THE
ILLNESS
NARRATIVES

Suffering, Healing, and the Human Condition

ARTHUR KLEINMAN, M.D.
To those who suffer chronic illness; to those who share the experience of disability as members of the family and social circle; and to the professionals who care for them.
The Meaning of Symptoms and Disorders

Whatever is real has a meaning.
—Michael Oakeshott
([1923] 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.
—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

*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
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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.

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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 exacerbations, 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, regrettably, 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 caretaker, 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 embodiments 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,” machineline 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 en-
ergy) 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 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 1988) 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 1972). 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—infoms 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 educa-

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tional, 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 'beautly,' '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 [Ebiobo 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 stodical, 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 metaphorical 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 naïve realists, like Dashiel 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 ethno-
graphic 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 symp-
toms 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 over-
whelmed 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 transfor-
mation 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 con-
tributed powerfully to this transformation.

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In the Gilded Age of late nineteenth-century America, the vapor-
ous 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 as-
associated with the very rapid pace of social change that was trans-
forming 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 con-
cern with the effect of this massive societal transformation on indi-
viduals, usually bourgeois and upper-class men and women,
whose symptoms were viewed ambivalently as the price that mem-
bers of society had to pay for their world to become fully modern.

Let us take another example of culturally marked illness: witch-
craft. 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 sexual-
ity. It represented an obsession with the control of jealousy and
envy, and with explaining the presence of misfortune and mali-
ficence 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 set-
ing, 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 of-
fered, furthermore, a magical means to exert control over seemingly
unjust suffering and untimely death.

In Chinese society over the millennia, severe mental illness—la-
abeled 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 schizo-
phrenic 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 familial 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 capitalism 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 exoskeleton 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-weakeness 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 (liLtah) affecting Malays. There exists a large assortments 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 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” (queto) 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 houseboundness 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
final assault of aging on the autonomy of the person. Relabeling alcoholism as an illness and child abuse as a symptom of family pathology are further examples of the widespread process of medicalization in Western societies, whereby problems previously labeled and managed as moral, religious, or criminal are redefined as disorder and dealt with through therapeutic technology. These problems open a window on Western society, showing its chief cultural concerns and conflicts.

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 insti-
tutions 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 idiosyn-
cratic meaning to supplant the shared moral and religious signifi-
cance that guided our ancestors on how to suffer (see Obeyesekere 1985). Lacking generally agreed-upon authorization for how to in-
terpret 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 an-
swer to our predicaments. Taking on a medical or scientific perspec-
tive, however, doesn’t help us 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 profes-
sions that work within it, as we have seen, are oriented to treat
suffering as a problem of mechanical breakdown requiring a tech-
ical fix. They arrange for therapeutic manipulation of disease prob-
lems 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 thinly
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 ontologi-
cally invalid; it has statistical, not epistemological, significance; it is
dangerous distortion. But to evaluate suffering requires more than
the addition of a few questions to a self-report form or a standard-
ized 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 re-
search 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

The Meaning of Symptoms and Disorders

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 sensi-
bility deep within. What is the metric in biomedical and behavioral
research for these existential qualities? And lacking such under-
standing, can the professional knowledge that medical science cre-
ates be at all adequate for the needs of patients, their families, and
the practitioner?

The problem of illness as suffering raises two fundamental ques-
tions for the sick person and the social group: Why me? (the ques-
tion of bafflement), and What can be done? (the question of order
and control). Whereas virtually all healing perspectives across cul-
tures, 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 psychoso-
matic models—or by joining their patients through adapting either
a common-sensical moral view or a more particular religious per-
sonpective. The difficulties of importing value systems into the pa-
tient–doctor relationship to fill a moral lacuna cannot be overem-
phasized. 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 alien-
ate, 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 nego-
tiated, but an occasion for the work of cultural processes to tran-
scend pain and dying. In fourteenth-century Europe, as already
noted, when the Black Death depopulated the continent to an un-
equalled 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 (non-random) 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, enrobed 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.