**IMMEDIATE ACTION NEEDED**

**Bodily Stress Syndrome...**
is a new diagnostic label that will be applied in primary care when patients seek medical care for bodily symptoms, but doctors think the source of the problem is psychiatric rather than medical\(^1\)\(^2\). (“It’s all in your head”, as it’s commonly known.)

**The “International Classification of Diseases”...**
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. The WHO has been working for years on “Bodily Stress Syndrome”, or “BSS”, as a replacement for the psychiatric category of “medically unexplained symptoms” in primary care\(^3\)\(^4\).

**Why Should This Concern You?**
Much of what’s proposed for BSS changes very little from the current diagnosis\(^5\)\(^6\), but the WHO plans to include some criteria\(^4\) that “serve as a decision node...on which conclusions on the absence of serious disease are based”\(^5\). These criteria are based on “symptom clusters”\(^7\) and they have not been tested for medical safety.

In fact, in the first study performed by the WHO, 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”\(^3\). The WHO stated its intention to improve the construct, but in their second study\(^4\) these concerns were entirely ignored. Moreover, in the second study only one in five countries found the symptom cluster criteria to be viable.

**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”\(^8\)\(^9\).

**How Were the Symptom Cluster Criteria Developed?**
These criteria have long been in use in Denmark, where the diagnosis is known as “bodily distress syndrome” (BDS)\(^10\). Danish psychiatric researchers studied the symptoms of contested conditions, including ME/CFS, fibromyalgia, premenstrual syndrome, tension headache, chronic pain that lacks verification, irritable bowel syndrome (IBS), and many others. Then they organized those symptoms into four clusters and added criteria, where moderate BDS involves at least three symptoms in one cluster, and severe BDS involves at least three symptoms in at least three clusters\(^11\). As a diagnostic tool, BDS has been shown to effectively “capture” six contested conditions as a single disorder classified in mental health\(^12\).
There exist no evidence-based evaluations of the BDS mental health approach as compared to the medical approach for ME/CFS, PMS, fibromyalgia, IBS or any of the other contested conditions. Because BDS has been shown to successfully “capture” so many contested conditions, it is commonly believed in psychiatry that its criteria will generally be successful in capturing symptoms caused by psychological distress in primary care.

Evidence-based support for a new diagnostic construct must show that it can capture all those who have the condition, and exclude all those with similar conditions that are actually distinct. No research has ever determined whether BDS criteria successfully exclude patients with known disease. For this reason, recommending these criteria in primary care would pose substantial medical risk for patients with contested conditions, unexplained symptoms, and difficult to diagnose diseases, particularly rare disorders and autoimmune diseases.

Why Hasn’t Anyone Heard About This?
There has been a lot of public attention to the parallel category in the general ICD, where the WHO has decided to replace the old construct with “bodily distress disorder” (which is much like “somatic symptom disorder” in the DSM-5). Many have believed that the primary care manual would have to adopt the same construct as the general ICD. That is not the case. The WHO has intended for years to give primary care its own diagnostic construct, based on Denmark’s bodily distress syndrome. Because the primary care ICD does not have a public “Beta Draft”, these plans have proceeded without much public awareness.

The WHO is apparently not concerned that that symptom cluster criteria in primary care would capture many conditions listed in the general ICD as medical diseases (such as myalgic encephalomyelitis), and direct them down the track of mental health care. It is important to note that because patients typically enter the medical system through primary care, symptom cluster criteria in primary care would prevail over medical diagnostic listings in the general ICD.

Where Do Things Stand Right Now?
Because BDS symptom cluster criteria failed in studies, the WHO recognizes that they cannot proceed with their original intention of using them as diagnostic requirements for bodily stress syndrome. Still, at this time, they have stated an intention to include them as a recommended tool for discerning which primary care patients should no longer receive medical testing and treatment. The final decision on this has not yet been made.

What Can We Do About It?
It is possible that with a widespread, unified, well supported objection to symptom cluster criteria for BSS, professionals in patient advocacy can convince the WHO not to include them in the new ICD for primary care.


13 Kole A and Faurisson F. *The Voice of 12,000 Patients: Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe*, Eurodis 2009:47-48.

