

Chronic Fatigue Syndrome has a New Name - Systemic Exertional Intolerance Disease

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Abstract

Chronic fatigue syndrome is a commonly used diagnosis to explain a myriad of subjective symptoms. It may be a comforting to some as they strive to explain their symptoms. The downside is that they become incapacitated and unproductive once that label is applied. Unfortunately, the Institute of Medicine has legitimized their symptoms with a new scientific sounding name. The new name: Systemic exertional intolerance disease is a step backward. This meaningless diagnosis is now proffered to explain our ignorance.

Keywords: *Chronic Fatigue Syndrome; Systemic Exertional Intolerance Disease*

Key Message

- 1) Institute of Medicine redefines Chronic fatigue syndrome.
- 2) Their "research" draws conclusions enabling this change.
- 3) Subjective symptoms are used to justify the diagnosis.
- 4) Chronic fatigue syndrome has no reproducible objective findings.
- 5) A new more dynamic title has been proposed: Systemic exertional intolerance disease.
- 6) Another "meaningless diagnosis" has been foisted upon us to cover our ignorance.

Following last month's article, Fibromyalgia - Fact or Fiction, it seemed like a natural extension to discuss another disorder that lacks definition and clarity. Government agencies including Health and Human Resources, Federal Drug Administration, Centers for Disease Control, and National Institute of Health all charged the prestigious Institute of Medicine's 15 member advisory panel to develop diagnostic criteria using consensus building methodologies to redefine chronic fatigue syndrome. Their research in a 235-page report recently released concludes "Scientific evidence that justifies the new definition SEID. They have declared and asserted that the condition is "real" and desires upgrading to this more sophisticated title.

In past years physicians have largely dismissed the diagnosis and patients have been viewed as complainers with poor coping skills. Now however, with this new epiphany, patients will be entitled to all of the benefits and empathy consistent with their new "disease." The Institute of Medicine estimates that between 835,000 and 2.5 million Americans are afflicted. Patients with SEID typically cannot perform normal activities of daily living and as many as 25 percent are considered homebound or bedridden.

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The condition has enjoyed numerous names in the past including epidemic neuromyasthenia, myalgia nervosa, and myalgic encephalomyelitis. None have endured scientific scrutiny. Likewise, the name Chronic Fatigue Syndrome has failed to depict the complexities of the disease and was considered unacceptable to both patients and their advocates.

The IOM panel struggled to find an alternate name that packed punch and wallop, was dynamic and meaningful. The words syndrome or disorder did not meet the full intent of the panel as they were perceived as being too soft and gentle. So instead we have a “disease” which carries with it all the privileges and gratifications of a novel diagnosis. ICD-10 codes will now distinguish it from prior diagnoses.

Where is the science to support this new disease? There are no laboratory tests, electrodiagnostic, imaging studies, or tissue biopsies to verify the diagnosis. There are no trigger points, taut bands or spasms. The diagnosis is made on subjective symptoms unsubstantiated by objective findings and only supported by testimonials of patients and clinicians. The Institute of Medicine does conclude that “Further research is necessary as many questions remain unanswered”.

Ellen Wright Clayton, M.D., J.D., an IOM panel member writes in JAMA, February 10, 2015, “The majority of affected patients are never diagnosed. This is unfortunate because effective symptom management is often available whereas the wrong interventions can make symptoms worse”.

So, what is considered appropriate symptom management? Rest, cognitive behavioral therapy, meditation, acupuncture, physical therapy, occupational therapy, aroma therapy, massage therapy, or pharmaceuticals? Do we now have an incurable disease on our hands? Has the IOM taken a condition only supported by subjectivity and elevated it to a position of respectability, credibility and codability and destined the victims to a life of hopelessness and despair?

SEID clearly would not pass the Daubert criteria in the courtroom which insists that opinions are based on scientific evidence not conjecture or speculation. Defense attorneys would destroy plaintiffs’ claims in short order.

An excerpt taken from JAMA 100 years ago, Meaningless Diagnoses (June 6,1908:50:1889-1890) authored by Harry Wiel, M.D. states the following, “We have not always been totally frank with ourselves, and the time has come when the profession should discard several ill-used and time-worn diagnoses that have expressed clinical entities, which if not fantastic, have at least never been proved to exist. These diagnoses have been used much too frequently to cover our ignorance and to pander to the desire of the patient to know what is the matter”. At that time, biliousness, gastric fever, and ptomaine poisoning were among the diagnoses that were proffered to patients to explain a variety of ailments. In the 21st century, are we still disguising our ignorance, only changing the names?

How are we expected to be productive and responsible citizens if we are saddled with a disease that has no causation, physical explanation or available treatment? The result may be to reverse the SEID initials to “DIES”.

Conclusion

Chronic fatigue syndrome as a systemic exertional intolerance disease has been proposed to explain a myriad of subjective symptoms that are unsubstantiated by objective findings. Many patients that are diagnosed with systemic exertional intolerance disease are unable to lead productive lives or contribute to society.

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