The Illness Narratives

Suffering, Healing, and the Human Condition

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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.

—Isaac 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.
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?

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 medico-centric 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 auditioned 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 chil-
dren, is 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
losta salt in everythin’.
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 hydrochlorothiazide 100 mg daily and alemote 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 alemote 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 Dresler 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.