

Chronic fatigue syndrome: a 20th century illness?

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The chronic fatigue syndrome has become the *fin de siècle* illness, now getting similar attention to that of neurasthenia, which dominated medical thinking at the turn of the century. Myalgic encephalomyelitis was an early term introduced in the United Kingdom in 1957 for this state, but it had little or no public or professional prominence. Until then “chronic fatigue had become invisible”, with “no name, no known etiology, no case illustrations or clinical accounts in the medical textbook, no ongoing research activity—nothing to relate it to current medical knowledge”. The reconstruction of chronic fatigue began in the mid-1980s, with the emergence of “chronic Epstein-Barr virus syndrome”, which was later converted to chronic fatigue syndrome. The former term, which first emerged in the mid-1980s, is now regarded as a misnomer and should be abandoned. In the popular American literature the term “chronic fatigue and immune deficiency syndrome” is preferred by the most active of the patient lobbies, while myalgic encephalomyelitis continues to be the usual label in the United Kingdom. The relevant research linking chronic fatigue syndrome with somatization is reviewed in this article. Understanding the nature of somatization can still shed some light on the meaning of chronic fatigue at the end of the 20th century.

Key terms immune deficiency, myalgic encephalitis.

Imagine feeling permanently exhausted, bloated and depressed, experiencing peculiar mood swings, feeling sick, going blind for short spells, suffering painful limbs and shaking fits, and being unable to sleep at night (1).

The above quotation is one of many descriptions of an illness known in the United Kingdom as myalgic encephalomyelitis (ME), or in the United States as “chronic fatigue and immune deficiency syndrome” (CFIDS). Numerous such examples can be found in the popular press over the last 10 years. The accompanying text conveys a clear message that the condition being described is a physical illness with an organic pathology. However, many physicians reading the same clinical description may conclude that psychosocial models are as relevant as physical explanations. This clash of attributions is at the heart of what is known as somatization—the conflict between physical and psychological explanations of illness. In this paper I extend some of my earlier work on the history of chronic fatigue (2, 3) and

its social purpose (4). Given the theme of the symposium at which this paper was presented, I have paid particular attention to the problem of somatization and its relevance to chronic fatigue (5). I shall begin by looking at specific issues linking somatization and chronic fatigue, using my perspective as an epidemiologic researcher and clinical psychiatrist. In the second part I use a broader brush and draw upon the popular literature to paint a picture of this new *fin de siècle* illness.

Arrival of chronic fatigue syndrome

Chronic fatigue syndromes are not new (2, 6), as exemplified by the rich and fascinating story of neurasthenia, which dominated medical thinking at the turn of the century, only to fade into obscurity (in the

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West at least). Between the demise of neurasthenia and the last 10 years, fatigue syndromes were not a major issue for physicians or for professional or lay journals. Certainly fatigue syndromes existed, and so must have fatigued patients. The occasional paper can be found on the patient who is "tired, weak and toxic" (7) or is "weak and fatigued" (8), and syndromes such as chronic brucellosis enjoyed some popularity in the United States. (See reference 6.) Myalgic encephalomyelitis, or ME, was a term introduced in the United Kingdom in 1957, but it had little or no public or professional prominence. Norma Ware (9) has appropriately noted that throughout this period "chronic fatigue had become invisible", with "no name, no known etiology, no case illustrations or clinical accounts in the medical textbook, no ongoing research activity—nothing to relate it to current medical knowledge".

The reconstruction of chronic fatigue began in the mid-1980s, with the emergence of "chronic Epstein-Barr virus syndrome", which was later converted to chronic fatigue syndrome (CFS). The former term first emerged in the mid-1980s, when papers from reputable researchers in Israel and the United States appeared in prestigious American journals. These papers sought to link evidence of infection by the Epstein-Barr virus to chronic fatigue. The high point of this endeavor was a consensus conference organized in 1985 by the National Institute of Allergic and Infectious Diseases. It is now clear that the serological tests introduced in the papers was flawed and that the role of Epstein-Barr virus in the new condition was exaggerated. The same authors who had presented the original data themselves concluded that chronic mononucleosis was a misnomer and should be abandoned.

This did not happen. The original proposers of chronic mononucleosis later declared themselves unprepared for the public and media attention that followed—"Physicians throughout the United States were inundated with requests to evaluate chronic fatigue" (10). The chronic mononucleosis papers had inadvertently articulated a need and also coincided with an "epidemic" of a mysterious disease that had been reported from the Lake Tahoe region of Nevada (11). The epidemic itself may have been partly iatrogenic—investigators sent by the Center for Disease Control to investigate the outbreak at Lake Tahoe reported that media attention had led large numbers of subjects from outside the area to refer themselves to the interested physicians for testing (12), while other physicians in the area were not seeing anything unusual (13). Nevertheless, the confluence of these two events made an extraordinary impact, described by one medical journalist as a "proliferation of support groups, research foundations dominated by patients with the syn-

drome, and fund raising and lobbying groups" (14). By 1990 a hot line at the Center for Disease Control was attracting over 2000 calls a month (15), a figure now nearer 4000. Only AIDS attracts more calls to the National Institutes of Health (16).

In the United Kingdom the term myalgic encephalomyelitis had been introduced earlier, and it was actually coined to describe a peculiar outbreak of a paralytic illness that swept through the nursing establishment of the Royal Free Hospital in London in 1955. (See references 2 and 17.) However, its rise to its current prominence paralleled the emergence of CFS in the United States. During 1988 the ME Association was Britain's fastest growing charity (18), with a rise in membership of 300% in just 6 months (19). At present this growth continues across, and more recently beyond, the Anglophone world.

Chronic fatigue syndrome

The reaction of the American medical establishment to the failure of the Epstein-Barr virus theory was to change the name to chronic fatigue syndrome (CFS). A similar, if more reluctant, process happened in the United Kingdom. The last few years have seen an explosion of interest in the subject of CFS. The literature on this subject has been remarkable for its multidisciplinary nature. Several general reviews have been published (20, 21). Readers interested in specific topics, including immunology (22), microbiology (23), management (24), psychiatry (25), psychology (26), neurobiology (27), and epidemiology (28), are referred elsewhere.

However, although the term CFS is now almost de rigueur for scientific and professional discourse, the same is not true of the popular literature. In America the term chronic fatigue and immune deficiency syndrome (CFIDS) is preferred by the most active of the patient lobbies, while ME continues to be the usual label in the United Kingdom. CFS has the advantage of being operationally defined and hence researched in a constructive fashion—in contrast CFIDS and ME are better understood as belief systems—a person has ME when they say they do. In this paper I first concentrate on the relevant research linking CFS with somatization, but then switch to considering the wider relevance of the conditions covered by the terms CFIDS or ME.

Even considering the subject of somatization in the same article with CFS is likely to cause offense in certain quarters. Some might consider it to be of only peripheral relevance to the subject—effort being better devoted to something more relevant, such as virology or immunology. That is not my opinion. All are relevant. Understanding the nature of somatization and its relevance to both operationally defined CFS and self-defined ME can still shed light on the nature of chronic fatigue at the end of the 20th century.

What is somatization?

Goldberg & Bridges have suggested an influential definition of somatization, seeing it as a process by which patients gain access to medical care. They define somatization as occurring when a patient with a psychiatric disorder seeks consultation for physical symptoms attributed by the patient to a physical cause. Finally, treatment of the psychiatric disorder would be expected to reduce or eliminate the physical symptoms (29).

Defined thus, somatization is a common, indeed the most common, process by which patients with psychological disorders consult their doctors (30). About 20% of new patients in general practice are somatizers, in contrast to 5% who seek help solely for psychological symptoms (29). Contrary to popular prejudice, somatization is a ubiquitous phenomenon, not restricted to any particular class, gender, ethnic group or level of intelligence. Instead, in one study that compared somatic with nonsomatic symptoms, somatizers were less depressed, had less social dysfunction, but had more unsympathetic attitudes towards mental disorder. Somatizers were also more likely to have received previous medical care, both as an adult and as a child (31).

A multidimensional approach to somatization

The two most common representations of somatization are a process (the Goldberg view) and a discrete disorder (the DSM-III view). However, somatization has other meanings. Sharpe et al (32) have persuasively argued that the concept could be usefully subdivided into several topics, and I shall follow their lead: (i) symptoms (number and type), (ii) psychiatric diagnoses (depression, anxiety, panic etc), (iii) cognitions (fear or conviction of disease) and attributions (illness belief), (iv) behavioral and functional impairment, and (v) pathophysiological disturbance (hyperventilation, inactivity etc).

Somatic symptoms and chronic fatigue syndrome

Whereas studies of CFS usually find subjects scoring midway between normal and psychiatric controls on most measures, such as the Beck Depression Inventory, the General Health Questionnaire, and so on, there is one exception. CFS patients endorse more somatic symptoms than even psychiatric referents. (See, eg, references 33 and 34). In our study, carried out at the National Hospital for Neurology, CFS patients had a mean number of 14 somatic symptoms, compared with 8 for neurological patients and 11 for depressed patients (35). Chronic fatigue by itself is also associated with an increased number of unexplained physical symptoms, both with and without the inclusion of symptoms that overlap with the concept of CFS (36). The number of somatic symptoms

is also related to prognosis—the more, the worse the outcome (37).

Psychiatric diagnoses and chronic fatigue syndrome

The majority of those seen in the CFS clinic fulfill criteria for a psychiatric disorder. (For reviews see references 25, 38 and 39.) A typical study found that around 75% of those with either chronic fatigue or CFS had current psychiatric disorders and current depression (40). Somatization is thus relevant on two levels. First, most of those seen in specialist care believe their illness is due to a physical process (*vide infra*). If they also fulfill criteria for known psychiatric disorders, they are thus somatizing according to one definition. Second, a subgroup will fulfill criteria for the specific category of somatization disorder.

Rates of somatization disorder. Whereas psychiatric disorder is common in CFS settings, somatization disorder is not. In one of the earliest studies Manu et al reported a prevalence of 15% (41). Most studies that use the criteria find that between 5% and 10% of those seen in specialist CFS clinics (but not primary care) fulfill International Statistical Classification of Disease (ICD) or Diagnostic and Statistical Manual for Mental Disorder (DSM) criteria for somatization disorder (33, 35, 40, 41–44).

One criticism that can be made of this finding is the problem of tautology, since the definitions of both CFS and somatization disorder require multiple symptoms. When Lane et al compared persons with CFS with chronically fatigued patients who did not fulfill the criteria for CFS, one of the chief differences between them was that the former were more likely to fulfill criteria for somatization disorder (40). They concluded that the multiple symptom criteria for CFS actively select for somatization disorder. When symptoms included in both syndromes were excluded, the prevalence of somatization disorder fell from 46% to 20% (33).

This relationship was further extended by Katon & Russo in 1992 (45) these authors showed that the greater the number of somatic symptoms in subjects with CFS, the greater the probability of a psychiatric disorder. My co-workers and I have also confirmed this conclusion in a primary care sample (46). These findings link CFS with the mainstream of psychiatric epidemiology, since it has been repeatedly demonstrated that a linear relationship exists between the number of somatic symptoms and the risk of psychiatric disorder (28, 47).

Somatization disorder is thus found in CFS clinics, but it is not the most common diagnostic category. Somatization disorder is also not unique to CFS clinics, and a similar situation exists in general medical clinics. The best survey to date (48) found a prevalence of 8% for all new medical outpatients, rising to 14% for those with doubtful medical diag-

noses, not dramatically different from the prevalence in CFS clinics.

On the other hand, somatization disorder is very uncommon in the community, the expected community prevalences ranging from 0.03% to 0.3% (49). It is also very uncommon in samples of chronically fatigued patients identified in general practice—with a prevalence of 0.6% in the ECA sample (36). No cases were found in two British community samples (50, 51).

Relevance of somatization disorder to chronic fatigue syndrome. Somatization disorder is a necessary, if unwelcome (to physicians, at least) part of medical life, rather than something intrinsic to CFS. Donna Stewart documented how one sample of patients with “twentieth century disease”, also known as total allergy syndrome, had, at various times, also been labeled as suffering from candidiasis, hypoglycemia, and now CFS (52). Other contributors to the symposium at which this paper was presented discussed such apparently diverse subjects as dental amalgam disease, food allergy and multiple chemical sensitivity. However, all of these topics are linked by the theme of somatization—indeed, a few would have consistently fulfilled criteria for somatization disorder throughout their illness, even if their own disease attribution changed. A small cader of such patients now appears in the guise of CFS and can appear in the self-help or media literature. Such patients may not shed much light on the nature of CFS as it exists in general practice, but they illuminate our understanding of the sociology of illness and illness behavior. This phenomenon is the theme of the second part of my essay.

Various groups have started to recognize this problem. The Australian researchers who have done much to promote the concept of CFS, and are particularly associated with immunologic theories of the disorder, have presented data showing that a minority (27%) of those seen in a CFS clinic can be differentiated from the majority by such variables as duration, prognosis, psychological morbidity and disability, and also by an index of immunologic dysfunction (53). They argue that the minority group should be classified under the somatoform disorders, the label CFS being reserved for those with shorter duration, fewer more “typical” symptoms, and less disability. The British consensus criteria (54) also suggest that CFS should not be diagnosed if the subject fulfills criteria for somatization disorder (whereas depression or anxiety are still compatible with a diagnosis of CFS).

The irony is that the same subjects for whom there is a growing consensus that the label of CFS is inappropriate are often those who cling the most firmly to the diagnosis. Chronicity predicts chronicity, and most au-

thorities advocate a strategy of “damage limitation” (55). It is ill advised to challenge disease attributions anyway, but particularly in this group with strong convictions, if any therapeutic alliance is to be maintained. Management of somatization disorder is already far from simple. Thus, although excluded from most current case definitions, and hence excluded from the research effort for CFS (in theory anyway), excluding them from the label of CFS or ME serves little purpose except to ensure that the patients do not consult you again.

Pathophysiology and somatization

The definitions of somatization that have been cited all include the statement that the symptoms must be “medically unexplained”. But how valid is this? Sharpe & Bass (56) have done a considerable service in highlighting how many of the symptoms encountered in somatization, far from being “unexplained”, are associated with numerous physiological processes. Hyperventilation, for example, although not as common in CFS as some have claimed (57), is one physiological mechanism implicated in the production of multiple and diverse somatic symptoms and exhaustion (58). Sleep disorder, which is indeed common, albeit nonspecific, is another. Sleep disturbance has well recognized effects on mood, fatigue, muscle pain, cognitive functioning, and so on.

One of the most clear-cut physiological mechanisms underlying the experience of somatic symptoms is the effect of inactivity. An extensive amount of literature exists on the inevitable physical, metabolic, biochemical, and psychological adverse effects of inactivity (59, 60). Inactivity also affects thermoregulation and is a potent cause of postural hypotension, both complaints frequently encountered in the setting of CFS. As Sharpe & Bass (61) point out, the degree of inactivity to produce these changes is not great—enforced sitting in a chair for one week is sufficient. Inactivity not only increases the sensation of fatigue but also reduces the desire for exercise. One of the consequences of neuromuscular deconditioning is delayed postexertional muscle pain (61), resulting particularly from eccentric contractions, where the muscle lengthens while doing work, and causing transient local muscle trauma and release of muscle enzymes (62). This is particularly prominent in the untrained person (63).

Finally Sharpe & Bass (56) also draw attention to evidence suggesting a physiological and a psychological basis for the attention paid to bodily symptoms. Evidence is beginning to emerge from the evoked potential literature that patients with somatization disorder manifest an impaired ability to filter out or attend to irrelevant peripheral stimuli. A disorder of perception, both of physical and mental effort, is one of the more attractive hypotheses explaining the apparent discrepancy between subjective symptoms and objective neuromuscular (64) and cognitive performance (65) in CFS.

Attributions and chronic fatigue syndrome

Attributions (a person's explanation for their illness) and cognitions (their thoughts about illness) play a role in understanding the development of CFS, and also in planning management.

It is now well recognized that the majority of those reporting to a CFS clinic believe their illness is predominantly physically based, and most of them already use phrases such as ME, CFS or postviral fatigue syndrome (PVFS) to explain their illness. This situation is in contrast to the picture in primary care (66, 67).

One of the most striking aspects of clinical interactions with many CFS patients is the intensity with which these beliefs are sometimes held, in contrast to the uncertainty with which the medical and research community views the topic. For example, Schweitzer et al (68) noted increased scores on the Disease Conviction scale of the Illness Behavior Questionnaire (IBQ), as did Hickie et al (69). Another group found that scores on the Illness Behavior Questionnaire were identical for CFS patients and patients seen in a neurological clinic with multiple sclerosis (MS) (70). This study is already being interpreted as showing that CFS also has a neurological origin, like MS—but it should be remembered that, unlike patients with MS, sufferers from CFS are not told by their doctors that they have a serious neurological condition. While MS sufferers have their neurological illness validated by their doctors, for CFS patients exactly the reverse happens for the vast majority. Thus, while the illness conviction of one group congrues with that of most neurologists, that of the CFS group is in almost complete contrast. This situation highlights one of the reasons for the enmity and mistrust so frequently described between CFS patients and the medical profession—the clash between attributions and the conviction which both sides hold for their beliefs.

Schweitzer et al concluded that some CFS sufferers were characterized by a strong conviction that they are ill, a reluctance to accept a psychological interpretation for their illness, and a tendency to regard their illness as the sole problem in their lives. Most clinicians with experience with CFS will recognize this situation in the case of some, but by no means all, of their patients.

Strength of feeling is also reflected in, and perhaps caused by, the media coverage of CFS. My colleagues and I have found that press reports carried in the British media were more likely to emphasize organic views of the condition, in contrast to the trend observed in the professional literature (71). As one journalist wrote, "there is no middle ground when it comes to CFS" (72). Such a media analysis, and such intensity of feeling, could almost certainly be mirrored for any of the other subjects considered in the symposium at which this paper was presented.

Cognitions, personality and chronic fatigue syndrome

A further factor relevant to the understanding of CFS is that of personality. The self-help literature, this author's own clinical impression, and now a controlled study (73) suggest that many sufferers have personalities characterized by high internal standards, devotion to duty, and perfectionism. In Norma Ware's words they "oversubscribe to social norms that dictate exhaustion as a way of life" (74). Sufferers often remark with regret upon their inability to convalesce after any triggering event, such as a viral infection. One told *Vogue* that it seemed like a bad bout of "flu from which [as usual] I did not allow myself time to recover" (75). Sufferers "work until they drop, whilst everyone else creeps to bed with the slightest headache or sniffle ... lazy people don't get ME" (76). Part of these stories are moral tales, intended to distinguish the sufferer from people who creep to bed or who do take time off work for no good reason, who, by implication, have moral or psychological problems that must be clearly distanced from ME. However, such stories may also reflect a genuine personality style of high standards, devotion to duty, and over achievement, which is also captured in the disliked term "Yuppie flu", which continues to appear in media coverage of the subject.

In consequence, patients with this and related illnesses often describe how hard they find it to accept anything "less than 100%", or to cope with the initial limitations of illness. The cognition that "if I can't do it properly it's not worth doing at all" is a frequent one. Alternatively, many sufferers have tried to "exercise away" their fatigue and hence have carried out activity that may be excessive in the light of their current (but not previous) fitness—it is frequently observed that athletes seem to be over represented in the ranks of sufferers (77). Delayed fatigue and myalgia, the hallmark of CFS, are an inevitable and far from mysterious consequence (62, 63).

My colleagues and I, and also others, have also outlined how cognitive factors (our conscious thoughts) play a role in at least the perpetuation, if not the etiology, of CFS (26, 78). For example, many patients, in an understandable effort to control and reduce symptoms by varying activity levels, become hypervigilant and over sensitized to physical sensations. The psychology of attention and awareness suggests that such symptom focusing may serve to exacerbate unpleasant sensations. For example, increasing the attention paid to one's heart rate may lead to the detection of nonpathological ectopic beat, which in turn gives rise to anxiety, and hence to more palpitation. The term somatosensory amplification is sometimes used to describe this process of hypervigilance and increased attention to bodily sensation and the health-related anxieties that may follow (39).

Two studies have found that CFS patients have an increased tendency to amplify bodily sensations or focus on symptoms, which are themselves associated with higher disability and functional impairment (68, 79). Such cognitive styles are indeed encouraged by frequent advice to "listen to your body", "live within your limits" and "always do 75% of what you are capable of ... unless you want to plummet down with another relapse you really must follow the rule of doing less than you think you can" (80), which is a Leitmotiv of popular literature on the subject and which reaches its reductio ad absurdum with something known as "aggressive rest therapy" (81, 82). There is no space in this discussion to describe the physical and psychological consequences of such advice—common sense will suggest most.

Cognitive factors have also been implicated in disability. Fear of illness, and uncertainty about its pathophysiology, are common. Patients restrict activity because of fear of the consequences. Catastrophic beliefs about the effects of activity are also common—any small increase in exertion may be believed to cause permanent disability, relapse, and long-term damage, and they are related to disability (83). Some literature is hardly reassuring. In one example from an extensive amount of literature, a newsletter for young sufferers notes that "Up to 30% of patients may suffer from cardiac complications, depending upon the strain of infecting virus. There is therefore a danger of pushing a child too far physically" (84). The same publication goes on to state that only 25% of sufferers (ie, children) make a complete recovery.

All of these conditions heighten the sense of anxiety and loss of confidence. As Kirmayer et al have noted for the related condition of fibromyalgia; "feeling of vulnerability and apprehension about having an illness of unknown origin may contribute to sufferers' activity limitations, inability to sustain a work effort and varied somatic distress" (85).

Cognitive factors (such as beliefs about health and illness) and behavioral factors (the use of avoidance as a coping strategy) are important determinants of the outcome in CFS, and, I suspect, related syndromes. Regrettably the outcome in CFS is poor—systematic follow-up studies are almost as gloomy as the anecdotal opinion expressed by Behan & Behan (86), who have extensive experience with CFS in this country, and wrote that "most cases do not improve, give up their work and become permanent invalids, incapacitated by excessive fatigue and myalgia". No laboratory marker has been shown to play any role in predicting outcome, in contrast to the strength of the belief in a solely physical cause of symptoms (37, 87, 88).

I need no convincing that neurobiological phenomena are relevant to the understanding of CFS and that real progress can be expected from the new generation of neuroimaging and neuroendocrine studies in this area.

However, I am also convinced that such studies will never explain the full picture of ME or CFIDS as currently encountered. The following grim story, occupying a full page of one of our national newspapers (89), might, I suspect, be better understood first by considering the cognitive, attributional and behavioral variables which I have only touched upon briefly, but more importantly by the cultural and social factors that I shall address later.

This story concerned one family's battle with ME (89). First, the mother and then her three children had been afflicted for 5 years. The consequence has been a life of "complete restriction and isolation. School is a memory". The mother told the journalist "each night when I went to bed I hoped I would not wake up in the morning. I even thought at times it would be better for the children if they died". Even allowing for journalistic hyperbole it is worth quoting the following subsequent paragraph in full:

Andrew will be 21 next month, but has no plans for a party because he has no friends to invite ... they may read for half an hour or so until they get tired, or listen to music which will be barely audible to most people—their ears are particularly sensitive. Sheena may attempt to write a postcard to a penfriend and then she will have to rest. Jamie, 12, may venture out into the garden to look at the pond for 10 minutes but will then sleep for hours.

Somatization in the 20th century

The world of fiction

To introduce this second section, I would like to use two fictional examples to set the scene for the remainder of the paper. The device of fiction is particularly useful, since it can portray the symbolic elements of CFS or ME without being encumbered by facts—fiction can deal entirely in perception.

The most widely viewed fictional portrayal of CFS came from the United States when the illness was featured in a popular television series, "Golden Girls", in September 1989. A full review was published in the *CFIDS Chronicle* (summer/fall, 1989). According to the review it was a major development because it was the first time CFS had featured in an "extensive national prime time program". It was as a "landmark event".

In "Golden Girls" we first see the image of the "bad" doctor, who is rude to the patient, keeps her waiting, finds all her tests normal and tells her to pull herself together, before finally diagnosing her condition as one of loneliness—a functional or mental problem. Another neurologist pronounces her well and recommends that she see a psychiatrist. However, she has already done so and produces two letters saying her problems are physi-

cal, not psychological (this off-stage role, the psychiatrist who pronounces the patient normal, is one of the few positive roles accorded psychiatry¹). In an ironic reversal of the usual script, it is the neurologist who pronounces the verdict that "what the hell do they know—psychiatry's not a science". The second neurologist is even more dismissive than the first—Dorothy's problems are her growing old, and they would be cured by taking a cruise or changing the color of her hair.

In the second episode we meet the other side of the coin—described in a review as "every CFIDS patient's wildest dream come true"—a good doctor who refers her to a virologist, after assuring her she is sane. The virologist tells her she has CFS and that he "believes she is really sick and not merely depressed". Dorothy observes with relief "I really have something real". In the final scene Dorothy celebrates that her disease finally has a name—even though the doctor told her he could do nothing about it! The denouement is reached when the previous unsympathetic neurologist enters the same restaurant and she is able to voice all her resentment towards him. The favorable reaction to these episodes should be contrasted with the opposite reaction to a single unflattering reference to "ME" in the British Television series "East Enders", which led to the British Broadcasting Company issuing an apology.

A second fictional treatment of ME occurs in Clare Francis' recent ecological thriller, *Requiem* (90). Clare Francis, round the world yachtswoman and best selling author, is also well known as an ME sufferer and founder of the campaigning group "Action on ME". Although *Requiem* is not ostensibly about ME, it is dedicated to fellow sufferers, and reviewers were not slow to grasp the connection. One scene in particular exemplifies some of the sophisticated dynamics at the heart of ME. The main character's wife has developed a mysterious but devastating illness, a combination of ME, multiple allergy and chemical sensitivity. Eventually the man and his wife consult a medical toxicologist, who, like the neurologist in "Golden Girls", exemplifies all that is viewed as bad in the medical profession. Of course the tests are all normal, so the consultant turns to the psychiatrist, who is present in the same room (possible in fiction). This psychiatrist is no longer the old image of the Viennese psychoanalyst with his couch, attempting

to explain symptoms in terms of previous psychic trauma. Instead he is much of his times. This psychiatrist, very English, is well dressed and articulate. He takes a biopsychosocial model, explaining that all illnesses have both physical and psychological components, and invokes the example of chronic pain. He explains antidepressants in biochemical terms and uses phrases such as cognitive therapy.

But it does not work. Throughout the psychiatrist is apologetic, as if he does not believe his own explanations. The husband sees it as a way of making the psychological acceptable, and only confirms his fears. His wife was perfectly healthy before. Why should she have succumbed? The husband accepts the psychiatrist's explanation that stress can affect the immune system, but she wasn't stressed. He rejects the psychiatrist, while his wife rejects all doctors.

The psychiatrist appears once more. The wife has died in odd circumstances, and the psychiatrist is called to the Coroner's Court. Now the psychiatrist is able to twist all the previous evidence into the diagnosis of depression. The psychiatrist was worried about the wife's mental state, felt her to be depressed, argued against her discharge, and now insinuates that she killed herself. However, the Coroner delivers an open verdict. The chapter concludes with the husband's relief on the verdict. He feels that it was his wife on trial and that she has only now been acquitted. "The charge—mental instability".

"Golden Girls" and *Requiem* provide several examples of what I identify as the crucial themes of the social history of CFIDS/ME: (i) the reaction to a psychiatric diagnosis, (ii) the imputation of malingering, (iii) the need for a name, (iv) the absence of validating evidence, such as physical signs or tests, (v) the newness of the disease, (vi) the disease as a medical mystery or controversy, and (vii) the need for political action.

Chronic fatigue, somatization and the fear of mental illness

Why do patients with chronic fatigue somatize? First the results of primary care studies show that most do not. Somatization in the context of chronic fatigue only becomes an issue when one moves into the area of specialist care.

¹A frequent figure in the literature is the good psychiatrist who declares the sufferer psychologically normal. For example, one non fictional neurologist, unable to find anything physically wrong with a sufferer, became "beside himself with wrath, and suggested that I see a psychiatrist ... The psychiatrist told me that I was no madder than the rest of the population and sent me back to the by now quivering and speechless neurologist" (Monckton C. The ME Generation. Evening Standard, July 25th 1988). It is often only by acting in this fashion that psychiatrists receive favorable mention in the CFS literature, even from professionals. Pleas are often made for a multidisciplinary approach to CFS, although this rarely extends to psychiatrists. One exception was provided by an epidemiologist who told a journalist that "there is need for multidisciplinary approaches. We are talking about a disease, the investigation of which requires epidemiologists, virologists, psychologists". However, "Why the psychologist? To prove you're not all crazy" (Grufferman, cited in Feiden, 1990).

For those that do, the answer is not hard to find. I have already drawn attention to the Manchester study finding that somatization in primary care is associated with more unsympathetic attitudes towards mental distress (31). This is particularly true of the hot house atmosphere of ME or CFIDS.

Underneath the ME-CFIDS movement (and often on the surface!) is a strong and passionate antipsychiatry rhetoric. This rhetoric has not arisen as a result of the interest shown by psychiatrists in the topic (few have much knowledge of, or contact with, sufferers). The first wave of publicity surrounding ME in this country already showed the suspicion of psychological medicine that would become its hallmark. This publicity led to the formation of the most radical of the patient's organizations in this country, the ME Action Campaign. In its first newsletter Claire Francis, the President of the Campaign and probably the most famous sufferer in Great Britain, wrote "psychiatry is the dustbin of the medical profession" (91).

At the heart of the ME-CFIDS movement is the rejection of any form of psychological causation or treatment. Being referred to a psychiatrist is "being black-balled" (92), being on trial (93) or "imprisoned for a crime I didn't do" (94). Courtroom analogies are apt, since the atmosphere surrounding the condition is now an adversary one, accompanied by a rhetoric of struggle and injustice—a typical headline is "Justice for the neglected and maligned sufferers of ME" (95). Paul Cheney, one of the most prominent doctors on the CFIDS scene in the United States says, that "we who believe that this is a real disease are almost in a death grip with those forces who would stifle debate, trivialize this problem, and banish patients who suffer from it beyond the edges of traditional medicine" (96). A leading ME campaigner compared the plight of ME sufferers in Great Britain to the 27 years incarceration of Nelson Mandela and the ordeal of the Beirut hostages (97). Such analogies run the risk of over statement, but attest to the passions involved. Others speak of bitterness, anger, and hate. The accusation is not just that the sufferer is guilty of being depressed, or of having a psychiatric disorder, but of not being ill at all—of being a malingerer, of having an imaginary disease. It would be tedious to list the number of variations on the theme of "ME exists. It is not a psychological illness" (98) that can be found in the media and popular literature.

External attribution, implicit in the process of somatization, protects the patient from the stigma of being labeled psychiatrically disordered (99). Viruses are the most common attribution encountered in the specialist setting—partly because they are so common, partly because some infections are indeed associated with increased risk (100), but also because "the victim of a germ infection is ... blameless" (101). In the context of CFS

"to attribute the continuing symptoms to persistence of a 'physical' disease is a mechanism that carries the least threat to a person's self esteem" (102). The reviewer of one self-help book for a British newspaper wrote "an infection is respectable. It has none of the stigma of a psychologically induced illness, which implies weakness or lack of moral fibre" (103). "Patients who suffer from unrelenting fatigue fear they have a serious, occult medical problem and worry that people will think they had a mental problem or a blameworthy characterological weakness of will" (104). One sufferer put it at its simplest—"increasingly convinced that I had contracted some kind of 'bug' that was steadily destroying my health, I determined to identify and eliminate the evil foreign agent" (105).

In a previous paper I discussed how the popular literature on ME was suffused with the underlying message that psychological disorders in general, and depression in particular, were diagnoses to be avoided (4). Sometimes such conditions are seen as unreal or nonexistent—"all in the mind". At other times they are viewed as a moral judgment on the sufferer—something reflecting qualities such as lack of effort, poor motivation, and so on. Hence when a chronically fatigued patient is diagnosed as depressed, it can be equated with the message that the sufferer is not really ill, is malingering, is shirking their duties, and so on.

Regrettably, such impressions are by no means inaccurate. Such perceptions, which to a practicing psychiatrist seem ill informed and naive, are all too often shared by the medical profession. Some doctors do equate psychological disorder with unreal disorder. A consultant physician who specializes in the disorder told a newspaper that "People with PVFS often have to put up with a lot of disbelief—there were many doctors who diagnosed this as a psychiatric disorder although on the whole it is taken much more seriously now" (106). A doctor agreed that it is important that psychiatric patients be separated from ME because "some neurotic patients devalue the tales of genuine sufferers" (107). Another is quoted as telling a medical conference that "ME is an imaginary disease ... for which the best treatment is psychiatric" (108).

Writing about the rise, and subsequent fall, of psychosomatic explanations for ulcerative colitis, Aronowitz & Spiro (109) noted that an uncomfortable attribute of the psychosomatic concept is the potential it has for blaming the patient for the disease. According to anthropologist Norma Ware, who has conducted a study of CFIDS patients in Boston, it "places the responsibility for illness on the shoulders of patients and, consequently, increases their suffering" (74). A recent article on chronic Lyme disease talked about the difficulties faced by patients in their dealing with doctors—"some were even considered malingerers. Many were referred

to psychiatrists when their medical physicians lost faith in the validity of their patients' complaints" (110). Doctors thus share many of the prejudices of the ME-CFIDS sufferer—psychiatrists treat imaginary, malingered or nonexistent diseases. Thus a social historian might conclude that, while our Freudian century has seen the general, and indeed uncritical, acceptance of psychological explanations for health and disease, the story of ME, CFIDS and MCS shows the limitations of such claims.

The consequences of this lack of validation are many and grievous. There is little doubt that those who later receive a diagnosis of ME-CFIDS recall the previous lack of a diagnosis which they could accept as a source of distress and react with relief when the label of ME is given (111), even if they are also told that the disorder is untreatable. "The day Nomi Antelman learned she had an incurable disease, she rejoiced" (112). Another sufferer was first told she had a virus that would go away. Later this optimistic prognosis was altered, as she learned she had ME, which would, in her own words, take away her independence, regress her to a being a baby and in which progress would be minimal. She "felt fantastic" (1). For another, even if the prognosis was uncertain "the mental relief was phenomenal" (113).

Psychological diagnoses are unacceptable for a variety of reasons, both emotional and practical. One sufferer was refused sickness insurance benefits because his policy excluded depression, of which he had a past history. His claim to be now suffering from ME was rejected, although he was informed that this decision would be changed if a test for ME were to be developed and he tested positive (114). Hence sufferers cannot afford to be depressed, both symbolically and literally.

CFIDS-ME began with the rejection of psychiatry. Over the years the reputation of psychiatry within ME circles has not increased. A few months ago, in response to a fairly standard piece of newspaper misreporting, columnist and critic Alison Pearson wrote that because doctors do not know the cause of ME they "decide it doesn't exist. Far less embarrassing to say people presenting the symptoms are nutters than to admit to being baffled yourself". She concluded that "one day ME will have a satisfactory medical definition. In the meantime we can always hope that the 150 psychiatrists contact a really vicious fictional virus" (115). In the same month the press officer for one self-help group wrote that a psychological explanation for CFS was "demonizing the patient" (98), echoing numerous similar letters to newspapers and magazines in the last few years. The intensity of such reactions led one medical journalist to describe the actions of aficionados of ME as "attempting to censure the encephalomyelitically incorrect" (116).

ME-CFIDS as a political movement.

"Censuring the encephalomyelitically incorrect" (116) introduces another strand, the rise of politically active patient groups. The extraordinary prominence accorded ME or CFIDS, and the speed with which it occurred, owes much to the sufferers themselves. One book began "Without the commitment of a loyal cadre of patient activists, it is uncertain when CFS ... would have gained the attention of the national press and the scientific community" (81). Patient support groups soon noted that the absence of medical research was one obstacle to the legitimization of CFS, and they used their lobbying skills to reverse this situation. In 1990 the influential *Washington Post* columnist Jack Anderson praised the crucial role of "constant grass roots action" and "heavy lobbying" that forced doctors to carry out research on CFS. Unlike most medical research, the impact and benefit of CFS research accrue before any results appear. The Center for Disease Epidemiological Study (117), described by the *Wall Street Journal* as having "one major goal ... to replicate experiments showing that people with the condition suffer from immune system irregularities and not psychiatric troubles" (118), gave "an official stamp of legitimacy to the syndrome" before a single patient was seen. When studies do report physical abnormalities the results have a political significance—recent research on immune abnormalities was further described by the *Wall Street Journal* as lending credibility to CFIDS patients in their struggle to confront reluctant politicians (118). In the United Kingdom a series of Parliamentary questions has urged the Department of Health to "fund research into physical causes ... of ME". Not all research is helpful, since if funding is given to research seen as psychiatric, then considerable harm is seen to be done. In consequence some activists lobby (sometimes using such devices as anonymous denunciations and allegations) medical research charities, government institutions and medical journals to prevent the funding, execution and publication of research felt to be inimical to the cause—I, and many others, have had experience with such occurrences.

The arrival of patient activism is not, of course, unique to ME-CFIDS and must be placed within the context of the rise of consumerism within medicine during the 1980s. One marker of this wider change in the relationship between patients and modern medicine is a general distrust of medical care observed by many (119, 120). The first editorial produced by the most radical of the patient's organizations active in this country noted that "doctors know all the answer ... to maintain their mystique and authority, doctors have had to rely increasingly on heavy drugs and less and less on listening to their patients" (91), often allied with alternative or "green" beliefs (vide infra). As historian Edward Shorter notes, physicians are frequently described as "heartless

ignoramuses, blinkered in the cul-de-sac of mainline medicine" (121). The first contemporary "first person" account of ME that I have been able to trace already called on sufferers to dispense with the need for doctors and find their own solutions. "We must keep our friends among gentle people. Not among the powerful. Why delude ourselves it was possible to have an honest relationship with such people?" (122).

Ironically the same self-help literature that is so critical of the medical profession also espouses a touching faith in the ultimate success of medical science in unlocking the enigma of CFS. The medical literature is followed in detail (all the self-help groups produce regular updates of medical research). A physician supporter of the illness commented that "it is ironic that millions of patients have learned to analyze the significance of medically arcane findings about natural killer cells and interleukin-2, while many physicians are still debating whether the illness exists at all" (Bell, quoted in 81). Papers are analyzed less on their merit than on how they help "the cause" (17). One of the British patient organizations announces the best and worst papers of the year—perhaps unsurprisingly a paper from the Institute of Psychiatry was the worst!

The self-help literature combines both a general suspicion of modern medicine (regarded as impersonal, reliant on tests and distant from the patient) with a belief that medicine possesses the answer, and that a test will be found. The relationship between ME-CFIDS and the medical profession is paradoxical, since one can see both "a vigorous attack on medical authority and the desire for its approval" (17).

The rise of ME-CFIDS, with its unique political dimension, is reflected in the changing nature of the medical consultation. It is this new aspect of the medical consultation that can so easily catch doctors off guard, and lead to mutual antagonism between patient and physician. Patients have experienced chronic fatigue since medical records began. I have already indicated that the labels of ME or CFIDS may be new, but syndromes of chronic exhaustion are not. What is new is that some modern patients come to the doctor not with symptoms, but with a diagnosis already made. "What is your position or view on ME?" is not an uncommon start to a consultation.

The British self-help organizations maintain lists of doctors who are known to be sympathetic to the cause, their American counterparts have "Physician Rolls of Honor". There is a vast amount of self-help literature on what to do if your doctor seems ill informed on the subject—advice ranging from presenting him or her with the latest research, changing doctors or making a complaint. Shorter suggests it is this process, the fixity of belief and the rise of consumerism, which gives ME its peculiar flavor (121). Whereas in the past sufferers were open to medical counter suggestion, this is no longer possible—the

balance of power between professional and lay models of illness is changing, no matter how much the former resist the change (123).

At this point it is worth emphasizing that, despite their prominence, the labels of CFIDS and ME are not common. Few of those in primary care with chronic fatigue consider they have ME—of the order of 1% (66). In our primary care survey only a third of those who fulfilled the most rigorous criteria for CFS thought that their problem was ME or CFIDS or another synonym, and only 10% were members of a self-help group. In contrast virtually every one referred to our specialist clinic already attributes their illness to CFS, and a third are members of one of the self-help groups (67).

Chronic fatigue syndrome is a 20th century disease

At an early stage CFS was characterized as a new disease. One of the first papers on sporadic CFS began "A 'new disease' is spreading in the civilized world" (124) incidentally also reinforcing the message that CFS is restricted to Western settings. By 1987 "the diagnosis of the year" was chronic Epstein-Barr virus (125); the following year and across the Atlantic "there is no doubt that the illness of the year is ME" (19). In order to maintain this "newness" it is necessary to update the period, so that from the "Malaise of the 80s" (126), CFS has become the "disease of the 90s" (127, 128) and even "disease of the fast paced 21st century" (129). The single most common headline chosen for newspaper articles on ME is "The ME Generation".

If this is a new disease, then some new cause must be found to explain its sudden appearance. Another article entitled "The ME Generation" opened with the words "What is modern life doing to us?" (130). The most frequent answer to that question invokes the concept of the immune system in trouble, weakening under the assault of late 20th century life. "ME is very much a disease of our time—an attack on the immune system exacerbated by stress, pressure and the demands of twentieth century life" (131).

There is scientific literature on immune dysfunction in CFS, but it is a confused, inconsistent and unclear picture, and there is little evidence of any relevant immune deficiency (22). In contrast the popular literature on ME-CFIDS makes much of the immune system, which provides a link with most of the other 20th century diseases. "Weakening" of the immune system is at the heart of the popular models of CFIDS—this occurrence can be the result of viral infections, nutritional deficiencies, chemicals, candida, and so on (132). Indeed, one of the few ways the popular literature acknowledges a role for psychological factors and even depression is via their alleged effect on the immune system.

As a result of this onslaught ME is "an overload disease unique to this century" (108), since "the body can tolerate so much stress from whatever source, but

at some point the bucket gets full" (133). One frequently encountered contemporary source of this "overload" is the alleged overprescription of antibiotics causing altered immunity. (See references 130 and 134 for example.) Another regular culprit is immunization. Claire Francis, whom we have already encountered as the best known ME sufferer in the United Kingdom, traces her illness to childhood when she "was given her first polio vaccine injection" from which "she never really recovered" (135). On another occasion she has labeled ME "an immune dysfunction disease, possibly caused by pollution" (136). From whatever source the resulting strain on the immune system destroys the ability to resist infections such as viruses (hence post viral fatigue) or candida, and also food allergies and intolerances that have previously been "hidden" (108). Another "overload" causing ME is the deteriorating quality of the air we breathe, the water we drink, and the food we eat (80), all of them contributing to our "toxic life-style" (137).

David Dowson, a leading alternative medicine practitioner, gave his explanation of ME to London's evening paper (138). The virus leads to depression of the immune system. He used a frequent immune analogy in which the body is a boat with a hole in its side. The immune system is trying to pump the water out, but the boat, overloaded with toxic products, continues to sink. Complementary medicine removes these loads, of which Dr Dowson identified seven. These are persistent infection, candida, magnesium deficiency, electromagnetic radiation, liver toxicity (due to solvents or pesticides) and depression. Lest anyone be alarmed by the last mentioned, "depression", and he is adamant about this, "is the *result* rather than the cause" (*italics in original*).

One can already see how these explanations are not mutually exclusive—indeed, the opposite is true. "Never in history have people been exposed to greater assaults on their bodies by environmental pollution. Food additives and drugs may also harm the body and adversely affect the immune system. Certain doctors even claim that long term antibiotics depress the immune system" (16).

What are the cultural sources of these explanations? HIV (human immunodeficiency virus) is one. "Who had heard of AIDS or ME ... 10 years ago?" (134). Some of the popular literature makes explicit a link between CFS and AIDS. CFS is "AIDS minor" or a "sister illness to AIDS" (139). According to the President of the CFIDS Association in the United States "you would have to be blind not to make the connection" (Marc Iverson, cited in reference 139). A complete issue of a New York magazine was devoted to making the links between AIDS and CFIDS—CFS was "the bottom of the AIDS iceberg". If that was so, then why did the medical "establishment" persist in denying this link? The answer was not just a cover up, but "the medical cover up of the century" (140).

"If it weren't for the emergence of AIDS, chronic fatigue syndrome would be the disease of the decade" (141), and, just in case we have failed to get the message, we are told that "Doctors at Harvard Medical School have gone so far as to question whether AIDS is actually a chronic and fatal form of ME" (142). Thus when it was announced that researchers had identified a retrovirus in patients with CFS (143) the storm of publicity was not entirely unexpected. The subsequent failure of other researchers (144, 145) to confirm this finding went largely unnoticed.

I have already noted how the term CFIDS (chronic fatigue and immune deficiency syndrome) has been adopted by the largest patient organization in the United States. This adaption has led to the ironic situation of a scientific paper being published under the title of CFIDS in which no patient had any observed immune deficiency (146). Some of the decision to adopt this name has been a conscious and stated attempt to draw upon the awareness, publicity, and political activism that surrounds AIDS. Another reason lies in the popular grasp of the HIV metaphor—the invisible but deadly virus destroying the immune system. Abbey & Garfinkel (147) note that "CFS built upon two of the most interesting themes in modern medicine, infectious disease and immunology". The result of the HIV epidemic is that the concept of a mysterious yet deadly virus that infects the immune system is now firmly in the popular consciousness, and it provides an apparently scientific framework for what are other concerns.

Another source for the assault on the immune system comes from contemporary views on internal purity and pollution. These concerns appear in the literature linking candida infection of the gut, altered immunity and CFIDS. The latter may be due to a "persistent and slight infection of intestines" (148). The candida infection itself, or the "toxins" it produces, or even simply the products of digestion, leak into the body and cause auto-intoxication (149), affecting, inevitably, the immune system. Thus "yeast toxins weaken your immune system" (132), but when your immune system is weak you develop yeast infections, illustrating the essential circularity of these models. For the ME patient candida is one more addition to the climate of fear—after all, the infection spreads to the "digestive tract, the lungs, the brain, the toenails. It was feasting on me" (138). In consequence colonic lavage is now a common treatment for ME in the United Kingdom, because it "is the best way to flush viruses out of the system" (19).

Chronic fatigue syndrome is not a 20th century illness

The range of etiologies visible in the popular literature on CFIDS and ME thus superficially reflect a variety of contemporary concerns—but just how contemporary are they? The answer is not very. Even the claim to be

modern is far from modern. The parent of CFS, neurasthenia, was also a "disease of our time". The phrase "disease of the century" was frequently used in the context of neurasthenia (150–152), also described as "a bitter comment on 19th century life" (153). Neurasthenia too was held to becoming more common, and to be a disease of civilization, often expressed in racial tones that would be impossible today.

What about etiologies? The modern popular explanations of "overload" from viruses, pollution, and stress all have strong resonances with the mechanisms and causes advanced for neurasthenia during the last century (2, 3, 147). Neurasthenia was seen as an exhaustion of the supply of energy within the central nervous system, causing "cortical weakness" (154) or "cortical irritability" (155). The causes were either local to the brain—a failure of cerebral blood flow (claims of which currently dominate media coverage on ME 100 years later) or a deficiency in energy sources, or they arise from distant sources. The increased demands on the system could be the result of toxic, metabolic, or infective insults. The idea that neurasthenia was the result of acute or chronic infection was the subject of numerous papers. (See reference 156.)

Even the idea that we are slowly poisoning our bodies from our intestines is far from new. As Shorter has pointed out, thousands of women lost various intestinal organs during the vogue of autointoxication and focal infection. The former idea that the products of the colon can leak into the blood stream causing toxic symptoms was part of Victorian medical culture. Guy's Hospital surgeon Willie Lane made his reputation removing such colons at the start of this century (157), ending his career as a surgical Baronet.

Colonic lavage and autointoxication is one the few examples in which the historical continuity so visible in the ME literature is formally acknowledged—Willie Lane's 1920 *Lancet* paper was reprinted in detail in one of the first publications of the ME Action Campaign, where it was called the "ME Hypothesis". Nevertheless, few of those modern ME sufferers who currently undergo colonic lavage will be aware of the historical basis of the treatment.

Overload was thus the mechanism that the Victorians most commonly invoked to explain neurasthenia—but the cause of this overload was variously attributed to the deteriorating quality of life, to new organisms, new stresses, new ways of working, the decline of leisure and the increasingly decadent and acquisitive nature of society.

I have shown how the concept of ME arising from overwork either at the start of illness, or alternatively excessive activity during illness, is central to the modern popular view of etiology. But overwork stress and strain is not unique to our time either. The neurasthenia experts were equally preoccupied with the deleterious consequences of overwork, which they too blamed on a variety of contemporary changes in society. Medical authorities viewed emotional strain and overwork, the agent by

which the nervous system became exhausted (which could be purely physical, mental or a mixture of both), as the inevitable consequence of a host of new social ills. Even before the introduction of neurasthenia, a variety of medical authorities was writing about the dangers of overwork. (See references 2 and 158.) George Beard, the father of neurasthenia, with his facility for similes, joined together a number of discontents into an explanatory model for his disease. For example, Beard, and many others, ascribed neurasthenia to the new, acquisitive nature of society, singling out, in a famous phrase, wireless telegraphy, science, steam power, newspapers and the education of women, summed up as "modern civilization" (159). Much of this was conveyed by similes drawn from business life (the exhausted businessman overdrawn on his nervous capital, overspent nervous resources and others) or from technology (the flat battery, the battery that could not give its charge). Mental strain was similarly implicated—in France public inquiries and commissions considered the problem of neurasthenic children, blamed on the alleged excessive mental demands ("surmenage") made by the new educational system (158); similar views could be found on the other side of the Atlantic. (See eg, reference 160 and others.)

The dramatic rise of neurasthenia seemed to confirm its status as a disease of modern civilization—indeed, its increasing frequency was "as certain as the fact of civilization itself" (160). Just as CFS today is the price paid for pollution, exhaust fumes, food additives, aerosols, antibiotics and so on, neurasthenia was the price to be paid for industrialization, the rise of capitalism, and the consequent strain to which the business and professional classes were exposed (161).

Chronic fatigue syndrome and other modern illness

Such views also link CFS to the other illnesses considered in the symposium at which this paper was presented. All are characterized by multiple unexplained syndromes. Professional studies frequently refer to the overlap between CFS and sick building syndrome (162, 163), candida (164), multiple chemical sensitivity (165), and between each other. If one ignores the scientific aridity of consensus conferences and operational criteria and moves into the world of patient literature, then the similarities are overwhelming. The list of symptoms held to be typical of CFS reappears in texts on yeast infections, food allergies, electromagnetic sensitivity, hypoglycemia, sick building syndrome, dental amalgam, chemical sensitivity, and others. The explanations are similar and overlap. CFS causes candida, candida is a cause of CFS. William Crook sold nearly a million copies of his book *The Yeast Connection* (166). In 1992 he then published *Chronic Fatigue Syndrome and the Yeast Connection* (132). Dental amalgam disease is due to the mysterious toxic properties of mercury amalgam, leak-

ing into our bodies and poisoning our immune system. It is a cause of CFS—some of my patients have had all their dental fillings removed at considerable pain and expense but for little benefit. Shorter has already traced the history of multiple chemical sensitivity, which depends upon the concept of immune system dysfunction, as does food allergy. Few of the popular self-helps on the subject fail to include some mention of themes such as food allergy, environmental sensitivity, hypoglycemia, candida, and so on (80, 82, 167, 168). Similar preoccupations are a regular theme of the magazines and newsletters of the patient groups. These are seen partly as etiologic factors for CFS, partly as overlapping diagnoses, and partly as complications.

Nowhere is this clearer than in the overlap between ME-CFIDS and allergy. ME is a form of severe allergy for many, and most self-help books include large sections on allergy. One sufferer from ME relates how he became a total allergic—"this is a slightly dramatic state because if anyone walked into our house wearing after shave, bang, I'd pass out" (97). A doctor with ME proved to be allergic to over 100 different foods (169). A young farmer with ME was tested by a clinical ecologist and found to be "seriously allergic" to every one of a 120 different substances. He subsequently committed suicide.

The logical conclusion of such explanatory models is to combine them into what might almost be called a "General Theory". The New York magazine *Christopher Street* has published a series of articles under the banner "The Age of Chronic Immune Dysfunction". CFS, AIDS and multiple chemical sensitivity are part of a "unified syndrome of immune dysregulation" (170). This article takes the familiar line of that these new illnesses are "being noted in ever greater numbers around the world, but particularly so in the 'civilized' First World". From this the author describes a syndrome in which the immune system is both regulated "up" and "down". The key elements responsible include the Western diet, which consists of too many additives and not enough vitamins, the use of antibiotics leading to candida overgrowth, virtually any infective agent, metal toxicity from pesticides, pollution and insecticides, mercury amalgam in teeth, immunization, radiation including electromagnetic emissions from power lines but also computers, word processors, and hair dryers and the ubiquitous stress (170). A popular magazine echoed these risk factors, as well as introducing many more, in a recent feature on the hazards of daily life (137); it included over 40 different suggestions about how to reduce this risk, such as placing the television against an outside wall, avoiding barbecues, not walking near the curb, avoiding canned food, and not talking for hours on a mobile phone. In another typical article the author explained how viruses alter the immune system and make the body susceptible to the effects of bacteria, toxins, candida, chemicals, stress, and

so on (171). The logical conclusion of this general theory is to see ME or CFIDS as a "signal of the sickness of the planet" (172) hence the solution can be nothing less than "improving the total environment" (173).

I conclude this section by observing that some aspects of the popular representations of ME-CFS-CFIDS are better understood not as the result of any unique or specific aspect of late 20th century life, but as a "fin de siècle" illness. Its modernity can best be understood as another manifestation of the perennial theme linking changes in society with unwelcome illness—the claims made linking various contemporary factors with the illness are thus better understood in metaphorical rather than literal terms.

Chronic fatigue syndrome as narrative

In this section I argue that explanations and descriptions of CFIDS-ME are not to be taken as literal truths, but as metaphorical descriptions. The use of metaphors is inescapable—one sufferer, himself a priest, admitted that ME is "hard to describe in neat non-metaphorical language" (174). Take the following example: Another sufferer related the following story. She "was married to an actor who was often away on tour making the relationship very difficult and she was left to cope with a toddler, breast-feed a young baby and run a house". Looking back she told the journalist that all the of these pressures left her "unable to fight off the viral infection which gave her ME" (175). Another sufferer who worked as a publisher described her life before ME as living a constant battle against stress, feeling a great deal of anxiety, and suffering from a range of nervous symptoms (176). However, when she finally became ill, it was not a simple continuation of these problems, but a new virus which "set in" to her body, and led to ME. The previous anxiety had acted to weaken her immune system.

One can see these and many other stories as telling a narrative. Certainly there is a role for stress, but not as a cause of psychological disorder, but as weakening the immune system. In Norma Ware's series the most common explanation provided by sufferers was of stress weakening the immune system and leaving it vulnerable to a virus, the final cause of CFIDS (74). The attack of the virus presumably signals the point at which the previous disorder, manifested as symptoms, gives way to disability and the inability to further maintain such roles as work or home. Experiencing stress is acceptable—succumbing to it is not, and must be explained by a linking biological mechanism.

Some readers will immediately comment that the narratives are actually a literal account of the pathogenesis of illness. Certainly there is a rich literature on the links between mind, brain and immunity, but most observers would conclude that the literature is inconclusive and cannot be interpreted so literally. Instead I will argue that these stories show the immune system as a

narrative device, a cultural explanation, and a method of linking mind and body that preserves self-esteem.

CFS thus serves as a conduit for the expression of social concerns and social ills. Concerns about the quality of the environment become expressed as an assault on our immunity, concerns about diet reappear in theories of intestinal intoxication, concerns about the threat of HIV reappear as mysterious viruses also destroying our immune system, even concerns about the quality of education can be translated into the cognitive effects of CFS. Just as spontaneous hypoglycemia "more actively medicalizes and biologizes social issues than even orthodox medicine" (177), so does CFS.

Indeed, at the extremes of language CFS can assume metaphysical properties. CFS is "demonic" (81), a "devil illness" (178). It is a modern pestilence—"another illness that makes up part of the sign Jesus said would mark the last days" (16).

Chronic fatigue syndrome as parody

What has also emerged during this essay is the manner in which some writings on CFS provide a parody of the prevailing scientific discourse. This has been a theme since the time of neurasthenia. When Beard constructed his illness, he consciously drew on current scientific discourses. These included Marshall Hall's discovery of the spinal reflex arc, Edison's electricity and Du Bois Reymond's electrical nervous impulse, Spencer's Social Darwinism, and so on (179). Beard's skill lay in mixing scientific advances with social theory and moral exhortation, and constructing out of these sources a single disease entity, designed to appeal to many of the concerns of the age, but couched in what seemed acceptable scientific terminology. Beard's neurasthenia parodied the science of the day. Some of his contemporaries noted this and ridiculed him in consequence, but most accepted his writings at face value—neurasthenia was a modern problem understood using the most up-to-date scientific concepts available.

For example, it seemed logical that, if neurasthenia was due to overwork, then the solution was rest. Rest conserved energy, the quantity which neurasthenics lacked. This line of thinking was given the necessary scientific respectability by reference to the new laws of thermodynamics, and institutionalized in the rest cure. Now that nervous energy was being understood in electrophysiological terms, it seemed logical that energy could also be replaced by electrical methods. George Beard was as well known for his writings on the therapeutic uses of electricity as for those on neurasthenia. Few articles on neurasthenia failed to refer to galvanic or faradic treatment—several dealt with nothing else.

Once again electrical treatments and diagnoses flourish for ME. One sufferer is diagnosed by a "biotron"—a machine which "tests the flow of energy through the acupuncture points" (180). An English doctor uses "galvanic currents" in treatment, another uses faradism (181), while a

New Zealand doctor treats ME with electromagnetic therapy—"a small pad giving off a low electrical field on her back" (108). Beard's explanations would however now be seen as archaic—in order to appeal to the modern patient, the jargon must correspondingly keep up with the times. This stance can be illustrated by the story of one particular treatment device currently marketed for the treatment of ME in the United Kingdom. Several of my patients have appeared in the clinic wearing a small device clipped to their shirts, costing over GBP 100. Readers of an ME journal were told by one of the best known alternative medicine practitioners in Great Britain that the device begins by analyzing the subject's brain waves, which are recorded and displayed on a computer. "The device to detect these waves is in a small head set ... which sits on the head of the patient". The detector is a quartz crystal, and through it light is shone (182). A sufferer takes up the story—the therapeutic part of the device "emits pulses of magnetism which are picked up by the nerves in the skin", transmitted to the brain, where they "stimulate certain areas which recent research has shown do not function properly in ME patients".

This passage illustrates my point. The nonscientific reader is likely to be impressed by such phrases as a quartz crystal or laser. There is a reference to recent research about brain waves. All CFS patients complain bitterly of such symptoms as poor concentration, impaired memory and so on, so it seems plausible that "brain waves" do not function in ME. As everyone knows, sufferers also lack energy, so replacing the missing energy with magnetic energy does not seem far fetched. It did not seem far fetched to George Beard and legions of Victorian doctors who treated neurasthenics with galvanic, magnetic or electrical stimulation either. The neurophysiological researcher whose work was been parodied did find it far fetched, and he was moved to write in another patient's magazine that the "scientific" principles behind Novagen were "fallacious at every step"—indeed, he traced another source for the device—"Fans of Flash Gordon will recognize the influence of Dr. Zarkov here" (183). The Victorians would have recognized the central themes of lack of energy, and the need to replace this precious commodity from some source or other—what has altered is simply the language in which it is expressed. What has not altered is the way in which language is a representation of the medical science of the day. We are indeed, as a society, more concerned about health, but not necessarily more knowledgeable about health matters (184).

The practical consequences

Contrary to the oft expressed opinion, CFS and related disorders are not untreatable (24, 185, 186). The converse nihilistic attitude comes from both sides of the CFS controversy. Those who regard it as little more than a disguise for hysteria or work avoidance feel that such people are beyond help, while those devoted to the cause

feel their main job is one of support and loyalty. It remains true that perhaps the most common advice that patients receive from a variety of sources is to rest, avoid activity, and wait for nature to take its course. An American self-help book (81) heads a section with the title "Rest, Rest and More Rest", and discusses "aggressive rest therapy", as does an English self-help title (82). The following quote again serves as an illustration of the considerable amount of literature, although I have also chosen it because it is a direct, albeit inadvertent, quotation from George Beard, the founder of neurasthenia: "The treatment is rest, and plenty of it ... the sufferer should always treat her energy resources as if they were money in the bank and be careful not to overdraw" (187).

My colleagues and I have outlined elsewhere how it is difficult to rehabilitate patients with these syndromes if one has no understanding of the belief structures that underlie disability and the reasons that lie behind the choice of illness label. Unless and until such patients' beliefs are recognized, and the reasons why they are held are understood, progress will be slow, if it occurs at all. The number and range of symptoms, the role of avoidance behavior, the strength of attributions, the role of physiological disturbances, and the nature of personality may all need to be appreciated before any rehabilitation program is embarked on (3, 188–190). With that background, management for the majority of sufferers is reasonably straightforward, and certainly rewarding. However, subjects who overlap with somatization disorder in terms of operational criteria, and MCS in terms of attribution, present a far more difficult, and sometimes insuperable, challenge (191, 192).

Concluding remarks

Understanding the legacy and consequences of somatization in the late 20th century is relevant, not only to the many clinicians who work in this area (and there are few general physicians who do not), but also to all those who are interested in the social and cultural history of medicine. In this essay I have attempted to use the example of CFS in its popular idiom of ME and CFIDS to draw attention to several relevant themes. These have included the modern preoccupation with the immune system, itself linked to the appearance of HIV, the belief that this system is being compromised by various features of contemporary life, the concept of "overload", the themes of toxicity and purity, the general increasing fascination with medicine, the increased promise of medical science, but also the reaction against modern medical science and the rise in medical consumerism. I have also shown how the genuine fear and stigma of mental illness and the need for explanations that are both protective of self-esteem and in keeping with modern views on sickness and health are also important. I

have used the example of CFS because it is the area in which I work, but I anticipate that others will be able to discern many of the same themes when considering other conditions that are also the subject of the symposium at which this paper was presented.

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