Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome

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The author examines suffering engendered by the socially constituted nature of illness through the delegitimation of illness experience in chronic fatigue syndrome. Cultural meanings of physical and mental illness are shown to be reflected in interactions with others to construct an illness reality in which chronic fatigue syndrome is defined as either nonexistent or psychosomatic. Disconfirmation of the subjective experience of illness leads to suffering arising from the threatened stigma of psychological disorder, the alienation resulting from a decision to keep the illness secret, and the shame of being wrong in one’s definition of reality. Patients also develop strategies for contesting the definition of chronic fatigue syndrome as “not real.” Delegitimation merits further exploration as a category for experience-near analysis of suffering in medical anthropology.

This article builds on retrospective accounts of illness experience in chronic fatigue syndrome to address the suffering engendered by the socially constituted nature of illness. Its specific focus is the suffering associated with delegitimation, defined here as the experience of having one’s perceptions and definitions of illness systematically disconfirmed (Kleinman 1992).

To organize and frame the discussion, I draw upon the concept of illness reality. In applying this construct to the analysis of cultural categories of illness, Good and Good have defined an “illness reality” as “a ‘syndrome’ of typical experiences, a set of words, experiences, and feelings which typically ‘run together’ for members of a given society, a set of experiences associated through networks of meaning and social interaction” (1982:148; see also Good 1977:27). My intent is to depict a set of words, experiences, and feelings that “run together” for individuals suffering from chronic fatigue syndrome.

Background

Chronic fatigue syndrome is a debilitating condition of unknown etiology that came to the attention of the medical community and the general public in the
mid-1980s. Its symptoms center on the experience of severe, persistent, and unexplained fatigue, but they also include a diffuse constellation of other complaints, such as muscle and joint pain, headache, sore throat, fever, weakness, dizziness, concentration difficulties, and memory loss (Centers for Disease Control 1990; Holmes et al. 1988). A significant number of chronic fatigue syndrome patients also suffer from depression before or after the onset of illness (Hickie et al. 1990; Kruesi, Dale, and Straus 1989).

Early etiological research on this illness focused on the Epstein-Barr virus as the probable cause of the symptoms (Jones et al. 1985; Straus et al. 1985). This initial explanation was abandoned when subsequent studies failed to replicate the association between elevated antibodies to Epstein-Barr virus and the syndrome (Straus et al. 1988; Swartz 1988).

The origin of chronic fatigue syndrome is presently a subject of lively debate among medical researchers. Some scientists continue to search for a viral cause; retroviruses (DeFreitas et al. 1992), enteroviruses (Gow et al. 1991), and herpesviruses other than Epstein-Barr have recently been posited as potential etiological agents. Others emphasize the role of immune dysfunction in the disorder (Lloyd et al. 1989). Sleep abnormalities (McCluskey 1992) and disturbances of the hypothalamic-pituitary-adrenal axis (as a final common pathway) (Demitrack et al. 1991) have also been put forward as explanations. Another line of inquiry centers on the relationship of chronic fatigue syndrome to psychiatric illness (David 1991). Etiological models integrating biological and psychological perspectives are also beginning to appear (Kendell 1991; Komaroff 1991).

The configuration of symptoms currently known as chronic fatigue syndrome closely resembles the clinical profile of neurasthenia, as historically minded observers are beginning to point out (Abbey and Garfinkel 1991; Greenberg 1990; Wessely 1990). Neurasthenia enjoyed considerable popularity as a diagnosis in late 19th- and early 20th-century U.S. medicine, when it provided clinicians and patients with a respectable physical explanation for complaints that might otherwise have been interpreted as indications of hypochondriasis, malingering, or outright insanity (Sicherman 1977). As a disease construct, it was gradually dismantled and subsumed under various affective and anxiety disorders as psychiatric nosology became more sophisticated and the usefulness of so broad and unwieldy a category was increasingly called into question.

Other medically unexplained, fatigue-related illnesses have also gained temporary prominence in U.S. medical history, only to come to similar ends. Exhaustion accompanied by dizziness, palpitations, and other symptoms in Civil War veterans coalesced into DaCosta’s or “effort” syndrome in the 1870s (DaCosta 1871). DaCosta’s syndrome flowered as a medical diagnosis for several decades, then was redefined and dismissed as a form of neurosis in the 1940s. Chronic brucellosis, a form of persistent fatigue attributed initially to the effects of bacterial infection (Evans 1947), was later shown to be related to “psychological vulnerability” (Imboden, Canter, and Cluff 1961). It subsequently disappeared.

In the 1960s and 1970s, chronic fatigue of unknown etiology was often attributed to hypoglycemia. Today, diffuse somatic syndromes in which fatigue plays a salient role may be classified as chronic fatigue syndrome or, alternatively, as fibromyalgia (if pain is predominant), candidiasis hypersensitivity syndrome,
or "total allergy syndrome" (Stewart 1987; Straus 1991). Thus the configuration of symptoms currently best known as chronic fatigue syndrome is not new, but rather has been constructed and reconstructed in popular and professional discourse over time.

Epidemiological research on fatigue is fraught with difficulties of design and measurement (Grufferman 1991; Lewis and Wessely 1992). Only a few attempts to assess the prevalence of chronic fatigue syndrome have been made to date. Preliminary estimates from this work suggest that cases fulfilling all criteria for the CDC definition may be rare in clinical as well as community populations (Gunn, Connell, and Randal 1992; Price et al. 1991; Komaroff, personal communication).

In contrast, complaints of disabling fatigue inside and outside doctors’ offices are widespread. Recent data from the National Ambulatory Care Survey indicate that fatigue accounts for approximately 6 million internal medicine visits each year (Nelson and McLemore 1988). Studies of the frequency of severe or extraordinary fatigue in general practice estimate its prevalence at 10 to 24% (e.g., Buchwald et al. 1987; Kroenke et al. 1988). Community surveys suggest that the prevalence of excessive fatigue in nonclinical populations may reach similar levels (e.g., Chen 1986; Cox et al. 1987; see Lewis and Wessely 1992 for a review).

Others have also applied the concept of delegitimation to the anthropological study of suffering but in somewhat different ways. Kleinman (1992), for example, in an examination of the experience and meaning of chronic pain, uses the term to refer to the loss of a "legitimate" world, that is, a world consisting of those ways of being that are culturally valued and defined as normative. Pain is construed, for the purposes of this particular analysis, as an effort to resist or transform the lost life-world, to "re-legitimate" one’s existence.

Whereas Kleinman is concerned with the delegitimation of experience, Das (1991) focuses more on the social order. She seeks both to expose the social origins of suffering and to demonstrate how suffering as experience may be transformed through social discourse into an authorization, a legitimation, of existing structures of power. We may think of Das’s work, therefore, as directed more toward the social production than the social construction of suffering.

The Research

Fifty individuals were interviewed as part of the research reported here. Interviewees were referred by Anthony Komaroff, Director of the Division of General Medicine and Primary Care, Brigham and Women’s Hospital, Boston, from the approximately 350 chronically fatigued patients he is currently following. These patients sought help for a debilitating fatigue that significantly interfered with their work or home responsibilities; approximately 80% meet the U.S. (Holmes et al. 1988), the British (Sharpe et al. 1991), or the Australian (Lloyd et al. 1990) operational case definition of chronic fatigue syndrome. The study sample is similar in age, sex, and educational background to the larger group but tended to have fewer objective laboratory test abnormalities.

The interviews were conducted over a period of approximately 18 months, beginning in the winter of 1989 and ending in the summer of 1990. Each interview
included the elicitation of data on life history and illness experience using a systematic series of open-ended questions. Interviews were tape-recorded and transcribed.

Eighty percent of those interviewed were women; 92% were white. Their ages ranged from 23 to 66 years, with a mean age of 39. Early anecdotal accounts of chronic fatigue syndrome reported it to be an illness of the educated and professional classes—a so-called yuppie disease (Time Magazine 1987). Almost half (48%) of this group of subjects, however, had left school before completing a bachelor’s degree; 22% had a high school education or less. Furthermore, the occupations of the 43 participants who reported having at some point been members of the labor force were almost equally divided between trades, clerical occupations, or direct service delivery (27, or 56%) and professional or managerial activity (e.g., consulting, teaching, administration).

Length of illness in the group at the time of data collection ranged from 1½ to 25 years. Fifty percent of the interviewees had been ill for five years or more at the time the interviews took place. The mean length of illness for the sample was 5.7 years.

**Defining Chronic Fatigue Syndrome as “Not Real”: The Experience of Delegitimation**

Two types of delegitimizing encounters appeared regularly in interviewees’ reports of their experience with chronic fatigue syndrome. The first stems from the apparent insignificance of the symptoms. Because everyone from time to time endures aches and pains, sore throat, feelings of depression, and fatigue, such complaints can be construed as minor, if discomfiting, consequences of everyday living rather than as indications of serious illness. Perceptions of the trivialization of symptoms by others converge for sufferers in the thematic phrase: “You’re tired? We’re all tired! So what!”

What you get [when you talk to people about the illness] is, “Well jeez, a lot of people are tired. What the hell is that? I’m tired, and I go to work! A lot of people are in pain.” Maybe they say, “Tsk, tsk, have another cup of tea.”

If you have cancer, you can tell your friends you have cancer and your friends understand. You cannot tell your friends you are tired. What are they going to say? “’I’m tired too!’ Several people have said that to me—‘I’m tired too!’

People think, “Oh, you’ve got a sore throat, and you’re tired. So? I’ve had sore throats and I’ve been nauseous. So?”

The second, and more damaging, delegitimizing experience for chronic fatigue patients is embodied in physicians’ definition of the illness as psychosomatic—“all in your head.” Interviewees report being given two different rationales for this definition. The first is that no observable evidence of disease in the form of clinical signs or laboratory findings can be found. The second is the fact that the illness has yet to be fully accepted as a diagnostic entity in the standard professional nosology.

Study participants repeatedly complained of being disbelieved or not taken seriously because they “don’t look sick.” They are neither thin and pale nor obviously disabled. They may function relatively normally, at least for a time, in
work and social settings. Convinced that the severity of the subjective experience of the illness is belied by outward appearance, they react with intense frustration to being told that they “look great!”

And that’s part of this illness. That everybody will always say to you, “Well, you look great!” Well, I’m tan and all that. What do you want?

The thing I hear from everybody is, “Gee, you look much too good to be sick!” I hear that all the time because I’m not emaciated and I’m not staggering, and of course when people see me, they see me on my good days, when I can get out of the apartment. They don’t see me on my bad days when I can’t get out of bed! Unless you’re in a wheelchair or in bed, people don’t really believe that you’re sick. They just kind of look at you and say, “Well, you don’t look sick! You don’t act sick!” It’s just obvious that people don’t believe you or think that it’s serious.

Because I’m not in agony or carrying a broken leg, there’s always that little doubt, “Well, how bad really is it?” I tell you—it’s bad. It’s bad. I’m sure if I had a rash, or was vomiting, or my arm dropped off, it would be lots easier for people to be nice to me. I look healthy as a horse! You should see me in the summer when I’ve been sitting around and I have a tan. People look at me and say, “God, you look wonderful!” And I have to say, “I feel awful!”

Part of the etiological controversy that presently surrounds chronic fatigue syndrome stems from the fact that the illness has yet to be reliably associated with any identifiable organic pathology. Laboratory tests undertaken for diagnostic purposes therefore prove consistently unsatisfying. Chronic fatigue patients have typically undergone extensive testing ordered by physicians. When the results of every test come back negative, the conclusion is that there is nothing physically wrong.

For chronic fatigue syndrome sufferers, the lack of recognition of the illness has meant that physicians could not definitively diagnose their condition. Many experienced this as betrayal by the medical profession and responded by consulting another (sometimes many other) doctors in search of an explanation for their distress. When this effort failed, they turned to alternative health care providers or fell back on various illness management strategies of their own devising.

Thus, the absence of observable evidence of pathology, together with the ambiguous status of the illness in professional medicine, precluded the possibility of a physical diagnosis for many chronic fatigue syndrome sufferers. And if an illness is not physical, it must, it follows, be mental. The cause of the symptoms was therefore often hypothesized to be depression, stress, or some other form of psychological disturbance.

That’s been my experience [with doctors] over and over again. They really try. They really listen. And then they try a whole bunch of things that they think might turn something up, and when everything fails, they just think you’re nuts. And then they get sort of angry.

They [doctors] would say things like, “You can’t be experiencing what you are experiencing. You need to see a psychologist. You’re not as sick as you think you are.”

I was going to a neurologist, and he could find nothing wrong with me. “Well, there’s nothing wrong on your X-ray but why don’t you try taking this, because
a lot of women”—he used the word “women”—“have a lot of trouble with depression that could cause other symptoms.” I was really sensitive at that stage about being told I was depressed when things had never been better. And I still have problems with that, because I still don’t feel like I’m depressed.

Forty-five (90%) of those interviewed reported delegitimizing experiences of the sort described above. Those who did not indicate that their symptoms had been accepted by others as real, either on the basis of observable evidence (e.g., swollen glands) or because they had heard of chronic fatigue syndrome and considered it a physical illness.

What, then, is the illness reality that emerges from these two forms of delegitimation? The trivialization of symptoms serves to characterize the sufferer as not sick. To classify complaints as part of normal life in effect disqualifies them as symptoms. The implications of the psychosomatic label are slightly different. In popular conceptions, a psychosomatic illness is an illness that exists, but as a product of the mind. Psychosomatically ill people are sick; they exhibit symptoms that, while “mental” in origin, are nonetheless located in the body. They are not, however, embodied in the sense of manifesting themselves either as physical sensation or observable bodily dysfunction. Part of the popular cultural meaning of psychosomatic illness is that its symptoms are defined as “imagined.” Thus chronic fatigue sufferers repeatedly find themselves judged to be either not sick or suffering from an imaginary illness. In either case, their complaints and their experience are discounted as being “not real.”

Suffering and Delegitimation

The experience of being repeatedly disconfirmed in their definition of reality led many to self-doubt. Those who had had such experiences described in frustrated tones how at one point or another they felt compelled to accept the possibility that what they were feeling might, after all, be “all in their heads” and that that might mean they were “crazy.”

I was beginning to think I was crazy! I couldn’t believe I could be this fatigued for this long... I’ve been fatigued because of the schedule I was keeping, but it didn’t keep me from doing anything. No matter how tired I was, I could still go another 10 hours. I thought I was imagining it. I thought, “Maybe I’m really depressed and that’s what’s causing it.”

I thought I was crazy. I thought I was a hypochondriac. There were things I didn’t want to tell the doctor because I thought he would think I was a fruitcake!

I remember standing in front of the mirror, and I looked wretched. People told me I looked like I was going to die! And yet the doctor said it was just a viral illness and that it would go away. And I’d look in the mirror and think, “Are you crazy? Maybe there’s nothing wrong with you. Maybe it’s all in your head.”

In fearing that their illness might, after all, be psychosomatic, self-doubters confront the possibility of psychological disorder and the stigma it entails. The suffering of self-doubt thus lies in the prospect of adding the burden of a stigmatized identity to that of living with a chronic illness that is severely debilitating, basically untreatable, and of questionable authenticity in the eyes of others.

The ambiguous nature of chronic fatigue syndrome causes some to retreat into secrecy. Rather than expose themselves to the pain of being disbelieved,
those who opt for secrecy actively try to hide the fact that they are sick. In casual conversations, they deliberately omit any reference to their condition. If asked how they are, they invariably reply brightly, "Fine!" They make great efforts to "pass" as healthy by struggling to hold onto jobs, to lead seemingly normal social lives, or simply to continue to perform the routine functions of daily living. For these individuals, dissembling, as difficult and demanding as it is, seems preferable to the risk of being disconfirmed in their experience of their illness.7

In explaining their reasons for choosing secrecy, study participants cited the awkwardness and embarrassment of trying to explain to someone that they have an illness whose symptoms are ill-defined, that has no "real" name or known cause, and that (at least at the time) most people have never heard of. The lack of shared knowledge of the illness and of meaningful terms in which to describe it made it difficult to argue convincingly for chronic fatigue syndrome as a disease. As more than one person put it, it would be easier in a more ways to have some serious but immediately recognizable disease like cancer.

Cancer would be better. I shouldn't say that, because I don't think it would be better. But it would be easier to share with somebody. I think I could tell somebody I had cancer, that I was dealing with cancer. I can't tell people about this, because, first of all, I don't know what to call it. I don't know how to describe it. Chronic fatigue syndrome? People have never heard of such a thing! It doesn't mean anything to them! It doesn't sound real.

Those who choose secrecy, however, not only carry the burden of keeping the secret, they also deprive themselves of the catharsis of talking about what is most on their minds and of receiving comfort in discovering there are others who care and may provide help when needed. Ironically, they also preclude the possibility of being affirmed in their experience of their illness. The suffering in secrecy thus lies in the alienation it entails.

As we have seen, the lack of recognition of chronic fatigue syndrome meant that many patients found themselves consulting physician after physician in the search for a diagnosis—often over months or even years. The failure of medical professionals to name their condition left patients feeling not only betrayed but also with no means of coping. Without a diagnosis, there was no treatment—no way of fighting the illness. Not knowing whether what they had was life threatening or what course it would take made life decisions and planning for the future impossible. The sense of paralysis that ensued was conveyed especially clearly by one individual, who also contrasted the experience of chronic fatigue syndrome to that of having cancer.

It would be easier in many ways if someone was to say to me, "OK. We've found out what's wrong with you. You've got a tumor the size of a grapefruit and you've got two years to live." OK. Now I know. That's what it is. I can get my affairs in order and sell my long-term bonds. OK. This is it. We pay off the car. We take a trip to Bermuda. I don't have to wonder what it is that I'm going to do with the rest of my life.

Of the various forms of suffering that experiences of delegitimation can engender, none was as devastating for this group as the humiliation that resulted from having their subjective perceptions and sensations of illness either trivialized or dismissed as psychosomatic. Other authors have written of the potential for
shame in the medical encounter when illness is experienced by the sick person as a deficit or when the vulnerability of the patient is overlooked by the physician (Kleinman 1988; Lazare 1987). The shame of chronic fatigue sufferers, however, stems not from the fact of having an illness but from being told that they do not. Their shame is the shame of being wrong about the nature of reality.

Contesting the Definition

Part of depicting the social process through which illness realities are constructed is to show how they are contested. To contest is to challenge and attempt to reconstitute a given definition of a situation by advocating an alternative interpretation.

Most efforts by study participants to dispute the definition of their illness were directed toward the designation of chronic fatigue syndrome as psychosomatic. The challenge to this definition took two principal forms. One was to argue that the illness is after all physical; the other was to present evidence that one is not psychologically impaired.

One way of making the case for the physical nature of chronic fatigue syndrome was to redefine psychosomatic as somatopsychic. In this approach, attention is directed away from the presumed psychological origins of the bodily complaints toward a possible organic explanation of psychiatric symptoms. If the cause of the illness can be assumed to be depression or some other psychological disorder, it can also be claimed that psychological disorders have biological roots.

I maintain that the psychological component is based strictly on neurological problems. I realize that a big part of it was a depressive episode. But it was a neurological problem. There’s some brain dysfunction there.

I don’t think it’s psychological at all. I don’t like having this illness, and sometimes I’m not as bubbly as I’d like to be, because it’s hard to take. And sometimes I tend to be short-tempered. But I don’t think that the psychological—no, not the psychological—the cognitive things I’m experiencing, or physiological things that I’m experiencing, come from a psychological origin. I think it’s physiological.

The presence of “observable evidence” was invoked to support a second line of reasoning in which the definition of chronic fatigue syndrome as a psychosomatic illness was contested. In struggling to convince themselves, as well as others, of the organic nature of their distress, patients would point to the presence of physical signs of pathology.

Every so often I ask myself, “Could I have this? Or is it psychological?” And then I feel these massive glands sticking out and I realize [I wouldn’t] have a fever and swollen glands and aches like I have [if I were depressed]. The thing that makes me sure I have chronic fatigue syndrome is the pain and the swollen glands and the fever, the definite physical symptoms I don’t believe would be psychosomatic.

[I knew I was really sick] because I had actual physical symptoms, even though nothing showed up on the tests . . . like sore throat, headache, nausea, temperatures that showed up on a thermometer. One test showed that there was some kind of actual weakness in the muscles. It showed up on this little graph. That was great.
The case for defining chronic fatigue syndrome as a physical illness could also be made by analogy. Likening the condition to a well-known and unquestionably biological ailment clearly implies that it should be considered biological as well. Opportunities for drawing such analogies arose when patients were called upon to explain their condition.

I say, “Well, it’s kind of like mono. You’ve heard of mono. The Epstein-Barr virus? Well, it kind of recurs in people. It appears at certain times and makes me lazy and gives me a fever.” I say, “It’s going through different research studies, and they’ve changed the name, and they’re not really sure, but there’s definitely something there because there’s some kind of ‘titer’ that’s high and stuff.”

If arguing for a physical definition of chronic fatigue syndrome is one way of rejecting a psychosomatic label, another is to find ways of proving that one is not, in fact, “crazy.” Most often this involved challenging the idea that depression causes this illness. Many such challenges began by invoking personal experiences of previous depressive episodes, the point being to distinguish depression from the experience of chronic fatigue syndrome. Depression, according to one interpretation, could be traced to some identifiable event or situation in the world, whereas the malaise in chronic fatigue syndrome was free-floating, unattached, seeming to “come out of nowhere.” The difference between loss of interest in activities in depression and fatigue in chronic fatigue syndrome was another frequently cited distinction. Individuals who had been depressed spoke of having lost interest in things, contrasting this with the feeling of having the interest but not the energy to be active since the onset of chronic fatigue syndrome. “This is not depression but exhaustion, and they are not the same thing,” is the message these claims are intended to convey.

To insist that depression is not the cause of chronic fatigue syndrome is not to deny that it is a part of it. Depressed feelings after illness onset were acknowledged by a large proportion of the study sample. Those who had known depression since becoming ill with chronic fatigue syndrome interpreted these feelings in one of two ways. Either they were intrinsic to the syndrome itself—a symptom, like muscle aches, joint pain, or fever—or they resulted from the experience of chronic fatigue syndrome, the predictable outcome of months or years of being seriously ill. “We are not depressed, we’re sick! And if we are depressed, it’s because we’re sick!” is the essence of the argument against depression as the cause of chronic fatigue syndrome.

Summary and Conclusion

My aim here has been to focus attention on experiences of delegitimation as socially constituted, nonbodily suffering in illness. The reality constructed for sufferers of chronic fatigue syndrome through delegitimizing experiences is that their illness is not “real” at all but rather a fabrication based either on the needless exaggeration of everyday complaints (in which case they are malingerers) or on the perception of imaginary symptoms (in which case they are “crazy”). In either case, the self-doubt and the threat of stigma, the secrecy and the social isolation that results, the psychological paralysis induced by the ambiguities of the illness, and the shame of being wrong about “really” being sick all contribute to the psychic suffering of the chronic fatigue victim. In spite, or perhaps because, of
this suffering, patients felt called upon to challenge this version of reality either by making the case that chronic fatigue syndrome is a real (i.e., physical) illness or by presenting evidence to prove that they were not psychologically disturbed.

A well-developed critique of biomedical thinking and practice now exists in medical anthropology. The historically rooted and culturally constituted nature of mind-body and other dualisms, biological reductionism, and scientific rationality has been repeatedly pointed out, along with the epistemological and clinical shortcomings of a natural science model of illness and healing (e.g., Lock and Gordon 1988; Good 1993).

Assaults on biomedicine have also been mounted from within the profession itself. "Biopsychosocial" theories of etiology, calls for "holistic" approaches to care, and curriculum innovations emphasizing the social, psychological, and moral dimensions of suffering and the emotional needs of patients represent attempts to reform medicine "from the inside."

Yet it is the standard biomedical paradigm that accounts for the delegitimizing experiences encountered by chronic fatigue syndrome sufferers. The definition of "medically invisible" bodily complaints as psychogenic and therefore imaginary is a direct reflection of scientific materialism, which accords primacy to substance, equates the real with the physically observable, and discounts or bypasses altogether the subjective experience of the patient. Thus, not surprisingly, delegitimation in chronic fatigue testifies to the intractability of the biomedical model. As long as biomedicine remains efficacious, politically entrenched, and consistent with core values and concepts in Western cultural tradition, we may expect this to continue to be the case (Gordon 1988).

Kirmayer (1988) has pointed to the moral implications of a diagnosis of psychosomatic illness and interpreted them in terms of the symbolic meanings attached to mind-body dualism in Western metaphysics, e.g., agency and accident, reason and emotion, control and chaos, accountability and blamelessness. In the case of "real" physical disease, medicine contrives through conceptual and practical means to distance the self from the body, thereby exempting the individual from personal responsibility for illness. In the case of psychological disorder, however, defining a problem as "mental" or "emotional" means linking it to the values associated with mind in Western metaphysics—hence the notion that psychiatric illness represents a failure of intentionality and volition, a lapse of rational self-control that must ultimately be recognized to be "one's own fault." Despite the fact that psychosomatic medicine was originally conceivable as an antidote to biological reductionism, an attempt to bring mind and body together in biomedicine in more or less equal union, in reality psychosomatic diagnoses have come to be classed with psychiatric disorders, reproducing dualistic thinking and sharing the stigmatized status of mental illness as a disability we "bring on ourselves." In making explicit the similarities between qualities of "mind" and the construction of the person in Western tradition, Kirmayer also argues for biomedicine as a sociomoral phenomenon that will resist change in the absence of a restructuring of categories and definitions at the level of culture.

An appreciation of the cultural underpinnings of delegitimizing experiences in chronic fatigue syndrome also opens the door to understanding their personal meaning. What is at issue in the struggle over the proper definition of reality in chronic fatigue—physical or psychosomatic condition, real or unreal illness—is
whether patients will be accorded the status of sane persons who are genuinely sick. If so, much of their psychic, if not their physical, suffering will be alleviated. If not, they must continue to deal with the implications of having a “not real” disorder.

The delegitimizing experiences reported by sufferers of chronic fatigue syndrome are strikingly similar to those encountered by chronic pain patients. As in the case of chronic fatigue, individuals who live with chronic pain routinely find their complaints of subjective distress discounted by medical professionals who, in the absence of an identifiable biological explanation, define the problem as psychosomatic and the pain itself as imaginary (Hilbert 1984; Kleinman 1988). Indeed, the same distinction between real (physical) and unreal (psychological) disorder that is crucial to the experience of chronic fatigue syndrome appears no less central in chronic pain, where patients also struggle to deflect stigmatization by defining their condition as organic (Jackson 1990, 1992).

The elaboration of suffering as an analytical category for understanding the lived, felt quality of human events requires that various forms of suffering be identified and articulated. This article experiments with delegitimation as a way of representing one particular form of nonbodily suffering in illness. As defined here, for example, delegitimation is likely to apply best to conditions classified in popular or professional consciousness as psychosomatic. Reconfigured, however, it might also prove useful for understanding experience in other types of psychological disorder or in illnesses that are unquestionably physical but highly stigmatized. For this reason, and because it seems to reflect experience more directly, with less built-in interpretation, than some other categories of potential relevance to the study of suffering, delegitimation merits further exploration by those interested in carrying out experience-near analysis in medical anthropology.

Notes

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1 The definition of suffering within as well as outside of illness is a complicated matter and not central to the aims of this discussion. For present purposes, a rather loose definition of suffering as “the subjective experience of enduring pain from which there is no immediately visible escape” will suffice.

2 In adopting the term “delegitimation” to refer to these kinds of experiences, I do not mean to imply that chronic fatigue syndrome has been accorded “legitimate” status by the medical profession. “Delegitimation” is used here to represent sufferers’ perceptions and interpretations of their experiences and implies the assumption of legitimacy on their part. The partially constructed status of chronic fatigue syndrome as a disease category in the medical lexicon is a separate issue that is also discussed.
The illness reality construct has been applied in research on clinical encounters between doctors and patients to characterize the process through which reported symptoms are made meaningful by mapping them onto existing cultural models of illness and healing. See Atkinson 1977; Gaines 1979; Kleinman 1980.

This may, of course, point to inadequacies in the definition when applied to epidemiological research (Grufferman 1991).

In fact, a review of NAMCS statistics through the 1970s and early 1980s reveals a marked drop in the number of physician visits reportedly prompted by fatigue. Interestingly, this may reflect a change in the definition of the construct rather than an actual decrease. It seems that in 1977 narrower coding criteria for fatigue were implemented in tabulating the data, resulting in an immediate 17% drop in incidence (Barofsky and Legro 1991).

The tendency in professional medicine to discount the complaints of women means that gender must also be examined as part of an analysis of illness experience in chronic fatigue syndrome. The politics of gender in chronic fatigue syndrome is the focus of one of several additional articles planned as part of this research.

Concealment of disability as a strategy for avoiding delegitimation is discussed in the context of chronic pain by Hilbert (1984).

REFERENCES CITED

Abbey, Susan E., and Paul E. Garfinkel

Atkinson, P.

Barofsky, Ivan, and Marcia West Legro

Buchwald, D., et al.

Centers for Disease Control

Chen, M.

Cox, B., et al.

Da Costa, J. M.

Das, Veena
1991 Moral Orientations to Suffering: Legitimation, Power and Healing. Manuscript in files of author, Department of Sociology, School of Economics, University of Delhi, Delhi, India.

David, A. S.


Greenberg, Donna 1990 Neurasthenia in the 1980’s: Chronic Mononucleosis Syndrome, Chronic Fatigue Syndrome, and Anxiety and Depressive Disorders. Psychosomatics 31(2):129–137.


Jackson, Jean E.
1990 The Stigma of Severe Chronic Pain. Manuscript, Department of Anthropology, Massachusetts Institute of Technology, Cambridge, MA.
Jones, James F., et al.
Kendell, R. E.
Kirmayer, Laurence J.
Kleinman, Arthur
Komaroff, Anthony L.
1991 Remarks delivered at the Workshop on the Definition and Medical Outcome Assessment of Chronic Fatigue Syndrome in Research, National Institutes of Health, Bethesda, MD, March 18–19.
Kroenke, K., et al.
Kruesi, Markus J. P., Janet Dale, and Stephen E. Straus
Lazare, Aaron
Lewis, G., and S. Wessely
Lloyd, Andrew R., et al.
Lock, Margaret, and Deborah R. Gordon, eds.
McCluskey, D. R.
Nelson, C., and T. McLemore
Time Magazine 1987 Stealthy Epidemic of Exhaustion: Doctors are Perplexed by the Mysterious “Yuppie Disease.” June 29:52.
Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome
Norma C. Ware
Stable URL:
http://links.jstor.org/sici?sici=0745-5194%28199212%293A6%3A4%3C347%3ASATSCO%3E2.0.CO%3B2-G

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References Cited

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