"BODILY STRESS SYNDROME" INFO SHEET

The "International Classification of Diseases" (ICD-11) …
is the manual that determines the diagnostic criteria, and diagnostic codes, used by medical and mental health providers around the world. It is developed by the World Health Organization (WHO) and its eleventh edition is due to be published this year.

Bodily Stress Syndrome (BSS)…
is a new diagnosis that will replace "medically unexplained symptoms" in a special primary care version of the ICD. *When primary care providers think the source of physical symptoms is psychiatric rather than medical, BSS will be the diagnosis*[i,ii]

Why Should This Concern You?
The basic form of BSS changes very little from the current diagnostic construct[iii], but the WHO plans to recommend some additional criteria that will make it extremely difficult for ME patients around the world to get medical care and support[iv,v]. These additional criteria, based on "symptom clusters", were specifically designed to capture patients with ME/CFS and route them into psychiatric care.

How Were the Symptom Cluster Criteria Developed?
Symptom cluster criteria have long been in use in Denmark, where the diagnosis is known as "bodily distress syndrome" (BDS)[vi]. Danish psychiatric researchers listed the key symptoms of a wide range of contested conditions, including ME/CFS, fibromyalgia, premenstrual syndrome, chronic pain that lacks verification, irritable bowel syndrome (IBS), and many others. Then they organized those symptoms into four clusters and added definitions, where moderate BDS involves at least three symptoms in one cluster, and severe BDS involves at least three symptoms in three or more clusters[vii]. These criteria have been shown to effectively "capture" six contested conditions as a single disorder classified in psychiatry[viii].

Symptom cluster criteria were developed before US governmental health authorities announced their conclusion that ME/CFS is a "serious, chronic, complex systemic disease"[ix] – before the PACE trials were discredited, before NICE decided to revise the UK guideline for ME. Though US authorities insist that ME/CFS guidelines should include "a clear indication that the disease is not a psychiatric or somatoform disorder"[x], BDS researchers have never undertaken research that could explain why it would be in patients' best interest to ignore that recommendation. Symptom cluster criteria simply ignore the range of biological research now underway in the US under the guidance the National Institute of Neurological Disorders and Stroke.

Has the World Health Organization Tested Symptom Cluster Criteria?
The WHO recognized that before they could implement BDS symptom cluster criteria in the new ICD for primary care they would have to do some studies outside of Denmark. In the first of those studies, physicians expressed concern that "a positive diagnosis…might make it more likely that a significant organic pathology would be missed", that these criteria "might lead to missing underlying/more severe illnesses",

and that “the variety of symptoms was so extensive that almost any patient could be labeled as such”[iv], while one country noted “chronic fatigue syndrome” as a condition that should not be captured by symptom cluster criteria. The WHO stated its intention to improve the construct, but in their second study concerns about medical safety were entirely ignored.

The WHO’s second study also failed to validate BDS, with only one country out of five concluding that symptom cluster criteria are a viable replacement for the current construct[v]. WHO researchers acknowledged that because of these failures symptom cluster criteria cannot be used to define “bodily stress syndrome”, the new diagnosis for primary care. Unfortunately, they also concluded that symptom cluster criteria should be included alongside the basic BSS criteria as a recommended tool for discerning when patients’ symptoms can safely be diagnosed and managed in psychiatry rather than medicine.

Why Would the WHO Recommend Criteria That Failed in its Studies?
Unexplained symptoms “form one of the most expensive categories of healthcare expenditure”, so researchers in this area have long supported the idea of “shifting some of this expenditure away from numerous investigations for organic disease and toward effective treatment of bodily distress”[xi,xii].

What About the General ICD and Its Online Draft?
There has been a lot of public attention to the general ICD, which has a “beta draft” online. Many have been aware that the category of “somatoform disorders” is under revision in that draft[xiii]. This is the diagnosis in psychiatry for physical symptoms caused by mental distress, and it will be replaced in the general ICD by “bodily distress disorder”, or BDD (which is a lot like “somatic symptom disorder” in the most recent DSM). Criteria for BDD are not particularly problematic for ME patients. They are compatible with construing ME as a biological disease.

There has also been attention to the category of ME in the beta draft for the general ICD. In November 2017 the neurology workgroup posted a proposal for that category suggesting that ME should be moved out of neurological diseases and into the signs and symptoms section of musculoskeletal disorders[xiv]. If implemented, that proposal would ensure that ME patients will be captured by symptom cluster criteria in the ICD for primary care.

Why Hasn’t Anyone Heard About This?
It has been reasonable for those who work in ME advocacy to focus on the beta draft for the general ICD. As that draft has publicly developed, however, a different ICD has been developed outside of public view that will only be used in primary care. The new ICD for primary care (known as ICD-11-PHC) does not have to adopt the same diagnostic constructs that are adopted in the general ICD. Plans have been underway for many years to adopt bodily distress disorder (BDD) in the general ICD, while the parallel category in primary care will be called bodily stress syndrome (BSS), and will have a different set of diagnostic criteria.

Which ICD Will Control Care for ME Patients?
The primary care diagnosis of BSS will have far greater power in determining how ME patients are diagnosed and treated than any diagnosis listed in the general ICD. BSS in primary care is designed to reduce the immense cost of contested conditions and unexplained symptoms in every national health system. The most effective way to do that is to ensure that patients with these conditions, including ME, are routed off of the medical track and onto the psychiatric track when they first seek care from primary care providers, before they ever shift into settings where the general ICD would apply. Symptom cluster criteria have been shown to be very effective at that task[xv].

What Can We Do About It?
It is very important to be clear and focused about the nature of the objection. ME advocates have no reason to object to the basic criteria for BSS in the ICD for primary care, ICD-11-PHC. In fact, it is in the interests of ME patients to encourage the WHO to adopt just the basic criteria for BSS as they are currently in place. Both studies by the WHO support doing so, and an additional, independent study in Austria also supports doing so[xvi]. This is the goal.

The ME community has very strong reasons to object to the additional recommendation of symptom cluster criteria for BSS in ICD-11-PHC. This is where attention needs to be focused.

Final decisions about ICD-11 will be made by the World Health Assembly, which meets once each year. These votes have long been planned for this year's Assembly on May 21-26, but at this time it is unclear whether ICD voting will take place this year or be rescheduled for next year. Physicians in WHO studies expressed concern that symptom cluster criteria are not medically safe. It is reasonable to expect that this would be a common reaction among physicians and physician organizations who become informed about BSS.

At this time it seems clear that the US health authorities driving the new biological approach to ME are unaware of the WHO's intention to route ME patients across the globe into psychiatry through the ICD-11-PHC. All of those researchers and governmental health leaders have strong reasons to object to the inclusion of symptom cluster criteria with BSS in ICD-11-PHC.

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