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Opinion: The real story of chronic fatigue syndrome

By Ryan Prior



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Understanding diseases from a different perspective can shed new light on the cause and cure.

Researchers published a study two weeks ago discrediting the link between the retrovirus XMRV and chronic fatigue syndrome (CFS), a little-known illness that the [FDA says](#) is as devastating as cancer, heart disease and epilepsy.

The study marked [an end to a three-year saga](#) in which much of the medical community believed the virus and syndrome were linked. That belief followed a 2009 study in *Science* that established a correlation between the virus and the syndrome. For many, the hope to identify the cause of the tragic illness [was dashed](#).

I've suffered from CFS since October 2006, and it continues to radically change my life. But I couldn't hardly care less about XMRV. I think researchers who focus on the single retrovirus are completely

missing the picture. I'll explain why.

But first, a little back-story:

One week during my junior year of high school I started staggering home from school and sleeping until the next morning. Every morning, after 16 hours of sleep, I'd wake up still exhausted and drag myself to school again. After two weeks, I had to drop out of school altogether. I essentially didn't go to school at all for the next seven months.

On days when I could hold my head up long enough, three teachers came to my house to teach me pre-calculus, literature, history, psychology and physics. They gave me tests at my dining room table, assuming I could stay awake long enough to finish them.

I saw about 20 different doctors that year from every specialty you can imagine.

It is almost impossible to describe how deeply that pain touched me, how it completely re-directed my life. The existential weight of knowing the smartest physicians around had no clue what was wrong with me and could give me nothing to ease my suffering fell on me. In those darkest, weakest moments when your body is nothing but dead weight, you learn to see God most clearly. You are reborn.

I channeled every hope I had into a research paper assignment on alternative medicines, specifically traditional Chinese and Ayurvedic medicine. It was the most logical thing to do. Western medical science was doing nothing for me. For awhile these alternate ways of viewing my disease were a grand refuge. Although finding an English-speaking acupuncturist in rural Georgia was a tough sell, simply understanding these alternate health philosophies and how to re-orient my relationship with food, drink, sleep and environment contributed much to easing my burden.

I mention this partly as personal history but mostly to set up the (false) dichotomy between East and

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West, between alternative and mainstream. There should be only one distinction. There is only one thing that works and what doesn't. This idea gets to the very deepest core of why we bother to try and research anything at all, be it XMRV or nuclear proliferation or development economics. It is because our very lives depend on it.

The acupuncturists helped a little but they were nearly as ineffective for me as the rheumatologists, the endocrinologists, the neurologists and the rest. I would have tried absolutely anything to get better: hypnotist, witch doctor, anything.

In those dark nights of searching with my only animating desire to find the truth, I finally stumbled upon the answer. It was very nearly hidden in plain sight.

There was a nation-wide network of fatigue clinics run by Jacob Tietelbaum, a medical doctor who himself had fallen victim to CFS as a medical student in the 1970s. They could hardly be more under-the-radar. Nearly every fact sheet you find and every doctor you talk to will tell you that there is nothing that can be done about CFS.

There was a clinic in Atlanta, two hours from where I lived. My first appointment there was a revelation. I would start a sentence and my new doctor would finish it. She essentially knew my every symptom before I even said it. Now contrast this with the "mainstream" medical specialists, who would listen to my symptoms for an hour, baffled, shake their head and say sorry, there's nothing that can be done. My new doctor would later tell me that she too suffered from chronic fatigue syndrome and took many of the same treatments she prescribed to me.

The treatment plan she ordered was robust. I would swallow about 20 pills a day (mostly vitamins and supplements), give myself a shot weekly and come to IV treatments every two to four weeks. Five years later, I still follow it religiously. This treatment is the reason I'll walk across the stage this December to receive my degrees, with high honors, in literature and international affairs.

When I sit in that row of large fluffy chairs with the needle in my arm every month (similar to receiving chemotherapy), I talk with the other patients. Many will speak of shadow lives of two decades being unable to work. They tell stories of the endless parade of doctors who told them all was hopeless until they finally found the right treatment at the Fibro and Fatigue Clinics. I've had people tell me in the most matter-of-fact tones that before coming to that clinic they had contemplated suicide or that they would have sold their souls to the devil to rid themselves of CFS.

Three years ago, when the first XMRV study came out, I asked my doctor what it meant, if perhaps I should be tested for XMRV. Was this the answer to all my problems? It didn't matter, she said. If I had XMRV, which 67% of CFS patients were believed at the time to have, it wouldn't change a single thing about my treatment.

Without explaining a phonebook-thick medical record, my own version of the syndrome can best be understood as a coalition of the malicious: a bit of Epstein-Barr Virus, some Lyme Disease, a cortisol deficiency, thyroid issues, mitochondrial dysfunction, magnesium deficiency, sleep disorder and a similar litany of smaller issues combining in a vicious cycle of ruination. Each problem can only be addressed in particular phases of treatment, and it can often take years to precisely undo each specific ail.

To dwell on the alleged link between XMRV is to understand a vital critique of the scientific method, and much of Western analytic thought overall (I hate to draw that distinction but it's useful in making generalizations). We create experiments in highly controlled environments to see what happens when we manipulate a single variable. Diseases are supposed to have one of these single causes. If one virus is disproved in its linkage, we start the process over and test another single variable by itself to see if that is the cause.

I have no doubt that works a lot of the time. But not every time. We are not simply circulatory systems or digestive systems isolated unto themselves. We're highly complex organisms with every physical system interacting all at once. What appealed to me so much in the more holistic, "Eastern" medical philosophy was this ability to see the whole body in its proper physical, emotional, spiritual and social context.

I see a similar cognitive approach working in what my doctor would call the SHINE (Sleep, Hormones, Infection, Nutrition, Exercise) approach. It approaches the body in the more holistic fashion, giving equal weight to lifestyle factors like nutrition and exercise.

Chronic fatigue syndrome is not a problem affecting the immune system. It is a set of problems

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affecting a myriad of anatomical systems. Until researchers understand this, there will continue to be one false alarm after another in the mainstream medical community. XMRV this week, who knows what next.

Ryan Prior is a Fall 2012 USA TODAY Collegiate Correspondent. [Learn more about him here.](#)