordon portrays this phenomenon as complex and deeply rooted, having to do with views about the potential of treatments for healing cancer, the importance of social relationships, and the tendency to deny death among Italians, who view time as cyclical rather than linear. An Italian psychoanalyst informed her that in Italy, "There is a sense of omnipotence, of eternity. It is a life based on the teaching that we exist always, thus also the future is a present. In other words, it is a cyclical time...At bottom, one doesn't

believe one will die; one knows, but one doesn't believe it. It's a type of separation between the head and the emotions" (p. 289). Such separation, Gordon argues, is dangerous in the case of serious illness, because healing must involve integration and incorporation. Illness and death can involve more suffering when the disease and the diseased person are seen as "other," when there is individual and social disembodiment.

Gordon's conclusion seems relevant in light of the American popular and medical conception of cancer as something against which war must be waged. Such an approach can result in alienation from the body in setting up a win/lose confrontation against the "other" - the disease in the body. The alternative need not be passivity or resignation, but a struggling for life and health as an integrated body-self.

In a study of the experience of stroke, Sharon Kaufman (1988) finds that many of the difficulties patients experience following a stroke are "responses to medicine's limits and scope as well as to reflections of medicine's goals and values" (p. 338). Medicine can offer no cure to stroke patients, and so patients are faced with both their own physical limitations and the limits of medicine. She found that rehabilitation therapy became the "battleground on which patients fought to restore the unification of body and self" (p. 346). Many patients wanted to continue therapy indefinitely because of their belief that medicine could cure

them or at least help them in some way. This expectation is coupled with the American cultural assumption that through training and perseverance, the individual can reverse disease outcomes and overcome nature (Gordon 1988). Kaufman notes that the most disturbing aspects of stroke are those not treatable by medicine:

Profound dilemmas regarding disruption of body- and self-image, impotence, and change that individuals face following a stroke...have their source in cultural understandings of individual autonomy, control, and will, and the contrasting reality of the illness experience...What threatens them is not the disease alone...but rather the existential awareness of loss, distortion, fear, and entrapment that emerges sometimes long after the patient's condition is medically stable (pp. 349-50).

One patient in Kaufman's study felt that he had failed because he was unable to reverse his disability despite great effort in rehabilitation therapy. But Kaufman notes that, "In actuality, the Western expectation of biomedicine's promise to transform the body and restore autonomy failed him, and he was left without an anchor, without resolve, alienated from the health care system, as well as from the body/self" (p. 350). He wanted to continue therapy, assuming that "more is better," but he had reached Medicare's - and medicine's - limits. Kaufman writes that neither this patient, nor any others in her study ever reached Gadow's (1982) third stage of progression in the body-self dialectic - that of "cultivated immediacy," in which conflict between body and self is resolved by mastery. The "struggle to overcome the body's limitations...never fully ended" (p. 348). The body thus

remains an object to the self, alienated from the self, as the limits of bodily integrity and medical effectiveness confront expectations.

Non-Western Cultures

In a study of the Chinese experience of the lived-body, Ots (1990) finds that emotions are experienced and expressed as bodily symptoms. In China, there exists a "long-standing tradition of repression of emotions that is mainly based on Neo-Confucian ideals concerning correct social behavior. Emotional excess is severely stigmatized" (p. 25). Because emotions are not readily expressed verbally, they are expressed in the body as, for example, the "angry liver," the "anxious heart," and the "melancholy spleen." The dichotomy between body and mind does not exist in traditional Chinese medicine; emotions are not considered distinct from somatological processes. Most Chinese patients seem "unaware of the emotional meanings of their complaints...experienced doctors of [traditional Chinese medicine] are able to read the somatic symptoms as an emotional message" (p. 53).

Irving Hallowell (1955) portrays the North American Ojibwa Indians as experiencing an intimate connection between body and self. Serious illness is often thought to be due to sorcery, which is thus perceived as a direct personal attack upon the self by an enemy. But the body is not equated with the self; for the Ojibwa, the soul is considered to be the

substratum of the self. The body's functioning is important because it is the form of the self. The Ojibwa value a balance between the intimately connected soul and body. After death, the soul lives on elsewhere and the "body becomes inanimate and 'selfless'" (p. 175). The Ojibwa self, then, can be disembodied, and is known to sometimes temporarily leave the body during life. Here is an example, in a non-Western culture, of a type of dualism characterized by a soul-self which gets its form through a physical body.

Manning and Fabrega (1973) describe the coexistence of three different medical systems among the inhabitants of the Chiapas Highlands in Southeastern Mexico. Each system is characterized by a profoundly different experience of self-body connectedness. For the Mayans, body and self do not possess logically independent status. They view the self and person as equally "diffused onto the family and the group." In what is perhaps an oversimplification, the authors summarize the Mayan view of the body as an "unrefined, undifferentiated, logically unarticulated 'black box,'" which becomes ill for sociomoral reasons (p. 266). The Mayans, they contend, lack a conception of self which is internally located, autonomous, and separated from other "objects."

For the Mestizos, "emotions provide the root metaphor" in their theory of disease, a humoral hot/cold system (p. 68). One's "illness propensity" depends on one's "constitution," such that illness represents the overcoming of one's strength.

The body and mind are on an interrelated continuum.

In contrast to the personalistic Mayan and Mestizo systems, Western medicine is an impersonal system. The body is viewed as an "autonomous entity having an almost machinelike quality" (p. 276). Emotional statements and meanings are avoided or minimized in the discussion of illness. Manning and Fabrega see a danger in the emergence of modern medicine, which has contributed to a "growing sense of a disembodied self, or a selfless body" (p. 283). As science increasingly replaces folk views of illness, self, and body, the self becomes detached from larger social meanings.

Summary

Phenomenological medical anthropology is a discipline which approaches the study of illness in various cultures as a lived experience. The person is viewed as a mind-body unity, inseparable from his or her culture. Cultural understandings, because they are all-pervasive and embodied, profoundly influence the experience and interpretation of symptoms, and the meaning of illness, disability, and death.

CHAPTER 3

MULTIPLE SCLEROSIS: BACKGROUND AND METHODS

Multiple Sclerosis: The Disease

Multiple sclerosis (MS) is a chronic degenerative disease of the central nervous system, commonly involving exacerbations and remissions. The disease strikes more women than men, and more whites than nonwhites, with an onset between the ages of fifteen and forty.

The cause of MS is unknown. Current evidence suggests that some type of environmental exposure before the age of fifteen may be involved, possibly a virus. The prevalence of the disease is ten to twenty times greater in temperate zones (50 to 100 cases per 100,000) than in tropical zones (5 to 10 cases per 100,000). Individuals who migrate before age fifteen assume the risk that is prevalent in their new environment, whereas those who migrate after age fifteen carry the risk prevalent in their place of origin. The disease is also more common in urban dwellers and in affluent socioeconomic groups. Genetic factors also appear to play a role, but the data is far from clear on this issue. Another hypothesis holds that MS is an autoimmune disease; antibodies against one's own neurons may be responsible for the damage. These three theories - viral, genetic, and autoimmune - are not considered mutually exclusive; each may contain some truth about MS causality.

What is known about MS is that demyelination - the

destruction of the myelin sheath around neurons - occurs in the central nervous system. Myelin is destroyed and replaced by plaques of hardened tissue (sclerosis) in multiple locations within the nervous system. Demyelinated nerves carry impulses more slowly; when extensive, conduction may completely fail in affected neurons. Myriad possibilities exist for the onset of symptoms and the course of MS over one's life. Symptoms include muscle weakness, cramps and spasticity, paresthesias (sensations such as numbness or tingling in the face, arms, or legs), double or blurred vision, tremor, fatigue, slurred speech, bladder and bowel problems, sexual problems, mental changes (forgetfulness, confusion, light headedness), and paralysis (sources: Cutler 1987; National Multiple Sclerosis Society pamphlets).

Why Study the Experience of MS?

Oliver Sacks (1985:viii) writes that in neurological diseases, the patient's "essential being" is very relevant, for such diseases come close to personhood or to "the neural foundations of the self, the age-old problem of mind and brain." MS affects the brain and spinal cord, and profoundly affects the person, her bodily sensations and mobility, her way of being in the world.

Along with the plaques in the central nervous system, MS creates existential dilemmas for those afflicted, not the least of which is that, although MS is not considered to be

fatal, there is no cure for the disease. Although medications can be given for alleviation of particular symptoms, no treatment has reliably been shown to alter the course of the disease (Cutler, 1987). MS patients thus confront the limits of medicine upon diagnosis, and are left to cope with increasingly unpredictable bodies.

Another existential dilemma in the experience of MS patients is the extraordinary variability in the course of the disease. The disease can be very mild with perhaps one or two exacerbations and complete remissions, can be rapidly progressive and lead to severe disability due to paralysis and/or blindness, or somewhere in between these two extremes. One never really knows with certainty what "type" of MS one has, whether it will continue to be mild, whether the pain and fatigue will keep getting worse, whether after losing the use of one's legs one could lose still more. Nor does one know, after receiving the diagnosis, just what "symptoms" are MS and what are something else, perhaps merely the result of aging. "Is this MS?" people often ask themselves. Or "Was I just wearing shoes that didn't fit right?"; "Am I just getting more tired like most of my friends say they are?"; "Is this weakness in my legs there because I'm not exercising?"

MS thus lends itself to phenomenological investigation for numerous reasons. A number of studies have examined certain aspects of the experience of MS, but none of these addresses lived experience in the manner attempted in this

study (Brooks and Matson 1982; Halligan and Reznikoff 1985; Matson and Brooks 1977; Samonds and Cammermeyer 1989; Stewart and Sullivan 1982; Walsh and Walsh 1989). In this study I have attempted to see "reality not simply as material or mental but experiential," (Kestenbaum 1982) to gain insights into the participants' experiences of illness, suffering, and healing.

Methods and Research Approach

The participants include seven women and three men. Two of the women are African-American; the others are all white. All but three of them have had MS for at least five years. Five use either a wheelchair or scooter most of the time; one uses a wheelchair occasionally, but can still walk several blocks without an aid; one uses a crutch and sometimes a scooter; and three are fully mobile and use no walking aids. The participants range in age from mid-thirties to early fifties, and include individuals from low income and middle class backgrounds, and urban and suburban dwellers.

The primary method used for obtaining data was interviewing. I interviewed participants on two or three occasions for one and a half to three hours per visit, usually in their homes, occasionally in a cafe or restaurant. Two of the participants, one man and one woman, I interviewed with their spouses also present and participating. I obtained interview questions from Patricia Benner and modified them for

use with MS patients (see appendix). These questions were designed to elicit lived experience narratives from persons with illnesses. The questions served as an inroad to their actual experiences living and coping with MS; through these questions I encouraged the participants to tell me specifically and in detail about situations or experiences which exemplify what it is like for them to have MS; further questions arose out of the situation with each person.

I tape recorded all interviews and, except for a few technical failures, transcribed them all verbatim.

I also obtained data in the form of journal writings, done either with my encouragement (and suggestion to "write whatever you want to write about") as part of this study, or writings done at some earlier time and offered to me to use for this study. Van Manen (1990) notes that journal writing can be a valuable source of lived experience data, but that one should be aware that writing tends to place one in a more reflective mode than the immediacy and spontaneity of face-to-face interaction. I found some journal writings particularly valuable, and draw upon them in one of the case studies (Joseph).

Participant observation is another way of gaining phenomenological data. With most participants of this study I was able to be with them for at least a short while in some context other than the interview setting in an attempt to "enter the lifeworld" (Van Manen 1990). I went to work with

several persons, to church with one woman, to a doctor's appointment with another, and to a class with one man. I attended a small MS support group with permission of one participant and the other members of her group at one of their homes.

Lastly, I asked each participant to "Draw your MS," after which I asked them to tell me about the drawing. Some of these drawings are included in the body of the manuscript. I found that this exercise sometimes helped me understand the meaning of MS for a person in different way than the interview questions. One man, for example, simply drew a cage, explaining to me slowly and thoughtfully, and with anguish as he stared down at the page - how the cage constrained him.

To protect confidentiality, names and other identifying information about the participants of this study have been altered in this manuscript. The approach used in writing the case studies is phenomenological and hermeneutic, or descriptive and interpretive. My goal has been to first of all describe, using their words as much as possible, how MS is lived by these ten persons, and secondly, to understand or interpret their experience - from my own perspective as an engaged participant in this study and through the use of relevant literature - as not just one person's particular experience, but as a meaningful human experience. I looked for strong examples in the transcripts with many questions in mind: How do they experience and cope with bodily symptoms?

What is the meaning for them of their symptoms, of MS? How is their experience of MS influenced by embedded cultural assumptions? In what ways has having MS reshaped the world for them? What is their experience of being out in the world as a different or disabled person? How do they cope with limits to their control over their lives and certainty about their futures?

Limitations of the Study

Some of this study's limitations have to do with the size and characteristics of the group of participants. A larger study would provide more experiences from which to draw for the case studies, and might help me to see differences and commonalities in a way that a study of only ten people cannot. A study with fewer participants, on the other hand, would have enabled me to spend more time with each person, to perhaps get to know each one over time and to see them in different situations.

I did not attempt to recruit a random sampling of individuals from a particular community. This study could be richer if I had a group more varied in terms of age, race, and socioeconomic background. The majority of individuals in this study were Caucasian, well educated, and middle class - and without serious financial concerns or worries about medical coverage.

As in any interpretive study, my interpretation of the

data is only one of many possible interpretations, "and no single interpretation of human experience will ever exhaust the possibility of yet another complimentary, or even potentially richer or deeper description" (van Manen 1990:31). And before the interpretation is the gathering of data. Langness and Frank (1981:60) point out the value of being aware of how one's personality may affect the types of responses one receives from interviewees. My questions and responses arise from my experiences as a member of a particular culture, subculture, and family. During the course of the field work, there were, no doubt, experiences which my own fears or discomfort prevented my pursuing, of which my awareness is surely only partial.

Doing this study, with all of its limitations, stems from a desire, to borrow van Manen's (p. 8) words, "to say something worth saying, to actually say something" - about the human experience of illness.

CHAPTER 4

THE EXPERIENCE OF MULTIPLE SCLEROSIS: CASE STUDIES

Case #1: Body and Self: Being "Full of Holes"

All of the cases to be discussed in this chapter explore relationships between body, self, and world in various ways. This case is an example of one woman's experience of MS as an ironically appropriate illness for her to have, given her image of herself as a flawed survivor of a "crazy life."

Carolyn is a Caucasian woman in her forties, a single mother of a teen-aged daughter, who depends upon the social service system for all of her income and medical care. She is able to slowly walk around her house, but uses a scooter whenever she goes out. I spoke with her in her home, as she sat up in her bed.

As Carolyn tells me about her life, themes of isolation and abuse emerge. She recalls having been unusually isolated as a child by her mother, who was often depressed. Carolyn had no friends growing up, and as a child, was often the victim of sexual abuse by an uncle. After moving out of the house, she went to secretarial school and married a man who eventually also abused her, and after several years she managed to leave him and move to another state. Carolyn feels that she never developed the capacity to trust others, and it seems that some of the people she most wanted to trust violated whatever trust was there.

She began having symptoms of MS in her early twenties,

while still married and in secretarial school. She initially had headaches, vertigo, and paresthesias - strange sensory symptoms such as numbness and tingling in her legs. A few years earlier, she had begun having bouts of suicidal depression and severe anxiety, sometimes panic attacks. She had been hospitalized several times for psychiatric treatment. She tells of her first experience reporting her MS symptoms to doctors:

They had this experience with me where I had overdosed and I had been in the ER...they knew I had some psych history from that...I told my doctor I was having a lot of trouble dealing with the pain and that I really didn't want to hurt myself but I had this razor there...In came a psychiatrist... what they did was give me thorazine...They discharged me from the hospital with the diagnosis of...migraine headaches with vascular contractions and I was hysterical. So throughout my young adult years I had various symptoms. I had parasthesias. But when I'd ask the doctor about them, they'd treat me like I was crazy.

It took many years for her to be properly diagnosed. She was in her late thirties and divorced from her husband at the time. Unlike many MS patients who are not diagnosed for such a long time (Stewart and Sullivan 1982), she is not relieved to receive a medical label for her symptoms. In fact, she would rather have just gone on being "hysterical":

I had this little thing, you see. Crazy I could take. I'll be crazy, just no MS! Those doctors could be right - I'm nothing but a hysterical female. Thank you, I'll take that over MS any day.

Her response to receiving the diagnosis was to be "tough." Throughout her life, she has valued her toughness - her ability to take care of herself and to not need others.

As she puts it:

Knowing that there was nobody there [when first diagnosed], I just had to be tough. I've always had to be tough. Even when I was a child, I had to be tough.

Her toughness has been a strategy for survival in an unpredictable world, a world in which others cannot be trusted, a world in which one must look out for oneself. Her difficult early life left her with an image of herself as flawed, an image, according to Carolyn, ironically consistent with her eventual diagnosis with MS:

[This disease] means certain things to me because of who I am and who I've felt that I am...all the problems that my life has given me...that I've gotten from...my crazy family...my crazy life...all this stuff I bring to this disease...[O]ne of the images that I had was that I was full of holes. It was something in my life and I was just full of holes. And it seemed ironic to have MS and then to see an MRI that seems like you're all full of holes. Because the way the plaques showed up on the glossies were these white spaces. They were holes...I'm right - I am full of holes.

Although she feels that she is "full of holes," Carolyn refuses to see herself as weak in any way; she values not only her personal "toughness," but also her bodily strength - both have helped her to survive throughout her "crazy life." Carolyn tells me how the onset of MS on the left side of her body confronts her sense of herself as strong:

[My left side went] numb...and what it was was that my left side was getting weak, but weak wasn't something that I related to. When I swam, my left leg didn't work like my right leg, but - not me, not weak. No, no! That wasn't a word in my vocabulary. So I knew something was wrong with me, but I had no idea what it was.

Now that she knows - and has known for several years - that she has MS, she still finds herself surprised by the effect of the disease upon her bodily strength. She is right handed, and often finds herself habitually using her formerly strong right hand, even though it is now weaker than her left. She describes the onset of the first exacerbation on her right side as a threat to her sense of herself as strong:

I couldn't write. I'd do crossword puzzles to go to bed at night and I couldn't - I found that I couldn't make the letters!...And I realized that there was something really wrong. Something was wrong, and I didn't have any strength...[Years ago] I was helping build [a] house and I put a roof on a house - Where was this strong person? All of a sudden, I couldn't do anything with my right hand.

Her body, once something she could rely upon as an anchor, as part of a flawed but strong self, is now unpredictable. From one day to the next, she may have extreme variations in her mobility and in her bodily sensations, such as her face feeling "like raw meat" and having a "metallic taste" in her mouth.

When I ask her to draw her MS (see Fig. 1), she draws a woman from the chest up with a blank expression on the face. The brain is visible and is full of holes. On the upper back and shoulder, limbs are propped. A leg dangles down the back, and an arm hangs forward over the shoulder, next to the neck. Two other figures each have heads full of holes and limbs that are improperly placed. One has feet for hands and hands for feet. She comments:

I guess that arms and legs get very confused when

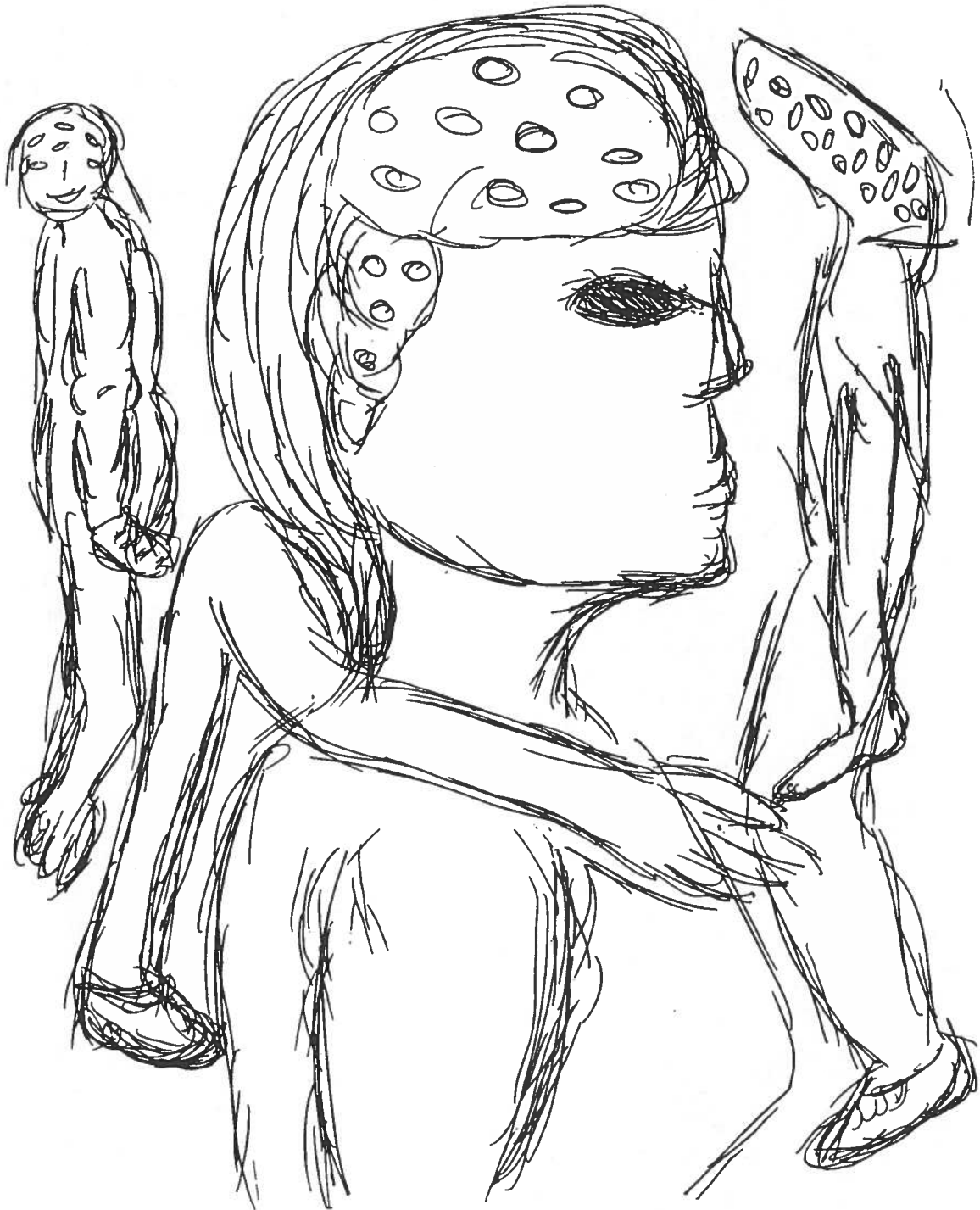


Figure 1: Carolyn's Drawing

you have MS because sometimes they switch places. Sometimes peoples' arms start being their legs and vice versa...I used to be able to walk with my walker better because my arms, I could walk with my arms. And I can't now. And I never know when one side or the other goes...They don't work anymore. It all becomes confusing...[W]hen you have MS, like I have it anyway, you don't know what's gonna be working from one day to the next. So it isn't like you can just become proficient, make up for the deficits in one by using the other, because you don't know what's going to work or what's gonna be there tomorrow...I don't know whether tomorrow I'll have optic neuritis and whether it'll be one eye or both. I don't know what's gonna happen to any of my senses from one day to the next...I don't know how my skin will feel. I don't know how my taste buds will work. I don't know what my face will feel like. It's all so - unknown.

Even with her body as unpredictable as it is, Carolyn is clear that she does not hold out hope for a cure:

I don't think you have to have hope. The way I live with it is, that's the way it is, and nobody knows what it is. Lots of people have lived with it and died with it. That is the truth. I must learn to accept that. I don't want to hope for the next drug. My feeling is, I've just got to do the best I can do everyday.

She doesn't think of herself as having "accepted" MS, but rather as "just...living every day with it." Part of living every day with it is not even attempting to get accustomed to the way she feels from day to day:

I can't really get used to one thing or the other enough to accept it, enough to say, "Okay, this is the way I am," because tomorrow I'm not gonna be that way. And then everybody says, "Oh, good, you're better. Oh, I'm so glad." I don't feel glad, and I don't think that I want them having these great feelings. 'Cause, yeah, it's gone till the next time it comes back, so what's the big deal?

Discussion

Carolyn's embodiment of MS parallels her understanding of herself as having been a victim in an unpredictable world in which she never developed the capacity to trust other people. Her unstable world has left "holes" in her - first experienced as holes in her self, later "confirmed" by an MRI as holes in her brain. Now her body, like her self and world, is "mixed up." She survives MS by "just...living every day with it," by accepting the reality of her body as unpredictable.

This example illustrates the experience of MS as shaped by one's experience of the world and one's image of oneself. Her symptoms threaten what has helped her survive - her bodily strength and her "toughness," her ability to not need others. An exacerbation causing weakness on her right side, for example, means that what used to be her reliably strong side is no longer so. And struggling with anxiety and depression, along with MS, means that she is entirely dependent upon the social service system and the medical and psychiatric care she receives as part of that system. She is able to survive without the help of friends and family but, clearly, not without these social services. As Erwin Straus writes in "Upright Posture," "an individual who has lost or is deprived of the capacity to get up and keep himself upright depends, for his survival, completely on the aid of others" (p. 139). Carolyn is aware of how much she needs others - her psychiatrist, her doctors, the social service system - in order to survive. She is able to ask for help from

professionals, but told me that she finds it very difficult to ask friends or acquaintances for help because they "expect things from you in return," and she is emotionally unable or unwilling to make that kind of commitment to others. And so the people most helpful to her are the professionals she sees on a regular basis, where the requirements and expectations are well-defined.

Drawing upon the work of Taylor (1979), Benner and Wrubel (1989:23) view persons as "neither fundamentally free nor unfree," but as having "situated freedom." They contrast this view with the currently popular idea of the self, which they trace back to mind-body dualism:

[T]he self is seen as purely instrumental and disengaged, one who sets goals and achieves them. Pleasure, in this view, is one of the most rational and powerful goals. People are seen as fundamentally free to abandon any commitment...simply because it is "stressful" and because it interferes with pleasant feelings.

The alternative view - of the person with situated freedom - acknowledges that "new possibilities can be learned, but they are encountered or introduced only in the context of the old habits, skills, practices, and expectations." As health care practitioners, we cannot expect individuals to want or to be able to achieve what would seem on the surface to be better for them. In the case of Carolyn, for example, to suggest that building a support network might be good for her emotional and physical health might be inappropriate and possibly quite alienating. As Lazarus (1985:281) in an

article entitled "The Trivialization of Distress" argues, social relationships "can simultaneously be a source of stress and satisfaction."

For health care practitioners to see Carolyn as "failing to cope as [she] should...fail[ing] through weakness to remain cheerful and optimistic in the face of misfortune," would make her not only the victim of illness, but also of the "attitudes and judgments of the very people who present themselves as wanting to help" (Lazarus 1985:280). Carolyn is coping in her own way, as both a victim and participant in her world.

Case #2: Overcoming Cultural Barriers

This case illustrates one woman's response to cultural assumptions about the disabled in America. At first internalizing the assumption that disabled people are less valuable, less worthy of an opinion and of others' respect and love, Sandra eventually rejects such limiting views of herself, instead affirming who she is and what is most meaningful to her.

Sandra is a Black woman in her early thirties. Like Carolyn, she is also a single mother. She was divorced several years ago and lives with her ten and fourteen year old daughters. She worked as a school bus driver until she became disabled six years ago. For her, MS has been a fairly stable entity over the years. She has none of the bizarre sensory symptoms reported by many others, but is almost completely

unable to walk, has diminished strength in her arms and hands, slurred speech, and moderately blurred vision. She uses a wheelchair except for brief courageous moments in her kitchen when she stands, supporting herself against the counters.

Sandra feels certain that her MS was "triggered - not caused but triggered" - by the turbulent break-up of her marriage. She began having difficulty walking:

I'm clumsy, so when it first started happening, I didn't think anything of it, and then after awhile...I would like miss my step. I'd think maybe where I needed to step was maybe a foot away, and maybe it was half a foot away...And...when I walked, it's like I'd have to walk next to a wall 'cause I couldn't walk without falling.

She remembers that a neighbor thought "maybe somebody was beating" her up, and that her supervisor and coworkers suspected a drug or alcohol problem, and began to follow her around, even into the restroom. But within a few months she was diagnosed with MS, after which she felt "relieved" because, she says, "I was goin' around havin' all these weird things happen and I didn't know what in the world it was." Not long after she was diagnosed, however, her difficulty walking progressively worsened. Within six months she was using a wheelchair and knew that she would never return to her job as a school bus driver. In fact, she would never drive again at all.

After the initial relief upon receiving a medical label for the "weird" things that were happening to her, the reality of her situation devastated her. Her marriage had ended, she

had two children to support, and she had become suddenly disabled. She began to feel that she had "nothing to offer" others, and closed herself off from friends and family. "I felt like I had no right to speak up about anything or to voice my opinion about anything," she recalls. She "wouldn't talk to anybody," and even changed her phone number. She explains how becoming disabled created another layer of difficulty for her:

I think that we as a people - meaning Black people - I think that we have more of a problem because, see, we're already minority. We're minority 'cause we're Black. We're born a minority. And then, if you take a woman, then you're minority 'cause you're a woman. And then you add onto it being disabled. So you're another minority.

Sandra was coaxed out of her self-imposed isolation by friends and family. After weeks of rejecting others' attempts to contact her, a good friend since childhood gave up on trying to reach Sandra by phone:

And so finally she came up here - she is very religious - and she brought me a mustard seed. And she said, see - you know how in the Bible it talks about havin' the faith of a grain of mustard seed? - She came over here and brought it to me and she say, "Now you had me at home cryin' 'cause you wouldn't even talk"...[S]he's been very good for me ever since.

Along with several very supportive friends, close family members - her grandmother, mother, and daughters - helped bring Sandra, as she puts it, "to the realization that I'm the same person as I was before. I'm just now disabled and have to use a wheelchair." She now considers MS to be a "blessing" to her:

Because it slowed me down. Not that I was one of those street people or something, but just oblivious really to my surroundings. Like my mother used to always tell me, "Sandra, stop and smell the roses." I never did that. Never. And since I've become disabled and had to use a wheelchair, I just take more time to do things. And like things that were insignificant to me before are now more significant. Like now I enjoy looking at a beautiful flower. I enjoy being with my family. More than I did before. I really am thankful for the friends that I have.

Sandra is also thankful for the retirement benefits and Social Security income she receives. Although she is no longer employed, she has complete medical coverage and enough income to support herself and her daughters. She is quite aware that had she not been employed at the time of her disability, her financial situation would be considerably worse than it is. Sandra feels that her freedom from financial worries allows her to concern herself more with the things that matter to her - her health, her family, and her friends. She knows what her priorities are, and this allows her to not become "stressed" about things that are less important. Sandra feels that having a clear sense of priorities has limited the severity of her MS:

I think that probably, I attribute a big part of why my MS hasn't progressed any more to my lack of stress. 'Cause I try now to limit the stress that's in my life. I don't get too upset about much of anything.

Since becoming disabled, Sandra has had experiences at restaurants where the waiter will ask her companion what Sandra would like to order, and avoid looking at or speaking directly to Sandra herself. She recalls being in a department

store with her mother when the clerk asked her mother if Sandra needed help finding anything, and being at a meeting when opinions were solicited from each participant except for herself; she was ignored. Sandra has changed her approach to the discounting behavior exhibited by others toward her. Whereas she used to simply allow others to not see her, or to speak only to the person she is with, she now makes herself visible: "I call them on it. I say, 'What, you don't see me? Am I invisible?'" She now refuses to be invisible.

Sandra also tells of "refusing" to accept not being able to write. Her MS had at one point affected her arms and hands so severely that she had to write an "X" in place of her signature at the bank:

That's part of what has me writing again now 'cause I just refused. I said, "Uh uh." 'Cause see I remember, not for myself but I know there was a time when, say, my ancestors couldn't do anything but write a "X"...For instance, I had [an aunt] - if she was living I guess she'd be hundred and something - aunt Louise was sweet as anything. And you know, she was very knowledgable to talk to, but aunt Louise couldn't read or write. See to me, to sit there and have to do an "X," to me that was just like goin' back in time...I'm about going ahead...I think that upset me more than getting the MS initially...I cannot tell you how much that bothered me...I was not gonna write that "X."

Regardless of the difficulty of writing legibly, Sandra forces herself to write because she doesn't want to go "back in time" to the way things were - and still, to some extent, are - for Blacks in America. Sandra's Christian faith also gives her the strength to do more things for herself, the courage to be more independent. She feels that living with MS

has "tested" her faith:

[T]he faith has always been there, but I believe that through MS, it has gotten much stronger and much more present, more there. It's like when you're a kid and your mom tells you, "Don't touch that fire 'cause it's hot." Well, that's because she told you. You don't know it's hot...Well see, I've dealt with MS, so I know. I know what I can do and I know what I can deal with.

Sandra draws her MS very concretely (see Fig. 2), as a spinal cord disrupted with blackened plaques which "interrupt whatever signals are goin' to your brain." She notes that she is a "black and white person," not one to search for deep meanings in her illness. She says that she has never visualized MS as people sometimes view cancer, as "Pacman"-like entities "eating up the good things or whatever": "I never thought of my MS as anything like that, because I guess in the back of my mind I just learned to accept it and deal with whatever -whatever may happen."

Discussion

Scheper-Hughes and Lock (1986) discuss the idea of the "disease and its double."¹ The disease of MS is the pathology in the brain and spinal cord; its double is the "ephemeral and spiritual second reality expressed in the cultural images, metaphors, and collective representations." Sandra, in many

¹Originally conceptualized by Franco Basaglia in an essay entitled La Maggioranza e il suo doppio in La Maggioranza Deviante (The Deviant Majority), by F. Basaglia and F. Basaglia Ongaro, 1971. Torino: Giulio Einaudi editore (cited by Scheper-Hughes and Lock 1986).

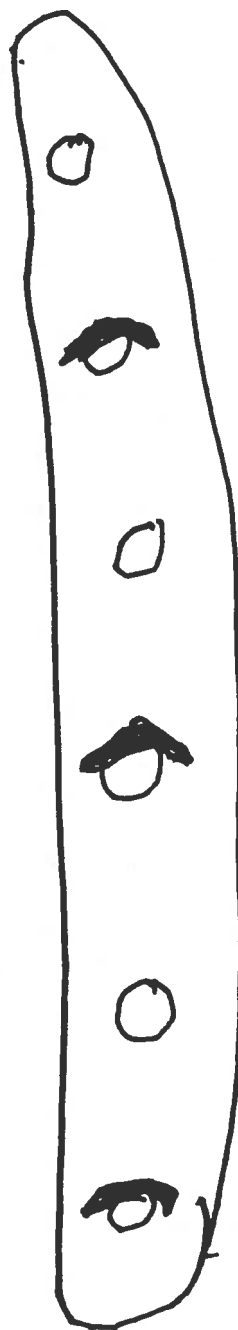


Figure 2: Sandra's Drawing

ways, has resisted the double - by refusing to write the "X," by refusing to remain invisible in public, and ultimately, by refusing to let MS and its resulting disability get her down, despite the great effort such resistance entails.

She has not only resisted the double of MS, but lives even more fully than before, through having "slowed down to smell the roses," and through knowing what is most essential in her life. Strong connections to friends, to three generations of women in her family, and to her Christian faith, moved her back into the world as a visible active participant, rather than an unseen isolated observer.

Case #3: Confronting Limits to Control and Certainty

The diagnosis of MS can take away one's previous sense of control and certainty about one's future. With MS, one doesn't know how one will feel tomorrow, where the pain will be, what strange sensations one might have, whether one will be able to walk across the room. MS confronts the delusion we hold onto about our ability to control our lives and about the stability of our future. Several participants of this study commented that with MS, one feels that one is aging sooner. One doesn't always know what is MS and what is just aging, but, as one woman remarked, "We are all temporarily able bodied." MS forces this fact into awareness sooner than might otherwise occur. This is a case of a man who struggled to hold onto the Enlightenment ideal of the rational self as

in control, as determining his own aims and purposes, with his body being a "constant reminder of the limits of reason" (Kirmayer 1988:76).

Bob is an engineer in his late forties. He is married with three children ranging in age from 6 to 13. I spoke with him and his wife together in their home.

He had only been diagnosed 8 months before the time of our first meeting. A man of large build, standing up straight and greeting me heartily and with humor, he showed at first no outward signs of MS. But when he walked toward the living room, the unsteadiness of his gait was apparent. He does not use a cane or a crutch, preferring instead to go without such aids for as long as possible.

Early in our first conversation, Bob tells me about starting his own engineering consulting firm. He is apparently very pleased with his work accomplishments. "In all modesty," he says, "I am fairly expert [in my field]...I built the business." He adds, "I like to stay on top of it...my wife says I like to show off. I have almost a photographic memory."

His business has been doing well for the past six years, but the diagnosis of MS raises questions for Bob about his ability to continue working: "Feeling good enough to do it is now a very important concern." Bob looks for "benchmarks" that will help him assess his abilities against what he used to be able to do or what is "normal," "what's to be expected"

for a man of his age:

I don't know what a person at forty-nine is supposed to have for an energy level, where the norm is, what is MS and what isn't. And the uncertainties of the disease are probably the thing that's hardest on me.

While washing the cars one day, Bob experiences himself as not measuring up to one of his "benchmarks":

I went out and washed all three cars one Sunday - I've always been a carwasher; my dad must have put it in my genome - and I did it. I mean, I did all three of them, but when I got through, I felt like I'd run a marathon. So I just got inside and I just - cried...I was so disappointed because that was a benchmark. It was something I've always done, and I try to measure against things that I've done to gauge exactly where I am on things...Put me in tears, actually, right in the kitchen. [emphasis added]

Bob referred several times during our conversations to this "very sobering" experience. This was what "really brought it home" for him - that he indeed has MS, and that the disease has resulted in a slow diminution of his physical strength. Whereas he "used to just dash that kinda stuff off before breakfast," he is now limited by an unwilling body. The sudden realization that his body is not what it used to be seems for Bob a signal of his own finitude. For it is ultimately not the prospect of dirtier cars that puts him in tears, but what not being able to wash them as before means to him. We can never really gauge "exactly where [we are] on things;" we never really know exactly how we're going to feel tomorrow, what misfortune may befall us or someone we love, how many years or months or days we have left to live. The

realization that he can no longer wash three cars took away his previously taken-for-granted assumption that he can not merely "just dash that stuff off before breakfast," but, more importantly, that he can be who he wants to be in the world, that he can carry out his goals and control his activities and purposes - even his own destiny.

Bob is not, however, willing to go down without a fight. He sometimes compensates for his unwilling body by willing himself to achieve a certain goal, to feel better, to get up and out the door by a certain time. He mentions that he has "beaten back" some severe headaches (it is unclear whether Bob's headaches are due to MS). I ask him how he does this - by lying down? He answers:

Yeah, lying down. Taking some medication, just changing what I was doin' and stopped 'em. And sometimes just plain tryin' for the world. I had to get in the office [by 1:30]...by about 11:45 in the morning, I was so dizzy and uncomfortable I could barely walk from my room to the bathroom...So I lay down and just put everything out of my mind and lay there, and I got down to the office at 1:30. I'd beaten it back to the point where it wasn't perfect, but I could function.

Being able to "beat back" a headache enables Bob to use his head - which he considers to be his "prime asset" - to overcome bodily vulnerability. He tells me that he loves to read, and that he feels fortunate that MS hasn't affected his cognitive abilities or his sight. And he will use his will to prevent bodily losses:

Even if eventually I lose the ability to walk, I can still use my head...I don't want to lose the ability to walk. She [his neurologist] said, "You

want a cane?" I said, "Hell, no. Not until I absolutely have to"...I would rather fight it to the last ditch and overdo it before giving up anything voluntarily.

Resisting the use of a cane gives Bob some sense of control over his gradually diminishing ability to walk. Giving in means losing abilities before he really has to, which, if he has any say in the matter, he refuses to allow happen.

Bob's wife told me that one morning she saw him up early, laboriously making his way up the stairs, not knowing she was there. When he noticed her following behind him, he told her, "You don't need to see this." I asked her to give me her interpretation of that situation:

Well, it's the pride. There's a lot of things he wants to hide, and that's fine. Everybody has things that they want to hide, that they don't do as well as everybody else, and that was just...a moment I should have given to gim by himself and not followed him up the stairs...it hit his pride...For the man, there's their masculinity that they're always worried about, and taking care of everybody and stuff like that...so they don't want to show these deficiencies. And that's the hardest thing, that he has to always acknowledge and admit to the changes that his body's making. And that's very, very hard.

Bob tells me that later in the day he can often "do much better at that," at going up the stairs. That morning was worse than usual: "I go up and down 'em, you know, all the time," he adds.

Bob has not had MS for very long - less than a year - but in that time he has become a little more accepting of his limits. Although he sometimes feels bad about having to lie

down in the middle of the day because of his MS-related fatigue, he says, "I realize now I don't feel guilty about it like I did four months ago. I just have to do it." And the exhausting car washing episode taught him to be more careful with physical activity. He still likes to "push the limits," but he's becoming more aware that the limits aren't what they used to be; MS has reset the limits, and will continue to do so as long as it progresses.

Discussion

This example illustrates the difficulty of accepting new limits to one's ability to control one's activities, and to one's sense of certainty about one's future. Feeling his strength gradually diminish, Bob plans to fight "to the last ditch" to hold onto his ability to walk. As Erwin Strauss writes in his phenomenological essay, "Upright Posture," walking has significance beyond mere mobility, for in order to walk, one must be able to stand upright:

[U]pright posture is not confined to the technical problems of locomotion. It contains a psychological element...The expression "to be upright" has two connotations: first, to rise, to get up, and to stand on own's own feet and, second, the moral implication, not to stoop to anything, to be honest and just, to be true to friends in danger, to stand by own's convictions, and to act accordingly... (p. 137)

Being seen by his wife limping up the stairs, according to her, hurt Bob's sense of "pride," threatened his "masculinity." The realization that he could no longer wash

three cars "put [him] in tears." He has struggled with guilt about napping too much and getting less done at work. Accepting these new limits has been a tremendous challenge for him, particularly as a male with traditional assumptions about his responsibility to provide for his family and to keep up with work around the house. Although his wife also works full time, the loss of his income would create difficulties for the family. Bob and his wife expressed fears about this possibility; his efforts to fight the headaches and fatigue seem to be his way of experiencing some control over a disease that threatens to slowly take cherished control away from him.

Allowing more ambiguity into one's life is particularly difficult for one accustomed to setting daily goals and achieving them with effort. If one wants to achieve more, one simply works harder. But MS is in conflict with the Protestant work ethic; as hard as one might try, one may not be able to overcome the limits the disease places upon the body-self. Bob cannot "beat back" every headache by "tryin' for the world;" sometimes the body simply says "no." To draw upon Sally Gadow's (1982) analysis of the body-self dialectic, Bob is not always able to achieve integration between body and self through mastery. Bob moves back and forth between attempting to acknowledge and accept his limits, and to fight them "to the last ditch." What makes it even more difficult for him are embedded cultural assumptions about the degree of rational control we actually have in our lives, and of the

power of the mind to control the body.

One of the greatest difficulties expressed by people in this study about MS is its tendency to progress, so that one can never "make peace" with what it has done, for one is ultimately unsure of what else it will do. A way to lessen some of the suffering related to MS, as in all illness and aging, is to develop a more cooperative relationship between body and self, a greater understanding of their unity, and an openness to listening to the body's own wisdom about what is now possible.

Case #4: Invisible MS

One woman, Karen, told me that the first words spoken by the neurologist to whom she had been referred were, "MS can be a very mild disease, you know." Karen is a partner in a small law firm, in her late thirties. She is married and has two children. She was diagnosed with MS two years ago. Of all the participants of this study, her MS was the least visible. She never appeared even the slightest bit unsteady, but rather seemed to literally bounce from her kitchen to her living room while carrying in the tea.

Karen's MS has resulted in unilateral hearing loss and ear pain, frequent numbness in her face and legs, occasional slight foot drop, and fatigue - a "pull the plug" feeling that can force her into a nap right after breakfast. MS to Karen is a "daily reminder" of the body's impermanence, similar to

the experience of aging: "It's the reality of small losses. And life is a reality of small losses, certainly physically it is. And that's what growing old is."

Her description of her visualization of MS (also represented in her drawing [see Fig. 3]), guided by a good friend of hers, captures how Karen copes with MS:

MS was embodied as a "Ms. MS"...The relationship I had with her, which was almost like a dreamlike experience, was very positive. I would have predicted that MS would have come to me in some very sort of diabolical form, some very threatening way, and instead she was a very graceful young woman. And the agreement [she becomes tearful at this point] was that she wouldn't give me any more than I could handle at a time.

Karen's experience of MS has been that she has had time to deal with whatever comes her way. Unlike dealing with cancer or a paralyzing accident, which give one "a big bite to swallow whole," her MS is "like eating hors d'oeuvres;" she can cope with it in small pieces.

Whom to tell can be a difficult issue for persons with invisible MS. Karen doesn't tell everyone about her MS, being particularly careful around colleagues and clients due to "a real fear of people seeing me as sick." "Incompetance is a real issue for me," she adds. "I'm afraid of being seen as somehow less, maybe, capable." Telling someone about it is like

telling them something very private, because I don't have to tell them...The quality of it for me really is that it is invisible. It's like having something on under my clothes that nobody can see, that only I know about.

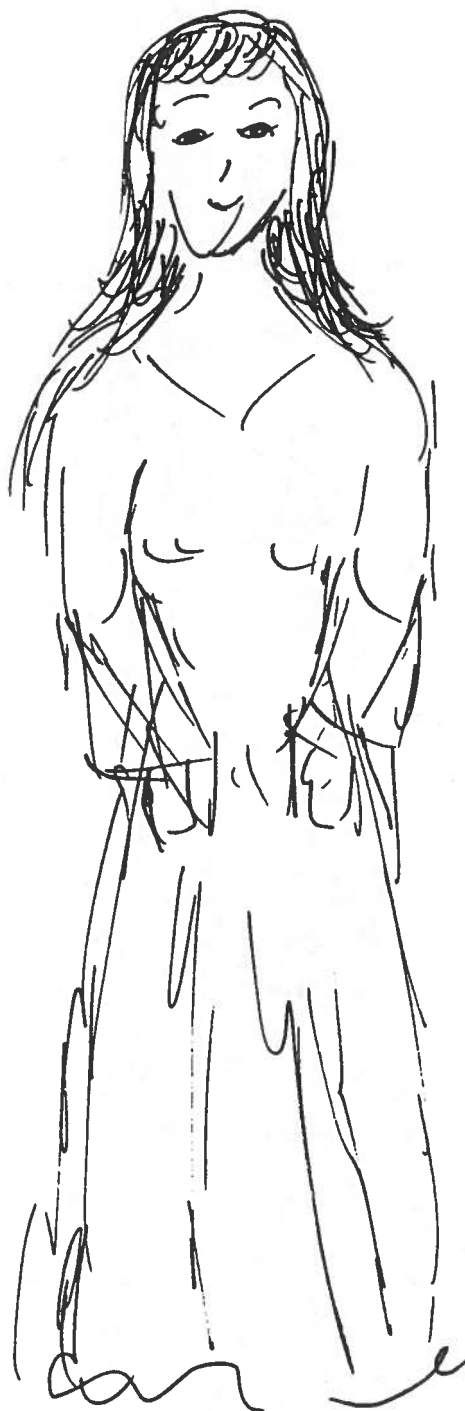


Fig. 3: Karen's Drawing

Because of this invisibility, there can be a sense of "unreality" to MS, both for herself and for people close to her, such as her husband. She tells of how seeing the diagnostic test results helped make the disease more real:

[My husband] pointed out that the MRI looked like somebody had gone through my brain with an eraser...[We saw] the evoked potential results and it was important because it made it real. It made it tangible - there was the picture of it. There's my brain and this is what is going on in it.

Valerie, who also has invisible MS, except for slight balance problems, expressed her sense of not belonging in either the "normal" or MS category:

I'm kind of in between because I'm not...I sort of feel like I don't belong because I'm not - I still am functional at this point. But I'm not really functional, do you know what I'm saying? That if you look at me and you see me, you think, oh, you know, she's just normal, and - did she have too many drinks or something?

MS that cannot be seen from the outside can still be disabling; the disease can suddenly "pull the plug," in Karen's words, requiring her to suddenly - and with no choice in the matter - lie down and sleep. This is what Valerie means by not being "really functional." MS fatigue can be as severe for Karen and Valerie who walk without a cane or crutch, as it is for someone who uses a wheelchair. Karen told me about one exhausting day when she came home early from work, threw herself into bed to sleep, and then woke up and did the rest of her day's work "in bed under the covers." Little did people on the other end of the phone know, she laughs, that "here I am snuggled up in bed...that it's not an

office - they're talking to somebody in bed!"

Karen spoke of the difficulties of being a professional woman with MS. She sometimes "overcompensates," feeling a need to "prove to everybody else" that she can do it. She balances her drive to work hard and be seen as competent by sometimes giving herself "permission" to rest, to work in bed, to take a nap after breakfast. Karen fears the disease's potential to take more of her energy away and to affect her cognitive abilities more than its potential to affect her mobility. She considers mobility problems to be "soluble," but "if I can't stay awake," she says, "and if I'm not fully present, I can't work."

Discussion

Karen and others with invisible MS live with what is now a secret with an unreal quality about it, with sensations that are theirs and theirs alone. Perhaps particularly difficult for women, because of the inequalities that still exist, is the issue of being seen as competent in the workplace. Telling others carries a risk of having perhaps another strike against one. Also, because the more severe cases of MS can be seen and validated by others in the social world, such cases look more "real" and may even feel more "real" to the person afflicted. Others can see a limp, a tremor, a wheelchair, and affirm that there is indeed something going on which may require special consideration, such as more

flexibility around work hours, rather than judging the person as "lazy."

The three women in this study with relatively mild MS were thankful and fearful at the same time, knowing that what they have seen happen to others with MS could become their MS, too. For now they live with daily "reminders" of the body's vulnerability.

Case #5: Disease without a Doctor

Several participants of this study expressed disappointment in their doctors, other health professionals, or in the health care system. This case is an example of one man's particularly profound disappointment in the treatment he received in the early weeks of the aggressive onset of his MS, and the ramifications of his early treatment upon his experience of MS over the long term.

Joseph is a thirty-three year old postdoctoral student in physics. He is single, living by himself in a house of his own. MS made itself known to Joseph four years ago, at a high point in graduate school. He had been rewarded for his six years of work by a significant new finding, for which he received considerable recognition. He had been invited to present his findings at numerous conferences and seminars. He would have his choice of postdoctoral positions at several prestigious universities. He loved his work, and his future seemed secure.

One day while engaged in his weekly basketball game, Joseph realized that his reactions were slowed. He was "never in the right position" during the game. He found that he wanted to be in a particular place on the court before he could actually get himself there. "I knew it wasn't just that I was tired or anything like that," he recalls. This was something different.

A week or two later, during a presentation of his research, he noticed something else. Turning from the overhead screen to face the audience, he felt strangely unsteady for several moments: "It would take a little extra time just to orient myself, each time I made a movement like that."

Hoping the problem would disappear as mysteriously as it appeared, he continued to write and present his work. But while attending a conference in Europe, he began having headaches, fatigue, and difficulty walking. At one point he also had chest pain and thought he might have a heart problem. During a walk in a beautiful garden, the pain became quite severe, but Joseph refrained from letting his colleagues know about his discomfort and, as he puts it, "decided instead to try to enjoy the garden as much as I could in case it was the last thing I saw." A visit to a doctor that day alleviated his fear of a heart attack, but did little to erase his growing sense that something was very wrong.

Back home, an MRI showing the characteristic plaques of

MS solved the mystery. For Joseph, the diagnosis was straightforward: "That was easy," he remarks. But "that's all that they were capable of doing." The following weeks and months found Joseph in a state of "utter panic" as he rapidly deteriorated. Within a month of his diagnosis, he went from walking to using a cane, then a walker, and then finally, a wheelchair. His body was "disappearing," and modern medicine could do little about it.

Four years after his diagnosis, my conversations with Joseph kept returning back to the first weeks and months of his illness. This was the period of greatest decline for him. He notes that the rapidity of the progression of his MS makes his experience much more like that of a trauma victim who is suddenly paralyzed than that of a "typical" MS patient. During his first exacerbation, Joseph was admitted to the hospital in a state of "raw terror," as he describes in his journal:

There was no chance I could sleep. Every sound jarred me, every light blinded me. Every sensation was beyond endurance. I knew I wasn't going to make it. I knew I had the wrong personality to survive this illness...The next day...my hands started violently tingling. That was the first symptom I had had in my legs and they were gone. When I saw Dr. G. again, I said, "My hands are going." He said plaintively, "Not your hands, too?" He had me grab his hands and told me, "Your hands are fine." I tried to believe him.

Joseph felt that his neurologist had no idea what he needed emotionally or practically. The doctor "avoided speaking to me" many times, he recalls. "My relationship with

Dr. G. and the course of the disease for the next few weeks are intimately connected," he writes. He felt alienated from his doctor from the beginning, but tried not to let it bother him:

Once...I suggested that MS was just a name for a collection of symptoms since no one knew what caused it. He replied in an offended tone of voice that it certainly was the name for a disease: "If you laid out on a table the spinal cord of an MS cadaver next to the spinal cord of a normal cadaver, the differences would be obvious." Not only did this seem irrelevant to my point, but I didn't like the idea of being a cadaver or of having my spinal cord laid out on a table. But I decided that it wasn't important whether or not I got along personally with my doctor, just as long as he knew what he was doing. There wasn't anything anybody could do for MS anyway, right?

Joseph slowly came to realize that, because modern medicine could not halt the progression of MS, he had other needs from the health care system:

The main thing a patient needs is help, physically and psychologically, dealing with his symptoms. This was not in Dr. G.'s line...My condition steadily got worse. After a week, I was using a cane, after two weeks a walker, and after three weeks a wheelchair. These were major changes and I had no help, advice, or support in dealing with them...I fell several times and in the process broke two toilet seats...I didn't know how to get in and out of my house...I didn't know how to wash myself...open the refrigerator door, carry a glass of water. I didn't know who to call to get this information. [Dr. G.] remarked, "Occupational therapists just come to your home and rearrange furniture."

Joseph was "surprised" at how little his doctors knew about disability. Several times - as if still reeling from the disappointment - he stated to me his view that "it seemed to me that somebody ought to know what to tell a person when

somebody has to use a wheelchair." It seemed obvious to him that "there must be a million things that a person who gets around in a wheelchair has figured out already and can tell me so that I don't have to figure them out all by myself."

Joseph felt that his body and world were out of control and coming apart. Unable to get reliable assistance, he struggled to keep his life together, but kept feeling that every day there were more and more things added onto what he should have done yesterday. An excerpt from his journal conveys his sense of alienation from his body:

I no longer had any clear sensations of my own. I remember looking at my leg and finding it hard to believe it was part of me. I couldn't move it, if I didn't see it I wouldn't know where it was.

With no centralized source of help in learning about how to live as a disabled person in America, Joseph felt overwhelmed by all that he had to face. Not only did he have to cope existentially with a newly disabled body and what this meant for him, he also had to figure out how to negotiate the world in a practical sense. Exhausted and terribly anxious, he had to make endless phone calls to get essential information - from contractors about having a ramp built at his house, personal care attendants, housekeepers, medical supply retailers, etc. "Everybody I talked to would give me another phone number or two that I should call for something or other," he remembers. Initially convinced that "there wasn't anything anybody could do for MS," Joseph felt entirely alone in the first traumatic weeks of his illness. He later

came to realize how helpful - and how simple - it would have been to have had a single person in the health care system who had the information he needed and could make calls for him to arrange for the necessary adjustments he needed to make in his life.

Joseph asserts that his early experience with MS "debunked my faith in medicine." Previously he felt that if he became ill, he could trust the health care system to take care of him. He now believes that "as long as you are conscious, you must not give up control."

After the initial crisis was over and Joseph was out of the hospital and in a wheelchair, he found a new neurologist. During his first visit with her, her simple suggestion that he place a cushion in his wheelchair for added comfort signaled to Joseph that this doctor was going to be different. Under her care, he decided to undergo treatment with cytoxan, an immunosuppressive drug which, in high doses, has sometimes slowed the progression of MS in some patients. He recalls her visits to him in the hospital:

She would come see me in the evening...I could talk about how I felt, but what was absolutely amazing to me after Dr. G. was that she would talk to me for twenty minutes or even half an hour about I don't know what, but I felt she really cared and this helped a lot. I could sleep this time.
[emphasis added]

Joseph experienced his new doctor as a sort of anchor, who prevented his body from sinking further downward:

Slowly things came back that I never thought I'd see again. One muscle after the other started

working. Each time I noticed an improvement, I felt I had received a gift. No one knows if this improvement was due to the treatment. It started rather early on, before the cytoxan should have taken effect. Somehow, I can't shake the notion that it had something to do with my improved emotional state. Now there was someone who knew something, on my side.

Joseph did not regain the ability to walk very far without using a wheelchair. His illness has not progressed dramatically since the initial exacerbation, and he has gradually become quite active again - swimming, travelling, continuing his research and teaching. But he still vividly recalls the "utter panic" and "raw terror" he experienced when his body was "disappearing" in the first weeks after his diagnosis with MS, and the disappointment of having a doctor and health care system fail in helping him cope, as he puts it, "physically and psychologically, dealing with his symptoms."

Discussion

Even if he had had his second neurologist from the beginning, Joseph's experience with MS would very likely still have been traumatic. Everything was suddenly out of his control; he lost the ability to walk and had no idea if he would be able to live anything resembling a "normal" life again. He wondered if he would be able to continue his work, to get in and out of his house, to learn how to carry a glass of water. Medicine was simply unable to stop his physical decline; his case truly demonstrates Scheper-Hughes' (1991)

statement, "MS is a disease without a doctor."

But Joseph's narratives also illustrate the lack of attention given to his lived experience by doctors and others within the health care system. His experience is an unfortunate example of biomedicine's focus on the material reality of the object body and neglect of human experience - the existential and practical concerns faced by people with illnesses. Even when there is no cure - perhaps particularly when there is no cure - the afflicted need assistance coping with the effects of the illness - a changed body, chronic pain, an immanent death.

In At the Will of the Body, a moving narrative of his own experiences with two illnesses, a heart attack and testicular cancer, medical sociologist Arthur Frank writes:

I may not expect emotion or intimacy from physicians and nurses, but I do expect recognition...I always assumed that if I became seriously ill, physicians, no matter how overworked, would somehow recognize what I was living through. I did not know what form this recognition would take, but I assumed it would happen. What I experienced was the opposite. The more critical my diagnosis became, the more reluctant physicians were to talk to me. I had trouble getting them to make eye contact; most came only to see my disease. This "it" within the body was their field of investigation; "I" seemed to exist beyond the horizon of their interest (p. 54).

The late anthropologist, Robert Murphy (1990:87), writes poignantly of his experience with permanent disability after a spinal cord tumor: "Nobody has asked me what it is like to be a paraplegic - and now a quadriplegic," not even physicians, who prefer "hard facts" and ways of reducing

experience "to neat distinctions of black or white and ignore the broad range of ideation and emotion that always accompanies disability." What frequently emerges in personal accounts of illness in America is the theme of being treated as just another body with yet another illness to be subjected to the "clinical gaze," to use Foucault's (1975) term.

After the crisis, Joseph was fortunate in finding a doctor who paid more attention to his feelings and practical concerns, but this does not erase the harm initially done, nor does it repair the fundamental problems that still remain in the system. Kirmayer (1988:84) calls for physicians to "give serious attention to the role of feeling and value in the practice of medicine":

This will only occur when both healer and sufferer are open to bodily-felt meaning and the social context of sickness and respond, not just with a flurry of technical activity, but with a human relatedness that nurtures the seeds of contemplation and compassion.

Joseph eventually experienced the healing effects of a physician who listened to him, who cared about him. He understood the improvement of his physical condition to be intimately connected to this healing relationship. For persons with MS and other chronic illnesses, for whom physicians can offer little in the way of treatment, such a relationship is particularly significant.

Case #6: Wholeness and Disability: A Dialectical Problem

This case exemplifies the experience of "living out a

dialectical problem," as described by Gelya Frank (1986:191) in the case of Diane, a woman with congenital limb deficiencies. The dialectic is between a person's desire to be seen as whole and intact, and his or her need to be understood as one with physical limitations. As this case demonstrates, one who does not always appear or act particularly disabled can experience profound difficulties in living out the dialectic. When the overwhelming desire is to be seen as whole, questions arise as to when and to whom one's limitations need to be mentioned, and how to sensitively inform others that one is unable, for example, to climb a flight of stairs, to walk very far with a new friend, to accept an invitation to dance. Because MS can be progressive and variable from day to day, one must continually discover just what one's limitations are on a particular day, in a particular moment.

Monika is a rather soft-spoken single Caucasian woman in her mid-forties. She is an artist - a painter - who works out of her own studio and teaches college courses. She has had MS since her early thirties. The disease has most seriously affected her walking; she uses a crutch most of the time, and a scooter for longer distances. She must also cope with the severe fatigue caused by MS; she has learned that a daily nap is usually necessary, but isn't always able to take it. Paresthesias are also present for her on most days - numbness or tingling sensations in either her arms or legs.

During one of our conversations, Monika noted her surprise as to how much she had forgotten about her early experiences with MS and her three exacerbations. She confessed that she has been, to a degree, "in denial" about her MS and the potential of the disease to disrupt her life: "I think I'm just somehow not letting myself face what's happening." She prefers not to think about her illness and to live as if MS were not a factor in her life.

A prominent concern of Monika's is wanting to be seen as a complete person. She sees a danger in feeling too much of a connection between MS and her self:

One of the things that bothers me about [many people with illnesses] is that they identify so closely with it that they become their illness. And I just think it's so dangerous.

It's been very important to me not to identify myself with my illness, not to say, "I am a person with MS," because I just want to be who I am, doing what I do. Just because I am...I just want to be a person in the world and not identify myself or be identified as a disabled person.

Identifying too closely with one's illness can, according to Monika, result in seeing one's illness as the "most important thing" about oneself, pushing other potentially important things out of one's realm of possibility. In the worst case scenario, one gives up on trying to do things. Monika knows that if she "lie[s] around all day," she gets tired:

I keep pushing myself to [be active] because I realize that I either do it or I give up. There's nothing wrong with resting, but I inevitably get tired if I've done nothing. So it occurs to me

that people who give up...are probably really tired from inactivity. I've had that experience myself of feeling weaker and weaker. When I am energized physically and feeling great or okay about myself, then my body begins to react to it.

Aware of her body's response to inactivity and afraid of giving up, Monika sometimes "forces" herself to do things, such as going swimming:

I realize that I can swim better now than I could five years ago, and I'm not sure of the reason for that, except that I think it's having done it and having the interest to not give up on it...One's sense of self worth and sense of excitement about what's happening can curb all kinds of things in the body, and I find that happens with me. I may be very tired, but that doesn't mean I can't rejuvenate myself and pick it up again.

While aware of the importance of balancing rest and activity, Monika admits that she is "not very good at" taking care of herself. She sometimes has difficulty in slowing down, in setting limits to prevent overexertion. She notes, however, that "if you begin to take too good care of yourself, then you begin to see yourself as disabled." Seeing herself and being seen as disabled are what Monika wants to avoid, and understandably so, given the value in our culture of able bodied independence and the stigmatization of the disabled.

But problems can arise when she is in situations in which her disability could impede her ability to do something, while wanting at the same time to be seen as whole and intact. In such circumstances, she may resist telling others that she cannot do something, and instead may overexert herself or avoid the situation altogether. She has experienced this

difficulty in both work-related and social situations. In her words:

Sometimes when I say to somebody, you know, "I can't do that," they say, "Well, I don't see you as disabled, so I don't even think of it that way." This happens quite often. And I realize that one of the things I have to learn to do...is to demand my rights. And I don't want to do that, because I don't want to be different, but in fact, I am different.

She has recently become aware of her need to "make certain demands," as exemplified by her complaint to the art department in which she teaches: "I come every time and there are chairs around the room and tables all around, and I've got to push all these things to the side." She is becoming "more assertive" about stating her needs, noting that "Nobody's gonna make curb cuts unless somebody who's in a wheelchair demands it...It's not such an enlightened citizenry."

Monika finds, however, that making her limitations known in social situations is far more difficult than in the workplace. She recalls the pain of meeting a man at a concert several years ago - when she walked with difficulty but without a noticeable limp - and agreeing to walk with him to a pub for a drink:

We started walking down a beautiful little street and I was just praying the whole way that I could make it to the pub. It was so difficult. I couldn't say to him that I have to walk slowly - I could have, but I had just met him...But if I had a crutch or a cane or something, and he had invited me out, it would have been easier. I wouldn't have had to pretend. On the other hand, the sadness that I feel is that he probably wouldn't have asked me if I had.

Monika told me that before MS, she was more outgoing, more extroverted. In the following excerpt of our conversation, which began with my asking her how she thinks other people see her, she explains to me how it is that MS has made her more "shy" or "introverted:"

M: It scares the life out of me because I don't know how [other people] see me...I'm usually very forgiving of people if they make a wrong move. They're doing their best. And I know how difficult it is because I sometimes have difficulty not knowing what a person needs. I don't know how people see me. I really don't...I wish I did. But now I really don't know, I mean, if I look terribly - crippled, or if I just look like somebody walking with a crutch and not terribly crippled.

C: Why is it so frightening to not know?

M: Oh, it's very frightening. [long pause] I guess I don't want to feel foolish, like I'm having unrealistic expectations...just the fear of rejection...There was a singles' party the other night and a friend had invited me to it - I had never gone to one of those - and I was about to go. I got ready, kind of, and then I backed off. I was afraid of...being rejected, not meeting anybody, not having anybody to talk to.

C: And you used to be so different.

M: Oh, yes.

C: You would just get up there and dance, and start conversations.

M: Right, right, right...and sometimes I have found myself at times at gatherings and parties and I do just fine, once I'm there. But to get myself up and out to go there is like, a big deal...That's partly because I don't know how people see me - so why is that scary? Just because I'm out of control [regarding] what I'm expected to do in a situation. I'm usually very honest with people. I say, "I have to sit down," you know, if I have to, but - it's like going to kindergarten the first day - it's scary.

The inseparability of body, self, and society emerges from Monika's narrative. Social situations open up the possibility that she may feel vulnerable and insecure because her body can fail her in ways that are painful to accept and to convey to others. She may need to sit down in the middle of a conversation with someone she has just met. She may have to decline an invitation to dance from a man who does not yet know that, although she once loved to, she can no longer dance. It is as if her now limited body is pulling the reins in on her self, once confident and outgoing, now at times unsure and tentative. She lives the dialectic every day, being both a whole and disabled woman. She tells me, "I still see myself as a dancer," but also has the painful memory of "watching somebody dance and wanting to get up and dance with him so badly and I couldn't." She summarizes her approach to coping with limits and loss:

My feeling is that we all have to create our own lives. And we take it from wherever we are and with whatever health we have, whatever energy we have. And if we forget that we are the creators of our lives, nobody else is going to create or recreate your life.

Monika embodies the above statement in her sense of herself as a dancer physically no longer able to dance; her past abilities remain a part of her and her orientation toward the world.

Discussion

The case of Monika exemplifies the restorative potential

of human creativity in coping with the ambiguities of a disabling chronic illness. While she experiences the pain of losing bodily strength and capability, and concern about how she now appears to others ("terribly crippled" or "just somebody walking with a crutch and not terribly crippled"), she asserts her desire to "just be who I am, doing what I do."

She does not define herself by her limitations, and wishes that others would do the same, because she knows what it means to be stigmatized. Goffman (1963:3) writes that a person who is different from others in an undesirable way is stigmatized, "reduced in our minds from a whole and usual person to a tainted, discounted one." Monika's difficulty in saying, "I can't do that" emerges out of a desire to see herself - and to be seen by others - for who she is and what she can do.

MS has imposed limits on Monika's ability to create her life. One of her greatest fears, she told me, is that she may someday lose the ability to work with her hands to create things, to do her paintings. She is unsure what she will do then; she has no answers for that future possibility. For now, though, she moves back and forth between the two poles of the dialectic of wholeness and disability, the dialectic which is grounded in what Becker (1973:26) describes as our "existential dualism" - being symbolic selves with life histories, and at the same time, finite material beings susceptible to disease, aging, and death. Because of the effects of MS upon her body, she must use a crutch, she can do

less, she is more fatigued. The disease forces her to recreate her life based on her current bodily abilities; body, self, and world are inseparable. Because MS - as life itself - is constantly changing, she, too must change with it, finding ways to live as whole and intact in an increasingly limiting body.

CHAPTER 5
CONCLUSION

Summarizing Discussion

Body, Self, World Relationships

Merleau-Ponty's theme, that lived experience unites body, self, and world, can be explored in studies which approach illness as lived, not merely as "a subjective accounting of an abstract 'objective' reality" (Toombs 1987:236). As Toombs asserts, attention to the experience of illness is essential because that experience constitutes the reality of the illness for the afflicted person. Lived experience of illness ought not to be seen as merely the "shadow" of the material brain (Straus 1966a). Illness can bring one to a greater understanding of the body's role in constituting self and world, and even to a reshaping of self and world.

In the case of Monika, MS has made her body less reliable in carrying out her plans and fulfilling her personal wishes. MS has taken away her ability to walk easily up a flight of stairs, to move tables and chairs around in a classroom, to go to a gathering without the fear of suddenly having to sit down due to weakness in her legs. She is less sure of her social self, more tentative, in her words, "more introverted." Because her body seems less under her control than it used to be, she fears the experience of being "out of control" in social situations and the embarrassment that might result.

Her world is now lived through the perspective of a more tentative body-self, one who must ask seriously of each situation, "Is this possible for me?"

For Carolyn, MS in her body "confirms" her sense of being "full of holes," a flawed survivor of a crazy life. MS threatens attributes she considers to have helped her survive - her "toughness" (she is now dependent on others), and her bodily strength. MS is another experience to survive ("just...living every day with it") - an unpredictable body in an unpredictable world.

Sandra's embodiment of MS contains elements of resistance to cultural assumptions about women, African-Americans, and the disabled. She has made a decision to define herself and to live as whole and intact, as someone worth knowing, someone worth seeing out in the world. Her refusal to write an "X" in lieu of her signature at the bank exemplifies body-self-world inseparability: Embodied memories of the history of her race in America inform her decision to not give in to a disease that would have her "goin' back in time," to when her ancestors couldn't read or write.

This study shows that symptoms are experienced in accordance with their meaning for the self in the world, such as in the case of Bob, for whom exhaustion after physical work signifies personal finitude and the end of control as he once understood it.

Limits of Medicine

Strong belief in the power of biomedicine pervades American culture, belief which is rooted in the Enlightenment ideal of continuing progress through science and medicine. Jonathan Miller writes, in The Body in Question, of a "great leap forward" in medicine's contribution to human welfare beginning in the middle of the twentieth century, which he attributes not only to "heroic procedures and the discovery of new drugs," but also to a "comprehensive and unprecedented understanding of what the healthy body is and how it survives and protects itself" (p. 9). Although Miller suggests a universality to biomedical understanding which has been seriously challenged (Armstrong 1983; Foucault 1975; Gordon 1988; Illich 1975; Scheper-Hughes and Lock 1987), and does not address the sociomoral and political forces which account for biomedicine's hold on Westerners, medicine's perceived successes do provide reinforcement for the Western belief in the potential of science and medicine to solve human problems. Where medicine fails, in cases of incurable illness, the afflicted confront the limits of medicine in their experience of illness. Realization of medicine's inability to cure becomes part of the existential struggle brought about by the illness. Faith in medicine may be shaken at the same time that one genuinely realizes the importance of the body in the constitution of self and world; when the body is threatened, so, too, are self and world as previously known.

Persons with MS find themselves up against the limitations of medicine beginning at the time of their diagnosis. Unlike the stroke patients studied by Kaufman (1988), who experience the most severe physical effects immediately after the event, MS patients are usually told that their illness may not get any better - in fact, it is more likely to progress than improve. Kaufman's stroke patients participated in short term rehabilitation after the event, with the goal of significant permanent improvement, whereas MS patients, if they receive therapy at all, must view it as an ongoing - perhaps lifelong - process, as is true of their illness. Physical therapy and exercises are sometimes recommended, as well as speech therapy, techniques for improving a hyperreflexive bladder, and other measures for specific problems (Scheinberg and Smith 1987). But, as many MS patients told me, something else can "go" at any time, so getting the diagnosis invites no battle to be waged for great improvement or cure. Rather, some degree of resignation about the limited possibilities for improvement or cure was expressed by each person with whom I spoke. In Carolyn's words:

Lots of people have lived with it and died with it. That is the truth. I must learn to accept that. I don't want to hope for the next drug. My feeling is, I've just got to do the best I can do every day.

Some of the participants did "hope for the next drug" and kept up with the latest research on MS. But their hope was

for the emergence of a treatment or cure for the future, not for help from any existing therapies. For now, there is nothing, they acknowledged. This is part of their lived reality of MS. Unlike patients with some types of cancer, they cannot fight their illness with surgery, drugs, or other therapy; they can only live it.

And so future possibilities of biomedical research seemed important to the participants of this study, but most of their hope involved their possibilities for living a full life given the current state of knowledge and treatment. Their hope was generally that their illness would not progress much further and, like Carolyn, they try to do the best they can do every day.

Several of the participants of this study expressed disappointment in the way in which their diagnosis was conveyed to them. Joseph remembers that his neurologist asked him, after all the tests were done, to guess what disease he had. Joseph concluded that it was difficult for this doctor to give him the diagnosis in a straightforward manner, that the telling might be eased if the patient were to guess, leaving the doctor with no real news to convey. Karen told of how her doctor simply read her the highly technical MRI report, ending with "probable diagnosis of multiple sclerosis." During the ensuing brief discussion, her doctor stated her opinion that sometimes it's better not to know that you have a "horrible disease." Karen interpreted the problem

as stemming from her doctor's discomfort in knowing and telling her the bad news. She wanted her physician to be direct, while also conveying an understanding of the significance of the diagnosis for her. If MS is a "horrible disease," she needs to learn how to live with it.

Physicians are trained to battle disease, and the inability to offer hope for a cure may leave some feeling that there is nothing else they can provide. This view is rooted in the failure of the biomedical (clinico-pathological) model to serve as a guide to the actual practice of medicine (Schwartz and Wiggins 1985). The case of Joseph suggests that a physician who neglects the lived experience of patients can actually do harm, leaving the patient feeling degraded, alienated, and terrified. Kirmayer (1988:83) argues for the need for physicians to give "consistent attention to the experience of illness and the sociomoral dimensions of sickness" lest the patient be reduced to merely physical findings. There will always be limits, of one kind or another, to medicine; as Comoroff (1986) has noted, medicine fails us because life fails us. Existential concerns stemming from chronic illness, disability and loss (of wholeness, control, certainty, the freedom to act, and the familiar world [Toombs 1987]) are essentially beyond the scope of medicine. But the diagnosis of an incurable illness like MS becomes a lived reality for the patient; the response should be "not just a flurry of technical activity, but...a human relatedness

that nurtures the seeds of contemplation and compassion" (Kirmayer 1988:84).

Limits to the Body's Predictability, Control, and Certainty

In a phenomenological study of the patient-physician relationship, Toombs (1987) describes what she calls the "eidetic" features of illness - essential characteristics of the lived experience of illness that remain unchanged throughout all possible illnesses. These characteristics include the perception of loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world. All of these features pertain to the experience of MS based on this study, but certain features stand out particularly strongly, and perhaps take a different form with MS than they might with other illnesses.

The loss of wholeness or taken-for-grantedness of the body in MS is perhaps best described as experiencing limits to bodily predictability. Many of the persons with MS in this study did not seem to experience their body as having lost wholeness or integrity - even the most disabled persons. Perhaps initially such loss was experienced by some, as in the case of Sandra, who closed herself off from others, feeling that she had nothing to offer as a Black disabled woman. And certainly Carolyn experiences herself as lacking wholeness ("I am full of holes"). But in talking with people about their experience of MS over many years, it becomes clear that losses

may come and go, losses may remain or "remit," losses may be mild or enormous. Individuals showed great variability in their sense of wholeness or intactness. Sandra eventually came to see, "I'm the same person as I was before. I'm just now disabled and have to use a wheelchair." Her experience is in this sense similar to that of Diane, the woman with a congenital limb deficiency studied by Gelya Frank (1986). Diane experiences herself as intact despite her lack of limbs. Rather than defining herself by her limitations, she emphasizes her assets, identifying with the Venus de Milo. The loss of wholeness is perhaps better understood as a "dialectical problem," as Frank describes as holding true for Diane and others, and as Gadow (1982:87) argues in her analysis of the "body-self dialectic," in which "the truth is in the whole."

The unpredictability of the body stands out for MS patients - the not knowing how the body will feel or move tomorrow, whether or not one may have that "pull the plug" feeling of MS fatigue. It is difficult to imagine getting used to the body's unpredictability such that the fluctuating body becomes familiar rather than strange. Odd sensations and reduced mobility make the body seem at times other-than-me. The body becomes something with which to cope anew each day or each week, less often in the background of being as before the onset of MS.

Another prominent aspect of the experience of MS is a

reduced sense of control. The case studies reveal that MS took away the body-self's ability to move through the world easily, to feel in control of one's life. There is no one to blame for MS, as one woman told me. MS just happens, and one is left with a body attacking itself out of control. Scheper-Hughes and Lock (1987:29) write that "illness, injury, disability, and death...deconstruct the world of the patient by virtue of their seeming randomness, arbitrariness, and hence their absurdity." Medicine can explain the "what" of MS (demyelination), but unlike many other diseases, the "how" remains a mystery (viral? autoimmune? genetic?), and the "why" is, as always, even more elusive (why me? why now?).

Many patients tried to regain a sense of control in several ways - lowfat diets, exercise, limiting stress and exertion, reducing exposure to heat. Bob tries to use his mind to "beat back" his headaches. Karen tries to plan her days very carefully, but sometimes needs to keep a "certain minimum amount of coffee" in her body to get through a day, or to come home and fall into bed to sleep for awhile, then stay in bed and finish her day's work.

It seems, however, that one's sense of control ought to be understood more broadly than just "doing" things to maintain it. What does control ultimately give us? The ability and freedom to act, to be sure, but also the ability to be - to define oneself according to one's abilities and strengths, to feel that one's attributes can move one forward

in life toward goals and dreams, toward others in the world. For Monika to still see herself as a dancer though she is no longer able to dance is a certain taking control of who she is, or as she might put it, a creating of her life. Doing exercises will not make her a dancer, but her sense of herself and her orientation to the world can keep her "dancing." Anatole Broyard (1990a), the literary critic who died of prostate cancer, wrote:

I saw on television an Afro-Cuban band play in the streets of Spanish Harlem. It was a very good band and before long a man stepped out of the crowd and began dancing. He was very good too, even though he had only one leg and was dancing on crutches. He danced on those crutches as other people dance on ice skates and I think there's probably a "dance" for every condition. As Kenneth Burke, one of our best literary critics said, the symbolic act is the dancing of an attitude.

MS sets up limits and opens up possibilities regarding one's sense of control in the world. Illness is also a reminder of bodily impermanence and personal finitude, and MS is no exception. "[T]he uncertainties of the disease are probably the thing that's hardest on me," said Bob. I have discussed the uncertainty about the body's mobility and sensations, and the uncertainty of one's ability to control and plan one's life. But perhaps the most unsettling uncertainty is that of the body-self's continuity in the world. One of Joseph's exacerbations reminded him of how "fragile" he is, and that he better do things that are important to him now. Toombs (1987:230-31) writes:

In the experience of illness the individual is

forced to surrender his most cherished assumption, that of his personal indestructability. And if this most deeply held assumption is no more than an illusion, what else in his hitherto taken-for-granted existence can remain inviolable?...Once shattered, the illusion of personal indestructibility can only be tenuously re-established.

Many in this study expressed relief that MS is not considered a fatal disease. One woman who had recently lost a friend close to her age to cancer told me that this experience "turned her to gratefulness rather than loss" about her own illness. Many participants also expressed gratefulness in not having a worse case of MS than they had. Each seemed to at least know of someone who had the worst possible case - bedridden, completely paralyzed, blind, etc. But the body's attack upon its own myelin does bring to awareness a sense of fragility. One may not believe MS will get one in the end, but one knows that something will; MS reminds them of the body's vulnerability and impermanence. As Karen put it:

And so no matter how you cut it, the next however many years I have are gonna be of slow losses, and that's what everybody needs to deal with, too. And I may have more to deal with, but it is not a pattern that goes against the grain of humanity [laughing], you know what I mean?...And I think in a way it's a gift to see that more up close...I feel like it's now to be done, because I could have a year at it, I could have twenty years, I do not know. But I better make the time count - at everything.

The Evolving Dialectical Problem

Many of the participants of this study exemplified a

struggle similar to Monika's, between wholeness and disability, capabilities and limits, alternately expressing hope and fear about what the disease might or might not do next. One man drew MS as a cat in a piano, explaining, "you never know where it's going to strike." Because of its tendency to progress, the notion of "adjustment" to MS, as some studies attempt to measure (Brooks and Matson 1982; Matson and Brooks 1977), seems a highly inadequate concept. How does one "adjust" to an illness whose very definition contains its uncertain future - "progressive," with "exacerbations" and "remissions." How far will it progress? How severe will be the exacerbations, how complete the remissions? Somehow a more fluid understanding of coping and healing is needed, one that acknowledges that "adjustment" is happening on some level every day, in every moment, and that healing, too - the recreation of one's life, or in Scarry's (1985) terms, the "making of the world" - is possible in chronic illness.

Epilogue

In a novel by Joy Williams called State of Grace, a character asks, "What can be beyond love? I want to get there." The sick man has got there: he's at a point where what he wants from most people is not love but a spacious, flaring grasp of his situation...

Anatole Broyard
"Doctor Talk to Me"

As a first year medical student consumed by gross anatomy, I once scribbled down a poem late in the night while studying the structures that make up the neck. In it, I tried to convey something about the emptiness of sitting in the library long after darkness had fallen, memorizing such things as the arterial supply to the thyroid gland. The next day, I gave the poem to my classmates. Before our next anatomy lecture, as we sat waiting in our seats, one of my classmates told me he had liked the poem, but didn't I think that anatomy was important?...because he certainly did. "No, no, no!" I wanted to shout, "You have missed the point!"

I don't believe I will ever know just what The Point was - of writing the poem, of handing it out, of seeing who responded and in what way. Did I want to make a connection with my new classmates that was deeper than the flesh we cut through in anatomy lab? Did I want to say something important? Was I simply momentarily bored?

Charles Simic writes, in his introduction to The Best American Poetry: 1992:

All the arts are about the impossible human predicament...Every poem is an act of desperation, or if you prefer, a throw of the dice...The world is huge, the poet is alone, and the poem is just a bit of language, a few scratchings of a pen surrounded by the silence of the night...

Van Manen (1990:13) notes that phenomenological research is "poetizing" in that there is no bottom line. The conclusion is essentially woven throughout the text. Far from poetry though it may be, this study is my "throw of the dice" in medical and graduate school, my attempt to get closer to a "spacious, flaring grasp," in Broyard's words, of the human predicament, of what it is to struggle and to suffer and to keep finding possibility in the midst of it all.

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APPENDIX

History and Anticipatory Coping Interview

1. I would like to know about your experience with MS over the course of your life. Tell me about your earliest episodes.

-How old were you?

-What were the circumstances of your life then?

-How did people explain what was happening to your body?

-What do you remember thinking, feeling?

-Tell me about when your MS was diagnosed. What were you told about MS?

-What were you told to do to take care of yourself?

-Does anyone in your family have MS?

-Family history of MS.

2. How would you describe your experience with MS since then? (changes in frequency of episodes, intensity, things that seem to trigger it, etc.)

3. What do you think is the cause of your MS?

4. How did you come to view it this way?

Probe: What were you told by family, doctors, etc.

5. How do you think this influences how you deal with MS now?

6. Are there any particular episodes of MS that really stick out in your mind? Describe them. What were you feeling, thinking, anything in particular? What did you learn most about how to manage your MS from those episodes?

7. What influence do you think MS has had on making you the kind of person you are? (Can draw info. from the first answer to help the person understand the question if there is difficulty)

8. Have there been any pivotal points, perhaps turning points in your understanding of your MS and in the way you approach your management of your MS over the years? Can you describe these for me? (Clarify the links between the experience, the understanding, and the changes in approach to self care).

9. Clarify from the above question:

-Have there been any changes in the way you deal with your MS as time has passed?

-If yes, what has changed?

Probe: In general, specifically.

10. If no, do these same things you do work as well now as in the past? Probe: For differences and consistencies.
11. What things do you do to keep yourself well?
12. What might make you overextend your limits?
13. How do you make these decisions?
14. What are the signs that your MS exacerbation is over? Probe: How do you know that you are better?
15. When you are having an exacerbation of MS, are people likely to be a help or a hindrance? Please explain.
16. How easy or difficult is it for you to ask for help when you are ill?
17. Who is likely to be most helpful to you? The least helpful?
18. How would you characterize the demands in your life right now? Have you experienced a lot of changes in the past six months?

Coping Interview

The purpose of this interview is to get a detailed description of your most recent exacerbation of MS. I am interested in how you felt, what was going on at the time of the episode, what you did about it, and what made it better.

1. Would you please give me a detailed account of your most recent exacerbation of MS? (Allow participant to tell the story without interrupting, then follow up with the following probes).
2. At the beginning of the episode, how were you feeling?
3. What were you doing at the time when you noticed a worsening of your MS?
4. What was your most immediate reaction to your sense that you were having an exacerbation of your MS?
5. Did the exacerbation create problems for you other than the discomfort of the episode? (e.g. interrupted plans; missed appointment; difficulties in getting treatment)
6. How did you feel during the worst of the episode? (Get a description of emotions and physical sensations, fatigue, fear, calmness, etc.)

7. Now let's go over all the things you did in response to the exacerbation from beginning to end of the worst of it. (Prompt participant to fill out the original description more fully, attempting to get the time sequence of actions, physical responses, and feelings)
8. How did you feel when the episode was over? (Again, get a description of emotions and physical sensations; e.g. relieved, aggravated, calm, etc.)
9. Looking back on it now, would you have done anything differently?
10. Who would you say, if anyone, helped you the most during this episode?
11. What would you say was the most helpful thing that you did to make yourself feel better or improve your condition during the episode?
12. How long did this episode last from beginning to end?
13. Was there anything unusual about this exacerbation? How was it similar or different from your usual experience?
14. What do you think led up to this episode? (Clarify and get the participant's understanding of what caused the exacerbation).
15. Do you think there is any way that you could have prevented this episode?
16. Did you learn anything new about the management of your MS with this episode?