whose stories I have recounted, are problem patients for their respective medical systems. There are several reasons for this cross-cultural similarity in the care of the chronically ill. Surely, frustration for patients, for families, and for practitioners can result from the sheer chronicity, poor outcome, complications, high costs, and the many other difficulties that beset effective care for this group of patients. Yet there is one source of problems in care that is close to the central theme of this book. Care of the chronically ill brings out the inherent potential for the patient's principal concern with the illness to clash with the practitioner's chief interest in the disease. And clash they often do. In the chapter that follows we will examine such conflict by observing the interaction between lay and professional explanatory models in the process of care.

7

Conflicting Explanatory Models in the Care of the Chronically Ill

> We . . . are in part living in a world the constituents of which we can discover, classify and act upon by rational, scientific, deliberately planned methods; but in part . . . we are . . . submerged in a medium that, precisely to the degree to which we inevitably take it for granted as part of ourselves, we do not and cannot observe as if from the outside; cannot identify, measure, and seek to manipulate; cannot even be wholly aware of, inasmuch as it enters too intimately into all our experience, is itself too closely interwoven with all that we are and do to be lifted out of the flow (it *is* the flow) and observed with scientific detachment, as an object.
>
> —ISAIAH BERLIN (1978, 71)

Explanatory models are the notions that patients, families, and practitioners have about a specific illness episode. These informal descriptions of what an illness is about have enormous clinical significance: to ignore them may be fatal. They respond to such questions as: What is the nature of this problem? Why has it affected me? Why now? What course will it follow? How does it affect my body? What treatment do I desire? What do I most fear about this illness and its treatment? Explanatory models are responses to urgent life circumstances. Thus, they are justifications for practical action more than statements of a theoretical and rigorous nature. Indeed, they are most

often tacit. or at least partially so. Not infrequently, they contain contradictions and shift in content. They are our representations of the cultural flow of life experience; consequently, as the epigraph to this chapter suggests, they congeal and unravel as that flow and our understanding of it firms up in one situation only to dissolve in another. Furthermore, these models—which can be thought of as cognitive maps—are anchored in strong emotions, feelings that are difficult to express openly and that strongly color one person's reaction to another's explanatory models.

The elicitation of patient and family explanatory models helps practitioners to take the patient's perspective seriously in organizing strategies for clinical care. Practitioners' effective communication of their models in turn assists patients and families to make more useful judgments of when to enter into treatment, with which practitioners, for what treatments, and at what ratio of cost and benefit. Negotiation among patients and practitioners over salient conflicts in models can remove an important barrier to effective care and almost always contributes to more empathic and ethical treatment. Practitioners' inattention to the explanatory models of patients and their families, conversely, may signal disrespect for clients, hubris in the face of alternative viewpoints, and failure to regard psychosocial dimensions of care as relevant. Such blatant disregard impedes the therapeutic relationship and undermines the communicative foundations of care. The following vignette illustrates the great clinical significance of explanatory models. This case narrative also discloses the central contribution patients and families make to the therapeutic process.

The Case of William Steele

William Steele is a forty-two-year-old white American attorney with a two-year history of asthma. His asthma has steadily worsened since its onset, and Mr. Steele is now following an extensive medication regimen that includes 20 milligrams of prednisone taken daily. He sleeps near a cool-mist vaporizer, uses various broncho-

dilator inhalers during the day, and drinks lots of fluids to keep his bronchial secretions moist. He has undergone allergy testing and desensitization for pollen and dust allergies, without effect. Mr. Steele has no family history of asthma, and he did not have asthma as a child, though he did experience frequent upper respiratory infections.

His doctor, James Blanchard, is an internist who serves as his primary care physician. Dr. Blanchard has explained to Mr. Steele that asthma is a disorder involving bronchial constriction that makes it difficult for patients to breathe; its ultimate cause is unknown, but allergies, stress, and sometimes—in Mr. Steele's case, regrettably—exercise contribute to flareups. He has made it clear to Mr. Steele that asthma is a chronic disorder without a cure, but one whose physiological effects can be well controlled with the proper medical regimen. Over the course of the two years, Dr. Blanchard has demonstrated to Mr. Steele that pipe smoking and drinking red wine lead to expectable exacerbations. Mr. Steele has discontinued both. Dr. Blanchard has responded to Mr. and Mrs. Steele's request for advice about acupuncture, self-hypnosis, and macrobiotic diet with the information that there is no scientific evidence that these folk treatments do any good. He has referred Mr. Steele to two specialists: a chest disease expert who concurred with Dr. Blanchard's assessment and treatment and suggested a battery of pulmonary function tests with which to follow this patient's course, and a psychiatrist who diagnosed a secondary depression owing to the asthma and the prednisone and who recommended an antidepressant medication and psychotherapy. Dr. Blanchard was reluctant to endorse the psychotherapy because, as he put it, "The patient is a Pandora's Box; who knows what will happen once the lid is removed?" He did accept the recommendation to begin low doses of an antidepressant (Tofranil), but discontinued the drug when the patient complained of side effects of dry mouth, dizziness, and constipation.

From Dr. Blanchard's perspective, Mr. Steele's progressively worsening course and the acute onset of the asthma in midlife without earlier symptoms were perplexing. He felt that there was probably an allergic cause, and he was considering further allergy testing and desensitization. Some months later, at the insistence of

Mrs. Steele, who was deeply distressed by her husband's condition, Dr. Blanchard finally referred the patient to a second psychiatrist for treatment. This psychiatrist elicited the following story.

From Mr. Steele's perspective, both the onset and the poor course of his problem could be explained. His asthma began with an attack of wheezing the morning after his fortieth birthday. On his birthday he had appeared in court to argue a difficult case, and he had been criticized by the judge several times for not providing sufficient information. As a result, he and his client had had an argument; when the argument got out of hand, the client precipitously fired him. That night William Steele, his wife, and his three children (aged ten through fourteen) celebrated his birthday. He remembers feeling greatly ambivalent about reaching "middle age"; he was under substantial stress in his legal practice (which was less successful than he had thought it would be by this time) and in his home life (his relationships with his wife, eldest son, and in-laws were increasingly tense).

> I felt like everything was going the wrong way for me. My career was going poorly. My wife and I had a worsening relationship, and I couldn't stand her parents, who had objected to our marriage in the first place and constantly told my wife I wouldn't succeed. My son—oh, God! I had some kind of learning problem myself as a kid. It depressed me that he had an even more severe one and would have lots of trouble in high school. It seemed like even with the kids, things were going badly.
>
> Well, that night, after the party, I just couldn't sleep. I tossed and turned and wondered to myself what would happen to me, to all of us. Suppose I didn't make it. Would my wife leave me? Would the kids despise me? What if I died? I had had such dreams of being a success in my life. You know, I wanted to be a great lawyer. But I feared my talent wasn't in the courtroom. The day of my birthday confirmed my fear. I'd have to give up the dream I had held since college and worked so hard at. What would I do? I felt lost and finally fell asleep.
>
> Well, during the night I had this terrible dream, like a nightmare. There was the courtroom, with me, my client, and the judge, and also my wife, my in-laws, and my son. I got up to speak. The judge told me that I had made a big mistake. My client chipped in and yelled at me for the same mistake. Then my wife, my in-laws, my son, they all joined in, shouting: "Mistake! Mistake! Failure! Failure!" Then a huge fire broke out in the courtroom and consumed us all. I woke up coughing, choking, and there was my asthma. You can't tell me they're unrelated. I think that's the cause.
>
> Since then it's been one damned thing after another; I feel like it's all over for me. I can't control my asthma and I can't control my life. I've missed so much work, my partners in the law firm are up in arms. I'm sucking on the inhaler, coughing, and waving away their cigarette smoke. I can barely attend to my work. At home I just want to be alone in my room without stress. I get into arguments with my wife and kids daily. I just can't take it. Either the asthma will kill me, or I'll kill myself.

Mr. Steele's wife also had a perspective on his illness. She had taken him to a natural food store and encouraged him to try a macrobiotic diet. Recently she had introduced him to an herbalist-acupuncturist. She believed that the asthma had frightened him and depressed him, that it had changed his personality.

> It's been disastrous for our marriage. We don't go out. All we talk about is his illness and medicines. He is afraid even to have sex with me because of how it may further hurt his health. And as for the kids, he can't tolerate their normal behavior. They fight and he starts wheezing. Our son's school problem is bad; he's dyslexic, and Bill can't figure out how to respond. All he does is hide. He's not like he was before. He's become frightened and completely absorbed with his symptoms. If this goes on, I don't know what we will do.

William Steele describes his asthma as follows:

> You know, it's terrible to have an attack. It's, it's like you are drowning, smothering. You can't breathe. I spend a lot of time worrying about it. I do all I can to avoid it. At the first sign of a wheeze, I increase my medications. I don't do anything for fear exercise will bring it on, as it has in the past. What do I do? I feel hopeless. Maybe they should just take me outside and shoot me.

Mr. Steele mentioned that as soon as he developed wheezing, even if it was very mild, he would get a panicky feeling and fear that he would die. As a result, he would take more of his asthma medication than prescribed and then would often develop signs of toxicity. He had insight into this vicious cycle but was unable to break out of it owing to his overwhelming fear that he might die because he was unable to breathe.

Mr. Steele had on several occasions changed his treatment regimen, without the knowledge of his physician. Once he stopped taking a drug altogether because he felt it made him extremely anxious, at the same time doubling the dosage of another medication, which produced a toxic reaction. On another occasion he followed the advice of his herbalist-acupuncturist and stopped his oral bronchodilator; he precipitated an asthma attack that landed him in the emergency room.

Both Mr. and Mrs. Steele believed that personal, work, and fam-

ily problems worsened his illness. But when they raised this issue with Dr. Blanchard, they felt that he discounted its significance; he did not encourage them to seek counseling. As their marriage and family problems worsened, Mrs. Steele insisted that Dr. Blanchard refer them for psychiatric evaluation. When Dr. Blanchard delayed in the referral for psychotherapy and resisted trying a second antidepressant (as previously mentioned, side effects had led to the discontinuation of the first), it was only at Mrs. Steele's insistence that he finally referred her husband to the second psychiatrist for treatment.

Mr. Steele's children had their own views of his illness. The oldest son feared that his poor school performance and the diagnosis of his learning disability had worsened his father's illness. The younger children thought that their frequent quarrels with each other contributed to their father's increased difficulty in breathing.

Mr. Steele's in-laws thought that there was a strong voluntaristic component to his asthma. They said he used the symptoms to gain sympathy from and to control his wife and children. His in-laws came from a midwestern populist background and belonged to a charismatic Catholic sect; they were outspokenly antiprofessional. They recommended natural diet, homeopathic cures, and religious healing. They remarked: "God is punishing him for something. Medical care can't work while there is some serious religious problem. We had a feeling from the start he was that kind of person."

After six months of psychotherapy, marital counseling, and a course of antidepressants, Mr. Steele experienced a significant change in his asthma symptoms and psychological state. His medications were significantly reduced and he was off steroids entirely. Over the next few years his marital relationship improved and he made a major career change. He gave up his legal practice and joined his father and brother in the wholesale fish business. Four years after this story began, Mr. Steele was off all asthma medication and symptom-free.

> You know, I think I was right. It wasn't allergies; it was my life. I was under such stress, it makes me feel terrible to think of it. I know I was going nowhere in the law. I had to give up my dream. But I couldn't let go. I worked harder, and things went from bad to worse. I think my body was telling me that I had to make some big changes. The psychotherapy helped a lot. But it was the life change that was crucial. Now I'm in a family business, feel good about it, and don't feel the pressure to be somebody I couldn't be and do something I couldn't do. I feel in better control.

By this time Mrs. Steele shared her husband's views, but Dr. Blanchard did not. He noted that it was extremely unusual for asthma to disappear solely for psychosocial reasons. He also pointed out that onset of asthma at age forty was very uncommon. Perhaps, he argued, there was a transient allergen (a pet or a new pollen or environmental contaminant) that had been responsible for the asthma and now was gone. The psychiatrist who initially evaluated Mr. Steele also did not fully accept the Steeles' rationale for the successful outcome. While he believed that stress reduction, improved social support, and treatment of the underlying depression had contributed to the outcome, he also assumed that some other physiological change had occurred as well. The second psychiatrist, who actually treated Mr. Steele, was more inclined to accept a psychosomatic explanation; but in his view, the depression was the main reason for the symptoms and its treatment the chief source of recovery. Mr. Steele's in-laws were convinced the outcome was an act of God. In this case, family and patient explanatory models are not the same, and, indeed, the clashes among these models also contribute to the Steels' problems. But it is of special significance that, in spite of the dramatic cure, the practitioners' models refuse to accept either the patient's contribution to the outcome or the powerful effects of the psychosocial intervention.

Dr. Blanchard also does not share the Steeles' belief in the usefulness of alternative therapies or self-care. He seems at best ambivalent and at worst frankly hostile to the place of psychosocial treatment in chronic medical disease. A senior, well-respected clinician, he paid little attention either to the biography of the patient or to the patient and family perspectives, which were elicited for the first time by the consulting psychiatrist. For Dr. Blanchard, medical treatment is the prescription of medications. This is not the viewpoint of Mrs. Steele or her husband. Unaware of his patients' concerns, Dr. Blanchard inadvertently colluded in the vicious cycle of noncompliance and psychosocial distress that intensified the asthma and made the medical treatment part of the problem rather

than the solution. Here we see exposed the profession of medicine's mischievous mind-body dichotomy, which assumes that only biological aspects of illness are "real" and only biological treatments are "hard" enough to produce biological change. While the remarkable outcome of William Steele's case is unusual, the contribution of professional orthodoxy to inadvertently heighten the passivity and demoralization of patients and their families is all too common in the treatment of the chronically ill.

Professional Explanatory Models and the Construction of Chronic Illness as Disease

The following interchange was tape recorded by a research assistant as she followed a patient with psoriasis, Mrs. Jill Lawler, into the office of a leading dermatologist. Mrs. Lawler is a thirty-five-year-old woman who has had psoriasis for fifteen years. She is extremely knowledgeable about this disorder, having read medical texts and even the latest research reports. She also holds a psychosomatic view of the relationship of life stress to illness, a view shared by most behavioral and social scientists and increasingly by many physicians. Because she has recently moved to a new city, she is making her first visit to this dermatologist, who is an expert in a new technological intervention to treat psoriasis.

MRS. LAWLER: I have an appointment with Dr. Jones.
RECEPTIONIST: Have a seat and fill out this form regarding your insurance and current health problems.
MRS. LAWLER *(after entering the doctor's office)*: Dr. Jones, I am here to see you because of my psoriasis. I understand you are an expert in the use of a new treatment.
DR. JONES: How long have you had psoriasis?
MRS. LAWLER: Oh, about fifteen years.
DR. JONES: Where did it begin?
MRS. LAWLER: I was in college, under lots of pressure from exams, and there is a family history of skin problems. It was winter and I was wearing heavy woolen sweaters that seemed to bother my skin. My diet was—
DR. JONES: No, No! I meant where on your skin did you first notice plaques?
MRS. LAWLER: My shoulders and knees. But I had a problem for some time with my scalp that I never—
DR. JONES: How has it progressed the past few years?

MRS. LAWLER: These have been difficult years. I mean I have been under great stress at work and in my personal life. I—
DR. JONES: I meant, how has your skin problem progressed?

The reader has probably had a sufficient glimpse at this interview to be able to share the patient's frustration at getting her story across. The expert in psoriasis is interested in the illness only to the extent that it provides clues to what is happening to the disease. His style is authoritarian and interrogative. He does not acknowledge that the patient's experience with a chronic disorder makes her an expert of sorts whose insight may be useful. Indeed, by this stage of the interview, Dr. Jones was well on the way to infuriating his patient, who, not surprisingly, decided not to return. Dr. Charles Jones, whom I know slightly, does not strike me as being as insensitive as this brief transcript makes him out to be. But he is an extremely busy clinician, and this was his first meeting with a new patient whose disease problem he wished to define as expeditiously as possible so that he could determine whether his new therapy was appropriate for her case. I believe I would not be exaggerating to say that in Dr. Jones's professional view (and in that of many medical specialists) there is no notion that the patient can make a contribution to clinical judgment about the disease and its treatment. In the care of an acute problem, an interrogative style may be necessary to help the practitioner diagnose a potentially treatable disease and commence effective technical interaction as quickly as possible, especially for life-threatening health problems. But it cannot be emphasized enough that this is an inappropriate clinical method to use with the chronically ill.

Elliot Mishler (1985), a Harvard behavioral scientist with long experience in the sociolinguistic study of doctor–patient communication, refers to that interaction as the setting for a dialogue between the voice of medicine and the voice of the life world. His research and his review of the studies of many other students of clinical communication show that all too frequently the voice of medicine drowns out the voice of the life world, often in ways that seem disrespectful, even intolerant, of the patient's perspective. Since the diagnosis of disease is based on the history of illness and is a semiotic act transforming lay speech into professional categories, careful attention to the illness account is essential, even when

the story is viewed in terms of narrow professional objectives (Hampton et al. 1975). When the empowerment of patients and their families becomes an objective of care, the empathic auditing of their stories of the illness must be one of the clinician's chief therapeutic tasks.

The message the practitioner indirectly transmits to patients and their families is this: your view doesn't really matter much; I am the one who will make the treatment decisions; you do not need to be privy to the influences and judgments that inform those decisions. This is a medicocentric view increasingly at odds with the kind of care patients and families want and today *expect* for chronic illness. Remember that the patient's and family's discourse is the original and most fundamental account of illness. It comprises the text that the practitioner interprets. I say to physicians, return to that original discourse! We live in a time of great concern for the practitioner's response to the patient's request. But the primary ground of care is not that response; it is rather the patient's discourse on illness. Physicians say that they listen to that discourse to diagnosis disease ("listen to the patient, he is telling you the diagnosis" is a famous clinical maxim taught to medical students). Yet practitioners must go beyond this concern, important as it is, and return to the time when as beginning medical students, with a foot in both lay and professional worlds, they audited the speech of their first patients with great intensity, with something approaching awe in respect for hearing the patient's story in his or her own words and with deep sympathy for the human condition of suffering. That, it seems to me, is the best way to come to understand the illness experience and take it into account in practice.

Professional Influences on the Recording of Disease

The recording of a case in the medical record, a seemingly innocuous means of description, is in fact a profound, ritual act of transformation through which illness is made over into disease, person becomes patient, and professional values are transferred from the

practitioner to the "case." Through this act of writing up a patient account, the practitioner turns the sick person as *subject* into an *object* first of professional inquiry and eventually of manipulation. The patient's record is an official account, in the language of biomedicine, that has legal and bureaucratic significance. Medical students are trained in how to construct a case report. They are taught how to record symptoms and medical history and how to reinterpret them as an official diagnostic entity in the authoritative medical taxonomy. Each student learns to reproduce an account that meets strict criteria and has a standard format. The evaluation of student performance is based in part on readings of these reports. Over a clinical career, physicians learn to write in the record with an eye to professional standards as well as to possible legal and bureaucratic appraisal; for the record is read by other doctors and also by nurses, peer review committees, medical ethics committees, clinical pathology review groups, and—if there is a court case—by lawyers, judges, and juries.

From an anthropological point of view, recording the case is an example of a secular ritual: it formally replicates a social reality in which core values are reasserted and then applied in a reiterated, standardized format to a central problem in the human condition. Like religious rituals, secular rituals express and manipulate key symbols that connect a shared set of values and beliefs to practical action. By observing in this light the writing of a case into the medical record, we should be able to see more clearly the influence of professional values (and the professional's personal preferences) in the care of the chronically ill. To accomplish this end, I will first provide a transcript of a doctor–patient interview and then describe the wording of the physician's formal write-up in the patient's record. I don't contend that the following example is representative; indeed I believe that the degree of professional insensitivity it depicts is unusual. But I do think that the physician's overriding interest in disease and disregard of illness is, regrettably, commonplace. (Note that I observed only one transaction in a long series of transactions, the totality of which might have given a rather different impression.)

The two protagonists in the transcript are Mrs. Melissa Flowers and Dr. Staunton Richards. Mrs. Flowers is a thirty-nine-year-old

black mother of five children who has hypertension. She lives with four of her children, her mother, and two grandchildren in an inner-city ghetto. She works at present as a waitress in a restaurant, but periodically she has been unemployed and on welfare. She has been married twice, but both of her husbands have deserted her. As a result, she is a single head of a household. Mrs. Flowers is an active member of the local Baptist church, which has been an important source of support to her and her family for many years. She is also a member of a community action group. In the household of eight she is the only wage earner. Her mother, Mildred, is fifty-nine and partially paralyzed owing to a stroke that was the result of long-standing and poorly controlled hypertension. Her oldest daughter, Matty, the unmarried nineteen-year-old mother of two small children, is at present unemployed and pregnant; in the past, she has had a drug problem. Mrs. Flowers's fifteen-year-old daughter, Marcia, is also pregnant. Their eighteen-year-old brother, J.D., is in prison. Teddy, a twelve-year-old, has had problems with truancy and minor delinquency. Amelia, eleven, the baby of the family, is said by her mother to be an angel. A year ago, Mrs. Flowers's long-time male companion, Eddie Johnson, was killed in a barroom brawl. Recently, Mrs. Flowers has been increasingly upset by memories of Eddie Johnson, by concern for how prison will affect J.D., and by fears that Teddy will get involved with drugs like his older brother and sister before him. She is also concerned about her mother's worsening disability, which includes what she fears may be early signs of dementia.

DR. RICHARDS: Hello, Mrs. Flowers.
MRS. FLOWERS: I ain't feelin' too well today, Doc Richards.
DR. RICHARDS: What seems to be wrong?
MRS. FLOWERS: Um, I don't know. Maybe it's that pressure of mine. I been gettin' headaches and havin' trouble sleeping.
DR. RICHARDS: Your hypertension is a bit worse, but not all that bad, considering what it's been in the past. You been taking your medicines as you ought to?
MRS. FLOWERS: Sometimes I do. But sometimes when I don't have no pressure I don't take it.
DR. RICHARDS: Gee whiz, Mrs. Flowers, I told you if you don't take it regularly you could get real sick like your Mom. You got to take the pills every day. And what about salt? You been eating salt again?
MRS. FLOWERS: It's hard to cook for the family without salt. I don't have time to cook just for me. At lunch, I'm in the restaurant and Charlie, he's the chef, he puts lotsa salt in everythin'.

DR. RICHARDS: Well, now, this is a real problem. Salt restriction, I mean a low-salt diet, is essential for your problem.
MRS. FLOWERS: I know, I know. I mean to do all these things, but I just plain forget sometimes. I got so much else goin' on and it all seems to affect the pressure. I got two pregnant daughters at home and my mother is doin' much worse. I think she may be senile. And then I worries about J.D., and here comes Teddy with the same problems startin' up. I—
DR. RICHARDS: Have you any shortness of breath?
MRS. FLOWERS: No.
DR. RICHARDS: Any chest pain?
MRS. FLOWERS: No.
DR. RICHARDS: Swelling in your feet?
MRS. FLOWERS: The feet do get a little swollen, but then I'm on them all day long at the restaurant—
DR. RICHARDS: You said you had headaches?
MRS. FLOWERS: Sometimes I think my life is one big headache. These here ain't too bad. I've had 'em for a long time, years. But in recent weeks they been badder than before. You see, a year ago last Sunday, Eddie Johnson, my friend, you know. Uh huh, well, he died. And—
DR. RICHARDS: Are the headaches in the same place as before?
MRS. FLOWERS: Yeah, same place, same feelin, on'y more often. But, you see, Eddie Johnson had always told me not to bother about—
DR. RICHARDS: Have you had any difficulty with your vision?
MRS. FLOWERS: No.
DR. RICHARDS: Any nausea?
MRS. FLOWERS: No. Well when I drank the pickle juice there was some.
DR. RICHARDS: Pickle juice? You've been drinking pickle juice? That's got a great deal of salt. It's a real danger for you, for your hypertension.
MRS. FLOWERS: But I have felt pressure this week and my mother told me maybe I need it because I got high blood and—
DR. RICHARDS: Oh, no. Not pickle juice. Mrs. Flowers, you can't drink that for any reason. It just isn't good. Don't you understand? Its got lots of salt, and salt is bad for your hypertension.
MRS. FLOWERS: Uh huh. OK.
DR. RICHARDS: Any other problems?
MRS. FLOWERS: My sleep ain't been too good, doc. I think it's because—
DR. RICHARDS: Is it trouble getting to sleep?
MRS. FLOWERS: Yeah, and gettin' up real early in the mornin'. I been dreamin' about Eddie Johnson. Doin' a lot of rememberin' and cryin'. I been feelin' real lonely. I don't know—
DR. RICHARDS: Any other problems? I mean bodily problems?
MRS. FLOWERS: No, 'cept for tired feelin', but that's been there for years. Dr. Richards, you think worryin' and missin' somebody can give you headaches?
DR. RICHARDS: I don't know. If they are tension headaches, it might. But you haven't had other problems like dizziness, weakness, fatigue?
MRS. FLOWERS: That's what I'm sayin'! The tired feelin', it's been there some And the pressure makes it worse. But I wanted to ask you about worrie me a mess o' worries. And I been feelin' all down, as if I just couldn't it anymore. The money is a real problem now.

DR. RICHARDS: Well, I will have to ask Mrs. Ma, the social worker, to talk to you about the financial aspect. She might be able to help. Right now why don't we do a physical exam and see how your doing?
MRS. FLOWERS: I ain't doin' well. Even I can tell you that. There's too much pressure and its makin' *my pressure* bad. And I been feelin real sad for myself.
DR. RICHARDS: Well, we'll soon see how things are going.

After completing the physical examination, Dr. Richards wrote the following note in the medical record.

April 14, 1980
39 year old Black female with hypertension on hydrochlorothiaziade 100 mgs. daily and aldomet 2 grams daily. Blood pressure now 160/105, has been 170–80/110–120 for several months, alternating with 150/95 when taking meds regularly. Has evidence of mild congestive heart failure. No other problems.

Impression: (1) Hypertension, poorly controlled
(2) Noncompliance contributing to (1)
(3) Congestive heart failure—mild

Plan: (1) Change aldomet to apresoline.
(2) Send to dietician to enforce low salt diet.
(3) Social work consult because of financial questions.
(4) See in 3 days, regularly until blood pressure has come down and stabilized.

Signed: Dr. Staunton Richards

Dr. Richards also sent a terse note for a consultation to the dietician, which read: "39 year old Black woman with poorly controlled hypertension who does not comply with low salt diet. Please help plan 2 gram sodium diet, and explain to her again relationship of salt intake to her disease and that she must stop eating high salt foods and cooking with salt."

Interpretation

The case that materializes in the written record seems quite different from the sick woman who speaks in the transcript. Melissa Flowers is reduced to her hypertension, her noncompliance with the medical regimen, her early signs of heart failure, and her medications. Gone from the record is Melissa Flowers as a sick person under great social pressure, worried and demoralized by difficult family problems (see Dressler 1985). Those problems are a reflection of the social breakdown, violence, and inadequate resources and limited life chances of the United States's black underclass. But while we might not expect Dr. Richards to include those social sources of Mrs. Flowers's multiple misfortunes in the medical record, it is deplorable that he fails to include her life problems, including the multiple family difficulties, the prolonged grief reaction, and the psychological effects of her troubled social environment. (Indeed, I believe a case can be made for describing social sources of illness in order to specify the social changes needed to prevent and treat such life distress.) But then again these are concerns that Dr. Richards either failed to follow up on with specific questions or actually stopped Mrs. Flowers from elaborating. That is to say, Dr. Richards permits Mrs. Flowers to speak about her disease but not about her illness. Physical complaints are authorized, but psychological or social ones are not. The diagnosis is, in fact, a systematic distortion of the interview: only facts that relate to the disease and its treatment are sought, allowed to emerge, and heard. The human suffering that is so much a part of this chronic illness is met with silence and seemingly denied.

Cultural issues are allowed to slip by, one after another, in a way that would be regarded as sheer clinical incompetence if the issues were biological. Mrs. Flowers uses the terms "pressure" and "high blood," which refer to folk illnesses in lower-class black American society (see Nations et al. 1985). These concepts help explain what Dr. Richards labels noncompliance; for example, high blood, a folk condition believed to result from blood rising into the head, is thought to cause headaches and is treated ("lowered," "thinned," "cut") with pickle juice. If Dr. Richards were to attend to this alternative belief system, he would have a more accurate understanding of Mrs. Flowers's behavior and would also have an opportunity to explain the biomedical view and negotiate with Mrs. Flowers to change potentially dangerous behavior. When Mrs. Flowers uses the word *pressure* she is drawing on holistic concepts that relate social and psychological pressures to blood pressure. Biomedical theory acknowledges a role of stress in hypertension grudgingly and only as a chronic long-term stressor, not as an important source of short-term fluctuations (see Blumhagen 1980).

Finally, noncompliance for Dr. Richards is a moral term indicating patient failure to *follow* the doctor's instructions. This view is predicated on a professional view of the doctor–patient relationship that is paternalistic and one-sided, a view that is increasingly rejected by popular demands for a more egalitarian relationship in which the patient is seen as a partner in decision making.

The difference between transcript and record, interview and written medical notation, is the difference between illness as the patient's problem and disease as the physician's problem. The core value structure of traditional biomedicine can be seen in this transformation of a sick person into a case. A rigidly biomedical approach to acute diseases, for which magic bullets can provide cures and getting the specific disease sorted out is essential to using the right magic bullet, is often appropriate and effective. Even for acute exacerbations of chronic disorders, where a life-threatening biological problem must be controlled, it has its place. But it is inappropriate in the long-term care of chronic illness, for all the reasons illustrated in this volume. Fortunately, a narrow professional approach, so commonplace in the past, is becoming less acceptable even in the medical profession. But it is still all too common, especially in situations where upper middle class doctors treat lower-class patients. In that context, general class relations in society are replicated in the actual medical encounter, and the political economy responsible for them enters into the clinic like the protagonists' shadows. It is doubtful that Dr. Richards would have been as insensitive if Mrs. Flowers were white and a member of his own social class.

It is important for the reader to recognize that the structure of the interview and of the clinical write-up is not idiosyncratic to Dr. Richards but is the result of his training into a professional culture; it reproduces a version of interviewing that he has learned and that I and many other practitioners also learned. That professional model, I have tried to show, is a reflection of a particular set of values about the nature of disorder, the work of medicine, and the nature of human beings that is frankly destructive in the care of the chronically ill. But putting questions of care to the side, simply as human beings we should be critical of a therapeutic method that dehumanizes the doctor along with the patient.

8

Aspiration and Victory: Coping with Chronic Illness

> Woe to the man whose heart has not learned while young to hope, to love—and to put its trust in life!
>
> —JOSEPH CONRAD ([1915] 1957, 338–39)

The patients' stories I have retold in the preceding chapters may seem to the reader excessively morbid and gloomy. There are many persons with chronic disorders and even severe disabilities who live lives of exemplary courage and often of remarkable stability and success. Such patients are not referred for psychiatric evaluation. Even anthropological studies of unselected patients may be biased by their focus on the patients whose life problems are the most formidable and whose therapeutic experiences are the most recalcitrant. It is important to balance the record with the description of a patient whose adaptation to illness is an undoubted success, whose illness problems are effectively dealt with in personal and medical settings, whose life is a model of mastery and grace under fire. To maintain one's aspirations in the face of grave adversity, to work hard to contend successfully with the daily assault of an impaired body on a robust spirit, to be victorious over the long course of losses and threats that constitute disability—these are lessons for us all, examples of what is best in our shared humanity.