Issues Involved in Name Change Recommendations
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In 1988, a group of researchers, many of whom were at the CDC, coined the name chronic fatigue syndrome (CFS) and developed a case definition (Holmes et al., 1988). Most patients feel the term CFS trivializes the seriousness of the illness (Name-Change Survey Results, 1997; Friedberg & Jason, 1998) and has contributed to health care providers having negative attitudes towards those with this syndrome (Anderson & Ferrans, 1997; David, Wessely & Pelosi, 1991; Green, Romei & Natelson, 1999; Jason, Richman et al., 1997; Shlaes, Jason & Ferrari, 1999).

The patient community has felt that the term chronic fatigue syndrome is inappropriate, as the illness is typified by many severe symptoms in addition to fatigue, and fatigue is generally regarded as a common symptom experienced by many otherwise healthy individuals in the general population (Taylor, Friedberg, & Jason, 2001). In addition, CFS is frequently confused with chronic fatigue, which is a symptom of many illnesses, including some psychiatric disorders. The negative stigma that is associated with CFS could also be due to the trivializing name that has been given to this disorder.

The name selected to characterize an illness, such as chronic fatigue syndrome, can influence how patients are perceived and ultimately treated by medical personnel, family members and work associates (Jason, Holbert, Torres-Harding, & Taylor, 2004; Jason, Holbert, Torres-Harding, Taylor, Le Vassuer, et al., 2004).

Two studies evaluated whether different names for CFS indeed prompt different attributions regarding its cause, nature, severity, contagion, and prognosis among samples of medical trainees and university undergraduates (Jason, Taylor, Plioplys, Stepanek, & Shlaes, 2002; Jason, Taylor, Stepanek, & Plioplys, 2001). Results of these studies suggested that participants' attributions about CFS change based upon the different diagnostic labels used to characterize it. The ME label was associated with the poorest prognosis, and this term was more likely to attribute a physiological cause to the illness, and less likely to consider the patient in the case study as a potential candidate for organ donation.

Many health care professionals and research scientists felt that if the name were to be changed, it would be best to have a scientific basis for the change. Unfortunately, few data have been collected to help guide the process of revising the name (Jason, Eisele, & Taylor, 2001).

Although it was expected that the name chronic fatigue syndrome would be eventually replaced as more information became available, this name has remained and has become the most commonly used label within the United States (Friedberg & Jason, 1998).
The term ME/CFS is now being used in many countries, as proposed by the Canadian Case definition (Carruthers et al., 2003). Jason, Torres-Harding, Jurgens, and Helgerson (2004) compared persons meeting the Canadian case definition, the Fukuda et al. (1994) criteria, and people experiencing chronic fatigue explained by psychiatric reasons. The Canadian criteria selected cases with less psychiatric co-morbidity, more physical functional impairment, and more fatigue/weakness, neuropsychiatric, and neurology symptoms. Below we provide some of the reasons for this finding.

To meet the criteria for CFS the case definition, the Fukuda criteria required the concurrent occurrence of at least four of the following eight symptoms including sore throat, tender cervical or axillary lymph nodes, muscle pain, multiple joint, pain without joint swelling or redness, headaches of a new type, pattern or severity, unrefreshing sleep, post exertional malaise lasting more than 24 hrs, persistent or recurring impairment in short term memory or concentration. However, because only four of these symptoms needed to occur to meet criterion, a person could be diagnosed without having three of the eight symptoms that were considered as being critical markers for having this illness (i.e., unrefreshing sleep, post-exertional malaise, memory and concentration problems). In addition, there were few efforts to devise reliable instruments to assess these core symptoms, and as a consequence, for studies around the world, it was unclear what criteria were being used to identify patients.

Our group wrote about the consequences of this lack of specificity in the case definition (Jason, Richman et al., 1997). One argument that we offered in our writings was that a person with Major Depressive Disorder, one of the most prevalent mental health problems, could be easily misdiagnosed with CFS. Many individuals with depression have chronic fatigue and other somatic symptoms that are part of the CFS case definition (e.g., unrefreshing sleep, joint pain, muscle pain, impairment in concentration). Although we recognized that some individuals with CFS might have comorbid depression, we were also convinced that the two illnesses were distinct. In one of our studies, we recruited individuals who had CFS and Major Depressive Disorder (Hawk, Jason, & Torres-Harding, 2006). Using discriminant functional analysis, we were able to successfully distinguish CFS from Major Depressive Disorders with 100% accuracy if critical predictors such as post-exertional malaise severity, unrefreshing sleep severity, and confusion/disorientation severity were used. In other words it is possible to distinguish these two conditions, but if the current case definition of CFS does not identify patients with these specific symptoms (e.g., post-exertional malaise and unrefreshing sleep), then it would be easy to miss some individuals who really have CFS and to include others who do not have this illness. If this occurred, it would be impossible to identify consistent biological markers of this illness, and then many researchers and clinicians would conclude that ME/CFS was a psychosomatic illness.

In 2003, a new clinical case definition for ME/CFS was developed in Canada (Carruthers et al., 2003). The Canadian case definition uses the term Myalgic Encephalomyelitis/chronic fatigue syndrome (Carruthers et al., 2003). For the first time, specific symptoms were required for a diagnosis (e.g., post-exertional malaise,
unrefreshing sleep, a significant degree of arthralgia and/or myalgia, and concentration 
and memory problems). One of the hallmarks of ME/CFS is muscle weakness following 
minimal exertion with prolonged recovery time. The extreme post exertional muscle 
fatigueability and relapse on exertion is quite distinct from what most think of as chronic 
fatigue or tiredness. In addition, the IACFS/ME in 2006 published guidelines for a new 
case definition for children and adolescents, using the name pediatric Myalgic 
Encephalomyelitis/chronic fatigue syndrome (Jason et al., 2006). In 2007, the IACFS 
changed its official name to IACFS/ME.

In 2003, the CFS Coordinating Committee¹s Name Change Workgroup recommended 
that it might be best to introduce an umbrella term and subtypes into the field, and 
clearly, some patients with this illness do have inflammation and others do not (Corradi, 
Jason, & Torres-Harding, 2006). If there are distinct subtypes within a diagnostic 
category, samples will not be similar, as they will have different percentages of critical 
characteristics, symptoms, and biomarkers. Similar to disorders such as cancer, it is 
highly likely that a number of distinct types exist and that the current method of grouping 
all individuals who meet CFS diagnostic criteria together is complicating the 
identification of biological marker that will help scientists unravel the pathophysiology of 
this illness. The recommendations by the Name Change Workgroup was not endorsed by 
the CFS Advisory Committee.

Controversy has occurred concerning whether ME should stand for Myalgic 
Encephalomyelitis or Myalgic Encephalopathy. Shepherd (2007), for example, states that 
the term encephalomyelitis indicates that widespread inflammatory change taking place 
within the brain (i.e., encephalitis) and the spinal cord (i.e., myelitis). Shepherd (2007) 
suggests that while there might be past or present inflammatory changes within the 
central nervous system in some patients, there is not evidence of this in all patients. 
Shepherd (2007) prefers the term encephalopathy which he states refers to the following:

“1. A significant and sometimes diffuse disorder of the brain that can involve both 
changes to structure and function. 2 A neurological disorder than can be caused by 
infections (viral, bacterial, prion), metabolic or mitochondrial dysfunction, exposure to 
toxins (e.g., drugs, chemicals, pesticides), lack of oxygen or blood supply to the brain. 3 
A disorder that commonly produces serious disturbances in cognitive function - involving 
memory, concentration etc. 4 Other neurological symptoms that can be found in an 
encephalopathy include myoclonus (twitching of muscles or muscle groups), nystagmus 
(involuntary eye movements), tremor, muscle atrophy and weakness, dysequilibrium (and 
unsteady gait), paraesthesiae (sensory disturbances), hypothalamic dysfunction, 
orthostatic intolerance and postural hypotension. 5 More serious neurological symptoms, 
as described in section 4.2.1.2 of the Chief Medical Officer's report (e.g., seizures), can 
also be found in encephalopathies. 6 Mood disturbances can occur. 7 Abnormalities can 
be found on neuroimaging, spinal fluid examination and electroencephalograms - 
depending on the cause of the encephalopathy.”

However, others point out that encephalopathy is too general and can be any dysfunction 
or disorder of the brain. The specific objection being that encephalopathy could cover so
many different types of brain and/or central nervous system pathologies it wouldn't be respected as the name of a particular disease by the medical community. Moreover, encephalopathy is usually not a stand alone diagnosis but is associated with other conditions. So while many encephalopathy examples may be accurate, the point is that there are many types. Furthermore, from a clinical standpoint, descriptions of encephalopathy often refer to dementia. The hallmark of encephalopathy is altered mental status. While accurate, patients have recognized that this could be problematic. Mental health professionals often argue that the boundaries between mental and physical aren't rigid and that they are very much interrelated. In other words, encephalopathy could be used in a psychiatric context, whether linguistically 'correct' or not. Patients also feel that because there is no definition for Myalgic Encephalopathy, so to promote this term without a definition leaves too much leeway for another broad definition which will allow the "misinterpretation" of the neurological symptoms as "unexplained somatic..." and thereby allow the continued misrepresentation the illness.

Another issue brought up by advocates of Myalgic Encephalomyelitis is that it is not that there is a lack of inflammation but that we do have conclusive evidence to confirm or deny the existence of inflammation. Advocates of Myalgic Encephalomyelitis also state that the name of an illness forms its identity and terminology has never required strict all encompassing scientific accuracy or proof. Malaria means bad air. Lyme is a town. Ebola is a river. The name poliomyelitis is not required to change to polio-opathy after the acute phase. In addition, the name Myalgic Encephalomyelitis has a 50 year history in the medical literature and it has been formally classified by the WHO as a neurological diseases in the ICD since 1969 and remains classified in the current ICD as a neurological disorder (ICD 10 G93.3). In contrast, Myalgic Encephalopathy is not defined as a specific condition and has no ICD status. Many advocates believe that we would lose that 50 years of historical lineage if we endorsed the term. Myalgic Encephalopathy.

Many feel that there is considerable benefit of maintaining the name Myalgic Encephalomyelitis, which is the most consistently used and most widely recognized name worldwide, with an established neurological WHO ICD code and a well documented history of outbreaks along with extensive epidemiological investigations. Researchers and clinicians need to be aware of the strong sentiments that patients have for Myalgic Encephalomyelitis, which is a historically correct (Ramsay, 1981) and has been used internationally (Hyde, Goldstein, & Levine, 1992).

References


