

IOM Gives Chronic Fatigue Syndrome a New Name and Definition

Miriam E. Tucker | February 10, 2015

The illness that has been called "chronic fatigue syndrome" (CFS) in the United States and "myalgic encephalomyelitis" (ME) elsewhere is a "serious, complex, multisystem disease" that physicians need to view as "real" and diagnose, the Institute of Medicine (IOM) says in a new 235-page report.

"The central point is that ME/CFS is a diagnosis to be made," according to the IOM's [report](#), "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining and Illness." To reflect the condition's hallmark defining symptom, postexertional malaise, the report proposes a new name be adopted, "systemic exertion intolerance disease (SEID)," defined in both adults and children by the following:

1. a substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest;
2. postexertional malaise (often described by patients as a "crash" or "collapse" after even minor physical or mental exertion);
3. unrefreshing sleep; and
4. cognitive impairment and/or orthostatic intolerance.

Both frequency and severity should be evaluated for postexertional malaise, unrefreshed sleep, and cognitive impairment, and the diagnosis made if the patient has these symptoms at least half the time with moderate, substantial, or severe intensity. Unlike some previous definitions, this is not a diagnosis of exclusion and can be applied to patients who also have other potentially fatiguing conditions.

Not a Figment of Imagination

"It's time to stop saying that this is a just figment of people's imagination. This is a real disease, with real physical manifestations that need to be identified and cared for," Committee Chair Ellen Wright Clayton, MD, JD, professor of pediatrics and director of the Center for Biomedical Ethics and Society at Vanderbilt University, Nashville, Tennessee, told *Medscape Medical News*.

Indeed, panel member Peter Rowe, MD, professor of pediatrics and director of the Chronic Fatigue Clinic at Johns Hopkins Children's Center, Baltimore, Maryland, told *Medscape Medical News*, "This is an illness that can have a profound impact on people's function, their ability to maintain their jobs or continue their education. This was very clear from the evidence that the committee reviewed."

Between 836,000 and 2.5 million Americans are estimated to have the illness, using the various ME or CFS definitions, but an estimated 84% to 91% of them are not yet diagnosed. The etiology is unknown, but [evidence](#) of biological disease has been mounting for the last several years.

The report summarizes the evidence for each of the components of the new diagnostic criteria, as well as for other clinical features that can be used to support the diagnosis, including a history of certain infections that preceded the onset of symptoms and various types of pain.

In particular, the panel found sufficient evidence linking the illness to immune dysfunction, especially diminished natural killer cell function, and infection, particularly Epstein-Barr virus.

Other symptoms, such as gastrointestinal and genitourinary problems, sore throat, tender axillary/cervical lymph

nodes, and sensitivity to external stimuli, are present in some patients and may also be used to support the diagnosis, according to the report.

However, these other manifestations, although common, were not specific enough to be included in the diagnostic criteria, Dr Clayton, who also penned an editorial on the report in today's issue of *JAMA*, told *Medscape Medical News*.

"There's a long history in medicine of symptom-based diagnostic names.... Until the etiology is better known, we wanted to focus on just the central symptoms of the disorder. This is really is the result of the current state of the science," she said

"A Unanimous Committee Report"

The report was sponsored by the Office of Women's Health in the Department of Health and Human Services, the National Institutes of Health, the Centers for Disease Control and Prevention, the US Food and Drug Administration, the Agency for Healthcare Research and Quality, and the Social Security Administration. The 15-member writing panel, consisting of experts and nonexperts in the field, based their conclusions on a comprehensive literature review; testimony from patients, clinicians, and researchers during public hearings held in January and May of 2014; and almost 1000 public comments.

According to Dr Rowe, "It was a unanimous committee report.... It was interesting for us who are clinicians in the field to see how obvious the direction of the evidence was for those who are scientists, but not specialists in this area."

Dr Clayton, who has participated in previous IOM committees but did not have expertise in ME/CFS before joining this panel, said the evidence was particularly strong in three areas: The characteristic decrements seen after 2-day cardiopulmonary testing, clear and reproducible findings of orthostatic intolerance, and neuropsychiatric test data that show evidence of slowed processing. "This isn't just things that patients are concerned about. These are reproducible things you can find on testing."

She added, "The level of response is much more than would be seen with deconditioning," with reference to the belief voiced by some clinicians that physical abnormalities in these patients are merely a result of their lack of activity.

Indeed, Dr Rowe noted, "That argument is untenable with people who have been physically active, some of them athletes, [before becoming ill]. The deconditioning argument is flawed in that respect."

The report does not advise that clinicians routinely perform expensive testing that was done in some of the studies. Instead, the diagnosis should be primarily based on appropriate history, physical examination, and targeted symptom-based workup.

Dr Clayton said, "We emphatically do not want clinicians to do all the objective tests we identify. They're expensive, onerous, and not uniformly available. Often you can get most of what you need from the history and physical."

Although the document doesn't address treatment, Dr Rowe said physicians can and should provide symptom-based care. "We've got good treatment algorithms for things like headaches, sleep disturbance, and certain [other] kinds of pain. No one treatment is appropriate for every person, but there's much out there that's helpful and available to [clinicians]." And, he stressed, even though the diagnostic criteria call for 6 months of fatigue, treatment of symptoms should begin as soon as they are identified.

Dissemination and Future Steps

To further assist with the diagnosis, the panel recommends that SEID be assigned a new code in the *International Classification of Diseases, 10th Edition*, and that the Department of Health and Human Services develop a toolkit to help clinicians screen and diagnose patients.

The report's final chapter outlines a broad plan for disseminating the new criteria, including outreach to professional organizations representing adult and pediatric primary care, obstetrician-gynecologists, emergency medicine practitioners, psychologists, psychiatrists, rheumatologists, gastroenterologists, sleep medicine specialists, infectious disease practitioners, and cardiologists.

Although the IOM aims to promote the new document widely, its content is also meant to be time-limited and revised pending new knowledge. Specifically, the panel called for a reexamination of the diagnostic criteria "when firm evidence supports the modification to improve the identification or care of affected individuals" in "no more than 5 years."

Part of that future reevaluation is expected to include identification of subgroups of patients within the broad SEID heading, Dr Rowe noted.

For the current report, "the amount of evidence available to look at subgroups was just not sufficient. In the pediatric literature, six or seven studies described interesting immune abnormalities, but none were replications of the others, so they were just single reports out there in isolation. Much more work needs to be done to replicate those kinds of studies, as well as development of subgroup studies," he told *Medscape Medical News*.

According to Dr Clayton, "We really think this is an area where things are moving relatively quickly. If, as we hope, what this report does is elicit greater interest and a greater recognition from entities that they need to be funding more research, and if in fact the research ramps up in the way we hope that it will, it would be lovely if we knew enough in the next 2 or 3 years that it was time to reexamine this. So, 5 years is an outer limit."

Dr Clayton and Dr Rowe have disclosed no relevant financial relationships.

"Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining and Illness." IOM. Published online February 10, 2015. [Description](#)

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