Feminism, Autonomic Imbalance, and Chronic Fatigue Syndrome

By Jens Wilkinson

"Women with apparently unexplained disorders are unfortunate individuals of the same gender, lumped together because medical theory and practice do not understand the mechanisms of their suffering." -Kirsti Malterud, MD, PhD (Fam Med 2000;32(9):603-11.)

Throughout history, women seem to have been inordinately stricken by what are called "mystery illnesses," or sometimes "phantom illnesses." There is a medical dimension to this problem, of course, but there are also deep social implications. We can gain some insight into these implications by examining two related "phantom illnesses" -- autonomic imbalance, and chronic fatigue syndrome.

Chronic fatigue syndrome, more popularly known as CFS, is a condition that is still only poorly understood.

However, it has become a major social problem in the United States. I first began thinking about the connection between it and feminism because where I live, in Japan, we don't have chronic fatigue syndrome. Or to put it more precisely, we don't have the diagnosis. Needless to say, there are tons of people with the wide-ranging symptoms of CFS ξ such as fatigue, dizziness, palpitations, tremors, insomnia, chronic diarrhea, muscle pain, etc. In fact, chronic fatigue itself may be more common here. One Japanese researcher, quoted in an article published in the New York Times, said that perhaps one third of the workforce here suffers from long-term fatigue.

The only thing that is different is the fact that these patients are not given the diagnosis of CFS. Instead, they are said to have an "autonomic imbalance" -- or in Japanese, "jiritsu shinkei shitchosho."

What, then, do I mean by linking feminism to autonomic imbalance, and CFS? It's not that feminists get them, though they are overwhelmingly diseases of women (it is generally said that 90% of patients are female). What I mean to explore is the possibility that the diagnosis itself is in a sense deeply related to the discourse of feminism.

The Mystery of CFS

One thing to understand from the beginning is that, at least at the present, CFS is always a "diagnosis of exclusion." What this means is that it is given to patients who have certain symptoms, such as chronic fatigue, for whom the doctor cannot find an obvious cause.
The criteria used by the U.S. Centers for Disease Control is that a patient must fulfill two criteria.

"1. Have severe chronic fatigue of six months or longer duration with other known medical conditions excluded by clinical diagnosis, and;

2. Concurrently have four or more of the following symptoms: substantial impairment in short-term memory or concentration, sore throat, tender lymph nodes, muscle pain, multi-joint pain without swelling or redness, headaches of a new type, pattern or severity, unrefreshing sleep, and post-exertional malaise lasting more than 24 hours."

The reason for this somewhat perplexing diagnosis is that there is no test for CFS. In fact, nobody really understands the cause, hence nobody knows how to make a test to determine if a person has it or not. There are, yes, diagnostic tests that can be used, but they are tests of symptoms rather than determinants of some fundamental abnormality that is specific to the illness.

This quote from The Economist, from 1999, illustrates something of the nature of the disease. "A mysterious epidemic spread through the Los Angeles County Hospital, in California, in 1934. Nurses and doctors succumbed to a strange mix of fatigue, muscle pain and emotional distress. The first suspect was polio ξ the symptoms were similar, and fear of the disease was rampant at the time. Yet tests for polio revealed nothing and, bizarrely, the hospital1s patients remained unaffected. A similar pattern of events occurred in 1955, at the Royal Free Hospital in London. Again, patients were untouched. And in both cases, most of those who succumbed were women."

Returning to the theme, then, the truth is that nobody really knows if CFS is really a new syndrome. In fact, women have apparently always been affected by similar ailments, but in the past they were not taken seriously. The problem was once known generally as "hysteria." Freud used the term neurosis, and other terms have been used in the intervening century include "neurasthenia" (meaning nervous weakness, essentially). In general, the (mostly) women who suffered from such disorders were given psychiatric diagnoses, and the treatments ξ principally, rest -- were consistent with these diagnoses.

Nobody really understands why these diseases are so much more prevalent among women than men. One theory, that seems most popular in Japan, is that women are under greater social stress, and hence become ill more frequently than men. This is in a sense a continuation of the hysteria idea, except that instead of saying the patient is susceptible to stress, it shifts the blame to society. However, it is still essentially a continuation of the idea that "It1s all in your head."

Another idea, that holds some weight, is that the prevalence may actually be fairly equal, but that men tend to "self-medicate" with alcohol, instead of visiting the doctor. In this case, there might be a difference not in the disease but in the recognition of it.

Finally, there is a hypothesis that there is some biological difference that leads to the bias in prevalence. Proponents of this idea can point to the fact that there is a certain class of diseases, which are well defined and have a known cause that are more prevalent among women. They are called auto-immune disorders, and include lupus as well as rheumatoid arthritis and Crohn1s disease. One theory is that these ailments may be more common among women because women carry babies, and hence must keep within their bodies an entity that is essentially foreign.

Japan and Autonomic Imbalance

The idea that CFS is a problem of stress leads in to the issue of Japan. Here, the diagnosis of CFS is hardly ever given at all. It is included in the home medical guide that I have at home, but only as a small footnote, not as an entry. There is a group at Osaka Medical University doing research and clinical practice, but primary physicians are usually not aware of the diagnosis, except perhaps as "something they have in the U.S."

So patients are not given the diagnosis of CFS in Japan. Which does not mean, however, that there are no patients with the symptoms. In fact, Dr. Iida Toshiho from Saku Central Hospital in Nagano Prefecture was quoted by the New York Times as saying that 70% of his patients suffered from chronic fatigue. There is another diagnosis, however, that is used in its place. The symptoms are pretty much identical. Imagine for a second, though, being told that you were ill with an "autonomic imbalance." You might be concerned, wondering if you were about to lose your balance and fall over . . . Actually, in Japan, people who go to their doctor and complain that they are ill, but without any clear problem, are often diagnosed with this syndrome, known as jiritsu shinkei shichosho. There are also many "self-help" books available on the subject, and they are out on the shelves in bookstores, right along tomes on more "conventional" illnesses such as cancer, diabetes or high blood pressure. An exact translation of the Japanese name would be "autonomous nerve dysfunction," but despite the serious-sounding name, autonomic imbalance is not generally a major problem. The books make it clear that it is a problem caused by "stress," and surprise, surprise, the treatment is mainly tranquilizers and rest. Sound familiar?

Feminism and CFS

So this is where CFS comes into the picture. I don1t believe it is a pure coincidence that the diagnosis was developed during the 1980s, when the effects of feminism and other ideas involving human rights ξ such as

patients' rights -- were being felt. The predominantly women patients began to lose patience at being told, "It's all in your head." And it is no doubt partially as a response to this that the diagnosis of CFS came about. Interestingly, although the diagnosis has changed, very little is understood about the condition, hence the treatment is basically the same as it once was ˜ tranquilizers, anti-depressants, painkillers, and rest.
Incidentally, I personally believe that there is more to CFS than a simple psychiatric issue, of the "stress of being a housewife" or the "stress of living in modern society." Just because we don't understand the etiology of an illness does not automatically means that it is "all in the patient's head." What is different between the US and Japan is that there is really no movement at all to find an organic cause for autonomic imbalance. The debate is dominated by health professionals, and there are no movements by women or other patients demanding changes in its treatment or social context.

Against Psychosomatic Illness

The idea of psychosomatic illness is that the physical symptoms of a patient are brought about by the mind. In other words, the patient does not really have any physical problem, but experiences problems due to stress or psychological problems.

As a patient there are obvious reasons to dislike this characterization. The patient feels poorly, yet those around the patient take his or problems lightly. At times they offer "encouragement" in the form of things like "Snap out of it."

However, this kind of stigmatization is not really a good reason to criticize the diagnosis. After all, if the notion is true, then there is little value in denying the truth just to remove these sorts of attitudes. It wouldn't change anything.

The problem, rather, is the possibility that it is not true. It is certain, yes, that patients with such "psychosomatic" disorders do not usually show any clear medical problems that could explain the symptoms. However, this only means that with the technology in use today, we cannot discover any serious problem.

And this is where the trouble starts. There would be some clear biomedical issue that really exists, and that could be corrected medically by some as yet unknown technique.

However, as long as the label of "psychosomatic" illness is maintained, little serious research goes into the pathology of such syndromes. There are a number of researchers who have dedicated themselves to changing this, but they are generally outsiders, without access to grant resources, and at times can be, to put it generously, a bit eccentric in their medical ideas.

Interestingly, to return to the theme of feminism for a moment, some women in the West argue that it is precisely because the disease is seen as a women's problem that it remains mysterious. They point to the enormous gap in resources spent on AIDS, which is still generally a disease of men, compared to CFS. CFS may have been called by different names, but perhaps reflecting its nature as a "women's ailment, " all seem to emphasize the emotional aspects.

It seems to me that a good way out would come from a frank recognition that there is a lot we do not understand. Rather than saying "It's just imaginary," we should frankly admit that there might be something there after all.