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An epidemic of chronic pain stalks America today. Nearly half of all Americans suffer from one or more chronic conditions, including illnesses and impairments, and the number is growing. Even as tens of millions struggle with such established chronic diseases as arthritis, diabetes, hypertension, and heart disease, millions more are afflicted with the new chronic conditions of late-twentieth-century civilization. The past two decades have brought a dizzying number of such ailments: chronic fatigue syndrome, repetitive strain disorder, Gulf War syndrome, environmental hypersensitivity, and among the newest entrants, fibromyalgia. Although the symptom mixes vary, these new disorders share many features. All lack a known organic basis and are difficult to diagnose. All lack a recognized cause but are worsened by stress. All are syndromes of related symptoms rather than true diseases. All are chronic and treatable to a certain extent, but incurable. Most target women in larger numbers than men.

In a culture that worships science, it is to scientific (or conventional) medicine that we first turn for help. Women desperate for someone to acknowledge and alleviate their suffering go to their doctors to name and ease their new pains. Professionally obligated to heal and motivated by humanitarian impulses, our doctors try to live up to our expectations. Although the treatment of chronic pain is one of scientific medicine’s most visible failures, in a time of shrinking resources, medical specialists are only too happy to have a new domain in which to apply their skills. Research scientists develop diagnostic criteria for a new syndrome, clinical scientists work out treatment protocols, and a new group of specialists emerges with a guaranteed stable of patients for life. Before long, a bona fide new disease has entered the medical and cultural mainstream. In this way, distress is transformed into disease, and the “diseasing” of social life moves ineluctably forward.

Most of us think that medicine can reveal the truth of our bodies because medicine is a science that claims to have direct, privileged access
bilitating symptoms. Fibromyalgia is similar in many respects to chronic fatigue syndrome; indeed, it has been called the CFS of the 1990s. The two conditions differ in one major regard, however: in sufferers of chronic fatigue syndrome lassitude is the dominant symptom, whereas in sufferers of fibromyalgia pain predominates. In some patients fibromyalgia is only mildly disruptive, but in others it is incapacitating, forcing them to scale back their lives and abandon careers to take care of their bodies. For these people the illness experience can be one of “absolute devastation.” Although fibromyalgia is not progressive, with no cure in sight it is considered a chronic condition likely to last a lifetime.

Fibromyalgia is a puzzling disorder whose cause remains unknown. Researchers are continuing their search for an organic basis for the symptoms, but so far efforts to discover a distinctive physiological or psychological pathology have brought little success. Currently, researchers explore a wide spectrum of possible factors, from metabolic dysfunction, viral infection, immune system dysfunction, a genetic disorder to injury, trauma, victimization, and prolonged stress. With so little known about causation, effective treatment for the condition has remained elusive. Although there is no consensus on the origin of “management” of fibromyalgia, current thinking stresses the use of medications for sleep and pain, combined with exercise and behavioral therapies such as restriction of activities that exacerbate the pain.

Specialists in the condition estimate that a significant minority of American adults—2.4 percent of the general adult population and 10 to 20 percent of rheumatological patients—suffers from fibromyalgia. People of Caucasian descent are more likely than others to be diagnosed with the condition. The disease is seven times more common in women than in men: overall, 3.4 percent of women but only 0.5 percent of men are diagnosed with fibromyalgia. While women of all ages suffer from the symptoms of the disorder, fibromyalgia tends to strike middle-aged and older women the most. The highest rates are found among women who are fifty or older; in this group between 5.6 and 7.4 percent of women are diagnosed as fibromyalgic.

Fibromyalgia in its current configuration is a young disease. Although the condition was named as early as 1927 (fibro for fibrous tissue, my for muscle, and algia for the condition of pain), for most of the twentieth century fibromyalgia scarcely existed as a clinical or research entity. In 1977 two Canadian researchers published a seminal article proposing diagnostic criteria. This article revived interest in a condition, fibrositis, that had been known for centuries but had languished in biomedical
counter: gender relations and the cultures of illness. Gender dynamics influence who has voice and power in the medical encounter. From novels to personal narratives to social surveys, many sources suggest that when the doctor is male and the patient female, the patient experience can be trying. At its worst it can be hellish. This case will add layers of new meaning to the concept of a patient hell. Both cultural beliefs about illness and popular cultural alternatives to scientific medicine color the patient’s views of the causes of illness and the therapeutic alternatives to conventional treatments. The case explored here will reveal how New Age and other alternative medicines that promise the sick person help and empowerment can end up hurting and disempowering her instead.

The particulars of this case make it especially suitable for studying the interrelations of science, gender, and popular cultures of illness. The doctor involved was ultrascientific, followed most of the rules of scientific medicine to the letter, and played his role as scientist of the body with utmost seriousness and sincerity. New models of physician empathy and egalitarian doctor-patient partnerships had not found their way into his practice. For her part, the patient was both an avid believer in scientific medicine and an eager consumer of the cultures of alternative medicine. Her gender identity was complex and contradictory, embodying the norms both of feminism and of white middle-class femininity (these latter, unconsciously). Although the consequences of the biomedical intervention were extraordinary, what took place during the eight-month encounter was but the ordinary workings of science, gender, and illness cultures. In this problematique I explain what I mean by the normal workings of medical science, gender relations, and illness cultures and introduce the constructs I use in the analysis that follows. In the final section I describe the book’s genre, auto-ethnography, and its intellectual and political significance.

**Science as Storytelling, Clinical Medicine as Science**

Most of us, laypeople and scientists alike, think of science as representational—that is, as something that tells us the real truth about the natural world, without artfulness or expressivity. We also think of the truths of science as objective, disinterested, and value free. We think, that is, that the methods of science insulate it against the intrusion of the scientist’s interests and values. It is on these bases that we have granted science its extraordinary cultural authority and social power over our lives.
him into a patient he can treat, the physician confines his attention to the body (objectification), turns the symptoms and signs he notes into numerical measures (quantification), and attaches disease names to the ills he discovers (pathologization). In creating the facts of the case and assembling them into a larger story, he uses the numbers he has gathered to fashion a diagnosis and prognosis (quantification) and then outlines the treatment program that must be undertaken if the patient is to get better (amelioration).

Clearly, the discourse has a marked effect on the story that is told. A patient presenting a certain set of symptoms would have quite a different story told about her if she were consulting a practitioner of, say, Chinese or Ayurvedic medicine or any variety of more homegrown alternative medicines. It makes little sense, then, to talk about right and wrong stories, since a story that is wrong from the perspective of one practitioner might be right from the vantage point of another. One can, however, talk about good and bad stories. Good stories are ones that fit the case. They describe the patient’s signs and symptoms and specify a treatment that works. Bad stories are ones that do neither.

When a biomedical practitioner tells a bad story, the limits of biomedicine’s discourses stand out with equal clarity. Unfortunately, it is the bad stories and the limits of medicine that must preoccupy us here.

Prone to Error

The physician must convince the patient that his story is true and objective, but a second look at these discourses belies the idea that a biomedical story can be completely either. Perhaps most obviously, a biomedical story must be partial rather than complete, since the discourses of medicine by definition exclude affective and mental components of illness and signs or symptoms that cannot be quantified. A story created from these assumptions may be not only partial, but even poor. The story might be weak because the discourse of objectification makes the doctor the expert on the patient. Although the patient’s knowledge might
the longing for a good relationship entwined itself with the longing for a well body, producing a degree of emotional investment in the relationship that was far greater than one would expect from existing work on the medical encounter. And when things began to go wrong, the emotional aftershocks—from depression to betrayal to anger—were as intense as the longing and hope that had preceded them. These emotional oscillations were as much a defining feature of the medical encounter to the patient as were the vagaries of the body. To capture these dimensions of the medical experience, which were central to the production of rebellion, we need to enlarge our array of concepts to include self, relationship, and emotion. And to develop these constructs, we need to broaden our conceptual terrain to embrace the fields of women’s psychology and feminist theory.

The centrality of identity, feelings, and connection to the medical experience led me back to the field of women’s psychology, the long-abandoned focus of my study and research as an undergraduate. In their work on women’s morality, socialization, and depression, described in detail below, Carol Gilligan and her colleagues Lyn Mikel Brown and Dana Jack have collectively sketched out important elements of the psychodynamics of women’s self in relationships with others. Their picture of these dynamics provides a veritable road map to the psychosocial odyssey on which the patient studied here embarked and to the emotional peaks and valleys she traversed along the way. Although this body of work has been subject to extensive critique in the women’s studies literature, it contains important insights and implications that have been overlooked by earlier readings of it as theoretically outdated and politically problematic. New readings of the Gilliganian corpus, on which I draw below, stress its radical implications for theories of identity and morality. In this book I highlight those insights that illuminate issues of gender identity. Gender identity is the core construct around which issues of emotion, relationship, and politics all cluster. Although Gilligan’s principal concern was women’s morality, not identity, here I appropriate her and her colleagues’ work for my own purposes, placing it within a theoretical literature that provides ways to avoid the intellectual problems that their critics have worried about.

**Gender Identities: The “Discursive Self” and Its Resistant Potential**

Questions of identity, self, and subjectivity—all of which refer to our understanding of who we are and how we live our lives—have been cen-
scarcely begun to explore. These larger implications of the analysis of patient identity and politics are explored in the book’s conclusion.

Cultures of Illness, Cultures of Blame

Biomedicine operates within a larger culture that today is obsessed with illness and the body. Spread by the media, books, and everyday conversations, popular beliefs about bodily suffering powerfully shape the sick person’s understandings of why he is ill and what he should do to get better. The effects of these ideas are often more powerful than biomedicine recognizes and more insidious than alternative medicine, a major purveyor of these notions, intends.

In her influential essay, *Illness as Metaphor*, philosopher Susan Sontag drew attention to our culture’s long-standing tendency to metaphorize illness. Through metaphor, the culture has turned a bodily disorder into a moral matter in which outward signs of disease are seen as evidence of inner flaw. Psychological theories of illness, she argued, are punitive, or they blame the patient as the cause—“she deserves it,” “she’s one of life’s losers”—and make her responsible for getting better. In the past few decades, not only illness but also health has become a moral matter. Whether promoting exercise, health foods, or other “wellness behaviors,” health crusaders portray the pursuit of a healthy lifestyle as a moral duty, the achievement of good health an “affirmation of a life lived virtuously.” Written twenty years ago, Sontag’s critique of our moralization of illness has even more bite today, when the metaphorizing she described has become a veritable industry: Alternative Medicine, Inc.

In recent years the public has grown deeply dissatisfied with mainstream approaches to chronic illness. But it has not given up hope for a cure to chronic pain. Building on this wellspring of public interest, alternative approaches to healing have flourished, becoming some of the major articulators of our cultural discourses on illness. Although many widely divergent alternative approaches exist, the ones that have gotten the most attention are not the well-established therapies such as Chinese and Ayurvedic medicine but the less proven self-help and New Age approaches whose manifestos crowd the shelves of bookstores around the country. These approaches are the focus of attention in this book.

Virtually all holistic approaches hold that the mind and body are deeply interconnected and that our thoughts and emotions powerfully affect our physical selves. Although framed as a critique of, and alternative to, main-
of the illness experience, it may also have restricted my vision in ways I cannot perceive. My intense moral and emotional engagement with the medical encounter featured in these pages may also have tempted me to overgeneralize from my own experience. Although I have tried to minimize these problems by embedding my arguments in the scholarly literatures on chronic illness and biomedicine, such problems are to some extent unavoidable in auto-ethnographic writing.

**The Rewards and Risks of Writing about Emotion**

Autobiographical writing has also been favored by feminist anthropologists, in part because of its ability to acknowledge and to reveal the role of emotions in the production of anthropological knowledge.\(^\text{124}\) In a series of introspective works published over the past decade, Ruth Behar has courageously pioneered this style of “vulnerable writing.”\(^\text{125}\) In this study I push this process of exteriorizing the interior further by acknowledging the role not only of emotions but also of physical suffering and pain in shaping the creation of anthropological knowledge.

Writing of emotion and pain, however, is risky. In the Western philosophical tradition, emotions are regarded as suspect and their purported opposite, reason, is deemed the sole legitimate faculty with which knowledge may be acquired.\(^\text{126}\) Writing emotionally thus leaves one vulnerable to charges of being irrational, particularistic, private, and subjective, rather than reasonable, universal, public, and objective. The risk is especially great for women, since they have long been associated with the emotional, irrational side of these binaries. Writing against the grain, the feminist theorist Alison M. Jaggar argues, persuasively I think, that feminists’ concerns about emotionality may be overdrawn. Far from threatening feminist scholarship, she suggests, certain kinds of emotions can play strategic roles in the development of critical social theory.\(^\text{127}\) In a thoughtful essay on the role played by emotion in the creation of knowledge, Jaggar argues that the familiar dichotomies set out above are artificial.\(^\text{128}\) Although feelings are experienced as private and particularistic, she demonstrates, emotions are actually social constructs taught to new members of society and shared by large categories of people. Moreover, far from being antithetical to knowledge, emotions are necessary features of all knowledge, influencing the values, observations, and thoughts that make up the process of intellectual inquiry. Most scholars, she believes, are unaware of the role of their emotions in their scholarship, because our culture encourages us to control or even suppress our
At forty-six S. was nearing the end of her rope. The stress of coping with a demanding new job in an unfamiliar work environment with little social support was taking its toll. On the scale of life stresses S. was off the scale: she had not just moved three thousand miles to a new part of the country. She had also changed jobs, fields, and types of organizations; disrupted her family life (her husband was still based in New York but had found work in several West Coast cities); and lost the social network that had held her hectic life together in New York. A heavy load of teaching and committee work prevented her from doing her own research and writing, making her feel she had lost her professional and personal identity and thus her very self.

Every stress in her life seemed to write itself out on her body. The connection between life distress and body symptom was now frighteningly close. Two days after a big blowup at the university, her right pinkie ballooned into the classic “sausage digit” of psoriatic arthritis, sending her back to her doctor for yet another round of prednisone. While the joints of her fingers had been a problem before, now the joints in her feet were swelling as well, making it working difficult. Her ability to sleep was impaired, leaving her physically drained and emotionally weak and, in turn, all the more vulnerable to the stresses of her new life.

Despite S.’s valiant efforts to stay in control, her life was becoming a vicious cycle of overwhelming stress, fatigue, and symptoms. The doctor to whom she had been assigned was not paying attention and seemed insufficiently concerned about the seriousness of her condition. As soon as she was allowed to change health plans, S. switched to a plan that offered freedom in the choice of specialists and immediately began the search for another rheumatologist. This one had to be a woman.

But the search for a woman doctor did not get far. For, quite by chance, around this time S. was put in touch with a fellow sufferer of psoriatic arthritis, and of many other conditions as well. The new friend, Anna, whom we will meet again in later chapters, told her about a doctor (male, unfortunately, and a short flight away in Seattle) with a radically different approach to rheumatological care. Anna had heard about him from her family in Seattle, where she had grown up. According to Anna, who had been seeing him for two years, Dr. D. used aggressive pharmacological intervention—in plain English, strong drugs—to make his patients as close to symptom free as possible. In many of his patients he diagnosed something called fibromyalgia, a condition involving widespread muscle pain and a sleep disorder. He resolved the sleep disorder with medication. This sounded extremely promising to S., for she was having great
difficulty sleeping. The thought of getting help with her sleep problem had powerful appeal.

Yet, Anna pointed out, there were also disadvantages to going to Dr. D. These were in addition to the inconvenience and expense of traveling to seem him. First, the doctor insisted on micromanaging his patients’ lives, with frequent appointments, endless tests, and other demands that were time consuming and intrusive. Second, he had a “bad bedside manner,” a blunt way of putting things that seemed uncaring at best, cruel at worst. In Anna’s case, he had put her on a drug that made her gain thirty pounds then endlessly berated her for not being able to lose weight. She felt miserable about this punitive treatment but believed she had no choice but to stay with Dr. D. because, as she put it, he was the only doctor who “would not give up on me.” So she stuck it out, despite the abuse.

To S., however, these sounded like small prices to pay for the promise of help with the arthritis and the tantalizing hope of getting some sleep. In her weakened and vulnerable state, with no one to look out for her and nowhere else to turn, she thought Dr. D. sounded like a dream come true. Another was a dream she could make true. Her new health-care plan covered appointments and lab work with doctors outside the primary service area. And Seattle was one of the cities where her husband had found work. If they coordinated travel schedules, when she visited the doctor she could also spend time with her husband.

Seeking more information, S. called relatives and friends in Seattle, who in turn called people they knew who had serious rheumatological problems. Within a few days S. had learned that Dr. D. had a reputation in Seattle as a committed and thorough specialist. He seemed to provoke strong feelings in people. While a few strongly disliked his style of practice, others adored him, calling him a hero to sufferers of chronic pain. Though he insisted on regular, in-person visits, he was willing to treat patients who lived at a distance, staying in touch with them between appointments by phone. He had contract arrangements with laboratories and radiology centers up and down the West Coast, making it easy for long-distance patients to have their blood work and other tests done near their homes.

This news about Dr. D. was both reassuring and encouraging. Although she was wary of male doctors after so many bad experiences in New York, S. was tempted by the apple of too-good-to-be-true promises. Desperate for relief from her pain and fatigue, hopeful that this
sleep disturbance: pain produces loss of non-REM [rapid eye movement] sleep, and no deep sleep produces more pain. [The fibromyalgia is a] manifestation of arthritis. Musculoskeletal sites of pain are not treated, so [you] get pain amplification—diffuse pain . . . Pain pathways are never closed so pain continues to exist, even to spread.¹ Problem exists because primary disease (PA) not treated. Also is referred pain, in which pain is referred away from the site of origin . . . [M]essages originating in one joint are sent elsewhere. Everything conspires to increase the pain. PA is the primary trigger. That combined with the osteoarthritis produces fibromyalgia.

5. Also some mild scoliosis, or curvature of the spine. Perhaps have always had this. (Diary, March 8, emphases added)

In cool, clinical language, the doctor listed these conditions, one after the other, making no attempt to rank them by importance or urgency, that some were serious while others were not. In spite of this, he was delivering a lecture to a classroom of students, not telling a nightmare story about her life. Nor did the doctor offer any sympathy, any gentle words to reassure her that everything was okay, that despite the number of rheumatological problems he had discovered, her overall condition was not that bad. To the contrary, he seemed to be trying to make it seem as bad as possible. This was troubling. Why had he listed the primary and secondary osteoarthritis as two conditions rather than one? Why had he included scoliosis along with the other diseases when it is merely a skeletal condition that often has no implications for health? He seemed to be trying to find as many physical problems as possible, put labels on them, and then pin these labels onto her.

S. felt terrible. Suddenly she was five times sicker than she had been before. And before she had been already pretty sick. As she struggled to grasp the enormity of the news her mind raced over the diagnoses, trying to understand what each one would mean for her life. The diagnosis of psoriatic arthritis was no surprise; she had known about that condition for years and had found ways to cope with it. The diagnosis of osteoarthritis—primary and secondary, no less—was harder to deal with. While she was aware of the sometime pain in her neck and knees and thumbs, having a technical name for it—osteoarthritis or, much worse, degenerative arthritis—made the problem seem much worse. Now it was no longer just an occasional pain in the neck and knees; now it was a real disease that would require medical attention. Moreover, the term degenerative arthritis, which the doctor had introduced
before its synonym, osteoarthritis, made it sound like the condition was going to get progressively worse: she would increasingly “degenerate” until all her joints were eroded. This is not what she had come to hear! And the scoliosis—how bad was that? The last thing in the world she needed was back problems!

Of the five labels, the strangest was fibromyalgia. Yes, she certainly had difficulty sleeping, so that part made sense. And the doctor had found all eighteen tender points (on which, more below), so there must be something there. But what was this “pain all over” he was talking about? She had not used those words. Nor did she feel pain all over her body; the pain was localized in a few joints. Why was he putting words into her mouth? But there was no time for questions now. The appointment had already run over its allotted time, and the doctor had not even begun to talk about treatment. That came next.

**The Management Plan: A Ten-Part Intervention in the Patient’s Life**

Dr. D. did not use the word *cure*. Occasionally he referred to the “treatment” of her conditions. But his preferred word was *management*, a not-so-subtle hint that the conditions he had diagnosed would not be going away. The plan he outlined left little room for hope that things would get much better. Quite the contrary, he seemed to be saying that they would get much worse—unless, that is, decisive action was taken immediately and on all fronts. His plan for action called for no fewer than ten interventions in S.’s life. Here they are, as she recorded them in her medical diary on March 8. More information on the drugs, which formed the core of the management program, will be presented in chapter 2. Later chapters will also clarify the meanings of the technical terms. Although

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<th>Disease</th>
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<td>is inherited. Mild scoliosis, marked by a curve of ten to twenty-five degrees, produces few if any symptoms. More severe abnormalities, which may produce backache and fatigue, are generally corrected in childhood or adolescence with a spinal brace and/or surgery. The prognosis varies with the severity of the deformity and the age at which the abnormality develops. Mild scoliosis is rarely progressive.</td>
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**Sources:** Wilson et al. 1991; Fries 1995; Wolfe et al. 1995; Berkow 1997; Taylor 1998
riously, and progressively ill person whose medical management required a comprehensive package of pharmacological and other intrusions into her life that he was best equipped to provide. In creating a patient whose ills “matched” his training and skills, Dr. D. was just doing what scientist-physicians generally do: he was creating a “do-able” problem and, at the same time, gaining patients for his practice (for more, see the Problematique). From these material and discursive elements, he had constructed a new, fully elaborated story about her body—complete with diagnosis, prognosis, and treatment plan—that both required and produced a new identity on her part.

How had the doctor changed her view of her life so quickly, so that after a mere five hours she had begun to view her body and life through his interpretive grid? Dr. D. was not only a good storyteller, he was also an artful practitioner of the science of medicine. In the initial consultation he had skillfully deployed both the discourses and practices of medical science to transform S. not only into a patient but into a willing patient whose emotional state made her eager to undergo the agonizing treatment that was to ensue. Dr. D. had turned her into precisely the kind of patient he was set up to treat. That patient was one who believed her body was badly damaged and becoming more so, who depended heavily on the doctor to know and treat her ills, and who trusted his scientific expertise so absolutely that she would never dream he could make a mistake. What other kind of person would put up with what was to follow? It also helped if she had ample time on her hands to make frequent doctor’s appointments, each two to three hours in length, and to manage the almost full-time job he had created around caring for her failing body. Remarkably, the doctor could help put time in his patients’ hands, too, although that is a story for a later chapter.

Ritualized Practices of Medicalization

The last section hinted at ways in which the ritualized practices of the initial consultation worked to turn doctor and patient into subject and object, knower and known, mind and body of medical science. Here I bring these techniques of medicalization together, emphasizing now the doctor’s practices rather than the patient’s reactions. I begin with general “patient-construction” practices and then turn to diagnostic practices.

During the medical history taking, S.’s record of her bodily past was erased, with D.’s literally written over it. What counted to her no longer mattered; what counted to him was to count for medical science. In the
clinical exam the doctor became the observer, the patient the observed. Lying prone on the clinical table, the patient body became an object of intense scrutiny and detailed inspection. Feeling and measuring, counting and writing, the doctor became the doer of Science and the definer of the truths of her body.

The rituals of the diagnosis—the doctor’s departure from the room, file in hand; the long minutes spent in his office; the heroic return and pronouncement of the truths of the body—worked to surround the labeling process with an aura of mystery, of truth being produced in sacred places that only the doctor could enter. Lifted up and away from the messy details of the feminine body-object, the labeling practice was elevated to the level of Science, which only the masculine mind-subject, working in silence and solitude, could perform. As if to say that no truth, no matter how small, could escape the medical gaze, the diagnosis consisted of five items, the management plan twice that. If everything else had not yet convinced the patient of the doctor’s inestimable authority and expertise, the fee announced in the closing minutes of the consultation, served as a pointed exclamation mark that the patient could not possibly misread: this doctor’s services were worth serious money!

The history taking and physical exam served also as diagnostic practices whose aim was to discover the pathologies of the body, bring to light their manifold signs and symptoms, and attach disease labels to them. But the patient body was inherently chaotic, a disorganized collection of aches and pains, complaints and sorrows. How was the messy stuff of the patient body turned into five neat disease labels? Proceeding like a laboratory scientist, the clinical scientist methodically gathered information from the patient’s verbal reports, her body, and her existing medical file. That information was then filtered through the experienced eye and trained mind of the clinician. Weighing it in light of “the literature” and cases of other patients he had clinically observed, he converted the chaos of life into scientific fact.

The diagnosis of psoriatic arthritis was easy to reach, since it had been attached to the patient before. Dr. D. reaffirmed its correctness by observing the characteristic pattern of joint involvement, extracting from the patient the telltale history of joint swelling and surgery, noting the family history of the disease, and examining the X-ray reports of bone deformity in the patient file. With all this evidence, there was a watertight case for this diagnosis.

The diagnosis of fibromyalgia was more difficult, since the patient lacked many of the characteristic symptoms of the disease. She lacked
To repeat, the reader must not think that the doctor was deploying his conversational skills self-consciously. To the contrary, as far as S. could tell her doctor spoke freely, with no awareness of the discursive structure, rhetorical style, or narrative shape of his talk. She came to this conclusion because the doctor often used corny metaphors—a favorite was “you have to prick your finger on a thorn before you can smell the roses”—that were so clichéd she could not help but wince every time he used one. (He stopped using them as time went by.) Presumably, had the doctor been aware of the linguistic features of his speech, he would not have resorted to such trite metaphors.

Objectification. The first and most powerful effect of Dr. D.’s discourse was to separate the objective from the subjective, the body from the emotions and mind, placing feelings and thoughts outside the focus of interest and making the doctor the expert on the body. Throughout the initial consultation the doctor’s intense focus on the patient’s body provided unmissable clues to the fact that the body would be the central—indeed, virtually the only—focus of medical concern. But the doctor did not leave it to his patient’s cunning to figure out where he stood on the issue of the “subjective” or emotional component of her health. Although depression is a common affliction of those with chronic rheumatological conditions, Dr. D. declared it off limits in his practice. While acknowledging that many fibromyalgic patients were depressed, he explained, theirs was a secondary depression that emerged because of the primary muscle condition. He would treat the muscle condition, and the depression would go away. (The depression associated with S.’s arthritis was never mentioned because, in D.’s view, fibromyalgia was S.’s main medical problem.)

If the body was to be the exclusive focus of concern, the doctor was to be the unchallenged expert on the body. We have seen how the routines of the medical history and physical exam made Dr. D. the authority on S.’s body. Discursive practices had the same effect of transferring the claim to know the patient body to the physician. In the discovery and designation of the tender points of fibromyalgia, for example, the patient felt no pain on her own, but the doctor was able to produce painful sensations by pinching her in special places. The truth of the designation and the pain was then backed up by offhand references to the authority of the medical literature, which indicated that there were eighteen such tender points, located at this and that place on the body, all of which she “had.” The discourse of medicine had attributed muscle pain to a patient who before had none. Similarly, in dispensing the diagnosis of...
collection of these results, S. came to be represented as a set of numbers, of normals and abnormals, in her doctor’s file. These numbers would later be used to measure the effectiveness of the drugs. The sedimentation rate, for example, provided an index of inflammation, which some of the drugs were supposed to reduce. The numbers would also be used to check for adverse side effects from the drugs, which often showed up early in biochemical anomalies of the blood. Thus, from the initial consultation onward, the state of S.’s musculoskeletal health was to be represented not so much by how she felt or how she thought she was doing as by how the doctor’s numbers were moving.

In general, quantifying signs and symptoms and then collecting numbers on them at regular intervals is a good way of gauging bodily change. But the doctor’s numbers counted some things and not others. While including signs of disease that could be assessed in the laboratory or examining room, the doctor’s numerical record omitted two classes of symptoms that would be crucial in S.’s case: symptoms the doctor considered important but could not measure (such as the quality and quantity of the patient’s sleep), and aspects of S.’s health that only she deemed important enough to merit medical concern (for example, her emotional well-being or her ability to think and write). Over time, these two evaluations of the patient’s health—the doctor’s numerical record and S.’s lived reality of her body—would produce widely divergent understandings of how treatment was progressing.\(^3\) The two assessments were so different that, to the very end, doctor and patient would never see eye to eye on what happened to S. under D.’s care.

Pathologization. The work of biomedicine is to find things wrong with patients, which practitioners then proceed to make right. Accordingly, medical discourse focuses on disease rather than on health. A core task of biomedicine is to affix disease labels to its objects; the more and the more serious the labels, the greater the scope for medical intervention.

If S.’s experience was any indication, Dr. D. was a masterful labeler of patients. His labeling practices had four attributes. First, his diagnoses were numerous. S. had not one illness or even two, but five. We saw above how this number was made to look so large. S.’s sleep problems were relabeled a “sleep disorder,” evidence of the presence of “fibromyalgia.” Osteoarthritis became primary osteoarthritis and secondary osteoarthritis. Scoliosis, most often a congenital condition that is diagnosed early in life, was made into an adult condition listed along with the bona fide diseases. In this way the list of diseases S. “had” grew from one to five.
a combination of a nonsteroidal antiinflammatory drug to reduce joint swelling and two drugs in a stronger class of disease-modifying antirheumatic drugs, which some evidence suggests might slow the process of joint destruction. In the class of antirheumatics the doctor wanted to increase the dosage of Methotrexate, which S. had been taking for four years, to the highest level recommended for a person of her size. In addition, he wanted to add a new drug in the same class, Plaquenil. Plaquenil is an antimalarial drug that has been shown to help patients with arthritis, although the mechanism by which it works is not understood. The Plaquenil would not kick in for six to eight or even twelve weeks, the doctor said, and treatment could not begin until S. had undergone a baseline retinal exam. Both drugs had potentially dangerous if rare side effects, Methotrexate on the liver and Plaquenil on the eyes. S. had tolerated fairly high doses of Methotrexate, with no apparent side effects. But she had refused to take Plaquenil for years, fearing about the potential for damage to her eyes. Dr. D. now dismissed those worries, noting that retinal damage could be avoided with regular use of ultraviolet-blocking sunglasses, weekly vision checks by the patient with an Amsler Grid (a printed square of vertical and horizontal lines resembling a giant Tic-Tac-Toe box), and semiannual ophthalmological exams. The use of Plaquenil was not optional; it was an essential part of a treatment package whose design was the prerogative of the doctor.

The changes in the antirheumatics could be introduced gradually over the next few weeks. What could not wait, the doctor insisted, was a switch to a stronger antiinflammatory. This was an urgent priority, for the inflammation in S.’s joints was serious and getting worse. The best drug for her, the doctor declared, was Indocin. He warned of potential side effects, including headaches and mental changes (Diary, March 8; see chapter 1 for details). But they did not worry Dr. D. If the side effects became a problem, the patient was to take megadoses of Extra-Strength Tylenol to suppress them until her body became acclimated to the drug. If she was like most patients, she could eventually be “tolerized” to it.

We now look to see how this pharmacological discourse was turned into practice. We are interested in three aspects of this practice: how effective the drugs were, what side effects or new symptoms the patient experienced, and how the doctor interpreted the new symptoms. (Whether the new problems were side effects of the drugs or new symptoms of S.’s diseases was the crux of the interpretation problem. In the discussion below I try to use the term the doctor and/or patient considered correct at the time.) Between March 8 and June 14, when a stable regime of med-
The day after she began taking the new medications S. started keeping a record of all the drugs she consumed and their effects on her body and mind. She created a private chart for a number of complicated reasons that she did not try to come to grips with at the time. Among those reasons was S.’s desire to help the doctor sort out the effects and side effects of the drugs. Another was her conviction that she was a better judge of her bodily state than her doctor. A third was her hope that a detailed log of any and all side effects would help to protect her from the risks associated with the strong drugs. In this chapter we draw on that chart for information on what medications S. took, when she took them, and with what result.

How effective was the Elavil? For the first three nights the patient took her pills two hours before bedtime and got about five hours of sleep. But the effect was not quite as anticipated. Instead of sleeping through the night she awoke at 2:00 or 3:00 a.m. and could not get back to sleep. In the afternoon she was overcome with a sickly, swooning feeling that left her no choice but to take a nap. The Elavil seemed to be putting her to sleep in the daytime while failing to keep her asleep at night. She called Seattle to report the problem. The doctor replied that Elavil rarely puts patients to sleep the next day. She should try taking the pills at bedtime instead. The swooning feeling, he insisted, was not drug related (Diary, March 11).

On the fifth day the headaches began. S. had never had headaches before. These were horrible: huge, throbbing headaches that made all activity impossible. On March 12, she noted in the chart, she had a “splitting headache.” On March 13 the headache was “50 percent worse.” She called the doctor again. Here is her account of what he said:

[D.] thinks the headaches are unlikely to be related to the Elavil; his two hypotheses are (1) Indocin and (2) neck pain, leading to headaches. Says the neck pain will come more to the fore as treatment proceeds, decreasing only over time . . .

When “we” walk away from a drug, it is for good, that’s the philosophy—so he wants to stick with the Elavil for a bit longer. He needs to know more about how the drug pharmacology interacts with my physiology. So, more experiments for the next few days. [N]ew strategy: (a) Use Tylenol with codeine to kill off the headaches. ([Possible] side effects: affects thinking, makes one nauseous, [gives one] stomach problems, constipation; is a narcotic but not addictive.) . . . Take . . . two pills four times a day. (b) Stick with the Indocin, four times a day. (c) Take one tablet of Elavil at dinnertime. (Diary, March 13)
new emphasis the doctor was placing on neck pain, she began to won-
der if maybe the swimming and added neck exercises were not making things worse. Despite her worries about letting a doctor into this sacro-
sanct part of her life—S. had a special relationship with water that went back to her childhood summers spent by a Maine lake—she wanted desper-
ately to get better. According to the doctor’s ideas about treatment, self-monitoring and self-management were the keys to improving her fibromyalgia. So she swallowed her worries and suggested the idea to her doctor. What he told her contradicted everything she had always known to be true about her health. Yet these perverse new ideas seemed to be supported in her own life:

Turns out that swimming is not particularly good for arthritis—too much strain on the neck. I was really feeling that last night while swimmin... that turning of the neck to breathe . . . Also, the neck-rangin...g exercises . . . [that] my New York physical therapist recommended are baa...(Osteo) arthritis [which I have in my neck] usually results from . . . excessive force on a normal joint, or normal force applied to an abnormal joint . . . Either tends to make . . . worse. So, it seems there’s no better than exercise. This is really baffling; everything I’ve always known to be “true” turns out to be wrong. D. says that 50 percent of the time, going to a physical therapist makes his patients worse! . . . So, no more neck exercises! (Diary, April 24)

Since swimming was now identified as part of the problem, it too was included on the list of proscribed activities. On April 30, after yet an-
other experiment with the sleep medications led to more headaches and sleeplessness, S. was ordered to cut back the Flexeril, take a full dose of Tylenol with codeine, and “cut out all swimming” (Diary, April 30). The ban on swimming appeared to bring immediate results: the headaches went away and stayed away—for three days. But then they returned, for no apparent reason. And her neck pain grew worse. Like so many other hypotheses the doctor had offered, this one received inconsistent support—on some days it worked, on others it didn’t. Yet despite the mixed results, the ban on swimming remained in effect on the theory that it was best to eliminate all possible sources of the new symptoms to make them go away. Once the symptoms had disappeared, the activities could be reintroduced gradually and in a graded fashion so that the symp-
toms would not recur.

S. was utterly despondent at the thought of giving up her swimming. (This story is told in a later chapter.) But she toughed it out and came to accept the doctor’s interpretation as her own. After all, she believed
Psoriatic arthritis takes a multiplicity of pathways. Based on my history, it seems that my arthritis is following the “rheumatoid pattern” seen in 30 to 70 percent of patients. This is progressive, erosive, deforming. [There is] no way to predict [the] progression of [the] disease. [But] I won’t crumble away. (Thanks!) Even if every five years a couple of joints are eroded, that is not so terrible! (Diary, March 18)

Although the prognosis for psoriatic arthritis is hard to call, the doctor presented some essentially meaningless numbers—a 30 to 70 percent probability of progressive disease, reflecting, no doubt, the mixed results of the scientific literature—to make an indeterminate conclusion seem more determinate. The doctor cautioned that the future of S.’s disease could not be known, but then proceeded immediately to “assure” her that her bones wouldn’t crumble away. In other words, what he believed was not that he could not know her future but that he knew her future, and what he knew was that her disease was erosive. It wouldn’t turn into crumbles because the erosion would occur slowly—over decades rather than years or months. In this shift of emphasis, a presumed so quickly and effortlessly, the future of the disease, which is actually uncertain because it is subject to many unidentified factors, has been rendered certain. The rhetorics of reification have done their work.

Hearing that his patient was upset by his dreary prediction for her life, the doctor added in soft, kindly tones that he liked to be “frank, not brutal” (Diary, March 18). This little phrase, which the doctor offered every time the patient grew noticeably distressed, worked to amplify the reality of what was distressing her by presenting the doctor as the candid (“frank”) teller of the unfortunate truths of her body. The phrase also worked to absolve the doctor from responsibility for what he was reporting or its effects on the patient: he was merely reporting the truth; he had no hand in its creation. The second part of the phrase—“not brutal”—called attention to the doctor’s deep consideration for his patient’s feelings. By accentuating his supposed concern for his patient’s emotions, these words deflected attention away from any selfish interests the doctor himself might have in telling the story he has told. The doctor cared only about his patients, the phrase said; he had no thoughts for himself. This little phrase, used in moments of emotional vulnerability, had deeply distorting effects on the patient’s understanding of what was going on. It was one of the most potent expressions Dr. D. kept in his big doctor’s bag of linguistic tools.

S. did not want to believe that her arthritis was progressive, but she could not deny that it had grown worse in recent years. Her sarcastic
“thanks,” in reaction to the doctor’s reassurance that she would not “crumble away,” suggests that she was not quite able to reject the fearsome “rheumatoid verdict,” even though she could not fully accept it either. She put the matter on hold until more information came in.

Heavenly Promises

After outlining for S. this rather too-graphic picture of a future marked by progressive erosion of her joints and deformation of her body, the doctor switched gears to offer some words of comfort and hope. No matter if your musculoskeletal system is falling apart, he said, what counts is how you feel and function. (Such words might be comforting to patients whose bodily decline could not be stopped.) And I will help you feel and function better. Just trust me. I am not worried about a thing.

Doc knew I was totally depressed by this talk of progressive disease… Trying to make me feel better, he said, “It is the critical measures of how much pain one is in and how one is functioning… What is going on under the skin, in the musculoskeletal system, does not really matter. I am not worried about anything (that’s so I don’t get depressed that the first ten days have made me feel no better and much worse).” (Diary, March 18)

Why should S. accept Dr. D. as the savior of her body? Because he could promise her heaven. Exploiting the rhetorics of scientific domination over nature, he stressed his ability to conquer her illnesses and make her, if not disease free, then at least symptom free. “What are we aiming at? Up to and including [a] symptom-free condition… in six months” (Diary, March 18). Dr. D. made these promises again and again in response to S.’s never-ending doubts and queries about where she was headed and why she should tolerate all the suffering. S. filed this report of the doctor’s extravagant assurances about the future:

Just saw [Dr. D.]. He does not accept the idea of limits—says there are none. [I] could be doing the marathon next year, once my shoes are properly fitted. That is quite comforting. Aim is to narrow the range of variation in the symptoms. And ultimate aim is to be symptom free [and] to get rid of all the medication. (Diary, March 29)

The doctor could not change the underlying conditions, which, he emphasized repeatedly, were genetic or biological and “would always be there lying in wait to emerge.” But, he promised, he could make her symp-
or 2:30 and never quite going back to sleep again... Really think there is something weird going on here. Even this doctor agrees that I am way outside the norm in terms of response to these drugs. (Diary, March 22)

More objectionable than her uncooperative body, however, was S.’s unhelpful attitude. It was her skeptical outlook, the doctor told her, that was the basic problem. But S. stubbornly refused to abandon her doubts until she had material proof that the drugs would work:

The problems [according to D.] are: I am skeptical that he/we can ever find anything to ease the sleep problem; and my expectations (for treatment, alleviation of conditions) are too high. I said I was willing to suspend judgment for quite a long time on the first point, but I have to remain skeptical until I have physical evidence that some sleep medication will actually work for me. This is only natural. (Diary, March 27)

The doctor also complained that S. was “forcing him” to make his regimen sooner than he would like. Again, if the treatment was not working, it was her fault, not his. She was being too aggressive, she was having too much sway over his medical decisions. This too was an attitude problem. In this case she took the blame on herself, calling herself “an impossible case, a ‘bad patient’” who needed to be made good:

Really have to stop being so hard on this doctor. [He says] I’m forcing him to make many more changes much faster than he would like, and then throwing the consequences back at him. It’s not fair. I really need to be the humble patient. I really am an impossible case.

After three days of one sleep regimen... I begged for a change, so he halved the dosages. The result was no sleep at all. So now I have to go back to the three-day routine and stick it out, trying to make it work. [The doctor says] I should be staying on a routine for two to four weeks if the side effects are tolerable. This is the rule of thumb. I am bad: I am forcing him to make changes that he really does not want to make. (Diary, March 27)

As for the patient’s suggestion that she might go off the sleep medications, the doctor said that though he couldn’t prevent her from doing that, it was a stupid idea since it would just delay discovery of a pharmacological solution—the only kind that would work—to what was a fixed, biological problem:

My idea of going off the sleep medication—well, he said he couldn’t and wouldn’t oppose it. It just doesn’t prove anything. If I get sleep that night, [there] will be no way to tell why. And the underlying sleep disturbance will be there, lying in wait, until some regimen is found to deal with it. (Diary, March 27)
D.’s response was very clever, for it downplayed the doctor’s authority, making the patient appear to be in control of the decision. At the same time, it framed the matter in such a way that only one decision—continuing the drug experiments—appeared sensible. Any other decision would “prove nothing.” The doctor’s tactics worked, for S. abandoned her insurrectionary plan and remained on the sleep medications.

**S. Develops a Private Discourse**

During the first few weeks of treatment the doctor was fairly successful in bringing his new patient around. Most important, she remained in treatment, even though the drugs had not resolved the sleep problem and, overall, had made her feel worse rather than better. Why did she hold on? Certainly the doctor’s verbal incitements, blandishments, and assaults had left their mark on her thinking. Some of his views—that he was a special doctor, that she was a difficult patient, that a few weeks of suffering was nothing given the severity of her conditions, and left a deep impression. There were others, including the prognosis and the threat of serious deterioration, that she regarded as dubious but could not quite shake off. Still others, in particular the sky-is-the-limit promises, she rejected as too implausible to be given any credence. The doctor’s imprint was real, but his words came to be enveloped by a larger understanding that grew out of S.’s own experience of the world.

For deeper insight into why S. decided to hold on despite the enervating new symptoms, we need to peer inside her private mental world, a universe of thought and feeling that remained sealed off from the doctor. There, we find, she was evolving a private discourse that reflected her own history of need and desire and provided an overarching framework of meaning within which she came to understand her relationship with Dr. D. Enfolding many of the views conveyed by her doctor, this pattern of meaning was structured around two central images: “the caring doctor” and “the knowing doctor.” These were the guiding images that sustained S.’s hope and kept her in treatment during that first difficult month and beyond.

*The Knowing Doctor*

From the day of the first consultation, S. was convinced that Dr. D. was not an ordinary doctor, but a singular expert on the rheumatological...
Second, the view that the doctor had made the tender points of fibromyalgia vanish rested on a most peculiar discourse according to which something the patient does not perceive on her own is turned into a real, nameable bodily symptom (“this is the ‘pain all over’ you feel,” he told her), when a doctor’s pinching produces sensations of pain. This discourse enables the doctor first to manufacture the symptoms and then to eliminate them, all with only the most minimal of patient participation.

Third and finally, the notion that the doctor had produced dramatic improvement also depended on ignoring all the new symptoms that emerged after treatment began. These new symptoms—headache, fogginess, upper-back and neck pain—were not what the doctor had set out to fix; they belonged to a different category of bodily phenomena. These costs of the improvements that counted were steep, but they carried no weight in the evaluation of how the patient was doing.

Like her doctor, S. was trapped in this distorting mode of understanding. Her bodily improvements were real, but the discourse, rhetorically amplified by the doctor, created some improvements where to her there were none and discounted those new symptoms and hard-to-measure old ones that to her were only too real. In effect, these rheumatological understandings enabled her doctor to claim credit for the positive changes that “counted,” while the patient had to assume responsibility for the symptoms that remained. During the spring months S. came to accept this discourse as a good representation of her bodily reality: the rhetorics of biomedical infallibility had done their work. She accorded her doctor credit for the improvements he had made, while forgiving him for progress that was only partial and taking all the other symptoms upon herself as the “price” she had to pay for the gains he had made. That is why S. believed that her doctor was a genius when the evidence from her body was mixed at best.

In this chapter we have seen how S. was transformed from a skeptical and subversive patient into a model patient, the kind who makes physicians feel that their efforts are not in vain. I have highlighted the central role of physician rhetorics in this process, showing how the doctor actively created a good patient through the use of verbal tactics that began with soft enticements but, when it became necessary, turned to hard-edged accusations and threats. At the beginning of the chapter I suggested that the patient’s cultural training in gender made her especially vulnerable
hood and adolescent accomplishments would show not only good marks in school but also an outstanding record of success in the institutions of femininity. She had been a Brownie Scout, a curved bar–rank Girl Scout, a junior varsity and varsity cheerleader, a high school beauty-queen candidate, and a Kappa Kappa Gamma sorority girl during her freshman and sophomore years at Bucknell University, where she spent two years before transferring to Wellesley. And she always had boyfriends—lots of them. S. had played by the rules and won again and again. What were those rules?

The rules of gender that S. had internalized and lived by can be boiled down to six fundamentals. These codes of male-female behavior applied not to all relationships with men, but to a small number of relationships that were intimate, sexually or otherwise, and of relatively long duration. The fundamentals are these: (1) Men have power. (2) A woman’s happiness and well-being depend on her ability to form intimate relationships with men. (3) The way for a woman to create and maintain these all-important relationships is to make herself pleasing and pleasant. (4) Open conflict and disagreement threaten a relationship and must be avoided at all costs. (5) When the woman’s views or goals differ from those of the man, the woman must subordinate her opinions and objectives, silence herself, and publicly accept the man’s authority. (6) Although a woman cannot challenge male authority openly, she can contest his decisions and pursue her goals indirectly by quietly working “behind the scenes,” either on her own or in alliances with other women, manipulating him and/or the environment to promote her interests. Although such silent forms of resistance cannot be expected to unseat or even destabilize male authority, they make women feel they have “done something” to right the wrongs in their lives.

Twenty-five years after she had abandoned femininity for feminism (or so she thought), S. unconsciously applied this very same set of gender codes to her relationship with Dr. D. From the very beginning it was clear that this relationship fell into the category of intimate relationships with men, for by the end of the first appointment the doctor had made massive interventions in her life by redefining her bodily reality and outlining a program for deep intrusions into her body and her life. This new medical relationship was not only intimate, it was also threatening, for the doctor wanted to use dangerous drugs to bring her newly identified conditions under control. To S. the stakes appeared very, very high. They were high because she now “had” five chronic rheumatological illnesses, this doctor presented himself as uniquely capable of treating them, and
evidence of “a rare respect for women’s human dignity.” Other patients—indeed, the doctor himself—might give it a less feminist cast. While we have noted the doctor’s mastery of rhetoric, we should not leave this letter without observing that S. was not averse to the use of rhetorical flourish herself. She ends this paragraph with such a splash, writing: “You have already done more for me in a month than any other doctor has done in a decade.” Rhetoric notwithstanding, the emotions expressed here are heartfelt. S. truly adored her doctor and wrote a patient “love letter” to tell him so.

It was so important to S. that the letter be taken in the spirit intended that she followed up on its reception very closely. Oddly, though, the doctor said nothing about it, not even a simple “Thanks for your letter.” As days turned into weeks, S. grew worried that she had overstepped her bounds or been too personal in expressing her feelings of gratitude. In the following diary entry S. stews about whether she has committed a serious faux pas:

Wonder if he got my letter. Is it not strange that he did not mention it to me? I will ask him if he got it, and if not, perhaps write letters once in a while. For me, if not for him, this is a pretty intense experience, invoking very powerful feelings. He of course has to protect himself against feeling those feelings, and he does so, appropriately, by drawing a sharp line between his professional and personal life. (Diary, April 27)

In an appointment with her doctor three weeks later, S. finally found an opening in which to inquire into these delicate matters. Here is her diary description of the conversation:

Had [a] chance to talk to doctor about... setting boundaries between what is personal and what is public or shared information. He had pointed out that it was important to maintain a doctor-patient relationship in the clinical room, to ensure that doctorly functions like injecting the patient’s fingers] can be effectively performed. (Guess it is hard to inject someone if you empathize with his/her feelings too much.) I wondered if this was an unintentional hint that I was overstepping those boundaries, or had somehow done so in the past. So I took the opportunity to inquire about that, focusing my question on the letter I had sent. I... said I had worried after I sent the letter that I might have overstepped some bounds, been too personal. He said, no, he appreciated everything I had said, especially the part about gratitude, and that it is rare for someone to express appreciation. So, I said, would he please let me know if in the future I overstepped that boundary, because I want him to feel safe with me. He promised he would let me know, and said he found the boundaries I had set totally fine, that I
looking her own needs, she takes one party out of the relationship, guaranteeing a failure of communication. And in prioritizing the social relationship over the bodily treatment, she takes an indirect route to healing that rests on a host of relational assumptions that might not apply in the medical encounter.

**Silencing the Critical Self**

S. succeeded in creating a warm and intimate relationship with her doctor, but her project of fashioning a sweetly compliant outer self imposed inner costs. To make herself agreeable in every interaction she had to suppress her concerns about her doctor’s more questionable practices. She had to silence her critical self, sometimes to the point of self-abnegation. S. stifled her worries not out of a desire to deceive her doctor but out of a deep-seated fear that if she allowed him to see her doubt and anger he would stop liking her and stop devoting special attention to her bodily needs. In her mind, good medical care was contingent on a close doctor-patient relationship, and a close relationship demanded the absence of open conflict. The only way she knew to eliminate conflict was to mute her own concerns. The ever-agreeable self she presented to her doctor was an inauthentic self, but S. was not aware of that at the time. The whole process of silencing the doubtful inner self and projecting a pleasant outer self—for these were two sides of the same coin—occurred unconsciously, as she enacted the routines of feminine acquiescence she had taken in at a tender age.

The pressure on S. to silence her inner self was particularly strong because it came not only from the rules of feminine docility but also from the codes of scientific medicine. The reader will remember how biomedicine severed the patient’s mind from her body, making the doctor the sole expert on the body. The discourse of biomedicine the doctor was applying not only did not invite patient participation in the diagnosis, prognosis, and treatment, it also excluded that participation by definition. Subjected to two powerful silencing mechanisms, S. had no real choice but to keep her thoughts to herself.

*The Energy Required to Suppress Inner Doubts*

S. may have appeared passively compliant on the outside, but on the inside she was devoting massive amounts of energy, both cognitive and emo-
are taboo—her feminist identity was not totally submerged. To the contrary, much of the content of the critiques S. and her friends developed was explicitly feminist, striking themes similar to those highlighted by the women’s health movement in its early condemnations of the authoritarianism of male doctors. Although one gender identity remained dominant, the two coexisted, jostling around inside S. in an uneasy tension.

This chapter takes us into those hiding places where S. waged her secret battles against biomedicine. In the first section we peer into her personal records and computer files, looking for resistances that never got waged. In the second section we eavesdrop on her conversations with friends, looking for rebellions that never got staged. While S.’s political options were constrained by her gender training, the reader should remember that her abilities to recognize and resist the dangers inherent in her doctor’s brand of biomedicine were also compromised by material realities of pain. In part because of her prior conditions, and in part because of the drug experiments the doctor was conducting on her body, throughout the spring her physical, emotional, and mental capacities were stretched almost beyond the limits of human endurance. These material realities contributed to a larger perspective on her situation or to mount an effective resistance to her doctor’s encroachments on her life.

Writing as Resistance

S. was silenced in the public space of the doctor-patient interaction, but there were other, more private spaces in which she could speak her thoughts and feelings. The most important of these spaces was her writing. From the day of the first appointment S. began keeping two records of her “adventure” with Dr. D., a medical diary and a daily chart. These records served diverse, sometimes contradictory ends. It was here, in the private space of her writing, that S. dared to articulate the tender feelings she had toward her doctor. It was here that she negotiated truces between the warring parts of herself, the part that hurt and achingly wanted his care and the part that sensed danger and urged wariness and caution.

Although the diary and chart had many embedded meanings, both served important oppositional functions. They were resistant modes of expression, because they recorded parts of S.’s bodily reality that she knew intuitively to be true but that had been excluded by her doctor’s discourses as irrelevant to her care. Without being fully conscious of it,
The first three items cover inputs into health: sleep medications, “other meds” (those for arthritis and pain relief), and “other factors affecting well-being.” “Other factors” was a category S. employed to cover any unusual activities, stressful circumstances, or interpersonal developments that might affect how she felt.

The next five items deal with the effects of these factors on S.’s physical health and mental capacities. These include four items measuring bodily well-being: the timing and pattern (or quality) of her sleep; side effects from the medications; “specific pain” associated with the arthritis; and “general pain” associated with the fibromyalgia. The category of general pain included headaches as well as muscle pain in her neck and upper back, both symptoms associated with fibromyalgia. S.’s inclusion of this item—which she later relabeled “neck, back, headache” and even later relabeled “fibromyalgia”—signals her growing conviction that she had the condition. The fifth item, “ability to function,” S. included to assess how well and for how long she was able to perform her research, writing, teaching, and other professional activities. The doctor expressed interest in the four bodily measures but he never once asked S. about her professional work. Yet her ability to work was of paramount concern to S. herself.

The last two items on the chart are elements of S.’s well-being that she considered critically important but that her doctor evidently did not, since he virtually never inquired about them. One of these was aerobic exercise, something that had been a central component of S.’s life and sense of well-being since childhood. The doctor asked about swimming, her favorite form of exercise, only after she had brought it up and then only to proscribe it. The other was “mood.” In including this item, S. wanted a place to note whether she was feeling depressed and pessimistic, which was only too common at the time she created the chart, or happy and optimistic, a state she wanted keenly to recover. Mood was important not only in its own right but also because depression seemed to have an independent and deleterious effect on her physical well-being. To chart changes in her emotional state over time, S. needed to describe her mood not only in words but also as numbers, which could be manipulated to obtain averages and trends. For this purpose she developed a scale that allowed her to rank her outlook on any given day from 0 to 5, with 0 meaning something like clinical-level depression, 3 indicating neither happiness nor sadness, and 5 signaling elation, feeling on top of the world.

The chart construction carried political significance of which S. was only partly aware at the time. As we saw in chapter 1, S.’s doctor had
reduced her bodily reality to a set of “objective” numbers, which he recorded privately in her file and used to determine how and how fast her health was improving. (In Dr. D.’s accounting system S.’s health only improved; it never got worse.) Without particularly thinking of it this way, in creating her own chart S. was giving the “subjective” parts of her life—especially her mental capacities, exercise, and emotions—equal weight, at least in her own accounting scheme, by turning them into numbers as well. S. was fighting her doctor’s numbers with her own; she was using quantification to resist quantification.

No sooner had she created it than the chart became an active participant in the medical process. From the beginning S. drew on it regularly in reporting to her doctor the effects and side effects of the drugs. In no time at all, the discourse of the chart—what it said about how she felt—became an important part of S.’s reality. That is, how she felt according to the chart became crucial in how she really felt. For example, including an item for fibromyalgia made S.’s “fibromyalgia” all the more real to her by keeping her focused on aches and pains that she might otherwise have brushed aside. Keeping such symptoms worthy of note. The daily ritual of filling in the form and discussing symptoms kept them in the mind, gradually solidifying her belief that she had the disease her doctor said she had. And the more she believed she had fibromyalgia, the more she suffered from its physical symptoms. Ironically, in using her chart to track her “fibromyalgia,” S. succeeded in enhancing her doctor’s power over her life. Clearly, the chart could work to support, as well as oppose, biomedical power.

Later in the spring, after the doctor had introduced his microenvironmental hypothesis of S.’s new symptoms, the charts became the basis for S.’s research into the activities in her life that were exacerbating her pain. Although the doctor maintained firm control in the public space of the doctor-patient relationship, because they reflected her own reality and priorities, these charts allowed S. to retain some control over her life and treatment throughout the spring and summer. In the fall the charts would enable S. to reclaim control over her life. By providing quantified evidence of how much her physical and mental health had declined, the charts literally saved her life. But here we are getting ahead of ourselves.

Friendships as Spaces for (Silent) Rebellion

A second space in which S. felt free to air her doubts and anger was provided by relationships with her sisters and a few close women friends.
tor’s violent words—violent because of their stark, terrifying message, delivered with no qualification at all—ripped into that comforting thought. S. could barely keep from crying while she was on the phone; the second she hung up the receiver she collapsed into hysterical tears. What distressed her was not the fear of her body in pain; it was the thought of her life shriveled and shrunk. S. had always imagined herself living a long and productive life. She would continue her writing and research work into her seventies, retire into a life of letters and quiet pleasures in her eighties, and die of old age in her early nineties. The doctor’s talk of a deteriorating body ruptured that happy image, forcing her to see her life and dreams as sharply limited by her illness. This thought was so devastating that she could not bear to consider all its implications, even to herself. Her diary includes a one-line paragraph simply recording this fearful new truth: “Seems like I have to accept the idea of real limits” (Diary, March 27).

The prognosis might not have been so desolating had S. had some physical or emotional resources that would help her cope with it. But weeks of largely unsuccessful drug experiments had left her body drained and exhausted, her soul devoid of hope that her physical problems could ever be eased. Coming on top of this, the prognosis pushed her to the edge of emotional collapse:

Well, this news Dr. [D.] has given me has really set back my progress toward getting out of this state of eternal depression. It’s bad enough to be told that you have not one, but [five], serious conditions, but when you add to that, feeling lousy absolutely every single day from all the drugs he is experimenting with, it’s really pushed me back to the brink, if not over. I really feel like someone told me I had a fatal disease. (Transition file, March 26)

Retirement, Disability, and Death: More Doctor-Talk

As if to make the prognosis more real, the doctor soon began to talk about her retirement. That was the last thing on S.’s mind. In a major career move, she had just moved to California to take a new job. From her point of view she was at the beginning of her life’s work, not the end:

Somehow we got onto the subject of what I want to do, and he suggested that I was planning to retire. Retire! Ha! I said, I haven’t even begun to do the things I want to do. And I repeated that, for emphasis. I simply couldn’t believe he was talking about retiring . . . I’ve just started my life work! (Diary, March 27)
I had lots of questions [for D.] about exercise. *I really cannot hold onto anything,* even my oft-stated feeling that “at least I can still swim; it’s one of the most important things in my life.” Such statements are dangerous because, since my body has changed, activities that were good for me before may not be now. [What the doctor is saying is] that I shouldn’t be swimming now and probably not much in the future. (Diary, May 2)

S.’s daily chart provides numerical traces of her descent into mental hell. In April, when she experienced improvements in her sleep and joint pain that offset the disheartening diagnosis and prognosis, her mood averaged 3.6, a little better than “so-so.” During May, when her upper-back and neck pain emerged in full force and she followed her doctor’s orders to stay out of the pool, her emotional state fell to 2.3, just above “moderately depressed.” A more graphic statistic is the proportion of days spent seriously depressed (a reading of 0 or 1 on her scale of 0 to 5). When she coded a day as 0 or 1, it meant that she cried almost the whole day long. In April S. was morbidly depressed “only” 15 percent of the time. In May she felt that way nearly 40 percent of the time.

“Fibromyalgia Is Forever”: Depression Becomes Despair

Dr. D.’s ban on swimming was rooted in his fibromyalgic interpretation of S.’s recent headaches and neck pain. It was not hard to identify that newly diagnosed disorder as the source of her distress. S. began to wonder what this meant for the future. How long would she have to stay out of the water? How long was fibromyalgia supposed to last? S. reread the notes on fibromyalgia that she had taken during appointments with her doctor. Strangely, he had said little about the duration of the condition. He had said that “fibromyalgia, left untreated, is almost always progressive.” But what if it were treated? Then how long would it last? The notes were silent on that crucial question.

Dr. D. Gives a Public Lecture

One night in late May Dr. D. gave a public lecture in Seattle on his specialty disease. Hoping to learn something that would help alleviate her condition, S. made a special effort to go by scheduling a doctor’s appointment, also in Seattle, the next day. S. arrived at the scheduled time and place, pencil and pad in hand.¹ Facing a packed room eager to learn about his favorite subject, her doctor was in his element. He spoke for
the disease and, in the process, to take charge of one’s life again. Being able to identify the environmental . . . sources of increased pain is an important part of the process” (Diary, April 30). S. was more than ready to take charge of her medical conditions, to empower herself and gain control over her disease. And she had the perfect tool with which to tackle the task: her daily chart, which provided places to note a wide range of factors feeding into the pain. Moreover, her summer and fall locations would provide ideal environments in which to conduct her self-science. The New York country home and the Maine cottage afforded almost completely controlled climates in which all the social stresses of her life at the university would be eliminated, leaving only the strain of her own activities to produce pain. Armed with multiple copies of her chart and optimistic that she could track down the causes of her pain and slay the monster on her own, S. set off for the East Coast, happy at last to be her own medical boss.

Initial Successes

On June 17 S. flew to New York with medical paraphernalia and writing materials in tow. Her husband would follow in a couple of weeks. The very next day she began surveilling her daily activities to see which of them contributed to her aches and pains.

Lessons for the Fibromyalgic: Issuing Orders to the Self

S.’s first task was to clean the large converted dairy barn that served as their home in the New York countryside. Unoccupied over the winter and spring, the barn had accumulated a respectable layer of dust, cobwebs, and mice droppings. On June 18 she spent five hours vacuuming, dusting, and generally restoring the barn to habitable condition. Her chart reads:

June 18: General pain—Backache from housecleaning

June 19: General pain—Backache from vacuuming

Two days later she began to take stock of the barnyard—five acres of original pasture and the lawn and flower beds she had put in over the years. Everything was crying out for attention. The tractor and hand mower needed to be readied for use. The lawn and pastures wanted to be mowed. Her flower gardens begged to be weeded, the flowers fertilized, the climbing vines trained to grow up their wires. On June 20 S.
might give faith to other patients who want badly to swim even though swimming seems bad for their joints.

I’ve been sleeping very well (7 to 8 hours a night), except for nights when my routine gets disrupted (which are invariably bad ones).

I do want to say that I think this heavy-medication approach to the psoriatic arthritis was a brilliant move. I’m remembering with a smile how I was willing to “suspend judgment” last March, but basically could not let myself believe I could get better. Of course, I am living in a rose-colored bubble here, suspended up and away from most of the stresses of normal life. The real test will come in January when I have to return to [my university in southern California].

Well, I hope that news was good enough to lift your spirits at least a little bit. I truly hate to spend all this time writing about myself, but I did want to stay in touch and there was no other obvious way to do so.

Signing off, for now...

Your grateful patient,

S.

This sugary letter was a product of older patterns of communication and of a new development as well. In late July, when S. was stricken by the seven-day headache, her doctor had neglected to return her first phone call, forcing her to call again four days later. Humiliated and fearful that her doctor had already forgotten about her, S. began to invest all the more heavily in her relationship with him, using her letters and phone conversations to bind him more closely to her. This letter shows the extremes to which S. took that strategy. Whereas during the spring and early summer, S.’s goal of making her doctor happy had been kept in the background, here it is foregrounded, becoming the explicit, indeed, the sole aim of the communication. S.’s desire to make her doctor happy literally frames the letter, providing both opening and closing statements. “You wanted to hear good news,” she declares at the outset. “Today [I] write with some.” And at the end she writes, “I hope that news was good enough to lift your spirits.” In addition to sharing her feelings of health and empowerment, S. expresses strong gratitude to her doctor, praising his heavy-medication approach to the arthritis as “brilliant” and thanking him for his “verbal magic carpets,” which gave her a “whole new way of analyzing and gaining significant control over [her] life.” The doctor must have been very happy to read this letter. In her efforts to find beguiling formulations, however, S. goes overboard, writing that she “like[s] to have pain some days because it provides an opportunity to learn more lessons about what to avoid.” This line, which sounds less funny than pathological, provides an early hint of the mental dis-order
When S. tracked the new symptoms that had emerged after treatment began, the numbers showed that she had legitimate grounds for concern. The neck and back pain, plotted in panel B, showed a pattern of marked worsening in the spring, followed by improvement as the summer wore on. Overall, the proportion of days on which S. suffered neck and/or back pain surged from none in the months before treatment to a high of 68 percent in May. The overall prevalence of pain in this region then began to fall, slipping to three days in ten by August. S.’s statistics allowed her to distinguish between mild and more severe degrees of neck and back pain. Here the news was better: during these same months, pain of moderate-to-severe intensity grew worse and then better, becoming negligible by August. At the same time, the prevalence of milder forms of pain grew, rising from nil in April to a high of almost 40 percent in May, then falling slightly to 20 to 30 percent in the ensuing months. Despite S.’s mighty efforts to reduce the back and neck pain, the extent of mild pain in that region had shown virtually no change over the summer months.

The most debilitating new symptom was the headaches. While severe headaches made it impossible for S. to do anything, even mild headaches took the edge off her mind, making it difficult to concentrate on her writing. The figures, graphed in panel C, showed a worrying increase in headaches over time. From a headache-free condition in the months before she had fallen under the “gaze” of Dr. D., the fraction of days marred by headache inched up to one in four in April. That number dipped in May and rose again to reach a high of two in five in July, before sliding back to one in four in August. The figure for July was particularly bad: in that month S. had a headache an average of three days a week.

To see changes in functional capacity, something her doctor had promised she could improve, S. added the number of days with headaches to the number of days with serious fatigue. The combined number gave the proportion of days in which she was essentially unable to do her professional work. The calculations, pictured in panel D, showed that during April S. was functionally incapacitated an appalling 75 percent of the time. In May that figure fell to about 60 percent. The extent of functional incapacity dropped to about 35 percent in June, climbed back to 50 percent in July, and then slid again to 35 percent in August. The decline between July and August was small comfort, for what the figures said was that, even in the best of times, S. was losing as many as one-third of her days to her fibromyalgia.

Overall, the statistics were hugely discouraging. They said that, even after she had cut everything fun out of her life and imposed rigid disci-
It was empowering, because it offered hope that she could regain control over her body and her life. Yet it was disempowering, because it placed the responsibility both for causing and for curing or “healing” her medical conditions on her. In locating the cause of the problem in the individual patient, the books on alternative and New Age medicine neglected the possibility that larger structural forces—the inequalities of race, class, and gender, for example, or even biomedicine itself—might be partly at fault in many cases. And by counseling acceptance of what is—the symptom, the disease, the diagnosis—they embodied the powerful assumption that scientific medicine does not or cannot err in its labeling and treatment of disease. At the same time, these approaches ruled out the possibility that continued struggle and search for the source of the problems outside the individual might be a better route to healing in some cases.

This chapter describes the messages S. took away from these books and the helpful and less-than-helpful things she did in a desperate attempt to make the mind-cure work where the body-cure had not. Fighting to push the monster of depression away, she struggled to stay focused on the positive, empowering message that if she just followed the right strategies, she could use her mind to conquer the pain in her body and remake her life along new and happier lines. It was a hopeful message, and she threw her energies into it for about a month. By the end of the summer, however, S.’s enthusiasm for mind work had fizzled out. Try as she might, the philosophy of acceptance and the techniques of creative visualization did not take her symptoms away or even help her forget about them. In the end she had to find her own way. That way was to keep fighting what everyone—from her doctor to the books to friends and family who echoed popular medical advice—said was the “truth.” That way was to continue searching for the source of her pain in locations outside herself. As she pursued her own alternative-to-the-alternative route, S. found that the pervasive cultural discourse of acceptance and individual responsibility, intended to help people, became yet another obstacle she had to overcome. These cultural messages were a hurdle on the road to healing, because they left her feeling accused and ashamed. She was to blame both for her pain and for her failure to get rid of it through mental techniques. Because she felt accused, her experiences with the cultural discourses on mind-body connections also left her feeling isolated from family, friends, and society at large. In the end she felt all alone in her struggle for survival.
I can create a new body... Therein lie[s the rationale for] my bodily goals... What might some be? (MANL Book, July 29)

A few days later S. set some short-term goals for her two conditions. She “gives them energy” by telling herself how eminently achievable they are and how capable she is of achieving them:

**Body/Dis-ease/Health: Personal Goals**

1. This summer the arthritis has miraculously disappeared!... So, my short-term goal ([for a] few months) is to keep the joints happy and well and to lower my sed rate further—to make [Dr. D.] happy! This is very do-able...  

2. On the fibromyalgia, my short-term (this week, a few weeks) goal is to reduce the proportion of days I have a headache (most common) or back and neck pain. I do this by constantly being aware of and avoiding things that promote headaches, then avoiding them on future days. This is not a matter of “suffering ever-more limitations on living”—it is a matter of feeling better, going through each and every day feeling fit and fine. I can do that!... (MANL Book, July 31)

To help ensure realization of her goals, S. used some of the creative imagery techniques that Shakti had suggested. Here she describes an “imaginary bubble” she can use to heal her ailments:

**Protective and Healing Bubbles**

I need some bubbles to start throwing energy into and moving me forward, so that when I leave my wonderful cocoon [in Maine], I won’t be subject to all the down-pushes of the real world. Here [is one].

“Peach Healing Bubble:” I often awake with an unpleasant, unwelcome headache. Here’s how to urge it away. In the morning, just after I awake, I’ll create a beautiful peach-colored... bubble. First it will surround my head. Then I’ll move it upward until it floats on top of my head. It will sit there for awhile, collecting together all the aches of the head, concentrating them outside of my head. Then, when I’m ready, it will float away with a breeze. (MANL Book, September 2)

**A Failure Twice Over: Blame, Shame, and Isolation**

This burst of enthusiasm and creative energy for alternative techniques came in late July. For a few days S. busily filled her notebook with lists and plans and devoted herself to meditations, visualizations, affirmations, and self-appreciations. But her zeal for the imaginative techniques of New Age teaching soon petered out. Somehow they did not feel quite right.
And mostly they did not work. For example, S. tried to use the healing bubble on a number of headaches. She felt a little silly, but figured she had nothing to lose and everything to gain if the peach bubble alleviated the pain even a tiny bit. Unfortunately, it brought not a modicum of relief. Discouraged, she stopped using the bubble technique.

Other techniques proved counterproductive. S.’s attempt to construct a “good things list” only reminded her that some things, such as the loss of her swimming, were simply not good and that the gap between how she really felt about this “distressing discovery” and how she was trying to feel was too great to be papered over with imagining techniques. Similarly, listing all her “negative, self-defeating feelings” about illness did not make S. see that her fears were “unhelpful and untrue.” To the contrary, her fears that she was becoming “dis-abled” and that her life was becoming “one big list of ‘No’s’” were rooted in a bodily reality that was only too real and true. Bringing these fears together in one place simply reminded her of how bad things had gotten.

Despite the efforts S. poured into the task, she could not trick her mind into accepting her diseases and her symptoms. The “master key to natural healing” was said to be shifting one’s attitude of acceptance, submission, and surrender. But S. could not make that mental shift. Her mighty efforts notwithstanding, she could not rid herself of the feeling that she was “suffering ever more limitations on living” and replace it with the view that she was “feeling better, going through each and every day feeling fit and fine.” The idea that she was supposed to “relax into physical discomfort” seemed especially cruel. How could she “relax into” weeklong headaches that came from nowhere, responded to no treatment, and then went away for no discernible reason? How could she accept these debilitating symptoms that she had never had before? Try as she might, she could not quiet her questioning mind.

As she tried again and again to make her mind heal her body and failed again and again to make it work, S. felt like a personal failure. Indeed, by the standards of the fields she was consulting, she was at fault twice over. Not only had she not succeeded in mobilizing her mind in service of her body, but she was also making things worse by continuing to struggle against “what is.” And her bigger wrongdoing was causing her illness in the first place. Gawain had placed the blame squarely on her shoulders: “People get sick because they believe . . . that illness is an appropriate or inevitable response to some situation.”28 Weil had emphatically distanced himself from the view that patients cause their illness or are responsible if they do not get better.29 But he had said nothing about why
end product, of the discourses and practices that had been applied to the patient’s body since she came under the gaze of Dr. D.’s brand of biomedicine. The treatment discourse that did not work pounded the nail into the coffin of S.’s sanity, but the coffin was built of other discourses that had been put in place earlier in the process. Among the most important was the symptom discourse that attributed all the new symptoms to fibromyalgia and then omitted them from the evaluation of the doctor’s success. Another critical plank in the coffin was the diagnostic discourse that bestowed on her “tender points” where usually there was no tenderness and defined her as “fibromyalgic” when she lacked the condition’s cardinal symptom. Last but most fundamental was the discourse of objectification that dismissed S.’s emotions as irrelevant to her bodily state and named the doctor the sole expert on the patient’s health. In the spring the gap between the lived reality of her body and the medical discourses imposed on it produced a profound sense of epistemological and ontological invalidation. In the fall the gap widened, leading to mental disintegration.

The chapter also recovers the doctor’s continued use of rhetorics that furthered the biomedical cause but impeded doctor-patient communication by silencing the patient. Faced with escalating complaints in the early fall, D. opted not to listen to them, but to deflect them with the same sorts of linguistic devices he had used to create a perfect patient in the spring (see chapter 3 for details). Foremost among these were accusations, threats, and trivializations of the patient’s concerns and rhetorical augmentation of the doctor’s own prowess in conquering the patient’s disease. Finally, this chapter charts S.’s slow, halting realization that her doctor might not be the solution to her problems but the cause of them. Slowly and sputteringly, the growing gap between her doctor’s rhetorics of “stupendous success” and her own reality of emotional and physical distress began to undermine the trust on which everything had depended. In this void between the two truths—doctor’s and patient’s—lay the seeds of S.’s eventual revolt against biomedical authority. But that is a story for a later chapter. Here the main plot is the obliteration of a patient’s life.

A “Profound Revelation”: My Personality Is Causing the Fibromyalgia

As we saw in chapter 7, at the end of August S. calculated the long-term statistics on her symptoms. The results came as a shock: she had thought
of his approach to their treatment. The issues S. wanted to raise had been bulldozed out of the conversation.

She did, however, find a space in the conversation to alert her doctor to the sharp decline in her emotional well-being. Although her emotions had been declared irrelevant to her condition, in this discussion S. forced them back onto the agenda. She felt that the downward tilt in her physical health had left her mental and emotional balance in a precarious state, and that her doctor, who was in charge of her health, should know this. She tried to explain how the diagnosis of fibromyalgia had been a two-edged sword for her: while it helped her name and find a solution to her sleep problems, it made her feel twice as sick as she had felt before. This comment produced silence on the other end of the line. Pressing the point, S. wondered aloud about the possibility of returning to the status quo ante. Overall, she asserted, she had been better off before the doctor’s treatment program had gotten underway. She proposed that they now simply “forget about” the fibromyalgia, drop the sleep medications from the drug regimen, and treat only the arthritis. The doctor must have been very disappointed to hear this, for it signaled his patient’s lack of confidence in everything he had done. He replied, lamely, that “after a certain point there is no going back.” His comment ended that discussion.

Having made little progress with this suggestion, S. shifted to a different topic. She next tried to convey her feeling that the important benefits she had enjoyed from her doctor’s treatment were won at significant cost. What she was doing here and in the conversation just described was mapping out her contradictory feelings about the treatment in hopes of opening them up for discussion so that together she and her doctor could decide how to deal with them. But her communicational strategy did not work. The doctor responded in characteristic fashion. Dusting off the rhetorics of biomedical infallibility, he told her that her feelings were part of her problem; they were obstacles that had to be removed before bodily healing could occur. How was she to overcome the emotional difficulties? By reading Elizabeth Kübler-Ross’s book, On Death and Dying. This book, he explained, “deals with issues that are always raised with chronic illness,” namely, that illness is a precursor to death, which is right around the corner. Once again D. was telling S. to think not of life, but of death. Apparently he was oblivious to the possibility that his death talk might worsen the patient’s emotional state, as it had done in the spring, or even become a self-fulfilling prophecy.

Here is S.’s brief record of that part of the conversation:
of the syndrome, the theory provided a way out of the trap of self-blame in which S. had been caught for so long. Although Dr. K. herself relied exclusively on drug therapies, her theory of the roots of women’s pain suggested new strategies for pain alleviation that centered on addressing the underlying psychosocial sources of symptoms rather than simply suppressing them with strong drugs.

If D.’s story had shortcomings, so too did Dr. K.’s. It may have overstated the role of childhood socialization in adult behavior. It failed to specify the mechanism connecting personality and symptom. Its psychological therapies might have been incapable of eliminating symptoms rooted in such deeply embedded structures of the personality. The theory might have applied only to certain ethnic or class categories of women. Yet at the time S. did not see these possible weaknesses of K.’s theory. In her neediness, she clutched onto the gender story like she might grab onto a lifeboat in a raging flood. The gender story was attractive in part because it fit S.’s life and intellectual predispositions like a glove. It also gave her fresh hope at a time when she desperately needed it. It seems to heroize K. and denigrate D.; it is for these personal, intellectual, and emotional reasons. Dr. K. gave S. the understandings and new hopes for a future without them.

Another Story of the Suffering Body

S. had spent a long time preparing what she would tell Dr. K. in the November 6 appointment. Her planned presentation, sketched out in detailed notes, is highly revealing of her mind-set at the time. Dr. D. had represented his story of S.’s ills—the multiple diagnosis, the dismal prognosis, the drug-intensive treatment—as the only credible story that could be told. S. had taken it as the final truth of her body. Believing her doctor to be a scientific genius and a medical miracle worker who could do no wrong, she had come to believe deep in her heart that she had his specialty disease and that her condition was serious and growing worse. Given these convictions, S. intended to start by telling Dr. K. the bad news about her fibromyalgia and what it had meant for her life. The questions she prepared for Dr. K. concerned only the third part of the story, the treatment program, and whether it contained hidden risks of which D. had not apprised her.

S. began the appointment by explaining briefly what Dr. D. had done. She then went on to relate, with emotion, how her once rich and rewarding
The myths of medicine’s infallibility and beneficence shattered, S. was finally able to see what had been happening all those months. Her newly acute vision was enabled by an underlying transformation in her gender identity. We have seen how, early in treatment, S.’s critical feminist voice was silenced by a highly controlling physician. Desperate for help with her illnesses, she unconsciously adopted a “feminine” identity with which she sought to obtain medical care, not through the direct means of voice and action but through indirect “girl games” of sweet self-subordination and silent consternation. If her feminine self lacked the political, intellectual, and emotional resources needed to resist the encroachments of biomedical power on the patient’s body and life, resistance had to emerge from another more “feminist” identity. Mercifully, S.’s verbally assertive and politically aware gender identity reappeared now because crisis was imminent—the feminine self was dying—and the emotional, intellectual, and political resources with which to recompose such a self were now at hand. Armed with such weapons, the “feminist” S. not only openly resisted biomedical authority by “speaking truth to power” in a final meeting with her doctor; she pressed on, beyond resistance, to undertake the publicly political act of writing this book.

This chapter tells the story of that final, high-drama meeting that S. staged with Dr. D. It relates S.’s sad yet angry tale of how her life had come undone and D.’s dogged refusal to hear her pain and his resolute denial of responsibility for anything that had gone wrong. Freshly empowered, S. was trying to talk a new language of the body in medicine and in society. But the doctor knew only the language of biomedicine—a language that sees itself as speaking the Only Truth—and could not or would not hear her words. It was not only the conceptual apparatus of biomedicine that kept D. from hearing S.’s critique of his handiwork, however. Although he probably was not fully conscious of them, he had real professional, material, and legal interests in not hearing what S. had to say. Dr. D. had every reason for not recognizing his mistakes.
I thought I was on the verge of totally losing it mentally.” The doctor remained voiceless. Perhaps he was thinking that these were common side effects of the drug. Whatever the case, he kept his thoughts to himself, so S. went on.

“And that is not even the end of it. There were also profound emotional effects, namely, sustained, chronic, clinical-level depression. As I saw my life shrink and slip out of my control, I grew terribly depressed. I mentioned to you many times that I was depressed by your multiple diagnoses. Getting five diagnoses rather than one made me feel five times sicker than I had been before. You had redefined my identity as a person with five disorders that you and only you could treat. It seemed that everyone in my social world and every book I read told me that I had to accept it, that by resisting the truth I was making things worse. “Relax into it,” they kept telling me. “Accept it,” you kept saying, again and again, adding that we are all dying anyway, so why did I insist? This advice, you will note, presupposes that the doctor’s diagnosis is right. But I never thought the diagnosis of fibromyalgia quite fit me. I was never fully comfortable with the idea that I had it.” D. looked mildly disgusted. S. ignored him and proceeded with her presentation.

“As I told you on the phone, struggling with these new images of myself and fighting the depression used up huge amounts of time and emotional energy. I cried constantly. I lost 10 pounds because I did not feel like eating.”

Unable to restrain himself, the doctor interrupted to correct the patient, saying that S. had lost only five pounds. S. countered that, in fact, her weight had fallen by ten pounds, from 118 to 108. Visibly annoyed, the doctor retorted that, according to his records, S. had previously weighed 115 and now weighed 108, bringing the loss closer to five pounds. With disdain she did not bother to hide, S. pointed out that the scale in the doctor’s office was inaccurate and weighing her fully clothed produced numbers of little value in any case. The doctor retorted that the numbers from his scale were the only measures he had, implying that his numbers on her body, however dubiously derived, were more accurate than S.’s own record of her weight. This matter could not be settled, so S. went on.

“I told you about the weight loss in July when I talked to you on the phone.” D. interrupted again to say that, aha, the weight loss happened after S. left the West Coast, so it was not his responsibility. His next thought was that, of course, the drugs metabolize more rapidly when the patient loses weight, a fact that might explain the worsened side effects.
sentially reached in and remade my identity, redefining me as a chronically sick person, thus taking charge of not only my physical, but also my emotional life!”

Dr. D. hooted with disbelief. He dismissed the argument about disempowerment entirely. He flatly denied that he had taken charge of her life: “I am not in control! It’s been a partnership!” Evidently the distinction between micro- and macrolevels of power was too subtle for him to grasp. He was right that it had been a partnership. S. had played an important role in much of what had transpired. But the word partnership implies a helpful relationship between relatively equal parties. The partnership between D. and S. was dysfunctional and hierarchical at best.

After this long disquisition S. stopped, not sure where she wanted to go next. So she threw out a challenge: “I’d like to know what you have to say for yourself.”

**Dr. D. Defends Himself in Characteristic Fashion**

Untypically, Dr. D. was at a loss for words. He appeared genuinely baffled by what S. was saying. He had thought this patient adored him. Now she was saying that he had ruined her life.

“You Are in Great Shape! Look at the Numbers!”

Dr. D.’s first reaction was to ask what on earth S. was talking about. Waving the most recent lab reports in the air, he cried out animatedly, “Look! The numbers are great!” He went on to read them out, exclaiming in all earnestness at how good the white blood cell count was, how low the sedimentation rate had fallen. And it was not only the blood work that was good. His numbers from the spring showed that the arthritis and fibromyalgia had been greatly alleviated. “You are in great shape!” he exclaimed. “We did everything we were supposed to! When you came in, you were in terrible shape. We did a lot to make you better!” To prove his point, he cited his own statistics on S.’s tender points: “When you first came in you had all eighteen of the tender points. By June that number had dropped to six. Today you probably have none.”

S. found these comments hilarious. She was reproaching him for reducing her to a body and ignoring the emotional and cognitive aspects
0 = no pain
1 (mild) = complaint of pain without grimace, flinch, or withdrawal
2 (moderate) = pain plus grimace or flinch
3 (severe) = pain plus marked flinch or withdrawal
4 (unbearable) = patient “untouchable,” withdraws without palpation

The study then went on to define grimace, flinch, and withdrawal. As clinical experience increased, other articles were published suggesting ways to streamline the process.

Although the ACR criteria did not include consideration of associated symptoms, since fibromyalgia is a syndrome rather than a disease proper, its diagnosis properly involves judgment about what disease label makes the most sense of the patient’s signs and symptoms. It was clearly appropriate for Dr. D. to consider the presence of related symptoms, such as the sleep disturbance, in diagnosing S.’s disease. However, she discovered, there were many more characteristic symptoms of fibromyalgia that she did not have at the time of the initial consultation. She did not suffer from morning stiffness, paresthesias (abnormal skin sensations), anxiety, headaches, or irritable bowel syndrome, all common in people with the disease. Furthermore, the symptoms that she did have were not unique to fibromyalgia. In the ACR study, for example, sleep disturbances were found in 75 percent of fibromyalgics but also in 27 percent of the controls, who were patients with other rheumatic diseases, primarily arthritis. Eighty-one percent of fibromyalgics suffered from fatigue, but so too did 39 percent of the controls. “Widespread pain,” from which, mercifully, S. did not suffer, was found in 98 percent of those diagnosed with fibromyalgia but also in 69 percent of those with other musculoskeletal problems. Even the tender points were found among the controls: fibromyalgics were found to have 19.7 of 24 tender points, the controls 8.0.

Moreover, a variety of “modulating factors,” which typically reduce pain in the fibromyalgic, had no effect in S.’s case. Virtually none of the characteristic pain modulators—warmth, massage, rest—eased her pain. Although the effectiveness of these pain alleviators is not required for diagnosis, their absence might have helped to rule out the presence of the disease. Yet Dr. D. had not inquired about them.

S. did not conclude that Dr. D. had deliberately misdiagnosed her. She had no doubt that he was doing what he thought best to help a patient in evident distress. But, she now realized, there were many points at which biases such as those his colleagues worried about could have entered into
few had written. Not to be deterred by D.’s brush-off, she wrote to three prominent international specialists in the disease. All had been involved in the study that established the ACR criteria for diagnosis. She posed the question this way:

17 January 1997

Dear Dr...:

I am doing research on the natural history of fibromyalgia... My focus is patients... with preexisting arthritis who then develop the symptoms of FMS.

I am looking for published studies that explain why, after the initial sleep and fatigue problems of FMS are brought under control, the pain in various parts of the body, such as the neck and upper back, comes to the fore... Why was such pain not evident to the patient before treatment for the sleep problem? And why would it be expressed after the sleep problem was resolved?...

One of the specialists responded within days by e-mail; the other two sent long letters with references and enclosures of published articles and patient handouts. S. was immeasurably gratified by their generosity. Two of these experienced researcher-clinicians thought the situation S. described was anomalous and did not know of any published studies on the problem. Frederick Wolfe of the University of Kansas School of Medicine (the pen pal mentioned earlier) registered these concerns: “I have problems with what you wrote. It is not my experience that after sleep and fatigue problems are under control then the pain comes to the fore. There are very few studies on secondary fibromyalgia [that arising from other rheumatological conditions], and none address this issue...” (E-mail, 23 January 1997). Adel G. Fam of the University of Toronto Medical School also thought there was something peculiar about S.’s case: “[I]n the clinic setting, fibromyalgia tends to be a chronic syndrome. Most patients who respond in the short term to... tricyclic antidepressants... often continue to demonstrate: a) the same number of tender points, and b) the same sleep anomaly... This is contrary to the situation that you have described in your letter...” (Letter, February 2, 1997). These letters seemed to place D.’s views outside the bounds of conventional thinking on fibromyalgia.

In the last letter, from one of the “fathers” of fibromyalgia, S. finally got an answer to her question. This kind gentleman wrote a four-page single-spaced letter to explain one of his pet theories to the curious anthropologist. Here are some excerpts:
Building a New Fragmented Self: 
Psychosocial Strategies of Growth

The strategies described so far were all aimed at ridding S. of the evils of the recent past. More important for the long run was her search for ways to move forward, to remake her self and her body’s place in society, so as to eliminate the psychosocial mechanisms that partly underlay the chronic pain. Equally important was to build a new self, one strong enough to resist the dangerous seductions of someone like Dr. D.

The symptoms that brought S. to Dr. D.’s office in early 1996 were clearly related to the overwhelming stress in her life. The greatest source of tension was her new job. By early 1997 her work stress had been appreciably reduced by the passage of time. S. had rotated off some time-consuming committees. Her courses were now established, freeing her to get back to her own research and writing and, in turn, to make that core part of her identity once more her own. She had learned, through trial and error, how to get her needs met in the gigantic bureaucracy of her university. The improved situation at work provided a good climate in which to begin therapy on the self.

Taking Dr. K.’s gender theory of chronic pain as her starting point, and extending it along lines suggested by feminist theory and psychoneuroimmunology (the science of mind-body connections), S. fashioned this theory into a working tool to guide her on her quest for self-renewal. Working with a wonderfully sensitive counselor, she set out to constitute a new, stronger self to replace the self that had been virtually extinguished in the encounter with Dr. D. Part of the task was to improve the role of the mind and emotions in her physical well-being. A central goal of therapy was to reduce her bodily pain by lessening the stress in her life and by getting her to stop turning stress and emotions such as anxiety and anger into symptoms. Although a good part of the symptomatology was undoubtedly rooted in biological mechanisms that followed their own logic, the idea was to work hard on the psychosocial issues to see how much physical improvement would result. Much of the distress and harmful emotion was rooted in the larger pattern of compulsive pleasantness and self-silencing, a dynamic learned during a lifetime of gender training. Undoing this dynamic meant learning new skills of assertiveness and self-expression, especially of hostile feelings.

Through the counseling and in many other ways—including, importantly, the writing of this book—S. began to assemble a new self, combining some pieces of the old (the exercise aficionado, for example) with
woman’s proper place as confining and decided to devote herself to a “steady lifetime of social study and service.” Soon after her marriage, Charlotte fell into a deep depression. After the birth of her daughter she grew fatigued and despondent, feeling “a constant dragging weariness . . . Absolute incapacity. Absolute misery.” Deeply concerned about her illness, Gilman traveled to Philadelphia to consult Dr. S. Weir Mitchell, the leading nerve specialist of the day. Finding no physical abnormality, the good doctor diagnosed her with neurasthenia and sent her off to undergo his famous rest cure. After a month of bed rest, rich foods, and massage, the doctor sent Charlotte home with the prescription: “Live as domestic a life as possible. Have your child with you all the time . . . Have but two hours’ intellectual life a day. And never touch pen, brush or pencil as long as you live.”

Gilman followed Mitchell’s directions for three months. Confined to bed and deprived of the social and intellectual stimulation that had made her thrive, she descended into a dark fog of distress and disability. As she describes it, “[I] came so near the borderline of utter mental ruin that I could see over.” Finally, in a moment of clear vision, she was able to “us[e] the remnants of intelligence that remained” to see that the doctor’s cure was part of the problem. She cast the specialist’s advice aside and began a life of lecturing, writing, and activism on political and social issues of the day.

Social science students of medicine have long worried about the dangers of the growing medicalization of social life. Because of the masculinist nature of biomedicine, however, those dangers are particularly great for women. Despite the growing interest in fibromyalgia, none of the emerging literatures on the subject—biomedical, patient self-help, or patient testimonial—acknowledges these dangers. Feminist health scholars and activists have amply documented the risks that women face when every phase of their reproductive cycle is managed by the high-tech world of scientific medicine. At the same time, they have neglected parallel problems of gender and power in the rheumatological domain. Yet chronic pain is a women’s health issue too. Women are the primary sufferers not only of arthritis, the major rheumatic disease, but also of most of the chronic pain syndromes. Women outnumber men in chronic fatigue syndrome, irritable bowel syndrome, chronic headache conditions, and fibromyalgia, among many other conditions. The large numbers of women affected by these conditions should also recommend the domain of musculoskeletal health to the attention of women’s health specialists. In the mid-1990s, 29 percent of women aged forty-five to sixty-
Question in Feminism (1986). Locke’s work provides a useful entry into these critiques, because he starts from the vantage point of the working scientist. This enables him not only to see the full range of procedural, theoretical, conceptual, and linguistic difficulties that might lead the scientist to make mistakes but also to convey a sense of the uncertainty and worry that consequentlly attend the scientific project. Locke’s work is also helpful because it systematically explores the linguistic and especially the rhetorical aspects of the scientific enterprise that have received less attention elsewhere. These two emphases in Locke’s work—mistake making and mistake-masking rhetoric—are central to the ethnography presented in the following chapters. Locke’s account neglects issues of power and gender, which are central in all scientific practice, including the practice of the medical scientist described in these pages. I treat these issues in the following section of the problematique.

14. Undoubtedly the best-known narrative account of a research science is Haraway’s (1989) work on primatology.
15. Sacks (1986). Narrative approaches to the work of medical practitioners are developed in Brody (1994); Epstein (1995, esp. pp. 25–73); Mattingly (1998). A sampling of such studies in the periodical literature includes Charon (1986; 1989); Sacks (1986); Stoeckle and Billings (1987); Donnelly (1994); Leder (1990); Monroe et al. (1990); Brown (1993); Jones (1993). Storytelling approaches have been more widely applied to patients’ experiences of illness. For work on illness narratives see, for example, Charon (1986; 1989); Kleinman (1988); Clark and Mishler (1992); Hawkins (1993); Oakley (1993); Epstein (1994); Frank (1995; 1997a; 1997b); Saris (1995); Hyden (1997). There are also numerous studies featuring the narratives of patients with specific illnesses.
16. A major exception is Baszanger (1998). Earlier sociological research on the structure, content, and sequential ordering of the medical interview certainly dealt with physician rhetoric in the sense of persuasive talk (see, for example, Mishler [1984]; West [1984]; Fisher [1986; 1995]; Todd [1989]; Waitzkin [1991]). The assumptions about power that underlay that work, however, differ from those of Locke and scholars working in a Foucauldian tradition, with important consequences for the content and function of rhetoric. Exaggerating the differences, one could say that in the earlier conversational analyses, power was generally construed as possessed and repressive; the doctor-patient relationship was depicted as hierarchical; and physician rhetoric was portrayed as enhancing the power of physician over patient. In the work of Locke and Foucauldian scholars, power tends to be positive and socially dispersed, the interaction is more collaborative, and physician rhetoric heightens the influence of scientific “truth” over the thinking of physician and patient alike. The content of the rhetoric of interest differs as well. Although my study falls in the latter tradition, the earlier work has greatly enhanced my understanding of doctor-patient interactions.
17. Traditionally there were two sources of medical knowledge and legitimation, “clinical expertise” or “experience,” and “clinical science,” better known as medicine-as-art and medicine-as-science. Physicians have varied in their allegiance to one or the other. In recent decades there has been a movement to make
to women rather than structurally induced by the larger systems of gender inequality in which they are embedded. The theoretical problems many see with this work surround the notion of identity. These are discussed below.


79. See Foucault (e.g., 1971; 1978; 1979); Butler (1990); Haraway (1991), among many others. My discussion of this large literature relies heavily on Hekman (1995), who creatively connects Gilligan’s work to this larger body of feminist writing on selfhood; and Weedon (1997). Selfhood continues to be a lively area of feminist theorizing. In recent work notions of fragmentation, embodiment, difference, relationality, emotion, and narrative—all central to the ethnography presented below—are central to the philosophical explorations of the self.

80. See Hekman (1995, pp. 71–112). In a fine exegesis of relational, postmodern, and feminist theories of subjectivity, she both traces the intellectual lineage of “the discursive self” and shows how it implies morality, agency, and resistance, or political action.


82. See, for example, Greeno and Maccoby (1986); Luria (1986); Gremmen (1994); Tavris (1994).

83. This critique is advanced by Stack (1986); Tronto (1987); and Lykes (1994), among others. Recent empirical research suggests that, unlike the middle-class white girls studied by Brown and Gilligan (1992), poor minority girls do not lose their voices in adolescence. African-American women silence themselves in adulthood, but, in contrast to white women studied by Jack (1993), they do not grow depressed as a result. These results are reported in Robinson and Ward (1991); Way (1995); and Carr, Gilroy, and Sherman (1996).


85. The critique of the unitary and stable nature of identity (or “voice”) in the work of Gilligan, Brown, and Jack is developed by K. Davis (1994) and Hekman (1995, esp. pp. 74–76), among others. L. Brown’s (1994) early response has been followed up by a major study emphasizing the complex and contradictory nature of girls’ subjectivity. See L. Brown (1998).

86. The classic article on “doing gender” is West and Zimmerman (1987). See also Fenstermaker, West, and Zimmerman (1991). West (1993) extends the gender-as-accomplishment perspective to physician-patient relationships. More recently West and Fenstermaker (1995) have extended the approach to race and class, prompting wide debate. For the controversy see Collins et al. (1995). This discussion was prompted by stimulating conversations with Valerie Jenness.


89. Gilligan (1982).

with a tumor of the spinal chord is unlikely ever to be surpassed for its reflexive
and ethnographic insight into the world of the very ill.

113. A wide-ranging review of recent medical ethnographies can be found in
Kleinman (1995, pp. 193–256). Ethnographic work in medical sociology is
illuminatingly reviewed in Charmaz and Olesen (1997).

114. In anthropology, the term auto-ethnography historically has been used
in two senses: as an ethnography of one’s own culture or as autobiographical
writing with ethnographic interest. The distinction between the two is now break-
ing down. A useful definition of auto-ethnography is a form of social narrative
that places the self within its social context. For more, see Reed-Danahay
(1997a).

115. On “writing culture” in anthropology, see Clifford and Marcus (1986)
and Behar and Gordon (1995).

116. I thank Susan M. DiGiacomo for prompting my thoughts in this section.

117. These ideas were stimulated by Susan M. DiGiacomo.

118. In some sections of the book, especially parts IV and V, the argument
develops chronologically, but the temporal narrative does not displace the the-
matic concerns.

119. Kleinman and Kleinman (1991); DiGiacomo (1992). See also Kleinman,
Das, and Lock (1997) on “social suffering.”

120. A masterful account of the discipline’s critique of classic ethnography
is Rosaldo (1989).

121. Linda Layne’s (1996) account of her struggles as a parent of a child in
neonatal intensive care is the first first-person account ever to appear in the
Medical Anthropology Quarterly, the journal of the Society for Medical Anthropol-
yogy. Another precedent is Susan M. DiGiacomo’s (1987; 1995) analysis of her
cancer experiences.


123. I thank Arthur Kleinman for reminding me of these shortcomings of the
genre.

the dilemmas women anthropologists have encountered in using personal testimony
for ethnographic purposes.

comes from Behar (1996). Perhaps the first ethnography to acknowledge the im-
portance of emotions in the creation of anthropological knowledge was Jean


Chapter 1. The Initial Consultation: The Making of a “Fibromyalgic”

1. Dr. D. subscribed to the “gate control theory of pain” elaborated in an
important article published in Science in 1965. See Melzack and Wall (1965).


———. 1994. “Narrative Representations of Chronic Illness Experience: Cul-


**III. Biomedical Literature, Works on Alternative and New Age Medicine, and News Reports on Developments in Medical Practice**


This index includes primarily items from the general discussions of medicine, gender, and illness cultures in the problematic and conclusion. From the ethnographic chapters, it includes only personal names and concepts and special terms not introduced elsewhere. It covers only general discussions of these terms, not how they play out in the medical narrative.

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