THE ILLNESS NARRATIVES

Suffering, Healing, and the Human Condition

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Preface

During the early 1960s, in my second and third years at medical school, I encountered several patients whose powerful experiences of illness, at either pole of the course of life, fixed my interest on the intimate and manifold ways by which illness comes to affect our lives.

The first patient was a pathetic seven-year-old girl who had been badly burned over most of her body. She had to undergo a daily ordeal of a whirlpool bath during which the burnt flesh was tweezered away from her raw, open wounds. This experience was horribly painful to her. She screamed and moaned and begged the medical team, whose efforts she stubbornly fought off, not to hurt her anymore. My job as a neophyte clinical student was to hold her uninjured hand, as much to reassure and calm her as to enable the surgical resident to quickly pull away the dead, infected tissue in the pool of swirling water, which rapidly turned pinkish, then bloody red. Clumsily, with a beginner's uncertainty of how to proceed, I tried to distract this little patient from her traumatic daily confrontation with terrible pain. I tried talking to her about her home, her family, her school—almost anything that might draw her vigilant attention away from her suffering. I could barely tolerate the daily horror: her screams, dead tissue floating in the blood-stained water, the peeling flesh, the oozing wounds, the battles over cleaning and bandaging. Then one day, I made contact. At wit's end, angered at my own ignorance and impotence, uncertain what to do besides clutching the small hand, and in despair over her unrelenting anguish, I found myself asking her to tell me how she tolerated it, what the feeling was like of being so badly burned and having to experience the awful surgical ritual, day after day after day. She stopped, quite surprised, and looked at me from a face so disfigured it was difficult to read the expression; then, in terms direct and simple, she told me. While she spoke, she grasped my hand harder and neither screamed nor fought off the surgeon or the nurse. Each day from then on, her trust established, she tried to give me a feeling of what she was experiencing. By the time my training took me off this rehabilitation unit, the little burned patient seemed noticeably better able to tolerate the debridement. But whatever effect I had had on her, her effect on me was greater. She taught me a grand lesson in patient care: that it is possible to talk with patients, even those who are most distressed, about the actual experience of illness, and that witnessing and helping to order that experience can be of therapeutic value.

The other memorable patient from my medical school days was an elderly woman who suffered chronic cardiovascular effects of the syphilis she had acquired from a serviceman in World War I. I saw her as an outpatient. Through months of conversations she gave me a poignant sense of what it was like to bear the stigma of syphilis; she showed me how it affected her relations with her family and the men she met, leaving her shunned and isolated. Each week she would detail for me the tragic personal experiences that had resulted from her diagnosis years before. Over time I realized that there were two sets of long-term problems: the insidious medical complications of the course of her chronic syphilis and the life trajectory that her illness had marked and inexorably shaped. I recognized, furthermore, that my medical training systematically educated me about the former but tended to discount and in certain ways even blind me to the latter. This patient, like her much younger counterpart, edified me about the difference between the patient's experience of illness and the doctor's attention to disease—a key distinction I will develop in the course of this book.

Over the past two decades, my interest in how chronic illness is lived and responded to by real people has led me to conduct clinical and ethnographic studies of the experience of illness among patients in China and North America. These studies have been published in technical articles and in books written for an audience of academic specialists. My clinical work, again centered on the psychological and social aspects of chronic medical illness, also has been described for a fairly narrow professional readership. My aim in this book is altogether different. I write here to explain to patients, their families, and their practitioners what I have learned from a career passionately devoted to this interest. I write because I wish to popularize a technical literature that would be of great practical value for those who must live with, make sense of, and care for chronic illness. Indeed, I will argue that the study of the experience of illness has something fundamental to teach each of us about the human condition, with its universal suffering and death.

Nothing so concentrates experience and clarifies the central conditions of living as serious illness. The study of the process by which meaning is created in illness brings us into the everyday reality of individuals like ourselves, who must deal with the exigent life circumstances created by suffering, disability, difficult loss, and the threat of death. Yes, chronic illness teaches us about death; the process of mourning for losses is as central to growing old as it is to healing. Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition.

We can envision in chronic illness and its therapy a symbolic bridge that connects body, self, and society. This network interconnects physiological processes, meanings, and relationships so that our social world is linked recursively to our inner experience. Here we are privileged to discover powers within and between us that can either amplify suffering and disability or dampen symptoms and therefore contribute to care.

This book is written as well for my fellow practitioners, colleagues in the care of the chronically ill. It is clinically useful to learn how to interpret the patient's and family's perspective on illness. Indeed, the interpretation of narratives of illness experience, I will argue, is a core task in the work of doctoring, although the skill has atrophied in biomedical training. That message is the same theme I wish to bring before laymen: illness has meaning; and to understand how it obtains meaning is to understand something fundamental about illness, about care, and perhaps about life generally. Moreover, an interpretation of illness is something that patients, families, and practitioners need to undertake together. For there is a dialectic at the heart of healing that brings the care giver into the uncertain, fearful world of pain and disability and that reciprocally introduces patient and family into the equally uncertain world of therapeutic actions. That dialectic both enhances the therapy and makes of it and the illness a rare opportunity for moral education. One unintended outcome of the modern transformation of the medical care system is that it does just about everything to drive the practitioner's attention away from the experience of illness. The system thereby contributes importantly to the alienation of the chronically ill from their professional care givers and, paradoxically, to the relinquishment by the practitioner of that aspect of the healer's art that is most ancient, most powerful, and most existentially rewarding.

The organization of this book aims to further the purposes outlined in the preceding paragraphs. Two introductory chapters set out an analytical grid to assess the meanings of illness. The next eleven chapters provide detailed accounts of particular illness experiences of chronically ill patients whom I have either studied in clinical research or treated. Each chapter highlights a different aspect of illness meanings. The last three chapters switch the interpretive emphasis from patients and families to healers. They are intended as a guide for caring for the chronically ill and as a program for altering the education of medical students and postgraduate trainees so as to improve such care. While there is much to admire and recommend in current medical practice, the care of chronic illness is not one of the great success stories of contemporary medicine. The provocative title of the final chapter is intended to suggest that when we take as our starting point the meanings of illness experiences, then our very understanding of medicine is challenged.

A note on the use of quotations from interviews with patients and physicians is in order. In chapters 3 through 14, I make extensive use of such quotations. Approximately half of these statements are

direct transcriptions of audio tapes that I used to record clinical and research interviews. The other half were written down, in my own system of speed writing, during the interviews. My written notes do not capture pauses, changes in voice pitch and tone, or "ah," "well," and other speech sounds. They also do not show when one voice interrupts another. Because my chief concern is the ease of reading the transcripts, I have for the most part removed intrusive elements of speech from the transcriptions of audio tapes as well, except where they seemed important to the person's meaning. This book is written for a broad audience, not a small group of experts. The speech quoted in this book, then, has been altered—perhaps tightened and simplified is more exact—but in only this and one other way. To protect the anonymity of patients and practitioners, I have removed or changed certain information that might identify them. When I have made such changes, I have drawn on information from patients with similar problems to make the alteration valid in the light of the experiences of the patient group as a whole.

—Arthur Kleinman, M.D.
Cambridge, Massachusetts
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Information contained in this book accurately conveys the spirit of my work as a physician and researcher, but all names, characteristics, and identifying details in the case histories have been changed.

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The Meaning of Symptoms and Disorders

> Whatever is real has a meaning.
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> —Michael Oakeshott
> ([1933] 1978, 58)

> For many Americans the meaning of disease is the mechanism that defines it; even in cancer the meaning is often that we do not yet know the mechanism. To some, however, the meaning of cancer may transcend the mechanism and the ultimate ability of medicine to understand it. For such individuals the meaning of cancer may lie in the evils of capitalism, of unhindered technical progress, or perhaps in failures of individual will. We live in a complex and fragmented world and create a variety of frameworks for our several ailments. But two key elements remain fundamental: one is faith in medicine's existing or potential insights, another, personal accountability.
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> —Charles E. Rosenberg
> (1986, 34)

Illness and Disease

When I use the word *illness* in this book, I shall mean something fundamentally different from what I mean when I write *disease.* By invoking the term illness, I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability.* Illness

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*In this volume I use the terms *sick person* and *patient* interchangeably. But in fact the former conveys a more accurate sense of my point of view than the latter. Individuals who are is the lived experience of monitoring bodily processes such as respiratory wheezes, abdominal cramps, stuffed sinuses, or painful joints. Illness involves the appraisal of those processes as expectable, serious, or requiring treatment. The illness experience includes categorizing and explaining, in common-sense ways accessible to all lay persons in the social group, the forms of distress caused by those pathophysiological processes. And when we speak of illness, we must include the patient's judgments about how best to cope with the distress and with the practical problems in daily living it creates. Illness behavior consists of initiating treatment (for example, changing diet and activities, eating special foods, resting, engaging in exercise, taking over-the-counter medication or on-hand prescription drugs) and deciding when to seek care from professionals or alternative practitioners.

Illness problems are the principal difficulties that symptoms and disability create in our lives. For example, we may be unable to walk up our stairs to our bedroom. Or we may experience distracting low back pain while we sit at work. Headaches may make it impossible to focus on homework assignments or housework, leading to failure and frustration. Or there may be impotence that leads to divorce. We may feel great anger because no one can see our pain and therefore objectively determine that our disability is real. As a result, we sense that our complaints are not believed, and we experience frustrating pressure to prove we are in constant pain. We may become demoralized and lose our hope of getting better, or we may be depressed by our fear of death or of becoming an invalid. We grieve over lost health, altered body image, and dangerously declining self-esteem. Or we feel shame because of disfigurement. All these are illness problems.

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chronically ill spend much more time in the roles of sick family member, sick worker, sick self than in the role of patient, which is so redolent with the sights and smells of the clinic and which leaves an afterimage of a compliant, passive object of medical care. I wish to place stress on the sick person as the subject, the active agent of care, since in fact most treatment in chronic illness is self-treatment and most decisions are made by the sick person and family, not by health care professionals. *Sick person* also sounds more appropriate for the model of care I will advance. Care for chronic illness is (or should be) more like a negotiation among therapeutic allies than actions the physician takes on behalf of a patient. The patient and the practitioner bear reciprocal responsibilities, a point I will develop in chapter 15, where I describe a model of care. In spite of these good reasons, it sounds excessively artificial to avoid the term *patient*; hence I use the two terms interchangeably with the same meaning: more person, less patient.

Local cultural orientations (the patterned ways that we have learned to think about and act in our life worlds and that replicate the social structure of those worlds) organize our conventional common sense about how to understand and treat illness; thus we can say of illness experience that it is always culturally shaped. Paradoxical as it sounds, then, there are normal ways of being ill (ways that our society regards as appropriate) as well as anomalous ways. But conventional expectations about illness are altered through negotiations in different social situations and in particular webs of relationships. Expectations about how to behave when ill also differ owing to our unique individual biographies. So we can also say of illness experience that it is always distinctive.

Illness complaints are what patients and their families bring to the practitioner. Indeed, locally shared illness idioms create a common ground for patient and practitioner to understand each other in their initial encounter. For the practitioner, too, has been socialized into a particular collective experience of illness. Disease, however, is what the practitioner creates in the recasting of illness in terms of theories of disorder. Disease is what practitioners have been trained to see through the theoretical lenses of their particular form of practice. That is to say, the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems. The patient may suffer pain that interferes with work and may lead to unemployment; self-absorption in a strict diet and severe gastrointestinal discomfort may intensify the stresses of school; or the fear of dying brought on by a heart attack may lead to social withdrawal and even divorce. Yet, in other cases, the physician diagnoses and treats elevated blood sugar that requires increased insulin, pain of uncertain origin that calls for diagnostic testing, or major depressive disorder that needs treatment with antidepressants. The healer—whether a neurosurgeon or a family doctor, a chiropractor or the latest breed of psychotherapist—interprets the health problem within a particular nomenclature and taxonomy, a disease nosology, that creates a new diagnostic entity, an "it"—the disease.

Disease is the problem from the practitioner's perspective. In the narrow biological terms of the biomedical model, this means that disease is reconfigured *only* as an alteration in biological structure or functioning. When chest pain can be reduced to a treatable acute lobar pneumonia, this biological reductionism is an enormous success. When chest pain is reduced to chronic coronary artery disease for which calcium blockers and nitroglycerine are prescribed, while the patient's fear, the family's frustration, the job conflict, the sexual impotence, and the financial crisis go undiagnosed and unaddressed, it is a failure. In the broader biopsychosocial model now making headway in primary care, disease is construed as the embodiment of the symbolic network linking body, self, and society (see Engel 1977). In the biomedical model the disease is an occluded coronary artery; in the biopsychosocial model it is a dynamic dialectic between cardiovascular processes (hypertension or coronary artery insufficiency), psychological states (panic or demoralization), and environmental situations (a midlife crisis, a failing marriage, the death of a parent from the same disorder). In the practitioner's act of recasting illness as disease, something essential to the experience of chronic illness is lost; it is not legitimated as a subject for clinical concern, nor does it receive an intervention. Treatment assessed solely through the rhetoric of improvement in disease processes may confound the patient's (and family's) assessments of care in the rhetoric of illness problems. Hence, at the heart of clinical care for the chronically ill—those who cannot be cured but must continue to live with illness—there is a potential (and, in many cases, actual) source of conflict.

To complete the picture, I shall introduce a third term, *sickness,* and define it as the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces. Thus, when we talk of the relationship of tuberculosis to poverty and malnutrition that places certain populations at higher risk for the disorder, we are invoking tuberculosis as sickness; similarly, when we discuss the contribution of the tobacco industry and their political supporters to the epidemiological burden of lung cancer in North America, we are describing the sickness cancer. Not just researchers but patients, families, and healers, too, may extrapolate from illness to sickness, adding another wrinkle to the experience of disorder, seeing it as a reflection of political oppression, economic deprivation, and other social sources of human misery.

Illnesses obviously vary in outcome. Some are brief, minimally disruptive of our life activities. Some are more distressing; they take longer to run their course. And the ones we are concerned with in this book never entirely disappear. Moreover, these chronic illnesses also vary greatly. Some lead to such devastating loss of functioning that the patient is almost totally disabled. Some, while less disabling, may yet eventually exhaust the family's resources and require institutionalization. And others ultimately terminate the patient's life. Imagine, as examples, the adolescent quadriplegic whose very life requires assisted respiration and round-the-clock help with all routine bodily functions and daily activities; or the business executive whose asthma is known only to his wife and children, who greatly, though secretly, limits his recreational, parental, and conjugal activities; or the young woman demoralized by the disfiguring radical surgery that removed her sense of self-esteem along with breast cancer and by the numbing realization that the signs of metastasis are omens of her own demise. For the first case, the illness problems arise from the total, inescapable life situation organized around the constant threat to vital functions and the necessity for continuous treatment; for the second, they stem from inability to deal with the feeling of vulnerability and loss of control as well as from the futile attempt to maintain two separate worlds—one free of sickness (work), the other where sickness is legitimized (home); whereas for the third, they center on the meaning of disfigurement and the menace of untimely death.

Chronic illnesses tend to oscillate between periods of exacerbation, when symptoms worsen, to periods of quiescence, when disability is less disruptive. By now a very substantial body of findings indicates that psychological and social factors are often the determinants of the swing toward amplification. The former include disabling anxiety, giving up. The latter are deeply threatening life event changes, impaired social support, and oppressive relationships that contribute to a vicious cycle undermining psychophysiological homeostasis (Katon et al. 1982; Kleinman 1986). Alternatively, the swing toward damping (a kind of internal health-promoting system that has received less research attention) frequently seems to be associated with strengthened social supports, enhanced sense of self-efficacy, and rekindled aspiration.

Periods of alleviation also reveal attendant diminution in anxiety and depression. There are rising feelings of mastery, often due to acceptance of a paradigm of care that substitutes a pragmatic notion of illness maintenance and disability reduction for the myth of cure.

Of course, swings from amplification to damping, and vice versa, need not reflect psychosocial influence: often biological change is responsible. As a result, there is uncertainty over the reason for exacerbation or remission, which, regretably, encourages a corresponding tendency to dismiss even the obvious social-psychological push of the swing. The upshot is conjoint (practitioner/patient, family) denial that chronic disorder is so influenced—a fateful complicity that in my experience correlates with pessimism and passivity. Not surprisingly, the effect is to worsen outcome.

The Meanings of Illness

Illness has meaning, as the cases I have mentioned suggest, in several distinctive senses. Each type of meaning is worth examining. From an anthropological perspective and also a clinical one, illness is polysemic or multivocal; illness experiences and events usually radiate (or conceal) more than one meaning. Some meanings remain more potential than actual. Others become effective only over the long course of a chronic disorder. Yet others change as changes occur in situations and relations. As in so many areas of life, their very ambiguity often supplies illness meanings with relevance, inasmuch as they can be applied now this way, now that way to the problem at hand. Chronic illness is more than the sum of the many particular events that occur in an illness career; it is a reciprocal relationship between particular instance and chronic course. The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history. Continuities as well as transformations, then, lead to the appreciation of the meanings of illness.

The appreciation of meanings is bound within a relationship: it belongs to the sick person's spouse, child, friend, or care giver, or

to the patient himself. For this reason it is usually as much hedged in with ambiguities as are those relationships themselves. But in the long, oscillating course of chronic disorder, the sick, their relatives, and those who treat them become aware that the meanings communicated by illness can amplify or dampen symptoms, exaggerate or lessen disability, impede or facilitate treatment. For reasons I will review later, however, these understandings often remain unexamined, silent emblems of a covert reality that is usually dealt with either indirectly or not at all. Powerful emotions attach to these meanings, as do powerful interests.

Social reality is so organized that we do not routinely inquire into the meanings of illness any more than we regularly analyze the structure of our social world. Indeed, the everyday priority structure of medical training and of health care delivery, with its radically materialist pursuit of the biological mechanism of disease, precludes such inquiry. It turns the gaze of the clinician, along with the attention of patients and families, away from decoding the salient meanings of illness for them, which interferes with recognition of disturbing but potentially treatable problems in their life world. The biomedical system replaces this allegedly "soft," therefore devalued, psychosocial concern with meanings with the scientifically "hard," therefore overvalued, technical quest for the control of symptoms. This pernicious value transformation is a serious failing of modern medicine: it disables the healer and disempowers the chronically ill (see chapter 16). Biomedicine must be indicted of this failure in order to provoke serious interest in reform, because a powerful therapeutic alternative is at hand.

There is evidence to indicate that through examining the particular significances of a person's illness it is possible to break the vicious cycles that amplify distress. The interpretation of illness meanings can also contribute to the provision of more effective care. Through those interpretations the frustrating consequences of disability can be reduced. This key clinical task may even liberate sufferers and practitioners from the oppressive iron cage imposed by a too intensely morbid preoccupation with painful bodily processes and a too technically narrow and therefore dehumanizing vision of treatment, respectively. In chapter 15, I will set out a practical clinical method that practitioners can (and should) apply to provide more effective and humane care of chronically sick persons. This alternative therapeutic approach originates in the reconceptualization of medical care as (1) empathic witnessing of the existential experience of suffering and (2) practical coping with the major psychosocial crises that constitute the menacing chronicity of that experience. The work of the practitioner includes the sensitive solicitation of the patient's and the family's stories of the illness, the assembling of a mini-ethnography of the changing contexts of chronicity, informed negotiation with alternative lay perspectives on care, and what amounts to a brief medical psychotherapy for the multiple, ongoing threats and losses that make chronic illness so profoundly disruptive.

Not the least of the reasons for studying illness meanings, therefore, is that such an investigation can help the patient, the family, and also the practitioner: certainly not every time, perhaps not even routinely, but often enough to make a significant difference.

Symptom as Meaning

The first kind of illness meaning that we shall consider, appropriately enough, is the surface denotation of symptom qua symptom. This is the ostensive, conventional signification of the symptom (for example, back pain, palpitations, or wheezing) as disability or distress. There is a tendency to regard such self-evident significance as "natural." But what is natural depends on shared understandings in particular cultures and not infrequently diverges among different social groups. The meanings of symptoms are standardized "truths" in a local cultural system, inasmuch as the groups' categories are projected onto the world, then called natural because they are found there. That is to say, we take for granted local forms of commonsense knowledge—a lump in the breast could be cancer, when overheated be cautious of drinking something very cold, suntanned skin is a sign of health, to be thin is better than to be fat, a firm stool once a day is normal—and these contribute to our shared appreciation of what sickness is and what is meant when a person expresses

the sickness experience through established patterns of gestures, facial expressions, and sounds or words.

As a result, when we talk of pain, for example, we are understood by those around us. Yet even surface significances can be fairly subtle. In each culture and historical period there are different ways to talk about, say, headaches. And these differences make a difference in the way the members of the sick person's circle respond to him or her. Think of the many ways to complain of headache in North American society: "My head hurts," "My head really hurts," "My head is pounding," "I'm having a migraine," "It's only a tension headache," "I feel a fullness and heavy feeling in my temples," "It feels like a ring of pain is constricting my forehead," "My sinuses ache," "My scalp is tingling," "When I move my head I feel dizzy, as if a veil were passing before my eyes." Each expression shades and colors the bald term "headache." In the lifetime course of chronic headaches, key words take on special significance to the sufferer and family that no eavesdropper could interpret. We differ as individuals in how effective we are in the use of these conventional illness idioms and special terms. Some are more skillful in the rhetorical deployment of these potentially powerful words to influence the behavior of others in the desire to receive support, to keep others at a distance, to obtain time alone, to convey anger, to conceal shame, and so forth.

Implicit in the first-level meaning of symptoms are accepted forms of knowledge about the body, the self, and their relationship to each other and to the more intimate aspects of our life worlds. For members of Western societies the body is a discrete entity, a thing, an "it," machinelike and objective, separate from thought and emotion. For members of many non-Western societies, the body is an open system linking social relations to the self, a vital balance between interrelated elements in a holistic cosmos. Emotion and cognition are integrated into bodily processes. The body-self is not a secularized private domain of the individual person but an organic part of a sacred, sociocentric world, a communication system involving exchanges with others (including the divine).

For example, among traditionally oriented Chinese, the body is regarded as a microcosm in symbolic resonance with the social and even planetary macrocosm (Porkert 1974). The body's *qi* (vital energy) is thought to be in harmony with that flowing in the environment. *Yin/yang* constituents of the body-self are in complementary opposition and also are in interaction with *yin/yang* constituents of the group and nature. Emotion correlates intimately with bodily constituents, which in turn correlate closely with the weather, the time, the physical setting, and the sociopolitical order. Conceptions of illness are based on this integrated, dialectical vision.

In India the body-self is held to be permeable to substances and symbols in social interactions (Daniel 1984). Health is a balance among the body's humors and the constituents of the outer world, mediated by diet and a hierarchy of social relations tightly organized around a systematic categorization of the world in terms of purity and pollution. A child is polluted by the touch of a menstruating mother because menstrual blood can enter the porous body (Shweder 1985), just as food received from someone in a lower caste gets incorporated into the body and pollutes it from within. The body is also permeable to supernatural and mystical forces.

Among the Navaho, the body is in perfect aesthetic and moral harmony with the physical landscape of the Navaho world (Sandner 1979; Witherspoon 1975). Body symbolizes landscape, and landscape body. A similar idea is found among the Chinese (Unschuld 1985) and many other societies. In these cultures bodily complaints are also moral problems: they are icons of disharmonies in social relationships and in the cultural ethos. Reading the Hippocratic medical texts suggests that, although some of the conceptions are quite different, a similarly integrative, dialectical view of body, self, and world was found in ancient Western society.

Meaning of a social kind is stamped into bodily processes and experiences, sometimes literally so, as, for example, when ritual circumcision and other forms of mutilation (subincision, tatooing, clitoridectomy, amputation of finger joints, scarification) mark life transitions and group and personal identity. Among Australian aboriginals a person's totem is embroidered into the skin through ritual scarification; the person receives a skin name that identifies his social group and personal status (Warner 1958; Munn 1973). Social experience is embodied in the way we feel and experience our bodily states and appear to others (Turner 1985). The tightly corseted female body in an earlier era in Europe constituted as much as expressed a particular vision of women and their role in society. The association in many societies of femaleness with the left side of the body—which also frequently symbolizes pollution, darkness, dampness, sinister motives, and a host of other negative oppositions to the male (right) side of the body—informs bodily experience as much as social categories with the moral meaning of gender (Needham 1973). The great concern in North American culture with unblemished skin surface, deodorized, youthful bodies, sexualized body shapes and gestures is part of a diffused capitalist system of commercialized symbolic meanings, which, like all cultural systems, orients the person to body and self experiences and to the priorities and expectations of the group. Indeed, through these embodied values social control is internalized and political ideology materializes as corporeal feelings and physiological needs. To understand how symptoms and illnesses have meaning, therefore, we first must understand normative conceptions of the body in relation to the self and world. These integral aspects of local social systems inform how we feel, how we perceive mundane bodily processes, and how we interpret those feelings and processes.

We do not discover our bodies and inner worlds *de novo.* All humans learn methods to monitor bodily processes and rhetorical idioms (verbal and nonverbal) to communicate bodily states, including states of illness. There are distinctive styles of eating, washing, laughing, crying, and performing routine bodily functions (spitting, coughing, urinating, defecating, menstruating, and so forth). And these styles of normal activities influence illness idioms (Nichter 1982). We learn how to identify and react to pain, how to label and communicate dysfunction. The idioms we learn are often the same channels used to communicate troubles of any kind. Chest discomfort may signal anxiety or angina, pneumonia or bereavement. Tension headaches may express a number of states: from exhaustion, chronic inflammation of the cervical spine, or the distress of an acute upper respiratory infection or of worsening diabetes to the misery that results from job loss, an oppressive work situation, or a systematically demoralizing marital relationship. Not infrequently, a bodily idiom will express several of these forms of distress simultaneously. Where a physiological stress reaction or a chronic medical disease provide the particular biological substrate, there is a specific channel of established complaints (including weakness, shortness of breath, chest discomfort, and abdominal pain) that can be amplified to express distress of various kinds. Hence, at the very core of complaints is a tight integration between physiological, psychological, and social meanings (Kleinman 1986).

Illness idioms crystallize out of the dynamic dialectic between bodily processes and cultural categories, between experience and meaning. Among New Guinea natives in the Sepik region, illness is indicated by the sick person's dramatic withdrawal (Lewis 1975). He shows the intensity of the felt experience by covering the body with ashes and dirt, refusing food, and remaining isolated. In some cultures illness idioms may be more gregarious and mundane, and in others they may be embodied as stoical silence. In some communities in India, for example, illness is expressed in the special tropes of that society's core hierarchical relationship between purity and pollution, which determines to whom one shows symptoms and from whom one accepts food and medicine. For the traditional Brahmin mother who is menstruating, the fear of polluting her son, even when he is ill, may prevent her from touching him and cause her to warn him not to come too near (Shweder 1985). In India as well as many other societies, illness behavior and care are demonstrated in the pattern of food sharing and diet (Nichter 1982). Diet is adjusted to right putative humoral imbalances. Special foods and indigenous medicines may be shared among individuals whose kinship or friendship ties bring them together into a lay therapy management team responsible for the patient's treatment (Janzen 1978). In small-scale, preliterate societies—for example, the Inuit of Alaska and the Kaluli of the New Guinea highlands—illness is expressed in the system of balanced reciprocity among members of the group that is the central structural principle of each of these societies (Briggs 1970; Schieffelin 1985). This system defines who shall do what for whom in return for who has done (or should have done) what for whom in order that in the future who will do what for whom.

In North American society we, too, possess these conventionalized understandings of the body, these customary configurations of self and symptoms. But given the marked pluralism of North American life styles; ethnic and religious backgrounds; and educational, occupational, and economic statuses, we must distinguish between popular cultural meanings that are shared and those that are restricted to particular subgroups. As a result, it is more sensible to speak of local systems of knowledge and relationships that inform how we regard symptoms; these may differ substantially from each other. Within these local systems shared meanings will be negotiated among individuals of unequal power who attempt to persuade others of the intensity of their distress and of the need for access to more resources. Members of such local systems may seek to deny the implications of an obvious abnormality, or they may try to enlist significant others in the quest for care. Obviously, individuals differ in their rhetorical skills in deploying idioms of distress (Beeman 1985).

Lay understandings of illness influence verbal as well as nonverbal communication. There may well be enough universality in facial expressions, body movements, and vocalizations of distress for members of other communities to know that we are experiencing some kind of trouble (Ekman 1980). But there are subtleties as well that indicate our past experiences, chief current concerns, and practical ways of coping with the problem. These particularities are so much a part of local assumptions that they are opaque for those to whom our shared life ways are foreign. Moreover, these distinctive idioms feed back to influence the experience of distress (Good 1977; Kleinman and Kleinman 1985; Rosaldo 1980).

I hear you say your headache is a migraine, or a tension headache owing to too much "stress," or that it is "beastly," "awful," "pounding," "throbbing," "boring," "aching," "exploding," "blinding," "depressing," "killing," and I interpret something of that experience and how you feel and want me to feel about it. (You also interpret your own language of complaining and my response to you, which will affect your symptoms.) It is a testament to the subtlety of culture that we share such a wide array of understandings of surface meanings of symptom terms. (Nigerian psychiatric patients, for example, frequently complain of a feeling like ants are crawling in their heads, a complaint that is specific to their culture [Ebigbo 1982].) I may no longer explicitly understand the Galenic system of hot and cold bodily states and the humoral balance and imbalance it connotes in Western folk culture, but I get your point that you have a "cold" and therefore want something "hot" to drink and feel the need to dress warmly to protect your "cold" from "the cold." Our understanding is based on a grand cultural convention that would make "feed a cold, starve a fever" incomprehensible to someone without this shared local knowledge (Helman 1978).

Yet there is obviously also great uncertainty at this outer level of signification. I am not entirely sure what you mean when you say your "head is splitting," because I feel I do not know you well enough to make full sense of your experience. Are you generally stoical, hysterical, hypochondriacal, manipulative? Understanding who you are influences how I interpret your complaints. The relationship we have will inform how I respond to your complaint of headache. That relationship includes a history of how I have responded to you in the past (and you to me), along with our mutual understanding of the current situation; in the case of chronic illness, it includes as well the pattern of response and situation that has already been established over hundreds of complaints. My interpretation of your communication of distress is organized by the pattern of our daily interactions in times of sickness. Indeed, the language of your complaints has become a part of the language of our relationship. Hence, even the superficial significance of symptoms qua symptoms is embedded in the meanings and relationships that organize our day-to-day world, including how in interaction we recreate our selves. This makes of even superficial symptoms a rich metaphoric system available for many kinds of communication.

A corollary to the meaning of symptoms is the semiotics of diagnosis. For the practitioner, the patient's complaints (symptoms of illness) must be translated into the *signs* of disease. (For example, the patient's chest pain becomes angina—a sign of coronary artery disease—for the physician.) Diagnosis is a thoroughly semiotic activity: an analysis of one symbol system followed by its translation into another. Complaints are also interpreted as syndromes—clusters of symptoms which run together over time—that indicate through their relationship a discrete disorder. Clinicians sleuth for pathognomonic signs—the observable, telltale clues to secret pathology—that establish a specific disease. This interpretive bias to clinical diagnosis means that the patient–physician interaction is organized as an interrogation (Mishler 1985). What is important is not what the patient thinks but what he or she says. Since 80 percent of diagnoses in primary care result from the history alone, the anamnesis (the account the physician assembles from the patient's story) is crucial (see Hampton et al. 1975). That tale of complaints becomes the text that is to be decoded by the practitioner cum diagnostician. Practitioners, however, are not trained to be self-reflective interpreters of distinctive systems of meaning. They are turned out of medical schools as naive realists, like Dashiell Hammett's Sam Spade, who are led to believe that symptoms are clues to disease, evidence of a "natural" process, a physical entity to be discovered or uncovered. They are rarely taught that biological processes are known only through socially constructed categories that constrain experience as much as does disordered physiology; this is a way of thinking that fits better with the secure wisdom of physical science than with the nervous skepticism of the medical profession.

The upshot is that practitioners, trained to think of "real" disease entities, with natural histories and precise outcomes, find chronic illness messy and threatening. They have been taught to regard with suspicion patients' illness narratives and causal beliefs. The form of those narratives and explanations may indicate a morbid process; the content may lead them astray. The way of the specialist diagnostician, which is not to credit the patient's subjective account until it can be quantified and therefore rendered more "objective," can make a shambles of the care of the chronically ill. Predictably, the chronically ill become problem patients in care, and they reciprocally experience their care as a problem in the health care system. Illness experience is not legitimated by the biomedical specialist, for whom it obscures the traces of morbid physiological change; yet for the care giver of the chronically ill who would be an effective healer, it is the very stuff of care, "a symbol that stands for itself" (Wagner 1986). Legitimating the patient's illness experience—authorizing that experience, auditing it empathically—is a key task in the care of the chronically ill, but one that is particularly difficult to do with the regularity and consistency and sheer perseverance that chronicity necessitates. The interpretation of symptoms in the longitudinal course of illness is the interpretation of a changing system of meanings which are embodied in lived experience and which can be understood through the acquisition of what amounts to an ethnographic appreciation of their context of relationships, the nature of their referents, and the history of how they are experienced.

Cultural Significance as Meaning

Illness has meaning in a second sense, insofar as particular symptoms and disorders are marked with cultural salience in different epochs and societies. These special symptoms and illness categories bring particularly powerful cultural significance with them, so to speak, often of a stigmatizing kind. Few North Americans have ever seen or heard of a case of leprosy, yet so fearsome is the mythology surrounding this category of disorder in the collective consciousness of the West that equally few would be likely to react without abhorrence or terrible fright if told that they or a close acquaintance were suffering from leprosy. No wonder the horrific name of this illness has been changed to the innocuous "Hansen's disease."

In the late Middle Ages, the Black Death (bubonic plague) depopulated the European continent by an astounding three-fourths. In so doing, the Black Death became a symbol of evil and terror. It came to signify several things: the wrath of God, man's fallen state of sin and suffering, and death as transcendence of the immortal soul (Bynum 1985; Gottfried 1983). Whatever particular religious meaning the Black Death had for a community was overwhelmed by the immensely powerful practical meaning the term held for the afflicted and their families. The application of this illness label placed home and neighborhood under the isolation of quarantine and made the inhabitants doomed outcasts who posed the gravest dangers to society. That the word *plague* radiates hardly any significance today is an illustration of the process of transformation of meaning that Foucault (1966)—using the example of insanity in the West—showed can substantially change the nature of the culturally salient mark certain illnesses impress on the afflicted. The disappearance of plague epidemics must have contributed powerfully to this transformation.

In the Gilded Age of late nineteenth-century America, the vaporous paralyses of hysteria, neurasthenic weakness, and neurotic angst due to crises of personal confidence over career and family responsibilities were specially salient disorders regarded as products of the age. They spoke of a widespread middle-class malaise associated with the very rapid pace of social change that was transforming a North American society anchored in eighteenth-century ideals and rural or small town life styles into the twentieth-century culture of industrial capitalism (Drinka 1984). There was great concern with the effect of this massive societal transformation on individuals, usually bourgeois and upper-class men and women, whose symptoms were viewed ambivalently as the price that members of society had to pay for their world to become fully modern.

Let us take another example of culturally marked illness: witchcraft. Accusations of witchcraft in the early New England Puritan world congealed many of the core fears of the time, including threats of deviance, egocentricity, antisocial behavior, and sexuality. It represented an obsession with the control of jealousy and envy, and with explaining the presence of misfortune and maleficence in a world ruled by a stern but just God. In twentieth-century tribal societies in Africa, witchcraft symbolizes a similar concern with the sources of jealousy, envy, and misfortune, though here the emphasis is on human rather than Satanic evil. In the African setting, witchcraft also conveys fears regarding threats to procreativity and village unity (Turner 1967; Janzen 1978). In both societies witchcraft became a major explanatory model of malignant illnesses that were random and unpredictable, like witchcraft itself; it offered, furthermore, a magical means to exert control over seemingly unjust suffering and untimely death.

In Chinese society over the millenia, severe mental illness—labeled insanity, *fengbing*—held particular salience (Lin and Lin 1982). Even today insanity places stigma not just on the sick person but on the entire family. A marriage go-between traditionally asked if insanity was present among members of the family; if it was, she ruled the family out as a suitable source of spouses—a catastrophe in the family-centered Chinese social system. Families of schizophrenic and manic-depressive patients in present-day China and Taiwan, and even among the traditionally oriented Chinese in the

United States, still experience such great shame and other negative effects of stigma. It is often preferable to the members of this familistic culture that the patient remain institutionalized or live apart from home. The diagnosis of mental illness among Chinese is so threatening that the euphemism "neurasthenia" continues to flourish in China in the 1980s, long after its vogue in the West and other non-Western societies; the term provides a legitimate physical disease label as a cloak to disguise psychiatric problems that remain illegitimate and unacceptable. In 1980 and 1983 my wife and I conducted research in China (Kleinman 1982, 1986; Kleinman and Kleinman 1985) which disclosed that neurasthenia conveys other tacit problems as well, especially serious political, work, and family crises that have given rise to demoralization and alienation. One of the neurasthenia cases from our research in China will be described in chapter 6 to illustrate the cultural meanings of illness. The Chinese example offers a remarkable comparison with neurasthenia in late nineteenth and early twentieth century North America and Europe. For although this quintessential biopsychosocial problem crystallizes certain meanings unique to each society, there are also many instances when the social iconography of neurasthenia as *sickness* communicates identical meanings.

Perhaps the disorders of our own period in the West that carry the most powerful symbolic loading are cancer, heart disease, and the new venereal epidemics—herpes and acquired immune deficiency syndrome (AIDS). The first—still a highly malignant, seemingly randomly occurring, largely uncontrollable problem—is a direct threat to major values of late twentieth-century American society. The specific values I have in mind include the transformation of chaotic human problems into closed-ended practical issues manageable by technological means rather than into open-ended questions concerned with moral ends. Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice—value questions, all—in the human condition. Cancer forces us to confront our lack of control over our own or others' death. Cancer points up our failure to explain and master much in our world. Perhaps most fundamentally, cancer symbolizes our need to make moral sense of "Why me?" that scientific explanations cannot provide. Cancer is also freighted with meanings of the risks of invisible pollutants, such as ionizing radiation and even the chemical constituents of the very foods we eat. These menacing meanings meld ancient fears of contamination with the great modern threat of man-made catastrophes that poison the environment with toxic wastes. They disclose our inability to control the effects of technology. The popular view of anticancer drugs as poisons extends the imagery of risk from causes to treatments and seems to implicate biomedical technology as part of this danger.

Contrary to earlier assumptions, the more we have learned, the more threatening our environment has become. Heart disease, like cancer, seems to implicate our very way of life: what we choose to eat, what we like to do. It points to the frenetic pace of an economy predicated on ever more rapid technological change and its accompaniment, disordered physiology. It speaks to us of the risks of our personality style (in fact, that narcissistic personality precisely crafted to be most successful in the capitalist system). Heart disease invokes the ubiquitous tension in our lives, the breakdown of intimate social bonds, and the loss both of leisure and of sustained physical activity in our workaday world (Lasch 1979; Helman 1987).

The society-wide response to each problem also tells us much about the value structure of American society. We manage as medical problems the symptoms resulting from the social sources of distress and disease. We blame the victim in the ideology of personal life-style change. We avoid the hard, value-laden questions that underlie public health concern with cigarette smoking, exposure to carcinogens, promiscuous sexual practices, and what is euphemistically called unavoidable stress (what Taussig [1986] calls the "nervous" system of modern society). Both cancer and heart disease intensify our awareness of the dangers of our times and of the man-made sources of much misery. But the governmental response is meant to obfuscate this vision of sickness as meaning something is wrong with the social order and to replace (medicalize) it with narrowly technical questions. Is there a better mirror of what we are about?

Like cancer and heart disease, we can say of genital herpes and AIDS that these disorders bring particular cultural meaning to the person (Brandt 1984). As in the cases of syphilis and gonorrhea before them, herpes and AIDS brand the victim with the painful (and in the case of the latter, deadly) stigmata of venereal sin. At the same time, the response to these diseases suggests that the dominant, commercialized sexual imagery of postindustrial capitalist society hides a double standard of both amoral promiscuity on behalf of individual rights and consumer values and highly moral, if archly hypocritical, condemnation of the venereal results. For each of these disorders meaning arrives with a vengeance together with the diagnosis: "She's got breast cancer and may die!" "I've got coronary artery disease and can't work any longer!" "Her boyfriend has herpes and infected her without warning her!" "Can you imagine, that fellow down the street has AIDS. You know what that means!" Each statement encases the patient in a visible exoskelton of powerfully peculiar meanings that the patient must deal with, as must those of us who are around the patient. These meanings include the fear of a lingering and untimely death, the threat of disfiguring treatment with the concomitant loss of body- and self-image, the stigma of self-earned illness, discrimination against homosexuals, and so forth. That exoskeleton is the carapace of culturally marked illness, a dominant societal symbol that, once applied to a person, spoils radically that individual's identity and is not easily removed.

Less solemn cultural meaning is exemplified by the lay perspective on hypertension in North America. Blumhagen's (1980) research describes the beliefs about hypertension held by a largely middle-class, college-educated clinic population in Seattle. The lay model takes the essence of hypertension to be too much tension, not necessarily high blood pressure, which is what the term denotes in biomedical usage. Blumhagen shows that the lay interpretation of hypertension as an illness is a North American folk model that helps explain the high rate of noncompliance with the medical drug regimens that characterize this disorder. Noncompliance is held by physicians to be a major obstacle to the effective management of hypertension. When patients feel "hyper-tense" they believe they are suffering the disorder and they take the medication. When they do not feel tense, they deny that they have hypertension and don't take the medicine. Here the illness model is the obverse of the disease model. The object of therapy is to control the blood pressure on a daily basis, independent of stress or tension. This folk model, with its important implications for care, appears widespread in North American society in spite of health education campaigns in clinics and in the media. Its persistence is a measure of the staying power of cultural meanings.

It is not just the labels of disorders that are value laden. Symptoms, too, can carry cultural significance. For example, in the ancient Chinese medical texts, "headaches," "dizziness," and "weakness" receive special attention; the same symptoms are highlighted by patients and physicians in clinical settings in modern China (Kleinman 1986). Benveniste (1945), in an early and still provocative account of the relationship of symptoms to the tripartite social division of ancient Indo-European society, notes that wounds, blindness, and a weakness-exhaustion-debility complex of complaints have held special salience in Western society and have been associated with military, priestly, and agricultural functions, respectively. The epidemic of chronic pain complaints in North America suggests that pain has peculiar present-day significance and seemingly has usurped the cachet of exhaustion-weakness complaints of neurasthenia. Perhaps North American culture's ideology of personal freedom and the pursuit of happiness has come to mean for many guaranteed freedom from the suffering of pain. This meaning clashes strikingly with the expectation in much of the nonindustrialized world that pain is an expectable component of living and must be endured in silence.

It is not just that certain symptoms are given particular attention in certain cultural and historical settings, but that the meanings of all symptoms, as I have already noted, are dependent on local knowledge about the body and its pathologies. Hence, weakness in local Chinese communities connotes loss of vital energy (*qi*), a central theme in traditional Chinese ethno-medical theories. Excessive loss of semen, through masturbation or an overly active conjugal sex life, has always generated marked anxiety among Chinese because semen contains *jing,* or the essence of *qi,* which in turn is lost when semen is lost. This makes semen loss a potentially life-threatening illness in Chinese medical theory. Because of this set of beliefs, tradition-oriented Chinese adolescents and young adults are particularly fearful of the consequences of nocturnal emissions and other forms of semen loss; their view stands in striking contrast with that of their counterparts in the present-day West, where it would seem to be positively valued. In South Asia, where Ayurvedic medical theory holds that both men *and* women contain semen, leucorrhea carries the same fearful connotation for women. That female semen loss is impossible in biomedical theory illustrates the great semantic gap between illness and disease.

Other culturally particular symptoms described in the anthropological and cross-cultural psychiatric literature include "fright" leading to "soul loss" in Mexico and in various Asian societies, "nerves" in North and South America, fear that the penis is shrinking among Southeast Asians, and startle-related copying and echoing behavior (*latah*) affecting Malays. There exists a large assortment of so-called culture-bound complaints (see Simons and Hughes 1985).

It is a sign of the marked pluralism of North American society that symptoms hold special significance not just in the society as a whole but also in the distinctive life worlds shaped by class, ethnicity, age, and gender. Menopausal complaints are a preoccupation of white, middle-class women in midlife. But women of most other cultures pass through the menopause with few serious complaints and no conception of this life transition as an illness (Kaufert and Gilbert 1986; McKinlay and McKinlay 1985). Yet menopausal complaints are highlighted by the media and the medical profession for economic reasons. They have entered the popular North American culture as a marker of the feared transition to old age and asexuality in a society commercially centered on the cult of youth and sexual attraction. Similarly, premenstrual tension is a symptom constellation unheard of in much of the world and among members of traditional ethnic groups in the United States; but it is increasingly commonplace in white, middle-class North America. Non-Western practitioners regard premenstrual syndrome as yet another example of the unwillingness of middle-class Westerners to endure any pain or suffering, no matter how limited and expectable. Perhaps its cultural significance lies in the strong ambivalence associated with traditional procreative functions and femininity among women in Western society. Rural blacks and poor whites in Appalachia complain of "high blood," "sugar," "fallin' out," "nerves," and other ailments that hold little, if any, significance in the urban Northeast and that define this population as much as does their dialect (Nations et al. 1985). Complaints of "soul loss" (*susto*) among working-class Mexican-Americans in Los Angeles, spirit possession among Puerto Ricans in New York, voodoo among Haitian immigrants in Boston, "airs" (*aires*) and hot/cold imbalance among working-class Cubans in Miami, and evil eye among recent refugees from Latin America serve a similar function. They mark ethnic, class, and recent immigration statuses. They should signal to health professionals major cultural differences that require sensitive evaluation. All too frequently, however, they stimulate traditional ethnic stereotypes that may exert a mischievous influence on care.

Culturally salient illness meanings disclose change as well as continuity over time and place. The meaning of a lump in the breast is no longer limited to wealthier and better educated women in North America, and the potential physiological significance of coughing and wheezing among smokers is much better appreciated now than in the past. Alternatively, the bloody sputum, hectic flush, and elegant pallor so well known to readers of nineteenth-century Western literature as signs of tuberculosis have lost their significance as a cohesive, popular cultural category. The significance of each of these disorders will hold a meaning different for Ethiopians than for Bostonians. Where acute disorder, starvation, and epidemic infectious disease are rampant it is unlikely that the symptoms of chronic conditions will hold as powerful a place in the local collective consciousness as they do in societies that have passed through the epidemiological transition to chronic disorder as the chief source of morbidity and mortality.

Baldness and impotence among middle-aged men, acne and short stature among adolescent males, obesity and eating preoccupation (bulimia and anorexia) among adolescent and young adult women, and cosmetic concerns among the elderly are culturally marked conditions that express the narcissistic preoccupation of modern Western society. Agoraphobia (fear of leaving the house) has been said to express through its symptom of houseboundedness the Western woman's ambivalence about the choice between having a working career and being a housewife (Littlewood and Lipsedge 1987). At present, the dementia of Alzheimer's disease captures popular attention in North America as an unacceptable index of the with that of their counterparts in the present-day West, where it would seem to be positively valued. In South Asia, where Ayurvedic medical theory holds that both men *and* women contain semen, leucorrhea carries the same fearful connotation for women. That female semen loss is impossible in biomedical theory illustrates the great semantic gap between illness and disease.

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To recapitulate our main argument, cultural meanings mark the sick person, stamping him or her with significance often unwanted and neither easily warded off nor coped with. The mark may be either stigma or social death. Whichever, the meaning is inescapable, although it may be ambiguous and although its consequences can be significantly modified by the affected person's place in the local cultural system. People vary in the resources available to them to resist or rework the cultural meanings of illness. Those meanings present a problem to patient, family, and practitioner every bit as difficult as the lesion itself.

A final aspect of this type of illness meaning deserves mention. The cultural meanings of illness shape suffering as a distinctive moral or spiritual form of distress. Whether suffering is cast as the ritual enactment of despair, as paradigmatic moral exemplars of how pain and loss should be borne (as in the case of Job), or as the ultimately existential human dilemma of being alone in a meaningless world, local cultural systems provide both the theoretical framework of myth and the established script for ritual behavior that transform an individual's affliction into a sanctioned symbolic form for the group.

The German phenomenologist Plessner (1970) makes the cultural point about suffering this way. Illness in modern Europe or the United States, he avows, brings the sick person to the recognition of a fundamental aspect of the divided nature of the human condition in the West: namely, that each of us *is* his or her body and *has* (experiences) a body. In this formulation, the sick person is the sick body and also recognizes that he or she has a sick body that is distinct from self and that the person observes as if it were someone else. As a result, the sick both are their illness and are distanced, even alienated, from the illness. T. S. Eliot may have had this in mind when he spoke of the "dissociation of sensibility" (cited in Rycroft 1986, 284) The modern Western cultural orientation contributes to our experience of suffering precisely through this reciprocal relationship between the actual experience qua experience and how each of us relates to that experience as an observing self. We might say that culture fills the space between the immediate embodiment of sickness as physiological process and its mediated (therefore meaning-laden) experience as human phenomenon—for example, as an alienated part of body-self, as a vehicle for transcendence, or as a source of embarrassment or grief. Illness takes on meaning as suffering because of the way this relationship between body and self is mediated by cultural symbols of a religious, moral, or spiritual kind. Inasmuch as the Western experience of the body-self dichotomy has throughout this century been exported to the rest of the world as a psychological component of modernization, perhaps the division of experience and meaning will become, at least for those most strongly influenced by Western values, universal in illness around the globe.

Let us restate the issue in sociological terms. Following Schutz (1968) we can view the individual in society as acting in the world by taking up a common-sense perspective on daily life events. The perspective comes from a local cultural system as the accepted way of conceiving (and thereby replicating) social reality. We create, not just discover, meaning in experiences through the process of meeting practical resistances in the real world, obstacles owing to the unequal distribution of available resources or the unpredictability and uncontrollability of life problems, for example. When we meet up with the resistance offered by profound life experience—the death of a child or parent or spouse, the loss of a job or home, serious illness, substantial disability—we are shocked out of our common-sensical perspective on the world (Keyes 1985). We are then in a transitional situation in which we must adopt some other perspective on our experience. We may take up a moral perspective to explain and control disturbing ethical aspects of our troubles, or a religious perspective to make sense of and seek to transcend misfortune, or, increasingly, a medical one to cope with our distress. In traditional societies, shared moral and religious perspectives on the experience of life crises anchor anxieties in established social institutions of control, binding threat in webs of ultimate meaning. In the fragmented, pluralistic modern world, anxiety increasingly is free floating and requires personal processes of creating idiosyncratic meaning to supplant the shared moral and religious significance that guided our ancestors on how to suffer (see Obeyesekere 1985). Lacking generally agreed-upon authorization for how to interpret misfortune, there is a definite tendency in the contemporary world to medicalize such problems and therewith to turn to the cultural authority of the health professions and science for an answer to our predicaments. Taking on a medical or scientific perspective, however, doesn't help us to deal with the problem of suffering: in contemporary biomedicine and the other helping professions there is no teleological perspective on illness that can address the components of suffering relating to problems of bafflement, order, and evil, which appear to be intrinsic to the human condition. Instead, the modern medical bureaucracy and the helping professions that work within it, as we have seen, are oriented to treat suffering as a problem of mechanical breakdown requiring a technical fix. They arrange for therapeutic manipulation of disease problems in place of meaningful moral (or spiritual) response to illness problems.

Clinical and behavioral science research also possess no category to describe suffering, no routine way of recording this most thickly human dimension of patients' and families' stories of experiencing illness. Symptom scales and survey questionnaires and behavioral checklists quantify functional impairment and disability, rendering quality of life fungible. Yet about suffering they are silent. The thinned-out image of patients and families that perforce must emerge from such research is scientifically replicable but ontologically invalid; it has statistical, not epistemological, significance; it is a dangerous distortion. But to evaluate suffering requires more than the addition of a few questions to a self-report form or a standardized interview; it can only emerge from an entirely different way of obtaining valid information from illness narratives. Ethnography, biography, history, psychotherapy—these are the appropriate research methods to create knowledge about the personal world of suffering. These methods enable us to grasp, behind the simple sounds of bodily pain and psychiatric symptoms, the complex inner language of hurt, desperation, and moral pain (and also triumph) of living an illness. The authenticity of the quest for such human knowledge makes us stand in awe because of some resonant sensibility deep within. What is the metric in biomedical and behavioral research for these existential qualities? And lacking such understanding, can the professional knowledge that medical science creates be at all adequate for the needs of patients, their families, and the practitioner?

The problem of illness as suffering raises two fundamental questions for the sick person and the social group: Why me? (the question of bafflement), and What can be done? (the question of order and control). Whereas virtually all healing perspectives across cultures, like religious and moral perspectives, orient sick persons and their circle to the problem of bafflement, the narrow biomedical model eschews this aspect of suffering much as it turns its back on illness (as opposed to disease). Clinicians struggle, therefore, to transcend the limits of biomedicine so as to respond to personal and group bafflement by broadening their professional framework to include other models—such as the biopsychosocial or psychosomatic models—or by joining their patients through adapting either a common-sensical moral view or a more particular religious perspective. The difficulties of importing value systems into the patient–doctor relationship to fill a moral lacuna cannot be overemphasized. For these can and frequently do create even more conflicts than they resolve. The practitioner's values may not be the patient's. A narrowly particularistic moral or religious perspective may alienate, not aid, the family. But what is the alternative?

Consider a situation in which a moral or religious view is shared, forming the basis for the group's response to suffering. The value orientations of Buddhism and medieval Christian theology make of suffering not a wholly disvalued experience to be managed or negotiated, but an occasion for the work of cultural processes to transcend pain and dying. In fourteenth-century Europe, as already noted, when the Black Death depopulated the continent to an unequaled degree, the problem of suffering, articulated as both the question of meaning and the question of control, was a fundamental crisis for society. Society responded by reasserting the core religious and moral meanings that were threatened by the highly malignant epidemic, as well as by applying those few social and technical controls available at the time. In our own time, the threat of man-made catastrophe raises similar questions of suffering; yet the societal response is almost entirely limited to rational-technical manipulations aimed at controlling practical problems, with scant attention to their deeper significance. Indeed, one reason for lay misinterpretations of the scientific discourse on risk is the tendency of laymen to reinterpret, in qualitative, absolute, personalized (nonrandom) terms, the scientists' quantitative, bell-shaped curves of the random distribution of risks in the population. That is to say, questions of the cultural significance of risk as bafflement come to the fore in spite of professional (and societal) attempts to expunge meaning and value from the equation of care. Suffering is not easily put aside by biomedical science; it remains central to the experience of illness, a core tension in clinical care.

2

The Personal and Social Meanings of Illness

> Unscientific utterances can, and indeed usually do, have double meanings, implied meanings, unintended meanings, and can hint and insinuate, and may indeed mean the opposite of what they apparently mean, especially if they are said in a certain tone of voice.
>
> —CHARLES RYCROFT
> (1986, 272)

> In successfully identifying and understanding what someone else is doing we always move towards placing a particular episode in the context of a set of narrative histories, histories both of the individuals concerned and of the settings in which they act and suffer.
>
> —ALASTAIR MACINTYRE
> (1981, 197)

Life World as Meaning

Illness has meaning in a third sense, a sense so central to understanding chronic illness that I will spend much of the rest of this book elaborating and illustrating it and expanding on its therapeutic implications. For in the context of chronic disorder, the illness becomes embodied in a particular life trajectory, environed in a concrete life world. Acting like a sponge, illness soaks up personal and social significance from the world of the sick person. Unlike cultural meanings of illness that carry significance *to* the sick person, this third, intimate type of meaning transfers vital significance from the person's life to the illness experience.