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OP-ED CONTRIBUTOR

A Disease Doctors Refuse to See

By Julie Rehmeyer

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SANTA FE, N.M. — TOO often, doctors don't understand chronic fatigue syndrome. They don't know how to diagnose it, and they frequently even believe that patients with the disease are just whining or suffering from psychological problems. This needs to change.

That was the message from the Institute of Medicine's recent report on the illness, which proposed new criteria to diagnose it and recommended ditching the syndrome's confusing and demeaning name. The proposed alternative: systemic exertion intolerance disease, or S.E.I.D.

As a patient for 16 years, I've dealt with plenty of doctors who were ignorant about the disease. So my questions were: Will this work? Is a report from one of the most prestigious bodies in American medicine, an arm of the National Academy of Sciences, enough to make doctors take the disease seriously? Will patients get diagnoses faster and be treated more effectively?

Early indications are discouraging. An article about the report on Medscape, a website for doctors, received 273 comments as of Tuesday, and most were dismissive. Here are a few examples:

- “Absent hard biological evidence, Chronic Fatigue Syndrome might” count “lots of people as ‘Sick’ who are in monotonous jobs, bad marriages, or plain bored with life.”
- “great, disability here I come! glad I got that plan a long time ago.”
- “Chronic fatigue and fibromyalgia — two wastebasket diagnoses in search of pathology.”

The nearly 300-page report explicitly argued against these sentiments with a thorough review of the scientific literature. It pointed out that chronic fatigue (the condition of being tired all the time) and chronic fatigue syndrome (an illness in which exhaustion is just one of many debilitating symptoms) are very different.

The hallmark symptom of chronic fatigue syndrome isn’t fatigue at all: It’s a dramatic worsening of symptoms after exertion (which for some patients can be as little as lifting a toothbrush). On top of that, patients have cognitive problems, sometimes so extreme they can’t talk or read; within half an hour of standing, their blood pressure drops or their heart rate soars; and sleep makes them feel no better. Most have additional symptoms, too, including pain and neurological and immune problems.

But many doctors, it seems, aren’t persuaded by this scientific evidence.

So what would persuade them? Doctors may be a scientifically minded lot, but they are also slow to change and are focused on their daily work. “Real” for a doctor often translates to “indicated by some objective test.”

Unfortunately, no one test can reliably distinguish patients who have chronic fatigue syndrome from those who don’t. The closest thing to a reliable, objective test is a two-day exercise-to-exhaustion challenge on a stationary bike. Sick patients of all varieties may poop out quickly on Day 1 but whatever they do,

they can generally repeat it the next day. Not C.F.S. patients; their performance tanks. Physiological measures ensure that the results can't be faked, and so far, researchers haven't seen similar results in any other illness. But large studies haven't been done. The test also has a big problem. It can leave patients much sicker for months.

A more practical test for exertion intolerance may come from examining the gene expression in the spinal fluid of C.F.S. patients after moderate exercise, which has been shown to be distinctively abnormal in small samples. But much more research will be required before doctors are able to order a test for it.

The other thing that would change doctors' attitudes is effective treatment, which is also what patients desperately need. The problem is, very few treatments have proved effective.

That may be about to change. Rituximab, a lymphoma drug, has produced remarkable remissions in C.F.S. patients in a small study and is now undergoing a large trial. In my case, I have improved almost unbelievably by taking extreme steps to avoid mold, an approach that has become an underground movement among patients but that has received very little study.

Developing tests and treatments isn't cheap. Every disease community argues that it needs more money, but the situation with C.F.S. is extreme: The National Institutes of Health spends a mere $5 million a year on C.F.S. research, when an estimated one million Americans are affected, with many disabled and some so ill they languish for years in darkened rooms, unable to move or speak. By comparison, the N.I.H. spends $3 billion on H.I.V./AIDS a year. Ellen Wright Clayton, the chairwoman of the committee that produced the report, is encouraging patients to advocate as AIDS activists once did and demand more research funding — a tall order for patients who are often housebound.

I hope, and believe, that this report will help some patients get diagnoses more quickly and accurately. But to get anywhere close to the care that patients so desperately need, no report is enough. It will require objective tests and effective treatments. For that, federal agencies will have to start making an investment in this disease that's proportional to the devastation it causes.

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