Proposal Mechanism, ICD-11 Maintenance Platform:


Proposal:

A new proposal for addition of exclusions for 8E49 Postviral fatigue syndrome; Benign myalgic encephalomyelitis; and Chronic fatigue syndrome under 6C20 Bodily distress disorder was submitted on December 02, 2019. This proposal was approved and implemented on January 17, 2020.

Rationale:

The author has no affiliations or conflicts of interest to declare.

In ICD-10, there is an exclusion for G93.3 Postviral fatigue syndrome under F48.0 Neurasthenia and its inclusion, Fatigue syndrome [1]. Chronic fatigue syndrome is indexed in Volume 3: Alphabetical Index to the G93.3 code [2].

The NHS Digital publication: National Clinical Coding Standards ICD-10 5th Edition (2018) provides the following guidance (on page 84):

"Caution is required when 'fatigue syndrome' is used as a diagnosis within the medical record. The Alphabetical Index takes the coder to F48.0 Neurasthenia which includes fatigue syndrome. However many patients actually have chronic fatigue syndrome, which is an alternative name for the postviral fatigue syndrome or myalgic encephalomyelitis (ME). Chronic fatigue syndrome is coded to G93.3 Postviral fatigue syndrome. Coders should therefore clarify the nature of the fatigue with the responsible consultant before assigning a code." [3].

For ICD-11, the ICD Concept Title, Postviral fatigue syndrome and its specified inclusions, Benign myalgic encephalomyelitis; and Chronic fatigue syndrome are coded at 8E49 in Chapter 08: Diseases of the nervous system, under parent: Other disorders of the nervous system [4].

For ICD-11, there are currently no exclusions for 8E49 Postviral fatigue syndrome and its specified inclusions, Benign myalgic encephalomyelitis; and Chronic fatigue syndrome under 6C20 Bodily distress disorder (which has subsumed and replaced ICD-10's F48.0 Neurasthenia and its inclusion, Fatigue syndrome, and most of ICD-10's F45.x Somatoform disorders).

In support of earlier submissions (which were rejected without adequate rationales being provided), I have already provided evidence that the new ICD-11 Concept Title term and disorder construct: Bodily distress disorder is being confused by academics, researchers and clinicians with the differently conceptualised, Fink et al (2010) Bodily distress syndrome (BDS), under which construct the authors subsume CFS, ME, IBS and Fibromyalgia under a single, unifying BDS diagnosis [5].

This was predicted and inevitable, since the term "Bodily distress disorder" has a history of being used interchangeably (since 2007) for the Fink et al (2010) "Bodily distress syndrome" construct.

While this concern has been acknowledged by Fuss, Jakob, Reed et al (2019) it remains unaddressed [6].

In their March 2017 submission, Chapman & Dimmock set out their rationale for proposing exclusions under 6C20 Bodily distress disorder for (Benign) myalgic encephalomyelitis; and Chronic fatigue syndrome (see Proposal item: 4.3 Exclusions under Bodily distress disorder) [7].
The authors recommended insertion of exclusions for these terms to mitigate the risk of misdiagnosis with, or misapplication of an additional diagnosis of Bodily distress disorder. Again, this proposal was rejected without adequate rationales being provided.

In this new submission for exclusions, I need to draw your attention to this book chapter:


In this book chapter, the authors state:

"Chronic Fatigue Syndrome"

"This condition, earlier described as "neurasthenia" and "post viral fatigue" in ICD-10, was not included in DSM-IV nor DSM-5. It is classified in ICD-11 under "other disorders of the nervous system" as "post viral fatigue syndrome." This category includes the illnesses termed "benign myalgic encephalitis" [sic] and "chronic fatigue syndrome." If the fatigue is not associated with a virus, it is recommended to consider coding it within "disorders of bodily distress," which can present with a single symptom (e.g., fatigue) or multiple symptoms (e.g., fatigue, pain, aches)."

However, not all cases of myalgic encephalomyelitis or chronic fatigue syndrome in adults or children are preceded by a viral infection [9].

The WHO, itself, has stated: "In response to the many proposals on Chronic fatigue syndrome, the WHO Secretariat has conducted a vast amount of research . . . The condition is characterized by chronic, profound, disabling, and unexplained fatigue and coinciding symptoms such as sleep problems or post-exertional malaise. There is no agreement on a reliable diagnostic symptom pattern. The etiology is still being discussed . . . As a result of this study, the category 'postviral fatigue' that is the indexing target, will not be changed as currently there is no evidence to suggest a better place. The entity will retain its name and remain within the Nervous system chapter. The Medical and Scientific Advisory Committee and the Classification and Statistics Advisory committee supported this decision. Team3 WHO 2019-Mar-04 - 22:58 UTC" [10].

Since ICD-11 includes no definitions, descriptions, criteria or any other textual content for any of the terms coded to 8E49 nor any guidelines for coders and clinicians on the application of this code, it is presumptuous and inappropriate for these authors to be recommending that paediatric Chronic fatigue syndrome "not associated with a virus" should be considered for coding under 6C20 Bodily distress disorder.

This book chapter, published this year by the International Association for Child and Adolescent Psychiatry and Allied Professions, and published ahead of implementation of ICD-11 by any member states, provides clear evidence that children and adolescents with a diagnosis of Chronic fatigue syndrome are at risk of the new Bodily distress disorder classification being misapplied.

It should also be noted that the WHO has published no field trial results or field trial evaluations on the validity, reliability, safety, prevalence and acceptability of the application of the core ICD-11 Bodily distress disorder construct in children and adolescents.

Will WHO classification experts and the MSAC and CSAC committees please consider the above when reviewing as yet unprocessed proposals and reconsider recommendations for insertion of exclusions for 8E49 Postviral fatigue syndrome; Benign myalgic encephalomyelitis; and Chronic fatigue syndrome under 6C20 Bodily distress disorder?
If WHO classification experts, MSAC and CSAC are not prepared to approve insertion of exclusions for these terms (which would also put ICD-11 at variance with ICD-10 and the clinical modifications of ICD-10, which explicitly exclude G93.3 under Neurasthenia) will a rationale for their decision please be provided?

References:

1 ICD-10 Version 2016: https://icd.who.int/browse10/2016/en#F48.0

   https://apps.who.int/iris/handle/10665/246208
   PDF: https://apps.who.int/iris/bitstream/handle/10665/246208/9789241549165-V3-eng.pdf

3 National Clinical Coding Standards ICD-10 5th Edition:

4 ICD-11 MMS Concept Title 8E49 Postviral fatigue syndrome:
   https://icd.who.int/browse11/l-m/en#http://id.who.int/icd/entity/569175314

5 Proposal for Deletion of the Entity: Bodily distress disorder:


7 Complex Hierarchical Changes Proposal: Rationale section: 4.3 Exclusions under Bodily distress disorder:
   https://icd.who.int/dev11/proposals/f/en#http://id.who.int/icd/entity/988657115?readOnly=true&action=ComplexHierarchicalChangesProposal&stableProposalGroupId=4b26ab6a-393f-4a39-9051-4ac1d4b1a55a


9 "The cause of ME/CFS remains unknown, although in many cases, symptoms may have been triggered by an infection or other prodromal event, such as "immunization, anesthetics, physical trauma, exposure to environmental pollutants, chemicals and heavy metals, and rarely blood transfusions" (Carruthers and van de Sande, 2005, p. 1)." National Academy of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. The National Academies Press. May 2015.
   https://www.nap.edu/catalog/19012/beyond-myalgic-encephalomyelitis-chronic-fatigue-syndrome-redefining-an-illness

10 Proposal Mechanism Rejection notice: Team3 WHO, November 19, 2018:
    https://icd.who.int/dev11/proposals/f/en#http://id.who.int/icd/entity/569175314?readOnly=true&action=DeleteEntityProposal&stableProposalGroupId=303c7493-554a-44c8-8e00-bd0c6c4cc6ef