

The mystery of chronic fatigue syndrome

October 3 2011, By Jay A. Levy and Daniel L. Peterson

For more than 100 years, medical literature has contained reports of a debilitating illness that causes prolonged fatigue, memory loss, headaches, cognitive problems and issues with digestion and sleep. Teddy Roosevelt, John Muir and Thomas Eakins all suffered from what was then known as neurasthenia.

At that time, the recommended treatment for women was [bed rest](#); men were advised to head to the Wild West. But neither treatment could be counted on to cure the disease.

Toward the end of the 20th century, doctors came up with the term chronic fatigue syndrome (or, in Europe, myalgic encephalomyelitis) to describe the set of symptoms that used to be called neurasthenia. But we still did not fully understand the illness, nor had we isolated its cause.

Patients have suffered because of this failure to fully understand the disease. Sometimes, doctors attributed the symptoms to anxiety, depression or hypochondria. Employers have been less than sympathetic.

Today, most health professionals have finally acknowledged that chronic fatigue syndrome is a real and serious illness. But its name, which focuses on just one of the disorder's many symptoms, has served to trivialize the condition, making it seem more psychological than physical and reducing interest in the disease among mainstream medical and scientific researchers.

This low interest among researchers is unfortunate because most of the

biggest unsolved problems with chronic fatigue syndrome are scientific ones. We need to learn what causes the illness and we need to use that information to develop tests to diagnose, prevent and treat it.

The current consensus is that chronic fatigue syndrome is probably caused by a disturbance to the immune system. In ways that are not entirely clear, this disturbance upsets the immune system for a prolonged period of time and leads the body to become hyper-responsive and produce a large outpouring of [toxic substances](#), which then cause the fatigue, muscle aches, headaches and mental confusion associated with the disease.

Scientists have speculated that the chain of events that leads to this prolonged immune disorder begins when someone is exposed to a triggering agent - a toxic chemical, for instance, or a bacterial or viral infection. But identifying such an agent has proved difficult.

One complication has been that by the time someone develops symptoms and seeks treatment, the underlying infection is no longer detectable, so there is no longer a way to identify the causative agent from blood tests.

To complicate things even more, the over-responsive immune systems of people with chronic fatigue syndrome can activate co-infections, including Epstein-Barr virus, CMV and HHV-6, which make it even more difficult to identify the initial trigger.

Some doctors are beginning to believe that there may not be one single cause of this syndrome but a number of causes that all produce the same disturbance in the immune system. But what those agents are and how they cause the disturbance are challenging questions.

In the last few decades a number of viruses and bacteria have been fingered as possible culprits for causing chronic fatigue syndrome, but

none ultimately stood the test of scientific scrutiny. The most dramatic example came two years ago when a group of researchers reported finding a mouse-related virus called XMRV, a pathogen in the same family as HIV, which causes AIDS. They believed they had identified this virus in the blood of a several patients with chronic fatigue syndrome, raising the hopes of patients everywhere.

Unfortunately, before this claim had been fully validated, many patients embraced XMRV as the long-sought cause of this illness and began considering potential treatments. Because of the similarities between the mouse virus and HIV, some of them even started taking AIDS drugs.

Then, we found out the truth.

In more than 10 follow-up studies, research in our UC San Francisco laboratories and elsewhere failed to find any evidence of XMRV in the blood of the chronic fatigue patients tested. Moreover, experiments indicated that this virus does not survive well in human blood, making it an unlikely source for a human infection. Other studies have suggested that the XMRV detected in the original studies may have come from contaminated lab materials.

So where does this leave the millions of people in the United States who suffer from chronic fatigue syndrome? Frustrated.

The medical community, and the agencies and foundations that fund medical research, have never given this illness the attention it deserves. That needs to change.

Some have suggested that a name change might help. Chronic fatigue immune dysfunction syndrome would be a more accurate name that would call attention to the fact that the disease is tied to a disturbed [immune system](#).

Next, we need to retrench, to reconsider the direction of research on this disease. We should embrace the fact that we still do not understand what causes it and that until we do, we will always be restricted in our ability to develop new ways of diagnosing, treating and preventing it. This will continue to be frustrating to patients and their families, but embracing science that is later disproved hasn't served sufferers well.

Until we determine the causes and work out the best treatments for this debilitating condition, people with [chronic fatigue syndrome](#) will continue to suffer. In the meantime, we must increase support for basic research and for finding the best, evidence-based approaches for treating the disease.

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Citation: The mystery of chronic fatigue syndrome (2011, October 3) retrieved 20 March 2024 from <https://medicalxpress.com/news/2011-10-mystery-chronic-fatigue-syndrome.html>

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