

“Chronic Fatigue Syndrome” no longer exists as a discrete entity in ICD-10-CM: potential impact in United States and abroad? – Lily Chu

The International Statistical Classification of Diseases and Health-related Disorders, better known as International Classification of Diseases (ICD), was developed at the beginning of the 20th century as an internationally standardized tool to record diagnoses. Clinical staff register diagnoses with codes after each visit or service provided; consequently, the codes are used by health/ disability insurance companies, patient organizations, policy makers, and researchers for multiple purposes, for example, to inform decisions about reimbursement/ coverage, to assess presence and level of disability, and to predict and plan for public health needs.

Since 1900, the ICD has been modified a total of 10 times, ending in 1990. The newest version, ICD-10, significantly expanded the number of codes from ICD-9 9-fold, from 17,000 to 155,000, and was intended to improve the accuracy of recorded diagnoses but in the case of ME/CFS, it is not clear that it will. “Chronic fatigue syndrome”, which originally existed separately (under 780.71) from both ME and post-viral fatigue syndrome (G93.3), is now classified with “chronic fatigue, unspecified” under the code R53.82. Meanwhile, the new Systemic Exertion Intolerance Disease (SEID) criteria continued to be studied with no code assigned yet. Regardless of differing opinions about ME, PVFS, SEID, and CFS and if/ how they relate to one another, one fact is clear: CFS is not the same as chronic fatigue.

In the United States, this has not been an issue until recently since the US set the deadline for adoption of ICD-10 rather late, in October 2015. Some early reports also suggested that the coding for CFS in the US might be handled differently. However, now that all US providers and healthcare entities are required to use ICD-10 as-is, I am concerned that inaccurate reporting of CFS, abetted by the new coding system, will have multiple detrimental effects downstream. In the US, most clinicians are not familiar with ME or PVFS and most likely, if they make a diagnosis, code it under “CFS”. It will not be possible to separate CFS from chronic fatigue easily under the new coding system. Furthermore, even if clinicians were familiar with ME and PVFS, not all CFS patients fit those definitions either.

I am currently in the process of learning about how the US government and other entities as well as non-US clinicians/ governments will/ have address(ed) this issue. It should be noted that ICD-10 is not 100% consistent across countries nor used in the same way and many countries make changes to fit their own needs. I’d like to hear from patients, clinicians, and others about whether you are concerned about this issue, how you have adjusted to the ICD-10, and what we, whether as individual clinicians/ researchers or as organization, should do in the present and future to resolve these issues. Send your comments/ questions to me at lilyxchu@gmail.com. As I learn more about this issue, I will update you in the Newsletter.

Here are two ICD-9 to ICD-10 “translators” in the meantime that might be of interest. Note that they may give slightly different level of details/ answers depending on the diagnosis.

<http://www.icd9data.com/>

<https://www.aapc.com/icd-10/codes>