

Public Comment
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Once again this Committee is meeting to discuss what should be done about the disease that the CDC has misnamed, misconceived, and mishandled for decades. Unbelievably, here in 2012, the CDC is still promoting an outdated 1994 case definition for chronic fatigue syndrome (CFS) [1] which fails to differentiate between fatigue due to depression, or an undiagnosed medical condition, and the neurological disease myalgic encephalomyelitis (ME).

An accurate case definition is one of the first principles of epidemiology. It must give the necessary and sufficient conditions for determining who has the disease. The CDC has failed even to get to square one with the epidemiology of CFS. The CDC does not know how to determine which patients have the disease and which do not. Its 1994 Fukuda CFS definition has only optional symptoms, in addition to inadequately defined fatigue. It lists no necessary symptoms other than fatigue. Consequently, CFS has little credibility with the medical community and the public. Almost nothing is reliably known about the disease's actual nature, its prevalence, its method of transmission, its pathogens, its etiology, and, most significantly, its treatment.

Last year, an international group of 26 experts on the disease from 13 countries published the landmark International Consensus Criteria (ICC) for myalgic encephalomyelitis [2], based on the 2003 Canadian Consensus Criteria (CCC) [3]. The differences from the CDC's unproductive approach are profound. The name CFS has never reflected the true nature of the disease. The ICC states:

The label 'chronic fatigue syndrome' (CFS) has persisted for many years because of the lack of knowledge of the aetiological agents and the disease process. In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term 'myalgic encephalomyelitis' (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization's International Classification of Diseases (ICD G93.3).

Contrast this with the educational information provided by the CDC and the CFIDS Association of America on the CDC's CFS website.

Various terms are often used interchangeably with CFS. CFS is the preferred term because it has an internationally accepted case definition that is used in research and clinical settings. The name chronic fatigue and immune dysfunction syndrome (CFIDS) was introduced soon after CFS was defined; there is no case definition for CFIDS, and the name implies an understanding about the pathophysiology of CFS that does not currently exist. [4]

The authors of the ICC have this to say about the CDC's "internationally accepted" case definition:

The problem with broadly inclusive criteria [15, 16] [The 1991 Oxford criteria and the 2005 CDC Reeves empirical criteria] is that they do not select homogeneous sets of patients. The Centers for Disease Control prevalence estimates increased tenfold from 0.24% using the Fukuda criteria [17] to 2.54% using the Reeves empirical criteria [16]. Jason et al. [18] suggest that there are flaws in Reeves' methodology because it is possible to meet the empirical criteria for ME without having any physical symptoms and it does not discriminate patients with ME/CFS from those with major depressive disorder. Patient sets that include people who do not have the disease lead to biased research findings, inappropriate treatments and waste scarce research funds [19]. [2] [See the paper for the italicized references.

The CDC also claims, "The name myalgic encephalomyelitis (ME) was coined in the 1950s to clarify well-documented outbreaks of disease; however, ME is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS." [4] If this is true, where is the CDC's case definition for ME? Why is ME not listed as an exclusionary condition for CFS research and diagnosis? Surely the CDC is aware CFS research is de facto applied to ME patients. Doctors in the US have not been educated about ME. They have no choice now but to misdiagnose with CFS patients who meet the criteria for ME.

Recently, New York Times writer David Tuller wrote a lengthy account of the CDC's involvement with the disease, "Chronic Fatigue Syndrome and the CDC: A Long, Tangled Tale." [5] I urge the Committee members to read it. The CDC's long, checkered history with CFS should be well known. In 1985, the CDC sent two inexperienced investigators to the Lake Tahoe region of Nevada after reports of an outbreak of an unknown illness. Based on a small amount of information collected and inconclusive research, a CDC committee named the disease chronic fatigue syndrome and developed the Holmes case definition in 1988. [6] This case definition listed a total of 11 symptoms and 3 signs, many of which indicated neurological and immunological involvement.

In 1991, small group of ideologically driven psychiatrists in the UK redefined CFS as only chronic fatigue with no required neurological or immunological symptoms, the Oxford definition. [7] Even though the criteria for the disease were changed beyond all recognition from the CDC's Holmes CFS, the group of psychiatrists unethically continued to call their creation CFS. They then proceeded to conflate their new CFS, which was only chronic fatigue, with the neurological disease ME, recognized by the WHO since 1969. They soon moved to the hybrid term CFS/ME in an attempt to increase their influence over, and seize control of, the treatment of the neurological disease ME.

In 1994, the CDC published its Fukuda, or so-called International, case definition of CFS. One of the authors of the deceptive Oxford definition of CFS, psychiatrist Michael Sharpe, was also an author of the 1994 Fukuda CFS case definition paper. [1] Another member of the CDC's International Study Group of advisors was the psychiatrist Simon Wessely, another Oxford-definition co-author, with extensive ties to the insurance industry and the military.

A third Oxford-definition psychiatrist, Peter White, director of the behavioral CFS/ME program at Barts Hospital, London, became an advisor to the CDC's program. White, also with major ties to the insurance industry, advocates denying aid and assistance to patients disabled by ME

because he believes it impedes their recovery. He made this and other similar comments, speaking for the Barts program, on proposed UK NICE guidelines for CFS/ME:

Where is the warning about dependence being encouraged and expectation of recovery being damaged by the message that is given in this intervention? [Providing equipment and accommodations such as a wheelchairs, disability parking permits, or stairlifts.] We are in no doubt that it is a powerful message for a therapist of any sort to provide such aids. [8]

Wessely, White, and Sharpe, members of the psychiatric "Wessely School" based on unscientific 19th-century concepts of disease causation, believe ME to be a psychosomatic condition best treated by a version of talk therapy, cognitive behavioral therapy (CBT), to correct the patient's false belief that he or she has a physical illness. With literally thousands of peer-reviewed papers indicating properly defined CFS and ME are physical illnesses, the basic premise of CBT as a treatment for CFS and ME is, itself, false.

The other psychiatrically based treatment, graded exercise therapy (GET), is founded on the unsupported belief that CFS and ME are the result of fear of activity and deconditioning. The hallmark feature of ME is an abnormal response to exertion, as is recognized by the CCC and ICC. Attempting to treat ME with exercise is like treating COPD with smoking or diabetes with sugar. It is medically dangerous, and the harm caused goes largely unreported. [9] Sadly, American medical centers, such as the Mayo Clinic, have been misled by the muddled approach of the CDC into adopting the false UK psychiatric model of the disease and recommending these ineffective and medically dangerous treatments.

There have been positive changes on the CDC's CFS website, such as removal of the list of not recommended medical tests and removal of a link to the psychiatrically oriented UK NICE guidelines. However, the CDC continues to claim CBT and GET are appropriate treatments for CFS. There is still a link on the CDC website to an outdated and unscientific pamphlet on GET produced by the Barts CFS/ME program. [10]

In defiance of the Committee's past recommendations, the CDC continues to do alleged CFS research using the Reeves empirical criteria. [11] The CDC has misused funds intended for CFS research doing these invalid studies, mostly with collaborators from the Emory University Department of Psychiatry and Behavioral Sciences where William Reeves of the CDC received a faculty appointment. Such cronyism and deceptive research is unethical and constitutes scientific misconduct.

In view of the new information published in the International Consensus Criteria, I request the Committee to make the following recommendations to the Secretary of Health and Human Services:

1. The name chronic fatigue syndrome, which has never been adequately defined, should be phased out in favor of the name myalgic encephalomyelitis. The term CFS, because of the invalid Oxford and Reeves CFS criteria, has lost all meaning and should be abandoned.

2. The International Consensus Criteria should be adopted as the standard case definition for ME for both research and diagnosis. Only research using these criteria should be funded by the CDC and NIH. The most severely affected bedbound and homebound patients should be included in ME research cohorts as a requirement to obtain funding.

3. The CDC should remove CBT and GET from the list of treatments for CFS on its website and caution against their use.

4. The DHHS should request the CDC to issue a statement that research done using the Oxford and Reeves criteria is invalid for both CFS and ME. The CDC's Wichita and Georgia cohorts selected using the Reeves criteria should not be used for further CFS or ME research.

References

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