Contents

List of figures  page viii

Foreword by ANTHONY T. CARTER  ix

Preface  xv

1 Medical anthropology and the problem of belief  1
2 Illness representations in medical anthropology: a reading of the field  25
3 How medicine constructs its objects  65
4 Semiotics and the study of medical reality  88
5 The body, illness experience, and the lifeworld: a phenomenological account of chronic pain  116
6 The narrative representation of illness  135
7 Aesthetics, rationality, and medical anthropology  166

Notes 185
References 208
Author Index 234
Subject Index 239
Figures

1. Opposing domains of the meaning of "blood" page 94
2. Opposing domains in personal and family history 95
3. Opposing domains in the body and the physical environment 96
4. Cosmological domains: the Old Kingdom and the New Earth 98
5. Digestion in classic Greco-Islamic medicine 104

Foreword

Byron Good delivered the Lewis Henry Morgan Lectures on which this book is based in March, 1990. This marked the twenty-eighth year in which the Lectures were offered to the public by the Department of Anthropology at the University of Rochester. As I write, the thirty-first Lectures are less than two months away. The Lectures were launched under the leadership of the Department’s founding Chair, Professor Bernard S. Cohn, with generous support from the Joseph R. and Joseph C. Wilson families. For twenty-eight years, from 1964 through 1991, the Editor of the Lectures was Professor Alfred Harris. The first five published volumes in the series were Meyer Fortes' *Kinship and the Social Order*, Fred Eggan’s *The American Indian*, Robert McC. Adams’ *The Evolution of Urban Society*, Victor Turner's *The Ritual Process*, and Ward Goodenough’s *Description and Comparison in Social Anthropology*.

The Lectures serve in part as a memorial to Lewis Henry Morgan, a prominent Rochester attorney as well as a founder of modern anthropology. Morgan was never dependent on the perhaps dubious pleasures and rewards of an academic position in mid-nineteenth century America. Nevertheless, as Professor Harris noted in his Foreword to Meyer Fortes’ inaugural Lectures, Morgan was connected with the University of Rochester from its beginning. A major early benefactor, he left the University money for a women’s college as well as his manuscripts and library. Until the creation of the Morgan Lectures, however, the only memorial to him at the University was a residence hall wing named in his honor.

The Morgan Lectures, the published volumes as well as the public lectures in Rochester, also are the site of a complex series of intersecting and overlapping conversations. Most importantly, of course, the Lecturer addresses other anthropologists and scholars in a variety of allied fields on his or her own behalf. The Lectures also provide an opportunity for the Department — undergraduates, graduate students and faculty alike — to engage in close interaction with scholars working on a wide range of problems in our discipline, many of which we cannot hope to represent in a single department. Ideally, their work challenges as well as complements our own. Through its selection of Lecturers, the Rochester
Department of Anthropology is able to convey its sense of the growing points of
the discipline as a whole. Here our audience is both local and international,
anthropological and interdisciplinary. First through the public lectures in
Rochester and then through the published volumes, the Lectures serve as a forum
in which scholars from a variety of disciplines and members of the public may
meet to discuss matters of general as well as academic interest.

I rehearse all of this for two reasons. The first is to honor the work of my
predecessors. It is a considerable privilege and responsibility to take up the legacy
of Professors Cohn and Harris and their distinguished Lecturers. The second is to
make clear that my appreciation of Professor Good’s book is necessarily partial
and incomplete.

*Medicine, Rationality, and Experience* is a large work. As Morgan
“discovered” or “invented” kinship as a cultural domain and an object of
anthropological investigation, so Good here finds a definition of illness, providing
medical anthropology with an object of study and a program of research. For
Good, illness is an aesthetic rather than a biological object. His approach is
interpretive rather than positivist.

Annie Dillard observes in *The Writing Life* that

> When you write, you lay out a line of words. The line of words is a miner’s pick, a
> woodcarver’s gouge, a surgeon’s probe. You wield it, and it digs a path you follow.
> Soon you find yourself deep in new territory. Is it a dead end, or have you located the
> real subject? You will know tomorrow, or this time next year . . .
>
> The writing has changed, in your hands, and in a twinkling, from an expression of
> your notions to an epistemological tool.

With observations such as this in mind, I say advisedly that Good “finds” a
definition of illness. This outcome is prefigured in Good’s earlier work and in the
first chapters of this one, but one of the charming features of this book is that it
provides glimpses of the way in which its final destination emerged after much
hard work. On the opening page of chapter 7, Good writes that

> Shortly after I finished writing the last major chapter of this book – on the narrative
> representation of illness – a former professor of mine asked what I had discussed in the
> Morgan Lectures. I replied that I was developing a theory of culture and illness from the
> perspective of aesthetics, examining how illness is formulated as an “aesthetic object.”
> I later thought back on what I had said with considerable anxiety, because with the
> exception of reviewing some of the literature on narrativity the book hardly addresses
> the issue of aesthetics at all. Furthermore, this surely represents a small part of what this
> book has been about and a very partial way of conceiving a program for medical
> anthropology. Nonetheless, my rather offhand comment suggested an interpretation of
> where I had emerged after nearly two years of work on this project, and may serve as
> the starting point for work to come (p. 166).

We have in this volume the record of a difficult voyage of discovery.

By my reckoning, Good’s argument may be divided into two parts. The first,
chapters 1 through 3, consists of preparatory work. Here Good severs the
subordinate relationship of medical anthropology to medicine and biology and cuts its
moorings in positivist epistemology. Medical science, he argues, is in part an
ideological formation. It does not mirror nature in any direct way and cannot
provide the foundations for a medical anthropology concerned with experience
and comparison. Instead, a meaning-centered approach is required, one which
recognizes that the language of medicine is a “cultural language” (p. 5) and a
historical formation.

In the latter part of chapter 1, Good argues that, in spite of the many advances
in medical diagnosis and therapy, the notion that medical science mirrors nature
rests on a culturally specific distinction between knowledge and belief. In
medical practice, public discourse and much anthropological writing, the other is
regarded as holding culturally determined beliefs, often erroneous, while “we”
have attained objective, empirical knowledge. Patients may have beliefs about
their illnesses; doctors have knowledge. As Good observes, however, following
Wilfred Cantwell Smith, our current concept of belief as something held to be true
without certain knowledge is itself historical in character, arising in English usage
only in the last three centuries. In earlier usage, belief had to do not with
propositions but with activity, being loyal to or loving. Specific to our own
culture, our modern concept of belief may be badly misleading when applied to
other times or other places. At the same time, our conception of scientific
knowledge as an objective mirror of nature has come to be less convincing. In
some quarters, at least, it, too, is seen to be shaped by culturally specific practices.

Good pursues the conflict between positivist and interpretive epistemologies in
chapters 2 and 3. Chapter 2 provides a broad overview of medical anthropology in
the twentieth century. It is focused on contrasting representations of illness, their
epistemological presuppositions and their implications for programs of research.
A preliminary account of writings about concepts of illness and healing from
before the Second World War grounds the discussion in mainstream anthropo-
logical concerns. The greater part of the chapter is devoted to an account of
debates among representatives of the continuing “empiricist tradition,”
cognitive and “meaning-centered” approaches, and “critical” medical anthropology in
the period since the 1950s when medical anthropology emerged as a distinct subfield
of anthropology concerned with work in international public health. The divergent
theories of knowledge inherent in these competing positions are not, Good argues,
more philosophical window dressing. They have important consequences for
programs of research and for the ways in which anthropologists interact with and
write about the people they study and with whom they live. In Good’s view an
interpretive or meaning-centered approach that remains “conversant with critical
theory” is essential if medical anthropology is to comprehend the claims of
medical science and biology while still recognizing “the validity of local
knowledge in matters of sickness and suffering” (p. 63).

Chapter 3 is the first ethnographic chapter of the book. (Here as elsewhere
Good discusses material gathered jointly with his wife, Mary-Jo Good, also a
distinguished medical anthropologist.) A fascinating preliminary report on a study
of Harvard Medical School’s New Pathway to General Medical Education, the
chapter uses Ernst Cassirer's theory of symbolic forms to construct a picture of medical practice as embedded in culture, "a symbolically mediated mode of apprehending and acting on the world" (p. 87). Medical students enter the world of medicine, Good contends, by participating in a distinctive set of what Marilyn Strathern might call knowledge practices, "specialized ways of 'seeing,' 'writing,' and 'speaking' " that "formulate reality in a specifically 'medical' way" (p. 71). This ethnographic account serves as a bridge between the two parts of the book. Looking backward, it provides evidence in support of the claim, developed in the first two chapters, that medicine is embedded in culture. Looking forward, it is a first concrete illustration, using relatively familiar materials, of an interpretive approach that takes as its "analytical focus the 'formative processes' through which illness is shaped as personal and social reality . . . " (p. 66).

The second part of the book, chapters 4 through 6, consists of a series of ethnographic analyses, using material gathered in Iran, Turkey, and the United States. Together, these analyses give substance to Good's suggestion that medicine is a symbolic form and to his proposal for an interpretive approach to medical anthropology.

In chapter 4, Good applies the notion of semiotic networks to a Boston woman's account of her difficulties with rectal bleeding and to the account of digestion in Galenic-Islamic humoral medicine. This amounts to a sustained attack on the notion that medical terms in different cultures or in different segments of a single culture have a common reference to biological facts external to culture that can provide a basis for comparison and translation. Their meaning derives instead, Good shows, from their place in dense semiotic networks. Medical terms have meaning "in relation to a field of signs" (p. 112). They have as much to do with experience, gender and society as with biology. Their interpretation requires attention to the complex array of conceptual systems in which they participate as well as to the practices through which these systems are enacted and reproduced.

Good has been concerned with the analysis of semiotic networks since 1977 and the approach has been widely emulated in medical anthropology. Chapters 5 and 6 push the interpretive perspective into fresh territory. Like chapter 3, chapter 5 proposes a phenomenological account of the construction, and destruction, of lifeworlds. But, where chapter 3 focused on medical students, chapter 5 revolves around a Boston man’s moving account of his life with chronic pain and is concerned with the experience of illness. Here Good suggests that medical anthropology "can bring method to the cross-cultural investigation of illness experience" (p. 134) by examining the phenomenology of these experiences, the ways in which they are narrated and the rituals employed to reconstruct the world that suffering has unmade.

Chapter 6 extends the analysis of the representation of illness in narrative, now focusing on Turkish informants' accounts of seizure disorders. Two aspects of the analysis in this chapter strike me as particularly interesting. Good draws upon Wolfgang Iser's theory of reading to argue that the "formative practices" that shape illness and illness experience are inherently social. For Good the meaning of illness is constructed through narrative practices in which sufferers, their families and other associates, and healers all participate. Like the meaning of a text, the meaning of an illness narrative, itself often the complex product of multiple authors, lies neither in the text itself nor in the reader/hearer but is a social product. It is socially distributed. Good draws upon Jerome Bruner to argue that illness narratives succeed by "subjunctivizing reality" (p. 153). Narratives are not closed accounts but endo/alternative perspectives and alternative readings, both retrospectively, looking toward the origins of suffering, and prospectively, looking toward the possibility of cure or alleviation of suffering.

In its own way, the narrative strategy that Good uses in Medicine, Rationality, and Experience also is socially distributed and subjunctivizes reality. As Good argues in chapter 2 and repeats in the concluding chapter, chapter 7, medical anthropology is heteroglossic, the socially distributed product of a multiplicity of perspectives and voices. This is necessarily so, he argues, for "[d]isease and human suffering cannot be comprehended from a single perspective" (p. 62). His purpose is not to eliminate the medical model but to carve out a distinct approach for an interpretive anthropology. If, as he suggests, "‘[m]edical anthropology’ is a kind of oxymoron" (p. 176), an impossible combination of positivist and interpretive epistemologies, the cyborg monster is nevertheless essential to cross-cultural understanding. The course of future research remains open.

Though Good adheres to matters having to do with illness and healing, the implications of his engagement with biological reductionism in its medical stronghold will reverberate across the spectrum of anthropology. Several elements of his argument have close analogs in other areas of the discipline, but the vigor with which he deploys them in the face of the dominant medical and belief behavior models is exciting.

Like medical anthropology, the Lewis Henry Morgan Lectures as an on-going series are socially distributed, heteroglossic and subjunctivizing. Any attempt to discern an overall direction in such a series is always provisional. Nevertheless, it is worth noting some of the parallels between this work and the last two volumes in the series, Stanley Tambiah’s Magic, Science, Religion, and the Scope of Rationality and Marilyn Strathern’s After Nature: English Kinship in the Late Twentieth Century. With Tambiah, Good emphasizes the historical character and cultural embeddedness of science and rationality. With Strathern, Good denies that society and culture are constructed out of elements external to themselves. As kinship, according to Strathern, is not constructed upon the facts of biological connection so, for Good, illness, suffering, and healing cannot be reduced to the biology of organisms.

ANTHONY T. CARTER, Editor
The Lewis Henry Morgan Lectures
This book consists of the Lewis Henry Morgan Lectures, which were delivered during March 1990 at the University of Rochester, and substantially revised and expanded during the subsequent two years. Having honored me by the invitation to deliver the lectures, members of the Department of Anthropology increased my debt beyond measure by their hospitality during the two weeks of my visit. I owe special gratitude to Professor Al Harris, who ably organized the Morgan Lectures for many years, and to Professor Tony Carter, who has now taken on that responsibility. To the faculty, graduate students, and others in the University community who were my hosts and engaged me in discussion, I offer my sincere thanks.

This book represents an effort to work through a set of ideas with which I have struggled for more than twenty years. During 1964–65, I spent a year as an undergraduate student at the University of Nigeria. I returned with a sense of the profound inadequacy of describing the world of my Ibo and Yoruba classmates in a manner that gave privilege to my own views of reality. It was that experience that led me to the comparative study of religion, and then to the study of anthropology. It was also that experience that provided the intuitive grounding for my intellectual engagement with symbolic anthropology at the University of Chicago.

When I turned my attention to medicine, eventually taking a teaching position in the Department of Psychiatry at the University of California, Davis, I began to confront the epistemological questions implicit in the position I intuitively held. Can we seriously contemplate an epistemological – and ethical – stance that does not privilege the knowledge claims of biomedicine and the biomedical sciences? If we accept such claims, what are the consequences for how we represent illness and healing in other cultural traditions? How do our analyses subtly reproduce and legitimate our own common-sense knowledge of medicine and the social world in which we live? On the other hand, if we deny the foundational claims of biomedicine, what alternative ways of thinking and writing are available to us?

This set of questions lies at the heart of much of what I have written during the past fifteen years. And it is this set of issues which I address in as coherent a fashion as I am able in this book. I attempt to show that our views of language,
meaning, and knowledge are subtly present in nearly all that we write in anthropology, and that medical anthropology is a key site in our discipline to address some of the most difficult—and exciting—issues that we face today.

Perhaps not surprisingly, the book turned out to be different than it would have been had I written it a decade earlier, when I first jotted down an outline for a similar text. The ensuing years have seen important developments in interpretive studies, on the one hand, and the rise of diverse forms of critical analysis, on the other, all influencing how we think and write today. In the course of preparing the lectures and elaborating the manuscript, I found myself struggling to reformulate many of the issues about which I have previously written. It is my hope that the text may provoke a similar struggle for at least some of those who read it.

This book includes the core of the lectures, augmented by several additional chapters. Chapters 1, 3, and 5 were presented as the first three Morgan Lectures, and have been revised for this text. Chapters 2, 4, and 6 have been added to fill out the argument. Chapter 7 grew out of my reflections for the concluding lecture, but is largely rewritten.

Given the history of this project, I want to acknowledge a number of individuals who have contributed to my thinking and to this book in particular. Present throughout this text are the voices of several of my teachers: Wilfred Cantwell Smith, who taught the comparative study of religions at Harvard Divinity School; Raymond Fogelson, who first introduced me to medical anthropology and provided enormous support during my graduate years; Clifford Geertz, whose seminar on the theory of culture at the University of Chicago put me to work on many of the issues addressed here; Victor Turner, whose energy and ideas about social drama, narrative, and experience inspired a generation of Chicago students; and Lloyd Fallers, a gentle scholar and my advisor, who died while I was in the field.

Present also are the voices of my colleagues at Harvard, the graduate students and post-doctoral fellows with whom I have been privileged to work, a small group of visiting scholars from Tanzania and Kenya who read and commented on the text, and a larger group of colleagues in the field with whom I have discussed these issues over the years. At Harvard, Leon Eisenberg, Stanley Tambiah, Bob and Sarah LeVine, Nur Yalman, Dan Goodenough, and Allan Brandt deserve special thanks. Students (and former students) who have taken my graduate seminars on theory in medical anthropology have discussed many of the issues of this book with me, quietly criticizing my formulations and influencing me immeasurably. Though I am certain to omit names that deserve mention, Terry O’Neill, Paul Brodwin, Eric Jacobson, Lawrence Cohen, Paul Farmer, Jim Kim, Anne Becker, Linda Hunt, Lindsay French, Michael Nathan, Julia Paley, and David Attyah are among them. Of special importance have been conversations with fellows in the Harvard program, including Peter Guarnaccia, Janis Jenkins, Tom Csordas, Cheryl Mattingly, Linda Garro, David Napier, and Bob Desjarlais; the latter three made extensive comments on parts of the text. Among my colleagues, Allan Young, Charles Leslie, Ronald Frankenberg, Amélie Rorty,
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The body, illness experience, and the lifeworld:
a phenomenological account of chronic pain

In his book *Objective Knowledge*, Karl Popper (1972: 106) outlines a “three-world” theory, which serves as the basis for his epistemological arguments:

we may distinguish the following three worlds or universes: first the world of physical objects or physical states; secondly, the world of states of consciousness, or mental states, or perhaps behavioral dispositions to act; and thirdly, the world of *objective contents of thought*, especially of scientific and poetic thoughts and of works of art.

What I have described as biomedicine’s “folk epistemology” is consistent with such an ordering of reality. Disease is located in the body as a physical object or physiological state, and whatever the subjective state of individual minds of physicians and patients, medical knowledge consists of an objective representation of the diseased body. I have argued for an anthropological alternative to such an analysis of medical knowledge, based on a critical examination of how medical practices and ontologies shape the objects of medical attention. However, the difficulties with the objectivist account are more immediately evident when we look closely at illness and its experience. For the person who is sick, as for the clinician, the disease is experienced as present in the body. But for the sufferer, the body is not simply a physical object or physiological state but an essential part of the self. The body is subject, the very grounds of subjectivity or experience in the world, and the body as “physical object” cannot be neatly distinguished from “states of consciousness.” Consciousness itself is inseparable from the conscious body. The diseased body is therefore not simply the object of cognition and knowledge, of representation in mental states and the works of medical science. It is at the same time a disordered agent of experience.

In a biographical account of his experience of major depression, *Darkness Visible: A Memoir of Madness*, William Styron writes of how he first began to notice the onset of his illness, “It was not really alarming at first,” he writes (1990: 42), “but I did notice that my surroundings took on a different tone at certain times: the shadows of nightfall seemed more somber, my mornings were less buoyant, walks in the woods became less zestful . . . .” Changes there were, certainly, in the body as physiological state, however much neuroscientists may still disagree about just which changes are decisive for melancholia or major depressive episodes. But for Styron, it was the world that first seemed to change. With hindsight, he came to interpret those changes as part of the process of the illness, but the body as physical object and as agent of experience did not belong to separate worlds. The illness was present in the lived body. It was experienced as a change in the lifeworld.

For some medical conditions, the objectivist rendering of the body has served medicine reasonably well. For other processes to which medicine attends — birth, or chronic illness, for example — the abstracting of a world of physical objects and physiological processes from social and meaningful phenomena (“birthing,” “illness”) has led to a rational but highly distorted form of medical practice. For yet other conditions, such as chronic pain, the distinction between the world of physical objects and mental states so obscures understanding as to render the phenomenon largely unintelligible. Chronic pain challenges a central tenet of biomedicine — that objective knowledge of the human body and of disease are possible apart from subjective experience (M. Good et al. 1992). The folk distinction between the world of objective reality and that of subjective experience also raises havoc in the management of pain in the “social body” and the “body politic,” where policies concerning compensation or disability payments break down over debates about how to provide objective markers of pain.1 The integration of human experience into accounts of disease is thus a constant challenge for medical discourse and policy debates.

When one turns to the human sciences for guidance, remarkably little is to be found. The literature on illness representations is voluminous — in history, literary studies, the social sciences, and the medical humanities, whether analyzed as beliefs or cultural models or illness narratives or mystified social relations. But detailed, ethnographic accounts of illness experience, or a well wrought theoretical vocabulary for the study of illness as human experience, are largely absent. We know intuitively that ritual practices of mourning and experiences of grief have important differences both within and across cultures, quite different trajectories and rhythms, and that the two answer to quite different analyses. But although the study of funeral rituals is extensive, it is nearly impossible to find experience-near accounts of grief.2 The same is remarkably true for the study of illness. Although descriptions of healing rituals are plentiful, the difficulty of finding full, rich accounts of the experience of important forms of illness is startling. More than that we hardly know what such studies should look like. Indeed the assumption that experience is subjective, belonging to the “dark grooves of the mind,” and therefore ultimately unknowable, undermines any effort to develop comparative studies of particular forms of human experience.

In medical anthropology, this is an issue we can no longer neglect. Research that attends only to semiotic structures or social processes seems to miss the essence of what gives illness its mystery and human suffering its potency. Even more importantly, however, any truly anthropological account of illness cannot afford to attend only to objective disease and to cultural representation, with
subjective experience bracketed as a kind of black box. A primary claim that I have been developing in these pages is that medical knowledge is socially and culturally variant, and that in part this is true because illness itself, the object of medical knowledge, is socially and culturally variant. An understanding of what this could mean, the development of a theoretical frame to account for findings of enormous variation in the course and prognosis of such profoundly debilitating diseases as schizophrenia, and the development of categories and methods for investigating how illness varies across cultures all require serious attention to what Arthur and Joan Kleinman (1991) have recently called the "ethnography of experience."

This chapter is written as a contribution to the development of a theory of illness experience. Rather than the body as site of domination or the object of medical practice, my primary attention in this chapter will be focused on the body as creative source of experience. The relations among embodied experience, intersubjective meaning, narratives that reflect and rework illness experience, and the social practices that mediate illness behavior are central to my account. More specifically, this chapter is a methodological exercise. It is an effort to provide an account of illness experience drawing on the phenomenological analyses of Alfred Schutz. A single case study of an individual suffering chronic pain serves as the primary data. My hypothesis is that as Styron describes in his memoir, serious illness, along with grief and other extreme experiences, provokes a shift in the embodied experience of the lifeworld, leading to what literary theorist Elaine Scarry (1985) calls "the unmaking of the world." I argue that we can specify in phenomenological terms several features of this process, which may prove useful in future comparative studies. I argue that social structures and practices mediate and further shape the "unmaking" of the lifeworld, requiring us to pursue a "critical" phenomenology. And I explore the hypothesis that narrative, the imaginative linking of experiences and events into a meaningful story or plot, is one of the primary reciprocal processes of both personal and social efforts to counter this dissolution and to reconstitute the world.

Data for my discussion are drawn from several studies on chronic pain carried out with my colleagues at Harvard Medical School. I begin with an analysis of the text of a single, four hour interview with a twenty-eight year old man suffering from chronic pain, and develop the themes of my analysis in relation to this case. I discuss the case in three parts: the "narrative," the "phenomenology," and the "symbolization."

The narrative: the origin myth and a life history of pain

"Doctor, is it possible that an experience in childhood can cause pain like this?" I was greeted at the door to my office in the Medical School by a sixty-four year old man bringing his twenty-eight year old son for an interview. The older man was tall and fairly thin, had a sagging face, and showed sadness and concern. The son looked even younger than his twenty-eight years, walked rather stiffly, his face frozen and expressionless, perhaps, it appeared, the result of medications. I deflected the question, though it remained among us, asked them to join me and sit down, explained that I was an anthropology professor, not a physician or a therapist, and invited the younger man, whom I'll call Brian, to participate in the study. He agreed readily, and with his permission, I invited his father to remain for the interview.

What followed was a remarkable story of a life of pain—a pain with a haunting origin myth, a pain that radically shaped the lifeworld of a young man, a pain for which he struggled to find meaning and a language for expression. After asking a few brief questions about his background, I asked Brian to tell me about his pain, to tell me the story about when it began and how he had tried to treat it. The narrative that evolved represented an effort to give shape to the pain, to name its origins in time and space, to construct a biography that made sense of a life of suffering.

He had a clear name for his pain—"I describe it as TMJ"—and a moment of diagnosis—the fall of 1984, November, recognized by a general physician who noticed snapping and clicking in his jaw when he opened and closed his mouth. But the description of his pain and its history quickly eluded ordered characterization, spilling out into his life.

...I always seemed to have these things happening to me. I'd encounter dizzy spells and not know why I'd had them. ...I was depressed and would just always be seeing counselors, would always be in a therapist's office for one reason or another. Then, [I had] the headaches, the dizzy sensations, sometimes had nausea that accompanies it. ...it erupts in different places in your body. It comes in my head, then I have pains in my chest. ...it starts radiating and going into your joints and going, traveling around inside your body, it's like a heat ...it's a burning type of a heat, and ah wrenching, and you feel it traveling along and then it ...

But when did it all begin? "it might have ...begun in adolescence, although it became more pronounced, as uh, as I got older ..." But did you seek treatment for it in high school? "I hadn't even thought of it or interpreted it as a physical problem." As psychological? "... even before I entered high school I think I was seeing therapists, and even when I was a child I was seeing therapists." So you have a long history with psychological counselors? "... a very long history ..." Since the time your father mentioned, since you were two? "Yeah."

There are no secrets here, no mysteries to find voice for the first time. A generation of therapists have heard the story. But it remains primeval, mysterious.

at about that time, Mother had become gravely ill and she wasn't able to take care of me, and Father didn't feel in a place where he could do... a good job of it either. He didn't want to have relatives come on the scene and take care of me. So, there was a... an... institution... an orphanage of some sort... So I spent a period of three months when I was two years of age and... it might have just come in right at that time... that stripped me of any parental attachment. And ah... it was very traumatic. I have no conscious memory of it, but... something that damaged my feelings in the process.
And so a story took shape. The mother of this small child had hepatitis and was hospitalized. His father chose not to leave him in the care of the family members, but to the care of an orphanage he trusted. The infant emerged three months later completely changed, a “zombie,” he says. Brian was considered to be of above average intelligence in his childhood, but he was extremely sensitive and suffered spells of anxiety, of panic.

During adolescence Brian began to have pain – increasingly intense pain, “chronic headaches, radiating pains in and around my head, in the ear canal, and my throat.” He had spasms in his mouth and felt he was being choked. His depression and spells of anxiety continued; he would get anxious, dizzy, feel the terror of losing control. And then, “over a long period of time the depression sets in, the chronic malaise and fatigue.” He has been treated with both anti-depressant and anti-anxiety medications, and was taking both at the time of the interview. The mysterious events within the walls of the orphanage, hidden from view and prior to symbolized memory, are inscribed in his personal history as well as his body, evoking terror unmitigated by medication or psychotherapy.

Overlapping this narrative, a second unfolds. In 1984, three successive physicians, treating him for congestion and pain in his ears and head, heard a clicking and popping sound in his jaw, suggested he might be suffering from “temporomandibular joint disorder” or TMJ, and recommended restorative dentistry. An ENT specialist explained his problem as “a malfunction of the jaw.” Thus began a reinterpretation of all of his pain. “I was still a little bit skeptical about the whole thing.” But when the third consecutive physician mentioned the problem, “I said well, now, there’s just no way of ducking it anymore.” As a consequence, “I began to think that this is something that may have a physical basis in my jaw and that I’d better start looking into . . . actually see where it leads me, and the whole idea was . . . one of hope, I guess, because now I had pinpointed something and defined it in a way. I can say that it’s in my head, but it’s not all in my head.”

Since that time, his life has been ordered in part by relationships with a succession of medical specialists. He has been to several dentists, who focused on the problem of misalignment of his jaw and treated him with occlusal devices. He spent over a year in treatment with a physical therapist, who undertook deep tissue massage of his entire body. Most recently he had gone to a surgeon for further evaluation. He has had periods of respite and hope, when treatments seemed to be having some benefit, but each has been short-lived. The latest set of x-rays and evaluation found no abnormality requiring surgery, and the surgeon recommended relaxation, meditation, and exercise. “And how did this strike you?” I asked.

Well, it sort of was an answer I may have been able to give myself actually. I didn’t need to see a specialist for that . . . it’s back to an ambiguity again. And then it goes back into my conflict about my body. Is it my body? Is it my thinking process that activates physical stresses? Or am I, or is it the other way around? It’s all that uncertainty that . . .

“No magic bullet,” I said.
Yeah, no magic bullet. Every time I look for one, I seem to encounter just another . . . maze or morass of things . . .

Two narrative structures, attempts to authorize the self, follow patterns all too recognizable to those who study chronic pain in Western culture. Soma is juxtaposed to Psyche. The body as object of treatment and source of hope is juxtaposed to life history as the source of suffering and psyche the object of therapy. These life stories represent competing narratives or plots, competing efforts to, as Paul Ricoeur (1981a: 278) says, “extract a configuration from a succession.” All narratives, as theorists from Aristotle to Kenneth Burke to Hayden White have shown, are stories about lived experience. They describe events along with their meaning for persons who live in and through them. They “emplot” experience, revealing its underlying form. The two narratives that emerged in Brian’s account are attempts to link his lived experience to an underlying coherence, a story line, a meaning. And the story has a quality Ricoeur (1981a: 277) calls “directedness,” a teleology, a sense that the story is going somewhere. The narratives are aimed not only at describing the origins of suffering, but at imaging its location and source and imagining a solution to the predicament. When the imagined outcome of the story fails to materialize, however, when suffering is not relieved, neither narrative gains authority, and the self is threatened with dissolution.

The phenomenology: the shaping of a world of pain

Elaine Scarry, in her book The Body in Pain: The Making and Unmaking of the World (1985), provides an arresting description of the nature of pain, based on analyses of descriptions of torture. Acute pain resists language, she says. It is expressed in cries and shrieks, in a presymbolic language, resisting entry into the world of communication and meaning. It “shatters” language (p. 5); indeed, “intense pain is world-destroying” (p. 29).

Unlike torture victims, for many pain patients, language is far from shattered in a literal sense. Brian was frighteningly articulate, though language at times seemed inadequate to express the subtle sentient quality of his suffering. As he sat stiffly and quietly, he described so rich an inner world that I listened with astonishment. At the same time, his pain has a “world-destroying” quality. It shapes his world to itself, resists objectification and threatens the structure of his everyday life.

“How would you describe what’s going on inside of your body?” I asked.
Sometimes, if I had to visualize it, it would seem as though there there’s a ah . . . aura, a demon, a monster, something very horrific, horrible lurking around hanging the insides of my body, lifting it apart. And ah, I’m containing it, or I’m trying to contain it, so that no one else can see it, so that no one else can be disturbed by it. Because it’s scaring the daylights out of me, and I’d assume that . . . gee, if anybody had to, had to look at this, that ah . . . they’d avoid me like the plague. So I redouble my
efforts to... say... I'm gonna be perfectly contained about this whole thing. And maybe the less I do, the less I make myself known, and the less I, I ah, I venture out or... or display any, any initiative, then I won't let the, this junk out. It seems like there's something very, very terrible happening. I have no control over it...

Through the haunting words and menacing images of his description, Brian provides us access to a world of pain. It is a shocking world of monsters ripping apart his body, a private world he fears to share with others, a world they could not possibly understand, and yet a world absolute and inescapable for him, which he wants desperately to construe as imaginary but cannot. At the same time, through great determination, Brian has continued to go to work every day as a claims processor in a private insurance company. He lives with his family, attends meetings of a support group, visits physicians and therapists, attends classes at night, and is a painter.

**Worlds of experience**

What do we mean by invoking the term "world" in this context, and how is it related to an analysis of experience? Do we gain analytic power by speaking of the world of the chronic pain sufferer? In what way can chronic pain be said to "unmake" the world for the sufferer?

The term "world" as used throughout this analysis is derived from a long history of phenomenologically oriented philosophers and social scientists – from Husserl, Merleau-Ponty, and Sartre to Nelson Goodman, and from William James to Alfred Schutz and various contemporary sociologists and anthropologists. For Husserl, the "life-world," the Lebenswelt, is the world of our common, immediate, lived experiences (see Cockelmans 1967). This world is often contrasted with the objective world of the sciences, and many assume that the latter represents reality in the strict sense of the word. Husserl and like-minded social scientists have argued that rather than the lifeworld presupposing this scientific world, the converse is true. Science is grounded in the lifeworld. It assumes a particular perspective, a particular attitude to be taken toward reality, and it constitutes distinctive forms of knowledge, but it presupposes dimensions of experience and its interpretation common to the lifeworld (see Brand 1967).

The scientific world is only one of several worlds or "subuniverses" in which we live, worlds which include those of religious experience, of dreams and fantasies, or music and art, and of the "common-sense" reality which is paramount in much of our lives. These are not simply forms of individual experience, but diverse worlds, with distinctive objects, symbolic forms, social practices, and modes of experience.

Merleau-Ponty followed Husserl in situating phenomenology between empiricism and transcendental idealism. Phenomenology is a descriptive science, he wrote, that "offers an account of space, time and the world as we 'live' them" and "tries to give a direct description of our experience as it is..." (1962: vii). The world is constituted prior to our entry into it; it is not a result of our thinking...

- we are thrown into it. (And thus he pursues a critique of transcendental idealism.) It is an intersubjective world, a social and cultural world, a world that resists our desire to shape it to our own whims, a world of social and empirical facts and realities that cannot be wished away.

In *Phenomenology of Perception*, Merleau-Ponty (1962) elaborates an analysis of the body as the ultimate medium of experience and thus of our understanding of the phenomenal world. Rather than beginning his analysis with the division between objective world and experiencing subject, he starts with the "pre-objective," the existential beginnings of "the experience of perceiving in all its indeterminacy and richness" (Csordas 1990: 9; cf. Merleau-Ponty 1962: 207–242). He then examines the movement of perception from the body, the grounds of experience and intentionality, to the objects as constituted in perception. His analysis has served as the basis for recent discussions of embodiment, in philosophy and medical anthropology. This phenomenological tradition suggests that in attempting to understand the experiential world of chronic pain, or to study illness experience cross-culturally, we must explore the organization of embodied sentence, of experience in all its sensual modalities, as well as the objects of experience. The rhythms and disruptions of experience presume a socially organized lifeworld, and a description of the contours of the social world as experienced requires attention not only to the cognitive shaping of experience, but to the sensual body as well.

In Brian's description, bodily experience assumes enormous proportions. Arising from the jaw joint, the pain quickly eludes narrow characterization, as Brian describes the flood of sensations and the anxiety it engenders. Panic merges again into his description of pain.

It goes into the head... the maxillary muscles... in the roof of my mouth would get all tightened up, and so I had to drink something warm to relax it. And it goes down here, and people would describe it as being choked or having this lump of... this sensation of being restricted all the way through here. [He gestured to his throat and chest.] And it starts going down. And then as your anxiety builds, and... and you start feeling other things, and... sensations of heartburn and ah... sometimes, I get... dizzy along with that. I start to breathe more rapidly. The scariest part of it is that I'm losing control... I attributed ah weakness in my leg to that and having stress in one leg more than the other... it's always my left hand that seems to be... have more pain in it than in the... these ah, muscle cramps that go down my ah left arm, and sometimes a numb sensation in my hand... Seems like at the worst moments, all my symptoms are ah prevalent... I have to do something. I've gotta get things done. I'm ah, I'm working and ah, why do I have to, have to have the illness of this type of, of affliction.

Pain becomes an "all," an experience of totality, not a single set of feelings but a dimension of all his perception. It flows out from the body into the social world, invading his work and infiltrating everyday activities.

The self is constituted in relation to a world, and it is not only through direct description of embodied experience but through the description of that lifeworld that we have access to the selves of others. Persons suffering chronic illness or
the “reality shock” of life-threatening conditions often describe their feeling that the world has changed.11 Much of the taken-for-granted of common-sense reality is recognized as conventional. The mutuality of the world, the sense that the world we live in is common to those around us, gives way. Significance shifts; quite different things in life come to matter. The challenge that chronic or life-threatening illness poses for the sufferer’s sense of reality, its threat to “unmake” or transform the world (Scarry 1985), suggests a method for investigating the phenomenology of illness experience.

Chronic pain and the unmaking of the “world of everyday life”

Alfred Schutz (1971), in his essay “On Multiple Realities,” follows other phenomenologists in distinguishing the “world of everyday life” from other primary forms of reality – dreams, fantasies, the world of art, science, the world of religious experience. Each of these has distinctive characteristics, distinct forms of organizing experience and modes of acting, which Schutz attempted to identify and analyze. For example, he showed that “common-sense” reality is characterized by the natural attitude, one in which objects are taken-for-granted rather than submitted to critical attention, as in the scientific attitude. It is the world of our everyday activities and projects, rather than a world of theory or imagination. Each form of reality is a distinctive “province of meaning” and mode of experience. It is my contention that Schutz’s categories of analysis of “common-sense reality” can provide the basis for inquiring into the world of chronic illness, examining how the everyday world is systematically subverted or “unmade.” I would argue that we can use this method to further social and cultural analysis, whether we follow Whorf and Hallowell in investigating the shaping of perception by language and culture, or Mauss and Bourdieu in investigating the socially informed body and cultural practices.12

Schutz (1971) indicates six features of common-sense reality, aspects of the making of the everyday world akin to Cassirer’s formative principles. For the body in pain, these formative processes are systematically deformed.

First, Schutz asserts that a specific “form of experiencing the self” is typical of common-sense reality. In the everyday world, the self is experienced as the “author” of its activities, as the “originator” of on-going actions, and thus as an “undivided total self.” We act in the world through our bodies; our bodies are the subject of our actions, that through which we experience, comprehend and act upon the world. In contrast, Brian described his body as having become an object, distinct from or even alien to the experiencing and acting self.13 He articulated several dimensions of this objectification.

The pain has agency. It is a demon, a monster, lurking within, banging the insides of his body. Pain is an “it” which “erupts in various places in your body,” a force which streaks around the body, which Brian seldom feels able to control. At the same time, pain is a part of the subject, a “thing” of the body, a part of the self. As a consequence, the body itself becomes personified as an aversive agent.

It is invested with menacing autonomy. “...I think it’s against me, that I have an enemy,” Brian said of his body.

In Brian’s world, the body has special primacy. As he eloquently describes, his body and its pain absorbs the world into itself, floods out into the world and shapes not only his experience but the experienced world. Brian struggles to continue to work, but the “illness of this type of affliction” threatens to overwhelm him. His body dominates consciousness, undermining his sense of being an “undivided total self” who is the “author” of activities, threatening to unmake the everyday world. It is only through “tremendous effort” that he can attend to what is for most of us our paramount world. He is absorbed, that is to say, not with the relevance of career, relationships, or other of the orienting rhythms of social life in North America, but instead, his attention and preoccupations are absorbed by his pain.

Second, Schutz (1971: 218–222) argues that a “form of sociality” is typical of common-sense reality. One of the most fundamental assumptions of everyday life, according to Schutz, is that we live in the same world as persons around us, that the world we experience and inhabit is shared by others. For many persons with chronic illness, this assumption is called into doubt. Their world is experienced as different, as a realm which others cannot fully fathom. They feel alienated from others, separated from the everyday world of work and accomplishment.14 “I feel left out,” another patient told me. “TMJ has really like put a hold on my life.” For many, medical activities come to dominate their lives, replacing their normal interactions, increasingly shaping their lives to the world of clinics and therapies and tests and medications, increasingly alienating them from the social relations and projects that have been central to their lives.

For the sufferer of pain, this sense of alienation from others is often particularly acute. Pain resists the objectification of standard medical testing; there are no pain meters, no biochemical assays for pain. It resists localization; most efforts to identify the site of the origin of chronic pain fail, despite all advances in imaging techniques, and nearly all surgical attempts to remove pain pathways are quickly undone by the body’s efficient generation of new pathways.15 Given the close link between the visible and the real in the clinical practices of medicine, resistance to imaging yields challenges to the reality of the condition and disaffirmation of the sufferer. Absolute certainty to the sufferer, pain remains ambiguous and unverifiable to others; it remains interior, resisting social validation (Scarry 1985: 4, 56).

Brian described his experience of the breakdown of a commonly shared reality. “People really can’t understand the TMJ person at all... They don’t believe in you. They think you’re just a little bit different and strange. Ahm, sort of ahm a misfit... inscrutable... Maybe this is just something you’re making up.” Brian
desperately wishes he could believe the pain were made up, that he could “explain it away... say that it’s all just imaginary, it’s a figment, it really doesn’t exist.” He cannot do so. On the contrary, pain is the central reality, dominating experience and expression. Verbal objectification, communication of one’s experience to others, and thus the extension of the self into the world are increasingly reduced to expressions of pain. But since others doubt the word, they doubt the world and its author. As a consequence, the self and the world of the pain sufferer are threatened with dissolution.

A third feature of the everyday world, Schutz argued (1971: 214–218), is the experience of having a “common time perspective,” one we share with others. This is far more subtle than we often imagine, as becomes clear when persons discover they have life-threatening illness and begin to reassess time. Such persons often report experiencing time differently than those around them. Time is precious, it is short, not to be wasted, experienced with impatience. For Brian, inner and outer time, what Schutz calls duree and cosmic time, seem out of sync. Even more terrifying, time itself seems to break down, to lose its ordering power.

it’s kind of strange when I come home at night and I lay down for fifteen minutes. I might drift off into sleep and I might not, but I’m sort of in an in between state and ah, then I won’t know whether half an hour has passed or a whole day, or ah three or four hours. Time becomes distorted.

For me... time... seems to be spreading out, almost like I can’t say anything is happening now. I have no way of pigeon-holing a specific span of time which I can get a few things done. Seems like I’m usually losing track of it. I can’t keep up with it. It’s all, everything’s caving in on me at once; the past, the present are coming together all at one time. . . . episodes that repeat over and over again: you know, physical episodes of pain that seem to repeat. I can remember a time in the past when you’ve had it, and you can’t even distinguish now from then. You really get a very warped and distorted view of what time is. So, that’s sort of, a very disturbing aspect of it.

Time caves in. Past and present lose their order. Pain slows personal time, while outer time speeds by and is lost. “I feel like the world is passing me by,” another patient told me. An act of will is required to order time, and time filled with pain is experienced as lost. Thus as articulate as Brian is about the world of pain, it cannot be sustained by language. It is a world threatened by dissolution. Space and time are overwhelmed by pain, and the private world not only loses its relation to the world in which others live, its very organizing dimensions begin to break down. Pain threatens to unmake the world, and in turn to subvert the self.

Schutz identifies three other dimensions of the everyday world, which I will describe more briefly. Common-sense reality has a specific form of consciousness: “wide awakensness” and full, active attention (1971: 212–214). Pain, by contrast, is distracting, tiring, and pain medications fashion a change in consciousness. The everyday social world, Schutz argued, is organized in terms of our intentional projects (pp. 222–226). For many pain sufferers, everyday life goals are subverted by the prominence of pain, and the world of suffering and of medicine come to be the paramount reality, replacing the prior social world. And Schutz argued that the natural attitude is to suspend doubt in appearances; we “take the world and its objects for granted until counterproof imposes itself” (p. 228). In particular, we suspend awareness of our mortality and the resulting “fundamental anxiety” concerning our death. We live as though the present extends indefinitely. For those with chronic or life-threatening illness, this epi- oche or suspension of doubt often fails. Vulnerability—of the body, and of the self—is an ever present companion. Many describe an irrational sense of betrayal, the feeling that faith in their body and the taken-for-granted world have been stolen away. With the irruption of awareness of mortality comes the sense that the world itself is untrustworthy. Thus the world of everyday consciousness and experience is systematically subverted.

Although the conscious body is deeply implicated in the “unmaking” of the life-world, it would be a mistake to underestimate the extent to which the social and political body is also a source and medium of experience. If experience is intersubjective and evolves in dialogue with those in the social environment, this dialogue and the structures it mediates are also constitutive of experience. In the case of torture, as described by Scarry, the conscious world is unmade by the systematic procedures of the torturer, which seem designed with a phenomenological cunning. In the case of chronic pain, much of the social and political world in which the sufferer engages is designed specifically to provide care and alleviate suffering. However, the institutions of modern medicine are most often shaped to the task of the “remaking” of the life world with all too little cunning. Indeed, the irrationalities of medicine as a social and political institution often contribute, both overtly and subtly, to the unmaking of the everyday world of the sufferer.

Chronic pain patients often become deeply involved in the health care system, as they persist in efforts to find relief and efficacious treatment. Their interactions with the medical system play a crucial role in shaping their experience. Of the thirty-two TMJ patients we interviewed, over 70 percent had been to ten or more different types of practitioners for treatment. For many of them, the health care system, along with the bureaucracy of insurance and welfare agencies, had come to occupy much of their time and activity. Their pain and feelings of self worth were often deeply affected by the consistent disaffirmation they encountered and their struggle for legitimacy (see Kaufman 1988). In some cases, they were also influenced in a primary way by the irrationalities of the reimbursement and disability systems to which they were subject.

A young woman in our research told me about one kind of downward spiral. Her pain forced her to take a leave from work, and she began a constant round of doctors and clinics. She tried to return to work, but her pain was so disabling that her physician recommended she take a leave. As a consequence, she lost her job; “that’s when everything went away,” she said, “and I haven’t really been back since.” “Now, actually we’re going to... welfare, and social security, medicaid. That’s enough to keep me busy, but still it’s nothing like... working.” She has...
continued to seek medical care, determined to find an effective treatment, go back to work, and get on with her life. Without insurance, however, she has gone from having a small savings to having unmanageable debts and relying on welfare. Despite her best efforts, to date she has not succeeded in being recognized as validly disabled and eligible for SSI payments. She is thus forced to seek medical care from practitioners who will wait for payment until she receives such insurance. She describes this experience as “very draining.” It “looked like the hole kept getting bigger. It didn’t get smaller, it just kept getting bigger and bigger, and then I knew I needed the treatment to try to help, but never did get any, never was nothing, not that much progress . . .” Thus, for this young woman, as for many chronic pain sufferers, conforming to the schedule of the health care system and attempting to negotiate the irrationality of the American welfare and insurance bureaucracies came to be a world of its own, replacing the everyday world which had preceded it. “It keeps me busy,” as this young woman said, but it does so at the expense of the world of work and accomplishment. The “political body” of pain and its management serves as source and medium for her experience, shaping her activities and forming her world to its own.

The symbolization: the struggle for a name

If chronic pain and other forms of chronic illness threaten to systematically deconstruct or subvert the lifeworld, this dissolution is countered by a human response to find or fashion meaning, to reconstitute the world, or as Scarry (1985: 6) says, “to reverse the deobjectifying work of pain by forcing pain itself into avenues of objectification.” Many medical activities, as well as traditional forms of healing, can be seen as devoted in part to such objectification and reconstituting of the threatened lifeworld. Diagnostic and therapeutic activities, as well as efforts to construct an effective narrative of suffering or to fashion meaningful careers in spite of illness, can be understood as efforts to counter the unmaking of the lifeworld. Diagnosis is an effort to depict the source of disease, to localize and objectify cause. It is also, however, an effort to “invoke” an effective response. Narrativization is a process of locating suffering in history, of placing events in a meaningful order in time. It also has the object of opening the future to a positive ending, of enabling the sufferer to imagine a means of overcoming adversity and the kinds of activities that would allow life experience to mirror the projected story.

One of the central efforts in healing is to symbolize the source of suffering, to find an image around which a narrative can take shape. In his classic account of the Dinka, Godfrey Lienhardt (1961) describes the response to those suddenly possessed. Ajak was a young man with an origin myth even more remarkable than that of Brian. He was born without testicles, and was about to be put into the river by his father; instead, the infant’s father was prevailed upon by his mother to offer a white sheep in sacrifice to Divinity, whereupon first one, then the other testicle appeared. Ajak was suddenly possessed by a power. He ran wildly for twenty minutes, and finally collapsed, sprawling on the ground. Lienhardt describes the response (p. 59):

Then a minor master of the fishing-spear came and, addressing what he said to the thrashing form of Ajak, asked whatever it was which troubled him to tell its name and say what it wanted. In his address he tried to elicit answers from several potential sources of possession, saying, “You, Power” (yin jok), “You, divinity” (yin yath), and “You, ghost” (yin atiep). No reply, however, came from Ajak, who continued to moan and roll about. The master of the fishing-spear then began to take to task the Power which troubled Ajak, as follows: “You Power (jok), why do you seize a man who is far away from his home? Why do you not seize him there at home where the cattle are? What can he do about it here? . . .”

Ajak mumbled unintelligibly; the spectators were clearly expecting something to speak through his mouth, and to tell us its name and business. They explained that in due course it would leave him (pad). When I asked what “it” was, I was told variously that it would be his (clan) divinity (yath), or the ghost of his father, or the free-divinity Deng, or “just a Power” (jok epath). Since it would not announce itself, how could one know?

The naming of the source of suffering, particularly for those in chronic pain, often resembles this mysterious scenario. What is your name? Why are you troubling him? the physicians seem to be asking. The response is often unintelligible. “It” refuses to speak. And if it will not announce itself, how can one know?

The young man I have been describing was possessed of such an entity. The pain has resisted symbolization, refused to answer to a name, though many names have been proposed. “Childhood trauma,” a generation of therapists have called out, and a narrative and treatments have been devised, but it refuses to answer. The name “TMJ” has been invoked, offering a moment of hope of localization and relief. But this too has failed. Brian recognizes the seductive quality of his longing for a somatic disease with a physical cure, because of his remarkable honesty. But too much is at stake to give up hope. To name the origin of the pain is to seize power to alleviate it, and the intensity of the pain demands urgency. To name the origin of the pain is also a critical step in the remaking of the world, in the authoring of an integrated self.

At the time when I undertook the interview, Brian stood at the threshold between symbolization and despair. He finds some relief in his art work, for him, it seems, a symbolic form of world making and self-objectification. When language fails as a medium of self-extension, he turns to surrealist painting.

There are times when I, when a lot of things that are ineffable about what goes on internally, I can find expression in the art. A lot of bizarre things I cant verbalize come out in the images I [construct] . . . If I have a shrieking person inside me, someone that’s yelling and screaming and trying to get out, sometimes I don’t do it concretely. You know, I don’t do it verbally. I do it by . . . it comes out in the [painting] . . .

Lienhardt provides a provocative analysis of the role of symbolization in healing. The Dinka “Powers,” these possessing spirits, may be understood to represent complexes of Dinka experience, he suggests, which they understand to be the grounds of their experience.
Without these powers or images or an alternative to them there would be for the Dinka no differentiation between experience of the self and of the world which acts upon it. Suffering, for example, could be merely “lived” or endured. With the imaging of the grounds of suffering in a particular Power, the Dinka can grasp its nature intellectually in a way which satisfies them, and thus to some extent transcend and dominate it in this act of knowledge. With this knowledge, this separation of a subject and an object in experience, there arises for them also the possibility of creating a form of experience they desire, and of freeing themselves symbolically from what they must otherwise passively endure. (1961: 170)

For Brian, the monsters and the demons contained in his body may be primordial forms of such images, visual images arising from the pre-objective imagination of one who expresses himself most clearly in the visual images of his art work, and thus forms of objectification of the grounds of his suffering. However, these remain latent sources of objectification. Unlike the experience of the Dinka, Brian’s demons are not fully integrated into the intersubjective world, social beings which serve to join consciousness to the social world, subject to ritual action and thus forces for healing. Instead, he seeks relief through the identification of his suffering as the result of a physical lesion or a psychological trauma. Unfortunately, in the absence of a shared cultural myth, medical, dental, and psychiatric care too have failed to provide a successful symbolization of his disorder, one which is effective in moderating his suffering. As a consequence, Brian has clung to his art work as a form of imaginative self-extension, of projecting of consciousness into the world. He also adheres to his work, to a career which maintains his relation to the social order. These courageous activities have enabled him to cling tenuously to the everyday world.

The making and unmaking of the world

In an essay on the French impressionist Cézanne, Merleau-Ponty described the painter’s vision of the world, which, he said, “penetrates right to the root of things beneath the imposed order of humanity.”

We live in the midst of man-made objects, among tools, in houses, streets, cities, . . . We become used to thinking that all of this exists necessarily and unshakably. Cézanne’s painting suspends these habits of thought . . . This is why Cézanne’s people are strange, as if viewed by a creature of another species. . . . there is no wind in the landscape, no movement on the Lac d’Annecy; the frozen objects hesitate as at the beginning of the world. It is an unfamiliar world in which one is uncomfortable and which forbids all human effusiveness. If one looks at the work of other painters after seeing Cézanne’s paintings, one feels somehow relaxed, just as conversations resumed after a period of mourning mask the absolute change and give back to the survivors their solidity. (Merleau-Ponty 1964: 16)

Merleau-Ponty compares Cézanne’s perception of the world to that of mourners, which provides an eloquent commentary on the nature of the grief experience, even as it describes Cézanne’s paintings. For the mourner, the world also appears unfamiliar; people are strange, the landscape unnatural, movement stops midstream. The mourner has an acute awareness of the conventionality of the objects we live among; nature appears alien. And then, at some time, the world gets put back together. Conversation resumes. For those who have suffered a serious loss, this is a long, tortuous process, requiring serious work, grief work, hardly a simple resumption of conversation. Indeed, with the appropriate ethnographic observation, one could show, I think, how mourning rituals in many societies are aimed precisely at rebuilding the conventional world, returning solidity to the social order of the survivors, returning the “houseness” to our houses, the “streetness” to our streets, masking the absolute change that has occurred.

Merleau-Ponty and other phenomenologists often drew upon studies of individuals with psychopathology or severe perceptual impairments – blindness, deafness, aphasia. As in the case accounts of neurologist Oliver Sacks (1985), an impairment of some neurological functions reveals hidden dimensions of taken-for-granted aspects of human perception and the perceived world. (Who would have guessed, for example, that a specific perceptual mechanism is necessary to prevent us from mistaking a wire for a hat, as Sacks showed?) It has been my contention that we can use this method in reverse, examining dimensions of perception and the perceived world as an approach to understanding illness and its experience. In particular, rather than simply trying to describe what illness “feels like,” I have suggested we focus on how dimensions of the perceived world are “unmade,” broken down or altered, as a result of serious illness, as well as on the restitutive processes of the “remaking” of the world.

“Sickness subjects man to the vital rhythms of his body,” Merleau-Ponty wrote (1964: 172). As such, it breaks into the normal rhythms of life. Lived experience is organized in natural social rhythms, moving from activity to rest, from work to play, concentration to relaxation. Exclusive involvement in one or the other is a sign of pathology, or a moral flaw.18 We have some sense from the anthropological literature of the social shaping of such rhythms, as social life moved from formal transactions to intimacy, from structure and hierarchy to ritual and communities, from the everyday world to specialized worlds of religious experience or aesthetics or philosophical contemplation, and on a larger scale, from periods of order and quietude to eruptions of social dynamism or revolution. Sickness and pain submit experience to the body’s vital rhythms, infusing everyday experience with its distortion presence, focusing our awareness on the body as object, alien to the experiencing self, the object of cultural practices. The normal personal and social rhythms of experience are often subverted, shaped to the body’s demands.

They are often replaced, to some extent, by the new rhythms of treatment and care. Robert Murphy begins the prologue to his account of his own paralytic illness with a brief, vivid description of the night sounds on the neurological service, a floor of the hospital inhabited by the irreversibly ill. Its residents “are not transients,” he writes (1987: 1), “here for one or two weeks, but habitués,
denizens. Their confines are not alien to them — which makes the situation no less unpleasant — for the rhythms of their care are part of a familiar routine.” At night, when guests from the outside world leave, “the reinstatement of the hospital regimen... allows the patients to fall back into well-worn paths, grown familiar through many hospitalizations. In a way, they are glad when their guests leave.” This moment, immediately contrasted with Murphy’s life as a professor before his illness, alerts the reader to a long process that will eventuate in the radical revision of the everyday rhythms of his life, providing a sense perhaps of a resolution that follows years of resistance to the encouragement of the medical establishment’s routines into his world.

The experience of chronic pain — in the phenomenal, social, and political body of the sufferer — has special characteristics in the context of American culture and the American medical system. Chronic pain lays bare the contradictions of our metaphors of mind and body (Kirmayer 1988). In Merleau-Ponty’s terms, pain begins in the pre-objective body. But in the process of its perception, it heightens the distinction between subject and object, mind and body. As I described in chapter 3, our medical practices are designed to localize suffering in a discrete site in the body, a site which can be made visible and subjected to therapeutic procedures. Chronic pain resists such objectification, defeats medical practices aimed at its localization time and again. It is thus proclaimed subjective, a functional disorder of the subjective self, now held responsible for producing its own suffering. The resistance of pain to objectification, which Scarry identifies, is thus amplified by ideological and cultural practices. And as we have seen in the case of Brian, this juxtaposition of subject and object, mind and body, and the resistance of pain to be located in either is represented in narrative accounts, as well as in therapeutic strategies.

There is a structural correlate of this ambiguity. Because pain resists objectification, the treatment of chronic pain is conducted in a liminal zone of American medicine, in a set of widely diverse institutions, pain centers, forms of therapies, and therapeutic ideologies. This is doubly true in the case of jaw joint disorders, because of their liminal position between medicine and dentistry. Chronic pain patients thus find themselves rejected by standard medical practice and referred to institutional settings which are then vilified as non-scientific, alternative, nonorthodox, and for which reimbursement is unavailable or only marginally legitimate. The resistance of the body to the treatment of pain is thus amplified in experience by the contradictions of the American health care system.

Over against both the phenomenological and social processes that unmake the everyday world for the chronic pain sufferer, I have argued that various restitutive processes can also be seen at work. I have focused on two linked interpretive practices which serve this end: “symbolization” and narrative. A word about each. I have several times described efforts to find a diagnosis as a form of symbolization akin to “invoking” the origins of suffering rather than “depicting” them. I follow here a distinction made by philosopher Charles Taylor, whose work I discussed in the first chapter. The usual medical understanding of diagnosis follows an empiricist, referential view of language — that language more or less accurately depicts the objective world, that other functions of language are metaphorical or subjective and secondary. Taylor argues that from the view of language as intersubjective and constitutive of lifeworlds, a position he develops and defends (1985a, 1985b), the invocative function is often more primary than the describing or depictive functions of language. He takes as his example religious or mythical language, in which “the words are true/right because they have power, they invoke the deity, they really connect with what he is” (1985b: 286). In these terms, religious statements — that “God takes the form of a bull,” for example — are not simply metaphors for something more real, some aspect of social structure or the means of production, but a way of invoking and formulating reality. Similarly, the symbolic naming of the sources of suffering serves to formulate the object of treatment and thus organize a set of social responses and therapeutic activities. Certainly in the treatment of chronic pain, but also in far more medical practice than we usually realize, I suspect, the defining of particular medical problem as the source of sickness, which is to be addressed through treatment, is more like invoking than depicting. In the context of complex medical problems, any representation is partial at best. As the medical student I quoted in the second lecture said, “you distort the real world a little bit to make it fit that nice pattern.” And it is standard in medical practice to use the patient’s response to treatment as an indicator of the accuracy or correctness of the representation. But this is precisely using language to invoke. And if we assume that response to nearly all treatment — even routine pharmacological treatment — is far more multidimensional than a simple drug response, which placebo research has made patently obvious (for example Moerman 1983), it indicates the extent to which diagnosis and symbolization of the sources of suffering serve to invoke a mode of experience and form of reality as much as to represent or describe them. As Taylor concludes in a discussion of Frege, “you cannot understand how sentences relate to their truth-conditions... until you have understood the nature of the (social) activity, the form of life, in which they get so related” (C. Taylor 1985b: 292).

I have also focused on narrativization as a process through which the lifeworld is constituted. Although I have suggested that the inability to localize pain in a particular site in the body provokes a crisis of objectification and a special need for narrative, pain is not unique in requiring the work of narrative. Disease occurs, of course, not in the body, but in life. Localization of a disorder, at very best, tells little about why it occurs when or how it does. Disease occurs not only in the body — in the sense of an ontological order in the great chain of being — but in time, in place, in history, and in the context of lived experience and the social world. Its effect is on the body in the world! And for this reason, I have argued, narratives are central to the understanding of the experience of illness, to placing pain or epileptic seizures, as we will see, in relation to other events and experiences in life.

Cross-culturally, there are various prototypical illness narratives, filled with moral pathologies, spiritual forces, efforts at ritual healing, and these stories
contrast sharply with the American stories of pain. American pain narratives seem inevitably to derive from the contradictions of mind–body dualism, the highly complex and often delegitimizing language of stress, and the quest for affirmation that accompanies the search for relief. But the American pain stories, as with illness narratives across cultures, bring a certain coherence to events. As Roland Barthes wrote, narrative “casually substitutes meaning for the straightforward copy of the events recounted” (quoted in H. White 1981: 2).

It would be a mistake to fail to see how much is at stake in the telling of the story, in the effort to tell the correct story. Hayden White writes, “If we view narration and narrativity as the instruments by which the conflicting claims of the imaginary and the real are mediated, arbitrated, or resolved in discourse, we begin to comprehend both the appeal of narrative and the grounds for refusing it” (1981: 4–5). Narratives are the source of contested judgments. Contests such as choice of which treatment should be given, about whether any treatment is justified, about whether one should be reimbursed for medical care or given compensation for injury are adjudicated in terms of such narratives. And narratives are the basis for “moralizing judgments,” as Hayden White says (1981: 2–3). A great many anthropological studies of illness have shown that sickness is universally experienced as a moral event, as a rupture of the moral order that invokes such “moralizing judgments.” And efforts to bring meaning to such events requires not only resort to theodicy, in Weber’s terms, that is to answering “why me?” (with an implied “why me rather than him?”), but to the yet more fundamental soteriological issues. What is the nature of this suffering? What is the moral order that makes sense of it? What are the sources for hope to go forward in this context?

In sum, I am suggesting that we can bring method to the cross-cultural investigation of illness experience, method quite different than that suggested by the standard paradigms of the medical behavioral sciences. The unmaking and making of the world are social as well as perceptual processes that can be systematically investigated. They lead us quickly to phenomenological dimensions of illness experience, as well as to narrative and ritual dimensions of efforts to reconstitute the world unmade. They also reveal the practices and ideologies that encode structures of social relations and power, as these shape the rhythms of illness and therapies, and are thus subject to a critical phenomenology. And they open onto moral questions provoked by suffering. This chapter is only a small beginning, then, in suggesting directions for our investigation of experiential dimensions of human suffering.

The narrative representation of illness

In 1988, I spent the summer in Turkey with my wife Mary Jo and a group of Turkish colleagues interviewing persons who had been identified as suffering seizure disorders by members of an epidemiological research team. The researchers were conducting a four nation study of the community prevalence of epilepsy, types of treatment and social disability associated with the disease, and the response of the condition to various medications, with the support of the Pharma International Division of Ciba Geigy. Our goal in collaborating with this project was to develop a set of anthropologically oriented case studies, drawn from a community sample (in contrast to more common clinical studies). The community base for the sample, the availability of neurological data on all individuals, and the link to an epidemiological study made this a special opportunity. We invited persons identified as suffering seizure disorders, along with their families, to tell us stories about their illness and to describe their illness experiences – to tell us about their seizures, their efforts to find effective treatment, the responses to their condition by persons in their community, and the effects of the illness on their lives.1

The larger project began with a public health concern. Figures indicate relatively low utilization of anti-convulsive medications in much of the Third World, although clinical evidence suggests that seizure disorders are prevalent.2 Anecdotal data and a few published reports indicate that epilepsy is not only prevalent but highly stigmatized in many societies, that it produces significant psychosocial disability and often leads to physical injuries suffered during seizures.3 At the same time, when competent medical care is provided, epilepsy is susceptible to fairly clear diagnosis and to medical therapies.4 Why then is utilization of medications typically so low? Does it reflect poor medical treatment, misplaced expectations of complete cure, the rejection of drugs owing to side effects, the primacy of treatment by non-medical healers, or some other factors? Because surprisingly few anthropological studies have investigated these issues across cultures, we took the opportunity provided by the Ciba Geigy project to investigate the meaning and experience of seizures in a Turkish community.

Data from this study provide the opportunity for addressing not only problems
of medical care and public health, but for reflecting on theoretical and methodological questions central to this book as well. In the last chapter, I proposed that the narrativization of suffering serves to reconstruct the lifeworld “unmade” by chronic pain. In this chapter, I examine in more detail the role of narrative in the constitution of illness and illness experience. In particular, I am interested here in exploring how illness narratives are structured in cultural terms, and how these reflect or give form to distinctive modes of lived experience.

During our interviews in Turkey, many of the conversations we had – with those suffering seizures, with family members, persons in the community, and health care providers – were made up largely of stories. We were told stories of the sudden and shocking onset of seizures or fainting, of particularly dramatic episodes of seizures or extended loss of consciousness, of years of efforts in which families and individuals engaged in a quest to find a cure, of especially memorable interactions with physicians and with religious healers, and of experiences at work, with friends, and, for example, in marriage negotiations that were influenced by the illness. Analysis of these stories – the specific episodes embedded in these narratives, as well as the overall “story” of the illness in the lives of individual sufferers and families – allows us to examine in more detail the narrative construction of illness experience discussed only briefly in the last chapter.

The opening response to our initial question in the first household we visited was a story so vivid and so unexpected that it set the stage for much of what we learned in this project. We had traveled to a rather small, rural town some distance from Ankara on Turkey’s central Anatolian plateau, and made our way to the home of Melih Hanım, a fifty-six-year-old woman identified in the epidemiological study as suffering primary generalized epilepsy. Two of my Turkish colleagues and I were welcomed into a lush garden courtyard by a warm gracious woman and her daughter-in-law. We sat down on cushions laid for us at the front of the house, shaded from the heat of the morning sun by vines and fruit trees. After introductions and an invitation to tell us her story – the woman had previously agreed to participate in the epidemiological project – we asked her simply how her illness had begun. The woman’s daughter-in-law interrupted to answer the question.

“*My mother-[in-law]’s father had already married two women; he married twice. In addition to her mother, he took a third. Of course, in due time, problems arose in the household – like her step-mother wouldn’t call her ‘my child,’ or her father ‘my daughter.’ So it was difficult for her. There were people who wanted to marry her, and her father wanted to force her to marry one of them. She didn’t want to be given to that man. In fact, with my current father, my father-in-law, she eloped. After she went off, her father attacked her with a knife. He came to the house that they had gone to. When he was hitting the door like this [she gestured wildly], he was stabbing the door, he smashed the door open, he came in, and when she saw her father with a knife in his hand, she received a ‘shock,’ she was frightened, and from that day until today, she has been fainting. Whenever she is nervous, each time there is something upsetting. And also it happens at night.*

“It generally happens at night,” the older woman herself interjected.

“While sleeping?” my colleague asked.

“While sleeping. For instance, while sitting here, I suddenly fall back. It can happen anywhere – in the toilet, in the stable, at my neighbors, while sitting there, I fall back. I don’t know how it happens.”

A quite complicated story emerged. Melih Hanım had been suffering from seizures – or “fainting,” as she described the episodes – for nearly forty years. When she was a young woman, she resisted her father’s wishes to marry a man he chose and instead eloped with her husband – or had been “kidnapped” by him: the terms are ambiguous in Turkish. A short time after they had gone off to live together, her father came to force her to return. When she heard him beating on the door and saw him going to the window, forgetting it was covered with bars, she fainted away in fright. Since that time she has had recurrent seizures.

According to the daughter-in-law, she loses consciousness, tears run down her face, she hiccups, and she jumps. Her husband later told us it is just as though she were asleep.6 In addition, Melih Hanım told us she sometimes sees visions during her fainting spells, visions of her father with the knife in his hand, the same knife with the black handle that he had when he tried to break into her house when she first fainted, and she has dreams of people being killed, dreams that she is being threatened.

Melih Hanım reported a long history of seeking medical care, both from physicians and from religious healers. She herself has a “powerful hand,” inherited from her mother, which she uses for healing infants. She has been to shrines and various *hoca*s, both men and women who are religious healers.7 As her husband later said, “I swear, the *hoca* in the nearby village built the second floor of his house with the money I gave him. I spent a lot of money, but found no remedy.” Doctors haven’t been much better. “They treat people like animals,” the husband told us. It remains unclear from the family’s account whether doctors ever established a firm diagnosis of epilepsy. Recently, a physician diagnosed her problem as hypertension, told her not to eat salt, and put her on medications for her blood pressure. Her husband told us the fainting had recently declined in frequency. She does not take anti-convulsive medications.

The conversations we held with Melih Hanım, her husband, and her son and daughter-in-law were quite different than we anticipated and left us feeling confused – though with a sense that the questions were more interesting than we had anticipated. Were these “fainting” spells she suffered really caused by epilepsy, or were they psychogenic or hysterical seizures, perhaps some culture-specific form of dissociation? Were they caused by the initial psychological trauma, or were they caused by some other medical condition? The neurologists, relying on clinical evidence gathered using a detailed interview schedule – no EEGs were conducted – had judged Melih Hanım to be suffering from primary generalized epilepsy, based on her long history of recurrent seizures and the description of the episodes. Was her use of the term “fainting” (bayılma) rather
than epilepsy (sárp'a) significant in any way? What is the meaning of “fainting” in Turkish culture?

As the interviews went on, it became evident that “fainting” is a cultural category often used to describe classical tonic–clonic seizures. However, the term is associated with a more general semantic domain that includes fainting occurring in times of acute distress or in the context of a life of suffering, and is less stigmatizing than the term “epilepsy.” “Epilepsy” is used most often to report a physician’s diagnosis or to discuss extremely severe cases such as those associated with mental retardation. In popular discussions, “epilepsy” is more closely associated with madness than is “fainting.” Thus our discussions were most commonly about “fainting,” even for those who also described their condition as “epilepsy,” and the narrative structure, the stories of illness and the life stories associated with the condition, were organized around this more general domain. As a result, however, the stories were often quite ambiguous as to the nature of the illness, and it was often unclear whether the stories were “reports of experience” or were largely governed by a typical cultural form or narrative structure.

The same issue was raised in our attempts to elicit a “history” of the illness – again, a problem shared by physicians who attempt to elicit a clinical history. The stories we heard were life stories, and the temporal structure was organized around events of importance to individuals and families. The illness was “emploted” within several typical narrative structures, one of which was represented by Melih Hanım’s story of a dramatic threat producing an episode of fainting, which then led to persistent fainting or seizures throughout life despite sometimes desperate and costly attempts to find relief. But were these stories reports of the way this illness, with its storm of electrical activity that either remains focalized in one part of the brain or generalizes throughout the brain, is provoked and inserted itself into the lives of sufferers, producing behavioral events reported by the narratives? Or did the cultural structure of the narrative dominate, producing a cultural fiction?

Our study was not designed in a fashion that would allow us to answer these questions explicitly. Neither, of course, are most clinical histories able to answer such questions. Clinicians may see a patient shortly after an initial fainting episode and follow that individual quite closely through their illness. However, very few of the individuals with whom we spoke in the Turkish study had such a history with physicians, and Turkish clinicians face many of the same difficulties I discuss here when they try to construct a clinical “history.” These difficulties fall generally under the rubric of the “mimetic” question, relevant not only to clinical medicine, but being asked with increasing insistence today in the social sciences and humanities – in history, literary criticism, and psychology. What is the relationship between story and experience? To what extent do stories report or depict events or experiences as they occurred? Conversely, to what extent do typical cultural narratives actually construct “events,” give events or experience their sense, produce what we mean by an event or history of experience? Does a good history mirror events and experience, or does it select events and organize them in a culturally conventional fashion based on an underlying view of what is significant? To what extent is social life itself organized in narrative terms?

The past decade has seen the development and elaboration of a technical literature on this broad topic. Although a full discussion is well beyond the scope of this book, it is my general claim that these issues cannot be avoided in our analysis of the relation between culture and illness, and that this literature provides analytic tools that allow us to address problems in medical anthropology in a fresh way.

Narrativity, illness stories, and experience

Phenomenologically oriented anthropologists, particularly those in the Boasian tradition – Whorf, Hallowell, and Geertz, for example – have argued that experience is cultural to the core. The “behavioral environment of the self,” in Hallowell’s terms, that is the perceptual world in which we find ourselves and to which we are oriented, is organized through language and symbolic forms, as well as through social and institutional relations and practical activities in that world (Hallowell 1955). Our primary access to experience is thus through analysis of cultural forms. In broad outline, this understanding of the cultural saturation of experience is widely accepted in anthropology today.

Narrative studies re-problematize this relation between culture or symbolic forms and experience. We of course do not have direct access to the experience of others. We can inquire directly and explicitly, but we often learn most about experience through stories people tell about things that have happened to them or around them. Narrative is a form in which experience is represented and recounted, in which events are presented as having a meaningful and coherent order, in which activities and events are described along with the experiences associated with them and the significance that lends them their sense for the persons involved. But experience always far exceeds its description or narrativization. New questions will always elicit new reflections on subjective experiences, and any of us can always describe an event from a slightly different perspective, recasting the story to reveal new dimensions of the experience. Much experience is given little significance: much of what we do and experience is not worth telling a story about, and only with close questioning are we able to recall fleeting aspects of our experience. In addition, experience is sensual and affective to the core and exceeds objectification in symbolic forms.

Narratives not only report and recount experiences or events, describing them from the limited and positioned perspective of the present. They also project our activities and experiences into the future, organizing our desires and strategies teleologically, direct them toward imagined ends or forms of experience which our lives or particular activities are intended to fulfill. Lived experience and social activities thus have a complex relationship to the stories that recount them.

Stories have a complex relationship to experience not only for those who recall
and tell the tales; that relationship is also problematic for anthropologists interested in the study of experience— or the study of social process or culture more generally. We understand the experience of others in some measure by the experiences provoked in us when we hear such stories, experiences which are affective, sensual, and embodied. Part of the task of anthropological writing is to retell stories in a fashion that will provoke a meaningful experiential response and understanding in the reader. Our own responses are themselves culturally grounded, embedded in quite a different structure of aesthetic or emotional response than that of the members of the society being described (see Becker 1979).

Unni Wikan tells the story of her discovery of the grief of a young Balinese girl at the sudden death of the young woman’s fiancé. Her public demeanor was “stage-managed” in a form familiar to those who have read Geertz on Bali. Her self-presentation was “smooth”; “she shone and sparkled” (Wikan 1987: 349). In more intimate moments, however, the young woman shared her sense of loss and grief with the anthropologist, as well as her fears that any expression of her sadness would be met with ridicule, her friends mocking her as a “widow.” But how are we to interpret this case of a young girl who appears on the surface to be more culturally different than intimate experience reveals? To what extent is our intuition of the meaning of the story based on an American or European view—culturally idiosyncratic, perhaps—that the private sharing of grief is one of the deepest forms of human intimacy, that it provides access to a deeper understanding of the experience of others, of what “really happened,” than the expression of other emotions—anger or fear, for example— or than the public enactments of emotions can provide? Are we thus misled by our culturally informed intuitions in reading Wikan’s account of her story and intuiting what the young Balinese woman really felt or experienced? I tend to think Wikan has the better of this particular argument with Geertz about the nature of some aspects of Balinese “psychology,” but there is the potential for serious confusion in such analyses of the quality of lived experience derived from stories we tell from field research.

Similarly, the telling of illness stories is often a highly personal and intimate matter in North American society, and such stories constitute a genre of popular and conventional literature in Western culture. These stories and the meanings and values associated with illness and suffering in our own society shape our hearing and retelling of the experiences of illness in other societies. It is critical that we submit to closer examination the telling of illness narratives, the interpretation of these by others in the societies we study, anthropological writing about such stories, the reactions of the audiences for whom we write, and thus ultimately the relation of culture, narrative, and experience. Otherwise, our own projections are likely to dominate our interpretations of others’ experiences of suffering.

The past decade has seen the emergence of a small but growing literature on narrative dimensions of illness, care-seeking, and therapeutic process. One stream of this literature is from within medicine; several literary-minded clinicians have provided detailed clinical accounts or stories of the lives of those with serious illness, expanding on the traditional genre of the case history and developing a more elaborate form of illness stories which also reflect on what disease tells us about suffering and the human condition. For example, Oliver Sacks’ accounts of persons with Parkinsonism (1973), migraine (1986), and other neurological disorders (1985) portray the human dimensions of quite dramatic medical conditions and the suffering they provoke from the perspective of a humanistic physician. These are not unlike, in some ways, those personal accounts of illness which have become an important genre in recent years, and which may serve as primary source material for our thinking about the narrative structuring of illness experience in our own society (see Murphy 1987 and DiGiacomo 1987 for reflective accounts by anthropologists on their own experiences). Howard Brody’s recent book (1987) extends an analysis of such narratives in an added direction. He draws on literary accounts and refers briefly to the “narrativity” literature to argue explicitly for the importance of an awareness of the narrative dimensions of illness in medical ethics, suggesting that aspects of illness central to ethical reflection and decision making are better apprehended through stories of illness than through abstract and rule-governed philosophical discourse.

A second stream of writing on narrative and illness has recently emerged from qualitative sociological research, in particular among those who have worked in the ethnomethodology and conversation analysis traditions. Mishler, who has conducted detailed studies of doctor–patient dialogue (1986a), has gone on to make a strong case for the narrative structure of conversation and to elaborate a fundamental critique of survey interviewing based on his analysis (1986b). Williams’ (1984) analysis of “narrative reconstruction” in chronic illness experience has attracted attention and been widely referenced in sociological writing. A recent issue of Social Science and Medicine (Gerhardt 1990) on qualitative research on chronic illness draws on these and other forms of conversation analysis to study the experience of chronic illness in North America and Europe. For example, Riessman (1990) demonstrates the usefulness of close textual analysis of a biographical account of illness, and Robinson (1990) draws on the narrative literature for analyzing the life stories of persons with multiple sclerosis.

Anthropological and cross-cultural analyses of illness narratives are surprisingly few. Early’s work on “therapeutic narratives” in Cairo was among the first by an anthropologist to focus explicit attention on the stories told about illness and care-seeking (Early 1982; cf. 1985, 1988). She sat with women in the traditional quarter of Cairo and listened as they told everyday stories of illness—of their children, family members, and themselves—and their efforts to find appropriate care. These stories, she argues, operate as a “middle level system between experience and theory.” They allow the women she studied to develop an interpretation of the illness in relation to a local explanatory logic and the biographic context of the illness, to negotiate right action in the face of uncertainty, and to justify actions taken, thus embedding the illness and therapeutic
efforts within local moral norms. More recently, Price (1987) and Garro (1992), both cognitive anthropologists, have demonstrated how cultural knowledge and scripts for care-seeking are encoded in illness narratives, whether naturally occurring or elicited through interviews (in Ecuador and North America respectively). Mattingly (1989) has made the most extensive and explicit use of narrative theory to explore the story/experience relationship and the use of narratives by clinicians (American occupational therapists, in her case) to organize their practice and the experiences of those they treat. She makes a strong case for the narrative structuring of clinical work, the role of clinicians in emplotting the illness experience and therapeutic work in which patients are engaged, as well as the importance of stories in shaping and evaluating their own work and clinical relationships.

Kleinman (1988b) has combined the anthropological and clinical traditions, reflecting on persons with chronic illness whom he has seen as a physician and researcher. He uses anthropological analyses to show how “meaning is created in illness,” how cultural values and social relations shape the experience of the body and sickness, and situate suffering in local moral worlds. He explores how experience is organized in narrative form, moving comparatively between North American and Chinese cases to demonstrate the importance of the social and cultural frames within which such narratives emerge. He argues that “the study of the experience of illness has something fundamental to teach each of us about the human condition” (p. xiii), and demonstrates how current practices in medicine have alienated the chronically ill from their care providers and led practitioners to relinquish “that aspect of the healer’s art that is most ancient, most powerful, and most existentially rewarding” (p. xiv).

Much of the literature on illness narratives has addressed the structural characteristics of illness stories, their relation to life histories, the kinds of illness knowledge and values they encode, and what they reveal about the impact of illness on people’s lives. In general, this “narrative turn” in writing on illness experience has benefited from broader interests in literary analysis in the humanities and social sciences. With the exception of Mishler and his colleagues and Mattingly, however, these authors have made rather little explicit use of literary critical theories of narrative and its interpretation. Although the issues many of these studies raise are important to my analysis as well, I take a somewhat different path into the subject here, continuing my examination of how illness and its experience are constituted through interpretive practices, and drawing explicitly on some aspects of narrative theory. In particular, I am interested in the relevance of “reader response” theory for analysis of stories that those who are ill tell us about their experience.

Anthropological analyses of narrative have been largely of two kinds: structuralist studies of folklore and mythology, and sociolinguistic studies of narrative performance. The Russian formalists and the structural linguists of the Prague school contributed to the French search for the fundamental narrative form. Propp (1968) argued that there are a limited number of basic character types and plot structures underlying all Russian folk tales. Lévi-Strauss (for example 1969) drew on Jakobson’s distinction of horizontal and vertical axes to develop his comparative study of the fundamental structures of narrative.

Over against efforts to develop a structural theory of narrative, performance theorists and many literary theorists have argued for the essential temporal quality of narrative, its unfolding in time, its working through of a plight to a resolution through interactions of characters among whom consciousness of the nature of the situation is unevenly distributed, all in the medium of what Ricoeur (1981b) calls “narrative time.” Victor Turner (1957, 1981) argued that such a narrative – or proto-narrative – structure lies beneath not only stories but social process itself, which moves relentlessly from a breach of an existing state to a crisis and redress. Narrative accounts, along with ritual, efforts at legal redress, and other social dramas, are organized in relation to the contradictions structured into societies (for example through kin systems), as well as to the “absolute indeterminacy” that becomes evident at moments of breach and crisis, Turner argues (1981: 153) – and all this can only occur in time.

Temporality is present not only in the structure of narrative but in its performance. Narrations and rituals are intersubjective processes, requiring performers and audiences along with “textual” forms, and have their effect as event within temporally lived experience (for example Bauman 1986; for relevant analyses of healing rituals see Schieffelin 1985 and Kapferer 1983).

Reading response theorists have elaborated on the temporal and intersubjective qualities of all narrative by giving special attention to the “phenomenology of the act of following a story” (Ricoeur 1981a: 277). Narrative is not simply that which is present in a completed story, whether a written text, a folk tale, or a story as told or performed. In order to constitute narrative, the story must be appropriated by a reader or an audience. Appropriation of this sort is not a passive receiving of an author’s message (as much of the speech act theory seems to suggest); instead, as Iser (1978: 21) shows, “the reader ‘receives’ [the message of the text] by composing it.” A plot, for example, is not simply present as the structure of a narrative but is created by readers moment by moment as they proceed through a text, finding themselves limited to “the blind complexity of the present” (Ricoeur 1981a: 279) and seeking to uncover and anticipate the structure and meaning of unfolding events. Both the art of narrating and the art of following a story thus require that we be able “to extract a configuration from a succession,” as Ricoeur says (1981a: 278), to engage in a form of aesthetic synthesis through which the whole – the story, the plot, the “virtual” text of the narrative – gradually comes into being.

Given this quality of narrative, Iser (1978: 22–23) argues, “the interpreter’s task should be to elucidate the potential meanings of a text.” Rather than identifying a single referential or authorized meaning, analysis involves “elucidating the process of meaning-production.” Meaning-production is inherent in neither the text and its structure alone, nor in the activity of the reader alone, but in the interaction between reader and text. Iser persuasively develops the hypothesis that “a
literary text contains subjectively verifiable instructions for meaning-production, but the meaning produced may then lead to a whole variety of different experiences and hence subjective judgments" (1978: 25). Investigation of the synthetic processes involved in following a story – entering imaginatively into the world of the text, shifting viewpoints to follow the perspectives presented by the narrative and the narrator, reconfiguring and revaluing past events and actions of the characters in the story as the narrative unfolds, the personal discovery by the reader of significance and new meanings through the experience of reading a text, and the personal change the reader experiences as a result of such understanding – has produced a rich set of theoretical ideas and substantive findings. For reader response theorists, analysis of narrative thus turns on both the phenomenology of reading and on the characteristics of stories that provoke and constrain the reader’s response.

It is my contention that reader response theory has special relevance for our investigation of illness narratives. The narrators of most illness stories which we as researchers are told, whether they are persons who are sick or their primary care-providers, are typically in the middle of a story. The narrators they produce are more akin to the “virtual text” of the reader of a story than the “actual” narrative text of a completed novel. They are stories that change as events unfold. They point to the future with both hope and anxiety, and they often maintain several provisional readings of the past and the present. They may be expected, however, to be deeply cultural stories, if all that we have learned about culture and illness is reflected in the narratives people tell to make sense of their experience.

The narratology and reader response literature provide a number of technical distinctions and analytic constructs that can be used for the analysis of illness stories, either as elicited through interviewing or as observed in natural discourse settings. I return to the Turkish epilepsy narratives and examine them in relation to three analytic concepts from this literature: the “emplotting” of illness, through which an ordered story is sought and authored; the “subjunctivizing” qualities of the stories, including their openness to multiple readings and potential outcomes; and the “positioning of suffering” in the local discourse setting.

### Embolment and illness experience

Narrative theory describes two aspects of plot: plot as the underlying structure of a story, and “emplotment” as the activity of a reader or hearer of a story who engages imaginatively in making sense of the story. Both are relevant to the analysis of illness narratives.

Plot is that which gives order to a story. It is the sequential ordering of events and the relations that connect them to one another. In Meliha Hanım’s story, the attack of her father is followed by her fainting, and that by a lifetime of fainting episodes which are deeply disturbing and associated with dreams or visions of the threatening knife. More than the frame of sequential relations, plot is the meaningful order through which experiences and events are joined together to make a story. Meliha Hanım’s story was not one simply of a trauma and subsequent fainting, but of an ambiguous elopement or kidnapping, undertaken against her father’s wishes, her father’s retaliation, and a lifetime of resulting illness, a predicament which her husband has sought to resolve through a wide variety of efforts to find a cure.

“Plot as I conceive it,” Peter Brooks (1984: xi) writes, “is the design and intention of narrative, what shapes a story and gives it a certain direction or intent of meaning. We might think of plot as the logic or perhaps the syntax of a certain kind of discourse, one that develops its propositions only through temporal sequence and progression.” Narrative “syntax,” at least in Western literature and recent historiography, has a distinctive form, which Ricoeur (1981a: 277) describes as follows:

Let us say, to begin with, that a story describes a sequence of actions and experiences of a certain number of characters, whether real or imaginary. These characters are represented in situations which change [and to which] they react. These changes, in turn, reveal hidden aspects of the situation and the characters, giving rise to a new predicament which calls for thought or action or both. The response to this predicament brings the story to its conclusion.

Predicament, human striving, and an unfolding in time toward a conclusion are thus central to the syntax of human stories, and all of these, as we will see, are important to stories about illness experience.

From the perspective of readers or hearers of stories that are in process, plot is less a finished form or structure than an engagement with what has been told or read so far in relation to imagined outcomes that the story may bring – outcomes that are feared, longed for, or seem ironically or tragically inevitable. The “plot” for Meliha Hanım and her family was incomplete; not only was the illness ongoing, but the family continued to try to find what is really happening, what the real story is, what story has the potential to invoke a cure. The reader is engaged imaginatively in constructing a “virtual plot,” in attempting to extract configuration from what has been heard, in determining the nature of relationships among events and characters, separating the related from the irrelevant, conceiving potential outcomes in the world of the text. The activity of “emplotting” thus has a special affinity to the experience of persons with debilitating chronic illness, and the literature on this concept is especially useful in understanding their stories.

When I read the transcripts of the Turkish epilepsy interviews we conducted with an eye to “plot” and “emplotment,” several things become apparent. First, the interviews consist in part, though not in total, of a corpus of stories of fainting or seizures, of other life experiences shown to be a cause or consequence of these episodes, and of efforts to find effective treatment. For nearly all those we interviewed, these episodes cohere as a larger narrative of an illness that has become a central organizing theme in the lives of the sufferers and their families. The most typical form portrays a predicament, associated with initial fainting episodes,
followed in most cases by prolonged and persistent striving to find a cure, an unfolding of the illness within the life of the individual and family, and an imagined end juxtaposed to persistent illness. In some cases the initial “predicament” followed by a quest for cure is key to the entire story structure, while in others a life history of suffering is thematized as central to the structure of the story of the illness.

Second, several prototypical plot types can be identified among the illness narratives, as well as among the specific stories of which they are constituted. These have a distinctive cultural form, rooted in Turkish popular medical culture. They are present as the plot structures of the narratives we heard. They are also available as cultural resources for those in the midst of illness attempting to make sense of their experience; that is, they are possible stories one might reasonably tell about such an illness, potential plots giving order to the events one is experiencing.

Third, with few exceptions, the narratives are not complete, the stories not finished. They are told from “the blind complexity of the present as it is experienced” (Ricoeur 1981a: 278). In many cases, the actors were still engaged in the striving, in a quest for cure – in imagining alternative outcomes, evaluating the potential meanings of the past, and seeking treatments. Such tellers of the stories were thus akin to readers who are in the midst of a story. They approached the understanding of their predicament, of the story they were trying to make sense of, with an available body of typical plots – what Barthes calls the déjà-lu, the “already read” – drawn from their cultural repertoire. And they were still actively engaged in “emplotting” the condition from which they suffer, in seeking a plot open to a desired outcome.

In this section I outline five typical plot types found among the narratives we were told. I will go on in the next section to describe the representation of “subjunctivizing” elements in the stories, imagistic elements that suggest indeterminacy, an openness to possibility and the potential for change and healing in the lives of the sufferers.

Our research included thirty-two case studies. Of these, six were drawn from Ankara, thirteen from a town some distance from Ankara, and thirteen from a small village in the Ankara environs. Twelve of the sufferers were men or boys, twenty were women or girls; seven of the thirty-two were under the age of twelve. Twenty suffered (or had suffered) primary generalized or partial epileptic seizures, according to the research team, two were considered probable cases of epilepsy, and ten suffered fainting or seizures judged to be non-epileptic.

The stories we were told of the illness histories had several identifiable plot forms. Although other typologies of plot could be formulated, I want to suggest five plot types organized in terms of onset of the illness, its temporal unfolding in the sufferer’s life, and the primary idiom for its expression.

The most common story form told how an illness began with a major emotional trauma associated with a frightening experience or a deep personal loss, which produced fainting that had continued intermittently for years following the experience. These plots were similar to those of “fright illness” we found in an Azerbaijani town in previous research (B. Good and M. Good 1982). In these narratives, the trauma associated with the beginning of the illness has a powerful effect on shaping the central meaning and configuration of the story. The temporal structure of the illness, with its traumatic onset often followed by an intense quest for cure, is central to this plot form. Melih Hanım’s story – of the threatened attack by her father – which I described in the beginning of this chapter, followed this pattern. Eleven of the thirty-two cases told stories of this form, and three others included stories of an emotional trauma as at least a possible source of their illness.

The second most common story form was of seizures beginning with a childhood fever or with an injury. High fevers in infancy, meningitis, an infant who fell from a bed, a young man beaten by a teacher – these were stories with their own drama of desperate efforts to find medical care, bitter memories of poor treatment from urban physicians and hospitals, remorse on the part of mothers for their failure to protect their children, and in several cases tragic outcomes with seizures associated with serious impairment or mental retardation. Although etiology often mirrors that of a medical narrative of these cases, the real drama of the stories often lay elsewhere. Eight of the thirty-two case accounts followed this form, and three others told stories of fevers or injury as potential origins of the seizures. Such stories were particularly prominent for persons whose illness had begun in childhood; stories told of all but two persons whose illness began before age twelve either followed this general form or (in two cases) described an attack by “evil eye” as producing fever secondarily.

Third most common (six persons) were cases of seizures that seemed to begin with no apparent cause. All of these were cases of generalized seizures that simply began – in all cases but one during early or late adulthood – in association with no recognized causal event. These stories were generally “unplotted,” in a sense. The narratives focused on the effect of the illness on the life of the sufferer, but neither beginning nor potential ending were featured in the stories. They were organized less as quest stories than those in which discussions of beginnings were matched by a concern for outcome. It remains ambiguous whether lack of origin stories results simply from a particular style of emplotment, from a particular pattern of onset of seizures, or from a medicalization of the condition and thus a focus on physiological site rather than temporal order in a life history.

Fourth, a number of women told stories of a lifetime of sadness, poverty, and suffering in which episodes of “fainting” were persistent and prominent. These narratives combined a typical rhetoric of complaint, voiced in the idiom of skınt (worry, suffering) and üzünü (worry, pain, sorrow), complaints of fainting (beylına), stories of onset associated with life tragedies, and a lack of extensive care-seeking. Nearly all such cases were of women who initially screened positive for a history of seizures but were ultimately diagnosed as having psychological rather than epileptic seizures. However, these cases join together a rhetoric of suffering and tragedy with seizures – explicitly described as
“fainting” — in a manner that shapes the meaning context of epileptic seizures more generally.

Finally, classical Middle Eastern stories of illness onset being caused by evil eye or being struck by jinns were the primary organizing feature of several of the narratives. Three case narratives were explicitly organized in this form: a fourth included such a story; and stories of encounters with religious healers and visits to shrines indicated that the potential for reading the epilepsy experience in such terms was widely present. This story form was held as a potential means of explaining seizures and thus configuring episodes and experience of illness for nearly all of those we interviewed.

These general plot forms were prominent structural features of the narratives we heard. They give stories coherence, order selection and sequence of episodes told, and make the accounts recognizable to others in the society. More than that, they are story forms available to individuals and families engaged in emplotting their experience — that is, in evaluating the potential sources of seizures or fainting, drawing into coherent relationship a number of life experiences, and anticipating the probable course of their illness and potential sources of efficacy. In a number of the cases, the stories we were told suggested that sufferers or family members held open the possibility not only of various possible endings to the story they were telling, but actively maintained several plots as potential ways of interpreting their illness. In the following section, I will examine more carefully the maintenance of competing plots as a strategy for “subjunctivizing reality.” However, before going on, a recounting of three of the epilepsy narratives will illustrate the plot structures of the narratives we heard and provide the data for looking in more detail at the stories in light of reader response theory.

Zeki Bey

Zeki Bey was a thirty-two-year old man whom we interviewed with his wife, a sister, and his mother in his house in an older gecekondu (“squatter settlement”) that is now part of Ankara. He has been suffering epileptic seizures since he was seventeen years old. He told us the story of how the illness began.

Zeki Bey: The news came to me this way. Early in the morning I left the house. My mother was with [my father in the hospital]. He died at 2:00 at night. I was in the car that usually brings me from work; ... a car coming from the opposite direction signaled Ismail [the driver]. When the signal was given, I understood, I understood, I said my father died. Of course he pulled off to the right, talked, came back, got into the car, and we went. I wanted to drop by the hospital before going to work. And there, the second man came, and when he said “condolences” (“baştaş sögolsun”), “I lost myself.”

Zeki’s Sister: At that time he fell down the stairs.

Zeki Bey: And meanwhile, I came to myself. I hit a man, Ali Haydar also hit him, and I also hit him. We went down to the morgue; what could I do in the morgue, since he had died at 2:00. Before we didn’t have a telephone at home, later, at night, I said where can I go, that place (street, or hospital) was kartışık (mixed up), I didn’t know, and when I hit that man, I was attacking him, I was going, he wouldn’t let me embrace [my father’s body] ... when I found the bowl [for washing the dead] I was so upset (siniri — nervous, upset) that I hit him in the forehead with it. Blood was everywhere, nothing could stop me, I wasn’t seeing anything, because of being upset; because of being upset I did ... we hit the man, of course they were outside, they didn’t know what was going on, what happened to me happened during that time, and after that it continued.

Zeki’s Sister: He fought with the guys there, he fell down the stairs to the second floor, he tumbled, his nose bled, he fell tumbling, they called him from downstairs ... Interviewer: When you were falling down the stairs, did you hit your head?

Zeki Bey: I’m telling you, when I was falling it happened suddenly ... Before I got the bowl, I couldn’t tell the difference between things. I got up ... I found the bowl, I just remember that I hit him on the forehead, and of course they took me out of there.

Zeki’s Sister: They gave him a “courage needle” (tranquilizer injection), they did it there. Until the death of my father, he had nothing. He wasn’t even working. After that, he began to work.

Zeki Bey had had generalized seizures for fifteen years. Yet he told the story with immediacy, drama and poignancy. The death of his father and his mad, violent grief in the hospital served not only as the causal explanation of his illness. More importantly, it gave texture and meaning to the larger life story. His sister and the interviewer suggested the possibility of recasting the story as an injury narrative rather than a story organized around the initial emotional trauma, but he eloquently resisted. His illness had a powerful and meaningful beginning, which gave shape and coherence to the larger narrative.

Zeki Bey’s seizures were reasonably well controlled — though at a cost. He was once treated by his “insurance doctor” with electroshock treatment, he told us, and has since been medicated with an extremely high dosage of phenobarbital. As a result, he suffers slurred speech and is often sleepy. He has been treated a number of times by hucas, who have written curative prayers for him, but with no noticeable effect. He says they tell him his problem is caused by stepping on jinns, but he doesn’t believe it. Meanwhile, he continues to work in a job at the municipality, where he is treated well by co-workers. His major concern is that he and his wife have had no children, and he wonders if either the illness or the medications are to blame. This, rather than treatment of the primary disease, organizes his interest in shaping the outcome of his illness story.

Omer

Omer was a six year old boy at the time of our research, who was diagnosed by the research team as suffering generalized, tonic-clonic seizures since infancy and prescribed anti-epileptic medication. He lives in an average village home with his mother and his father, who is a factory worker in Ankara, his paternal grandmother, and several other children. The boy’s mother and grandmother participated in the interview.

The interview began with the grandmother expressing concern about what their village neighbors say about the boy — that he has difficulty speaking and understanding — and the gossip resulting from the visits from the medical research team.
They then launched immediately into describing how desperately they had sought care for him. "How many doctors we took him to, how many hoca®S we took him to, we took him to [a hoca] in K—, we took him to [a shrine in] B—, everywhere they said ‘he’ll get better, he’ll get better, he’ll get better...’”

“What is there in K—?” we asked. They said that it is a shrine (yatir) with a “deep hoca,” that when they took the child there at age five he still could not speak, and that he had begun to speak after being taken to the shrine.

They told a story of their experience at the shrine – first in brief form, a story with gaps and contradictions, then following our questions a more elaborate version of the story.

**INTERVIEWER:** What happened when you took him to the yatir?

**OMER’S MOTHER:** We took him to the yatir, he slept there.

**OMER’S GRANDMOTHER:** Dede (“grandfather, dervish, sheikh”) said “he should sleep until he wakes.” He said “he himself should wake up.” We held the baby, he was sleeping until we arrived at K—.

**OMER’S MOTHER:** [he said] we should stop when he woke up.

**OMER’S GRANDMOTHER:** The hoca was offended. “You took the baby here before anyone gathered around him, before the baby recovered,” he said. “You just came here for the trip,” the hoca said. The baby, we came to K—, he said he came to consciousness (?). When you bring adults, they come quickly; they do not come quickly to children, but they do gather around them.

They went on to tell the story in more detail. The yatir is a place with tombs of saints and a fountain “that appeared from God.” People who are paralyzed come and sleep there, and while they sleep, “they gather around that person; when they shake him, he wakes up,”

“Who gathers around?” we asked.

“Whoever you see,” Omer’s mother said.

“Jinns, peri®S, unseen creatures that disturb people by gathering around them,”

the grandmother interjected.

“The person who goes there gets well,” the mother said.

“She and I and his father, the three of us took the baby there in our arms. He slept there,” the grandmother said.

The mother went on, “he slept very comfortably. If he had slept longer, he would have ‘gone’ (died?)...” But before he awoke, they took him to the cab – since they were paying by the hour, it was getting expensive – and left.

The story included a brief explanation that the hoca said the illness had begun because the child had “stepped on dirt” after evening prayer. It led immediately to another story of treatment at a different shrine, which concluded with the healer pronouncing, “by the time he is ten years old, he will get well.”

A simple question about how old the child was when the illness began produced another story of the beginnings of the illness when the child was eight months old.

**MOTHER:** In essence, it happened to him because of an evil eye. There is a woman in this village, if she looks at you she destroys you. That woman looked at him when he was eight months old, the next morning he couldn’t speak. His mouth foamed.

**MOTHER:** It happened to him because of an evil eye. The baby was eight months old. His mouth foamed. He didn’t open his eyes until the next morning. When he opened his eyes, he was staring. He couldn’t speak.

**INTERVIEWER:** And then what happened?

**MOTHER:** He fell into a coma. They took him to the hospital. They told us, “he can’t speak, he can’t eat.”

They went on to describe how the woman had stopped by and stayed for dinner one evening, though she was dirty from painting her house.

**MOTHER:** Before she left, I dressed the baby, I put on his white dress. The baby was asleep, the father brought him near her. “Where did you find this ‘Bulgarian seed’? Where did you find this ‘foreign seed’?” she asked.

**GRANDMOTHER:** Don’t even say it!

**MOTHER:** To the baby, she said just this. The baby didn’t recover. In the morning he was seized with the illness. The evil eye was cast upon the child. . . . He was very beautiful. He was bright and clean. You should have seen him!

They went on to tell stories of trips to the doctor, of leaving the infant in the hospital, but of his failure to recover and his seizures continuing monthly. They told of his unruliness, their terrible anxieties about disciplining him, and their fears about what he may be like when he grows up. This led to stories by the grandmother of children she had who died in infancy, of her leaving her first husband when he took a second wife, and of the pension she received when her second husband died, which she now dedicates to the family. The visit drew to a close.

In this case, the underlying plot was of an innocent infant being struck by an evil eye, leading to a sudden fever, fainting, and an illness and disability which has persisted despite desperate efforts to find a cure. Stories recounted inadequate treatment at hospitals and some limited benefit from religious healers. Hope for resolution of the condition was mixed with serious anxiety about the child’s future.

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**Kerim Bey**

Kerim Bey was a twenty-six year old man, identified as epileptic by the research team, who had suffered generalized seizures since he was seventeen or eighteen years old. He lives with his wife and child on the third floor of a three story house, whose other floors are home to his parents and his brother with his wife and child. Kerim works as a security guard at a nearby factory. He responded to our initial questions about how the illness had begun with a clear story of a frightening experience that produced his initial fainting. His reflections on this experience later in the interview, as well as his wife’s discussion of his illness during a separate interview, will be described in the following sections of this chapter.

“Do you remember how it started?” we asked. He answered with a story.

“Down below here there is a street. It was two or three o’clock at night. My brother’s wife was having her baby. They told me to take the news to her mother and father. ‘We are taking their daughter to the hospital, so they should have the news.’ They woke me..."
and I got up. While my eyes were closed, I went out onto the asphalt, the main street, I went down three blocks. I don’t know if you saw the Employment Office building there. There I went to the left, then again turned to the right. After going 100, 150 meters, three black dogs—I don’t know whether you watched the late night movie yesterday, what do you call those dogs?"

INTERVIEWER: "Doberman."

"Three of those dogs came out. When they began barking, I suddenly was startled, I turned and ran from there back home. Here I fell and fainted. One year later, when I was jumping into the truck... I was on the truck in the evening... In the evening I had come from work, I had gone to cut the wood, I came, I took a shower, I got out of the shower, I ate garlicy mantı. I slept so heavily that I didn’t keep account of how long I slept. (In the evening I was unloading the truck.) I fell from the top of the truck, from seven and a half or eight meters, I fell from left to right. I had a fall that took my breath away. I landed on my father’s chest. My father was ill. I was hanging from my sweater on one of the hooks of the truck. They took me immediately to the hospital doctor. He said, ‘it is the initial stage of epilepsy.’ He asked whether I had eaten garlicy mantı. ‘This is the beginning of epilepsy,’ he said, ‘don’t allow him to worry about things, don’t let him be anxious, don’t let him have less than eight hours of normal sleep, don’t wake him before he has had eight hours of sleep.’ This kind of advice he gave."

This young man went on to describe how he is able to work as a security guard with the support of his superiors and fellow workers. ("The company doctor told my supervisor that I had to go on disability because I had epilepsy and I couldn’t work as a security guard. But my supervisor rejected this; he said that my condition was no worse than his other workers who had diabetes, heart disease, or wore strong glasses.") Nonetheless, he feels his life is seriously constrained by the illness. He cannot seek other jobs, though he believes he is capable of doing them. He cannot consider going abroad — to Germany, for example — as many others have done to advance their personal or family well-being. "The problem is I can’t accomplish the things that I want. I always have this fear that I might faint." Indeed, he does continue to have seizures, though he is on medication, in part associated with having to switch periodically between day and night work shifts. When he faints, he feels embarrassed. "I feel depressed. I feel angry. For instance when I recover from fainting I see my friends looking at me. They don’t look down on me but still I don’t want to be in that position. I always ask myself, ‘Why am I fainting? Can’t this be cured?’ So I feel angry."

He has had regular medical treatment and drug therapy. Still, he reports that one of his physicians “told me that if I had an operation I could get well. But nobody does this operation in Turkey, so he told me that I would have to go to Germany or the United States.” By this means he continues to imagine a cure, a life without seizures or fear of them, and thus a life open to new possibilities. But this openness of the story is represented not only by his describing a possible medical treatment that could change the ending of the story, but by his maintenance of several over-lapping plots that make sense of the mysterious appearance of the frightening dogs, as became evident as the story unfolded.

**"Subjunctivizing" elements in illness narratives**

Narrative discourse accomplishes its effects by “recruiting the reader’s imagination,” by enabling or provoking the reader to enter the world presupposed by the text. The reader of a well told story grasps the situation from the points of view of the diverse actors of the drama, experiencing their actions and the story as indeterminate and open, even though the text or the story has a fixed structure and ending. Narrative succeeds by “subjunctivizing reality,” a phrase I take from Bruner (1986: 26), by exploring the indeterminacy of reality and stimulating such exploration in the reader. "To be in the subjunctive mode is... to be trafficking in human possibilities rather than in settled certainties," Bruner writes (1986: 26). A central task for the critic set out by reader response theory is to examine how a text stimulates readers’ entry into the subjunctive world of its actors, draws them into the diverse perspectives of the actors, invites concern about how the story might turn out.

Illness stories contain subjunctivizing elements not merely because they are narrative in structure and are performed to elicit an imaginative and empathetic response from an audience. They also have such subjunctivizing elements because the narrators — the person with an illness, family members participating in their care, medical professionals — are in the midst of the story they are telling. As I have argued, those who told us stories of their experiences with epilepsy were actively engaged in making sense of the illness and in attempting to influence its outcome. They were deeply committed to portraying a "subjunctive world," one in which healing was an open possibility, even if miracles were necessary. The analogy of the reader in the midst of a story, drawn almost against his or her will into the world of the text and moving forward, reinterpreting the past in light of the emergent present and future, makes sense of several elements of the narratives we recorded. I want to mention just two aspects of the Turkish narratives that maintain "subjunctivity" and illustrate from the cases I have described.

First, the narratives maintained multiple perspectives and the potential for multiple readings. They contained stories of episodes associated with the onset of seizures or with encounters with care-providers that allowed multiple interpretations of the source of the illness, alternative readings of prognosis and course, and thus maintained the potential for cure. Often these perspectives were represented through juxtaposed stories, independent episodes in the larger narrative, with the narrator making no effort to establish the relations among stories or to select a single coherent interpretation. The narratives thus maintained multiple perspectives and disparate points of view, all representing aspects of the narrator’s experience and the possibility of diverse readings of what had happened and what the future might hold. The provisional quality of the story thus has a creative potency. Several examples will illustrate.

The young man we called Kerim first told us the story of his being frightened by the barking dogs as he was running across town, leading to his fainting, and of having had his first major seizure while working on a truck a year after this event.
later in the interview he told of an encounter with a healer that suggested a radical reinterpretation of the “fright” story as he had first presented it.

He described a conversation with an acquaintance who was a hocea from a family of Sheyhs who live primarily in the Diyarbakir region in eastern Turkey, in which he had lamented that his illness could not be cured.

I told him I was going to be married in September, and I will pay the necessary money to have an operation in the United States. The doctor here said that “two veins are inflamed,” and for that he gave me the pills. He said you have an 80 percent chance of being better if you use them. I told this to my friend (the Shehy). He was surprised. It was during Ramazan (the month of fasting), and he was going to Diyarbakir (in eastern Anatolia) for a visit. So he went there, and he asked the senior members of his family, who are dedes, and they said, “Did you do such and such?” He said, “I didn’t.” He did [the things they said]. Roughly speaking, since Ramazan, I haven’t been ill.

His friend returned to the senior Sheyhs the next year, and was told to “do the same thing again.”

In my case this happened. We were sitting here like this. He doesn’t treat everyone, also he doesn’t treat for money. He does it as charity. . . He lighted two candles. He put water [in a bowl]. The dogs which I saw when I was sleepy at that first incident, I closed my eyes, the same scene appeared. The man said that this is speaking with the jinns, according to the Koran. So the jinns tell the shehy that I had walked on them and had killed their children. The jinns said, “That is why we disturb him, we make him ill. He can’t be cured.” The hocea began to tremble, he closed the book (the Qur’an), and said that he could not go on. He looked again in the water one week later. Later he again looked, and the jinns said, “OK, we won’t disturb him anymore, but he has to pray such and such suras, before he goes out. We are always behind him.” I said if I am not well by September, I will go to the doctor and explain the situation and tell him that the pills he prescribed didn’t help, that they cause harm, so an operation, he took an x-ray for an operation. Let me have an operation . . .

Kerim Bey told us this story following an account of a mysterious experience he had had of seeing Sari Kiz, a “Golden Girl” (or pale, blonde, or “yellow” woman) late one night. When we asked whether the story had any relation to the original “fright” that caused his illness, he told the story of the jinns, framing it by saying it was from the perspective of “old custom” (eskı adet).

The jinn story is told from the point of view of a religious healer. It provides a clear alternative to a more straightforward reading of the original event as a “fright” or “shock” that caused fainting and the eventual onset of epilepsy. But the framing of the story by a different account of the cause of the illness (“inflamed veins in the head”), presented from the perspective of a physician, maintains these alternate readings of the experience and alternate plot structures without resolving them. Indeed, later in the interview Kerim gave a very brief version of another experience that might be related to his epilepsy. (“Before I fell down from the truck, I had a fight with one of our neighbors. A stone hit my head. This might also cause my illness.”)

For those of us who were told the story, as for Kerim himself, no single account, no single point of view adequately renders the experience. As Iser (1978: 109) writes, “The reader’s wandering viewpoint is, at one and the same time, caught up in and transcended by the object it is to apprehend.” Each story casts doubt on the others, or provides a potential alternative interpretation of the illness and of other stories about it. New experiences call for reinterpretation of past experiences and suggest new possibilities for the future, in life as in reading. (“It is clear, then, that throughout the reading process there is a continual interplay between modified expectations and transformed memories” [Iser 1978: 111].) But the telos and the desire that drive the story forward are not simply those of the imagination, as for the reader of a story. They are the desire for a cure in everyday time, an urgent desire to imagine and achieve an alternative outcome. The imagination of a possible cure the surgical procedure in the United States, or coming to terms with the jinns lends hope to the author and subjugativity to the narrative.

The juxtaposition of contrasting and complementary perspectives on the illness, represented through the stories of personal trauma, fainting episodes, and encounters with healers, could be illustrated from many of the interviews. Meliha Hanım told of her illness beginning when her father came and threatened her with the knife, and organized her narrative in relation to that event. However, at the end, she and her husband discussed her “diabetes” and her current low salt diet for “high blood pressure,” which seemed to be helping. She discussed physicians’ treatments and prescriptions, and at the same time talked of a particularly memorable meeting with a healer at a shrine that led to relief “for a period of time.” The conflicting implications of these stories were left unresolved. The mother and grandmother of Omer told of the child’s illness beginning with a fever, but then incorporated that story into a larger story of the neighbor’s evil eye. The hocea’s diagnosis was only noted in passing. Unsatisfactory experiences with doctors and hospitals are contrasted with the visit to the shrine, which led to the boy beginning to speak.

The diverse accounts of the illness in these narratives represent alternative plots, a telling of the story in different ways, each implying a different source of efficacy and the possibility of an alternative ending to the story. My point is not that persons having access to a plural medical system do not simply choose among alternative forms of healing but instead draw on all of them, often at the same time – by now a truism in medical anthropology. It is rather that stories of illness and healing experience which represent quite distinct and often competing forms of composing the illness are present in narratives precisely because they maintain the quality of subjugativity and an openness to change. Those narratives of the tragic and hopeless cases, in particular of persons who were severely mentally retarded, showed little openness of this kind. Those who had simply accepted their illness as a chronic disease to be treated with medication also maintained little of the multiplicity that was present in the narratives I have been describing. For these, the disorder was a part of the “horizon” of their experience, rather than “thematized” as central to their lives. However, the multiplicity of perspectives was particularly evident in the narratives of persons in the early stages or the
“middle” of the story, those still actively engaged in re-evaluating the past and seeking to open their future to change. For these, subjunctivity was a central element in their construction of the object of their suffering.

Subjunctivity was also represented in the narratives through stories of encounters with the mysterious – with what C. S. Lewis, in his lovely essay “On Stories,” calls “the marvelous or supernatural” (1982: 12). Lewis argued (pp. 10–15) that one of the functions of art is “to present what the narrow and desperately practical perspectives of real life exclude.” He was especially fond of children’s stories and science fiction because they awaken in us a sense of the “idea of otherness” and thus of the creative imagination: “To construct plausible and moving ‘other worlds’ you must draw on the only real ‘other world’ we know, that of the spirit.”

Illness narratives often include stories of experiences of the mysterious, stories which suggest the possibility of sources of potency which we seldom seek in everyday life. In the Turkish narratives, these were represented in stories of uncanny experiences, as well as those of encounters with healers and their vision of the “supernatural.” For Meliha Hanım, the threat of her father, what she described as his “wickedness” (ser), was not a distant memory but a live and mysterious force, which erupted in her fainting spells and dreams. She described how two nights earlier she felt that she was going to be ill as she went to bed.

“At that moment, they told me that somebody’s son had died. Go over there, they said. I went there. What are you doing here? I said I don’t know, I locked the door and came. They said that my landlord had died. It happened exactly like that. I was coming, actually, my husband in my dream had died. Did your father die? they said. My father also died. My father was saying, this knife with its black handle is your enemy, daughter, my father said in the dream.”

The daughter-in-law interrupted: “You see, the same knife, she still sees it in her dreams.”

“The same knife,” she went on, “the knife in my father’s hand, that night appeared in front of me again. They say that knife will kill you. I was screaming, screaming, screaming. I was sweating in my dream. I woke up and found myself in bed. I have been suffering from this for a long time, for forty years.”

For the psychiatrist reader, this passage will raise questions about the possibility of dissociation or post-traumatic stress disorder as a diagnosis, rather than epilepsy or some other diagnosis. From a narrative point of view, what seems especially powerful is the sense of mysteriousness, of the active presence of the father’s evil in memory and its eruption through “fainting” into Meliha Hanım’s life.

In Kerim’s account of his illness, the mysterious was present not only in his story of the healer who saw the jinns, but in his encounter with the Sarsi Kız, which he described in response to a question about the relation between being startled or frightened and his “fainting.”

... it was about four months ago. I was assigned to the outside depot. We had a guard house there. It is in the cold of the winter. In the winter you have snow and rain. A friend of mine, whom I like, said come, let’s boil some tea, the place where we are is nearby... I am sleepy [he said], I said go and rest, you can sleep... So I went to this place to punch the clocks. That place is very dark and desolate. There are always birds. Suddenly a cat appears; they call it a cat, but I don’t know what it is. A sound came from the cat, like a new born baby was crying, like a mourning song (ağıtlar). Something was there... I said to myself, “My God, what is this sound?” I loaded my gun. I was ready to shoot... Perhaps one of these is coming.” I thought. I went to some other places.

Before, one of our friends had gone to that place. As a joke they told him there is a Sarsi Kız there, like a jinn, there is a Sarsi Kız, they said, there is a baby. I remembered these things. “Is there a cat?” I said. I loaded my gun. I was going to shoot it. I finished my rounds. I came back to the guard house. We had decided that my friend and I would meet there from 6:10 till 7. I boiled the tea. We had bread, breakfast and so forth, and we drank tea. “Friend, I am going to go,” I said. Just after I went out [of the guard house], I fell down [in a seizure]. If I had fallen inside I could have fallen on the stove and burned myself.

This story was told with no conclusions drawn. Kerim would almost certainly have denied any explicit belief that encounters with the spirit world trigger his fainting episodes, just as many deny that they believe what the hocalı tell them. Such denials are not only a result of recognition that physicians and university faculty (such as those conducting the interviews) consider such beliefs superstitious, but deep ambivalence about such “traditional beliefs” is part of the Turkish cultural discourse on secularism. At the same time, uncanny experiences associated with seizures and with visits to shrines are represented in vivid memories and recounted as narratives. While not entirely “rational,” the stories represent the presence of the mysterious and the potential for change. Narratives are especially appropriate to such representation. As C. S. Lewis wrote, “The story does what no theorem can quite do. It may not be ‘like real life’ in the superficial sense; but it sets before us an image of what reality may well be like at some more central region” (1982: 15).

These two “subjunctivizing” elements in the illness narratives – the maintenance of alternative perspectives and the representation of the mysterious – are by no means the only examples I could point to. The stories have “gaps,” the unspoken or unexplained, that represent unknown or unknowable dimensions of reality that offer hope that potent, untapped sources of efficacy will yet be found. The quest structure of the narratives – the stories of a search for cure from doctors and shrines all over the country – presupposes subjunctivity. The openness of time horizons – the representation of the future as a potent source for change and healing – is a central subjunctivizing theme in many of the stories. And others could be identified as well.

Taken together, these subjunctivizing “tactics” of narrative representation provide insight into the nature of illness experience. Disease as represented in biomedicine is localized in the body, in discrete sites or physiological processes. The narratives of those who are subjects of suffering represent illness, by contrast, as present in a life. Illness is grounded in human historicity, in the temporality of individuals and families and communities. It is present as potent memories and as
desire. It embodies contradictions and multiplicity. As with aesthetic objects or complex narrative texts, illness cannot be represented all at once or from a single vantage. It is constituted, rather, as a "network of perspectives," in Iser's words, ("As the reader's wandering viewpoint travels between all these segments, its constant switching during the time-flow of reading intertwines them, thus bringing forth a network of perspectives, within which each perspective opens up a view not only of others but also of the intended imaginary object") [1978: 197]. And illness, present in imagination and experience, is constituted with an openness to change and to healing.

The narrative positioning of suffering

Before concluding this chapter, it is important to discuss briefly some aspects of the pragmatics of illness narratives. It would be a grave error to conceive illness narratives as the product of an individual subject, a story told by an individual simply to make sense of his or her life. Anthropological interviews conducted in clinical settings, with only interviewer and subject present, can easily produce the illusion that such is the setting in which stories have their natural lives. Indeed, my account of Brian's narrative of chronic pain in the last chapter gives little sense of the dialogical and intersubjective quality of his story and his experience. The interviews we undertook in Turkish homes, though far more formal than most of our ethnographic work, gave lie to such illusions. Melih Hanım's story was first told to us by her daughter-in-law. Later she herself told a variant of the story, and again later her husband entered the discussion and told yet another version of their "eloping" and of his efforts to help his wife find care. The stories of the lad Omer were told exclusively by his mother and grandmother. Kerim's wife and sister-in-law told us stories indicating quite a different view of his illness from his own, as they discussed his condition when he was not with us. In nearly all the narratives we heard, family politics was not only present as a subtext of many of the stories, but was also central to the pragmatics of their telling. The narratives were intersubjective in a direct and obvious way: they were stories that utilized popular cultural forms to describe experiences shared by members of a family; the stories were dialogically constructed, told often by interwoven conversations of several persons, stories whose referents were often the experiences of persons other than the narrators; and they were stories positioned amidst authors, narrators, and audience.

The stories told with several family members present often seemed to represent a strategic compromise. The tensions resolved by a particular narrative form often reemerged in later variants of the stories or in the pragmatic and rhetorical dimensions of performance of the narratives. Again, I can only briefly illustrate some of the pragmatic dimensions of these illness narratives, beginning with the account of a woman I will call Emine.

We found our way to the home of a twenty-three year old woman in the provincial town we were working in, entered a central living room, and found ourselves amidst part of a large extended family of Kurdish background. Emine had been identified by the neurological research team as suffering fainting spells of psychological origin, "conversion reactions" they were labeled on the form. Emine sat in the middle of the room, enormous, quiet, appearing depressed, holding a child. She was surrounded by her in-laws – a strong, rather majestic woman who was mother of the family, an older son and his wife, and the youngest gelin, the most recent bride to come to the family, who sat shyly. Though we addressed our questions to Emine, she spoke only a few sentences throughout the "interview." Her mother-in-law and older sister-in-law quickly joined in describing her problem. She becomes sikinti whenever you say something to her, she takes things negatively. She becomes upset, she becomes numb, she faints. When did it start? She came three years ago, we don't know if she had it before she came. She is too fat. She doesn't like crowded places. Does she fall down when she faints? Yes. She feels depressed (bunaltyor). "I cry and then I feel better," Emine inserted. "I have pain in my back, in my arms, and in my breast."

Emine, we were told, came from a nearby Kurdish village three years ago to marry one of the sons of this family. This son – her husband – has mental problems. He was hospitalized and still takes medications. A previous wife left him. He fought and injured someone, but was not jailed because the doctor said he had schizophrenia. But he is fine now and works at the municipality as a cleaner.

And then the sister-in-law, joined by the mother-in-law, told another story. One day, the sister-in-law said, Emine explained to her that while she was in the field with her previous husband, she got sick, she felt dizzy, she didn't drink water until the following day. She fell into a faint. Whether it was from sun or nerves we don't know, the sister-in-law said.

We asked Emine to tell us the story, but the sister-in-law went on. Her first husband died. I don't know, perhaps she became ill because of that. She says that she has been ill since that time. They had been married for six months when the accident happened. Her first husband shot himself accidentally and she was with him. They were alone. He hung his gun in a tree, and when he reached for it to stand up, he shot himself. She was frightened, crying. She ran away. The shepherds found her. Did she recover from that terrible fright? Yes, she returned to the village and recovered. She was two months pregnant when the accident happened. She said she wouldn't get married if she had a baby boy. But the baby died after she gave birth to her. Then, of course, she got another.
a year past being the youngest bride. Her story evoked a previous husband. She was fat. She had pain. Only in her silence, her depression, did she seem powerful. The image of her sitting quietly while others told her story reminded us of the role of local power relations in the pragmatics of narrative. Relations of power and gender are expressed not only in the structure of the story, in the point of view it assumes, but in the elementary framing of who is allowed to articulate the story, who has the authority to speak, to construct the illness which belongs not to an individual but to a family.  

I return for my final example to the case of Meliha Hanim. As I mentioned briefly, the story of her eloping with her husband and of her father’s appearance with the knife was told several times, each framing the event somewhat differently, each positioning her suffering and the care provided by members of her family somewhat differently. 

In the middle of our conversation, before Meliha Hanim’s husband joined us, the daughter-in-law retold the story, reshaping its plot. 

About this elopement, she herself [that is Meliha Hanim] usually explains ... Now my father-in-law – he had been married twice – because she didn’t want to marry him, they prayed, he and one of his neighbors, they prayed on two figs, two ordinary figs, and a hoca prayed on them, in the old way of course. ... They gave her those figs, and after she ate those figs, she didn’t resist going with my father. Later, after they had gone a little ways ... she was regretful that she had gone, and she wanted to return. When she wanted to return, of course there were two people that had taken her, my father and his friend. They threatened her with a gun. You have to go on with this, you have come this far and you have to go on. So she had to continue going on. 

This story of the marriage situates Meliha Hanim’s husband in a different relation to the original events of the illness than the previous story. Along with whispered comments to our research assistant, the story highlights his previous marriages and his treachery, passionate though it was. It also casts question upon his self-representation, in his story of the onset of her illness and his efforts to find effective treatment for her. He told the story as follows: 

... there were no hocas, hajjs, doctors that I didn’t take her to. There was a hoca in K. village, he was building a two story house. I gave him the money for the second story! But I found no cure. We thought she had epilepsy. ... Actually, it’s not proper to say this, I wanted to marry her, but her father wouldn’t give her to me. We eloped. I was at work ... fifteen days later he came and beat on the door with a knife, someone told her, “Oh my god, your father has come, he will kill you with the knife.” They came into the house, her mother, may she rest in peace, said to the husband, “All, come in through the window.” Because they locked the door, she didn’t remember that there were bars over the window, so suddenly she fell to the floor. From then to now ... 

This story not only casts the gender relations differently than the previous versions, but situates the narrator, Meliha Hanim’s husband, differently. In his concluding comments to us, he expressed his continuing devotion to his wife and to finding a cure for her.

"Does anyone ever say that her illness comes from jins or peris?" we asked. "Yes, of course," he replied. "Even a doctor in S— told me to take her to a hoca. I said ‘Doctor Bey, I came to you as a last resort. I took her to hocas, to doctors. They recommended you, so we came here.’ By that day’s money – it was nearly fifteen years ago – I gave him 20,000 lira by that day’s money. But I found no remedy. But until I die, I will continue to carry her on my shoulders. Let me die, not her. If she were to die, I couldn’t continue, to go on. I will carry her on my shoulders until I am broken."

Meliha Hanim’s husband was a man who had grown up in the village, moved to town, and worked in a factory. He was a gentleman, refined, seemingly sweet and affectionate to his wife. In light of the whispers about his previous marriages and his eye for other women, his expressions of dedication to his wife’s care remained subject to alternative interpretations to the end. And so it was with all the illness stories we heard. They represented the narrator even as they told of the illness. Suffering was positioned in the field of social relations, in particular in the dynamics of Turkish family politics. The stories were shaped by the pragmatics of the social relations as well as by the intractability of the illness and its dramatic episodes.

Thus, the illness narratives represented “fainting” as residing amidst conflicted social relations. The stories themselves were “compromise formations,” configurations that concealed dynamic relations as well as representing a coherent ordering of experience. Many of the stories are best viewed, as Brooks (1984: xiv) says of the narrative text, as “a system of internal energies and tensions, compulsions, resistances, and desires.” In particular, in the Turkish case, such “energies and tensions” are present in the embedding of “fainting” in family relations – in gender relations, conflicts across generations, and among affines, especially new brides and their in-laws. This was evident in the stories themselves, in particular when variants were told, as well as in the pragmatics of their narration.

Other examples of the positioning of suffering through the pragmatics of story-telling could be illustrated. For a number of the women with non-epileptic fainting, their stories of how they fainted when they became nervous or anxious suggested that such episodes enhanced their power within their families, at the same time that it articulated a life of suffering. Stories told by family members or others, when the sufferer was absent, reminded us that most of the narratives we heard were told from the perspective of those who were ill. They were designed not to represent experience dispassionately, but to elicit a particular understanding or interpretation of the condition, and in some cases to elicit a particular intervention on their behalf by the interviewers.

My goal in this section has not been to provide a full set of categories for analyzing these issues, a full sociolinguistics or pragmatics of illness narratives, but to attempt to show that narrative theory provides new ways for anthropologists interested in illness narratives to engage a close reading of our interview transcripts and ethnographic observations.
The narrative shaping of illness

In this chapter, I have examined what we can learn about the cultural shaping of illness through a careful analysis of the stories people tell about their experience. Two kinds of conclusions are appropriate: first, a few words about what we can learn about epilepsy in Turkish culture from such analysis; and second, a more general review of the role of narrative in the shaping of illness.

I began this chapter with questions about the relation of “fainting” to “epilepsy” in Turkish culture provoked by Meliha Hanım’s stories about her illness. Through the course of our research it became clear that epilepsy belongs in popular discourse to the larger domain of “fainting.” This should come as no surprise, not only because fainting is less stigmatizing than epilepsy in Turkish culture. Although epilepsy is generally represented in biomedicine and in popular American medical culture as a disease with origins in a discrete location in the brain, clearly distinguishable from hysterical or functional fainting of psychological origins, this was not true as recently as the nineteenth century in Europe and America. Hypnotism, hysteria, and epilepsy were closely entwined in the history of European psychiatry, and the leading neurologists of the last half of the nineteenth century – Charcot with his colleague Paul Richer at the Salpêtrière in Paris, and William Gowers at the National Hospital in London – devoted much of their writing and research to describing “histeroeilepsy” and identifying seizures resulting from lesions in the cerebral cortex. Indeed, recent work on “temporolimbic epilepsy” has again sought to expand the category epilepsy to include a wide variety of behavioral disorders which appear to be accompanied by unusual EEG findings from the temporolimbic region (see Spiers et al. 1985 for a summary). Thus the phenomenology does not allow a neat distinction of types or origins of seizures or “fainting.”

“Fainting” as a cultural object condenses a network of meanings. This semantic network includes traumatic experiences of fright, shock, and loss; generalized expressions of suffering, anxiety and grief (iskindi and uznun); attacks by jinns and being struck by “bad glance” or evil eye; and severe forms of seizures, including those labeled epilepsy, as well as mental retardation and madness. These are linked to fainting not only symbolically, through various “semiotic connections,” explanatory models, and idioms of distress. They are also joined through the special logic of narratives. Stories organized around prototypical plot forms find the mysterious origins of seizures in these diverse domains of experience. The “network of perspectives” available in these stories allows the “wandering viewpoint” to constitute an “intended imaginary object” that both exceeds and is exceeded by the dramatic behaviors and loss of consciousness associated with seizures (Iser 1978: 197). And these stories do not neatly distinguish epileptic and non-epileptic fainting.

The stories we were told also recall vivid experiences with physicians and healers. Nearly all those we interviewed had sought treatment from physicians, though their experiences were quite mixed. Some remained on standard anti-convulsive medications, some continued in active search for a treatment that would produce cure, and some had despaired of effective care. Nearly all had sought religious healing, and stories representing the healers’ perspective enlarged the imaginative domain of the illness, though they were often told with skepticism and irony. Stories also told of shattered ambitions, loss of status and opportunity, and threats to family honor, all of which are part of the experience of recurrent seizures. At the same time, many epileptics continued to work, to be married and have children, and to have friendships they described as little influenced by their illness. These stories, as much as those about cause or about dramatic seizures, are included in the corpus of stories that constitute fainting as a domain of Turkish popular culture.

It is tempting for a medical social scientist to enumerate the cultural beliefs concerning the cause and workings of epilepsy, then compare these with beliefs in other societies. People of course reason about illness, and culture provides the logic of that rationality. I have resisted, however, focusing on the structure of reasoning. The transformation of these narratives and the modes of aesthetic response associated with stories into “beliefs” or “explanation” would be extremely misleading. The language of belief and rationality sets forth a whole chain of analytic assumptions associated with progressive science, authorizing the language of medicine and heightening the sense of distance between ourselves and the other, as I described in chapter 1. More than that, it describes quite poorly the similarities and differences across cultures in the narrative shaping of reality, the complex relations between story and experience, and the aesthetic response associated with stories and the constitution of illness as a cultural domain. It has been my claim that detailed attention to narrative and narrative forms of representing reality provides insight into the synthetic processes through which illness is constituted, while telling us a great deal about our practical concerns about the cultural shaping of illness associated with such dramatic disorders as epileptic seizures. This leads me to some final observations about the analysis of illness narratives.

There is an obvious reason for rejecting the analogy of illness and its interpretation to the reading of fiction. Illness is all too real, and its attendant fears and misery “cannot be wished away.” Any analogy of such experience to “fiction” has the potential to devalue suffering and misrepresent the very essence of the experience. However, disease as embedded in life can only be represented through a creative conceptual response. Its “thereness” in the body must be rendered “there” in the life. And this process, even more than the referential or “locutionary” processes of biomedical representation, requires an aesthetic response, an active, synthetic process of constituting in an effort to grasp what is certainly there but is indeterminate in form.

Literary scholars and philosophers since Aristotle have sought to reduce the gap between aesthetic objects and reality, by finding powerful references to reality and significance in poetry and fiction. Ricoeur (1981a: 274–296) argues similarly for reducing the gap between “fiction” and “history.” Although illness experiences
are far from "fictional," there are reasons to reduce the gap between fiction and reality in the context of cultural studies of illness—real illness in contemporary, living sufferers, not simply its representation in literature or tribal myths—by investigating the narrative qualities of illness in all its reality. Several reasons may be enumerated.

First, much of what we know about illness we know through stories—stories told by the sick about their experiences, by family members, doctors, healers, and others in the society. This is a simple fact. "An illness" has a narrative structure, although it is not a closed text, and it is composed as a corpus of stories. Second, stories are not only the means by which illness experience is objectified, communicated, and reported to others; they are also a primary means for giving shape to experience and making past experience available to sufferers themselves. Significant experience is stored in the stockhouse of memory as stories, and remembering and recounting those stories provide access to the attendant experiences.

Third, illness narratives—both the corpus of story episodes and the larger life "story" or illness narrative to which they contribute—have elements in common with fiction. They have a plot; succession is ordered as history or event, given configuration. They have indeterminacy and openness; therapeutic actions, motives of participants, the efficacy of interventions and events are open to reinterpretation as life goes on, revealing hidden aspects unavailable to the blindness of the present. There is no final judgment about their meaning or significance. Narratives are organized as predicament and striving and as an unfolding of human desire.

Fourth, illness stories once told break free of their original discursive or performative setting. They are "contexualized," in Ricoeur's (1981a: 197–221) sense of the word. They are told and retold, made available to multiple "readers." Their effects and interpretations are unpredictable; they cannot be controlled by the author, by the teller of the tale.

Fifth, the sufferer is not only a narrator of stories but is, in several important senses, similar to a "reader." Those with an illness find themselves in the midst of "reading" a story, often helpless to affect its outcome, constantly revising interpretations, judgments, hopes, and expectations as the narrative time progresses. The illness can only be comprehended, constituted by a synthetic act, by giving larger sense to what can only be experienced in discrete moments and from limited perspectives. Medical treatments lead the sufferer into new imaginative worlds, whether into the specialized worlds of biomedicine or of other forms of healing. Quite new aspects of experience are "themalyzed," while others recede to the horizon. Illness is confrontational; it captures our attention. It is filled with "gaps," with the unknown and the unknowable, which provoke an imaginative response. All of these are characteristics which Ingarden (1973), Iser (1978), Ricoeur (1981a, 1984), and others have shown to be present in the phenomenology of reading.

Finally, illness and illness narratives have the potential to recast reality in relation to the unexpected, the non-ordinary, a predicament, the mysterious. Bruner (1986: 24) writes that "stories of literary merit... render the world newly strange, rescue it from obviousness, fill it with gaps that call upon the reader, in Barthes' sense, to become a writer, a composer of a virtual text in response to the actual. In the end, it is the reader who must write for himself what he intends to do with the actual text." And so with illness. At the same time that it offers suffering, pain, and misery, when illness is transformed as narrative it has the potential to awaken us to conventionality and its finitude, provoking a creative response and revitalizing language and experience.

C. S. Lewis argued that narratives must be organized as a series of events if we are to consider them as stories, but that this series "is only really a net whereby to catch something else. The real theme may be, and perhaps usually is, something that has no sequence in it..." (1982: 17). The struggle between plot and theme, between the succession of events and the grand ideas we feel are represented by this particular set of events, is as characteristic of life as of stories. And as in life, the grand ideas often elude the stories as well. No surprise, Lewis concludes (1982: 19). "If Story fails in that way does not life commit the same blunder?... If the author's plot is only a net, and usually an imperfect one, a net of time and event for catching what is not really a process at all, is life much more?... In life and art both, as it seems to me, we are always trying to catch in our net of successive moments something that is not successive." Stories, perhaps better than other forms, provide a glimpse of the grand ideas that often seem to elude life and defy rational description. Illness stories often seem to provide an especially fine mesh for catching such ideas. It is for this reason that anthropologists often turn to stories of illness and suffering to be awakened to the ideas we sense are present in the lives of others, present but not readily described.