Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
An IOM Report on Redefining an Illness

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Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a multisystem and often long-lasting disorder, with manifestations that can cause substantial morbidity and can severely impair patients’ health and well-being. It is estimated that between 836,000 and 2.5 million individuals are affected in the United States.1,2 Patients with ME/CFS are typically unable to perform their normal activities, and as many as one-fourth are home-bound or bedridden, sometimes for extended periods.3 As a result, the personal and social effects and ramifications of this disease are enormous.

However, ME/CFS is poorly accepted and poorly understood, and the characteristics necessary to make the diagnosis are contested. Patients’ concerns are often met with dismay and skepticism, if not outright dismissal. Clinicians, in turn, are confronted by competing definitions, which were usually developed for research and are quite complex and difficult to implement in a busy clinical practice. Patients who are fortunate enough and persistent enough to receive a correct diagnosis frequently report long delays before their disorder was identified. It is almost certainly the case that 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.

Making the diagnosis is essential for providing appropriate care. To that end, the Department of Health and Human Services (HHS), together with the National Institutes of Health, US Social Security Administration, US Food and Drug Administration, Centers for Disease Control and Prevention, and Agency for Healthcare Research and Quality, tasked the Institute of Medicine (IOM) to develop “evidence-based clinical diagnostic criteria for ME/CFS for use by clinicians, using a consensus-building methodology,” with input from patients and clinicians; to “recommend whether new terminology for ME/CFS should be adopted”; and to create plans for disseminating these conclusions to clinicians. To meet its charge, the IOM committee heard testimony from patients, clinicians, and researchers, carefully reviewed almost one thousand public comments, and conducted a comprehensive literature review. Currently available evidence permitted the committee, in its newly released report,4 to identify symptoms and findings that collectively identify the disorder for which a new name was proposed, as discussed below. These criteria are set forth in the accompanying Box.

To assist with diagnosis, the committee developed an algorithm incorporating these criteria as well as an extensive list of findings on history, physical examination, and, when needed to clarify symptoms, tests that support the diagnosis. Further details, including recommended checklists, are contained in the committee’s report.4 The committee called on HHS to develop focused, evidence-based tools that will help clinicians make this diagnosis efficiently. Patients with ME/CFS, like many other patients, often have comorbid conditions that clinicians also must be prepared to identify and treat.

The committee concluded that a new name—systemic exertion intolerance disease—was warranted to capture the essence of this disorder until causation and pathophysiology are better delineated by research. Although patients differ in their triggers and manifestations, the salient feature of this disorder is that any kind of exertion—physical, cognitive, emotional—can adversely affect these patients in many aspects of their biological function and in their lives, frequently severely and often for a prolonged period. “Myalgic encephalomyelitis,” for which many people who provided input to the IOM study through testimony and public comments advocated, simply does not describe this disorder. “Chronic fatigue syndrome” fails to depict the complexity of this disease and is also unacceptable to many patients and their advocates, who reported that this term leads clinicians and others to belittle or even dismiss their

Box. IOM Diagnostic Criteria for Systemic Exertion Intolerance Disease

Diagnosis requires that the patient have the following 3 symptoms:

1. A substantial reduction or impairment in the ability to engage in preillness 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 AND
2. Postexertional malaise* AND
3. Unrefreshing sleep*

* Frequency and severity of symptoms should be assessed.
The diagnosis of systemic exertion intolerance disease (myalgic encephalomyelitis/chronic fatigue syndrome) should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.
disease. The new name, which should be accompanied by a new International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) code, also distinguishes this definition from previous ones. Thus, patients who meet these new criteria should be diagnosed with systemic exertion intolerance disease even if they also meet criteria for earlier variants of ME/CFS.

Patients will not be identified and treated if clinicians do not know about the disorder and how to diagnose it. To that end, the IOM report sets forth a variety of strategies that must be pursued to facilitate dissemination of these recommendations to clinicians, patients, and K-12 education professionals, such as school nurses and psychologists. The IOM is creating educational materials for patients and clinicians.

Although the committee was able to make high-quality recommendations based on the available evidence, the need for more research is clear. Most of the research that has been conducted to date has compared small numbers of affected patients with healthy controls, not with patients with other complex fatiguing disorders. This fact, coupled with years of limited funding, means that despite the dedicated efforts of researchers in this field, many questions remain unanswered. More needs to be learned about what causes this disorder, what factors affect its course, and what therapies work for which patients. New knowledge may make it possible to identify subsets of systemic exertion intolerance disease and to provide the foundation for better diagnosis and treatment.

The IOM’s new report provides the foundation for greater action to diagnose and treat patients with systemic exertion intolerance disease and to learn more about the disease that affects them. This opportunity must be seized. These patients, who for too long have received inadequate attention in research and clinical settings, deserve better.

ARTICLE INFORMATION
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