November 15, 2013

Donna Pickett
National Center for Health Statistics - CDC
3311 Toledo Rd
Room 5419
Hyattsville, MD 20782

Dear Ms. Pickett,

We are writing you to oppose the proposed insertion of Somatic Symptom Disorder into the ICD-10-CM Tabular List and Alphabetical Index in regards to the proposals on September 18-19, 2013 meeting of the ICD-9-CM Coordination and Maintenance Committee

Specifically referenced: Diagnostic Agenda, Page 45: Additional Tabular List Inclusion Terms for ICD-10-CM

Add Somatic Symptom Disorder to ICD-10-CM Tabular List under F45 Somatoform Disorders as inclusion term to F45.1 Undifferentiated somatoform disorder.

Add Somatic Symptom Disorder to ICD-10-CM Alphabetic Index. - Requestor for proposal: Unspecified

We are objecting on the grounds that:

1. There is no body of published research on the epidemiology, clinical characteristics or treatment of the APA's Somatic symptom disorder construct.

2. There is a paucity of rigorous evidence for the validity, safety, reliability, acceptability and utility of the SSD construct when applied to adults and children in diverse clinical settings and across a spectrum of health and allied professionals.

3. NCHS/CMS has insufficient scientific basis for the approval of SSD as a valid new disorder construct for inclusion within ICD; has published no independent field trial data and provided no rationale to inform public responses.

4. SSD does not meet NCHS/CMS criteria for "new diseases/new technology procedures, and any minor revisions to correct reported errors in these classifications" and should not be considered for approval during a partial code freeze.

In DSM-5, the requirement for eight symptoms has been dropped to just one or more persistent, non-specific, distressing somatic symptoms and the clinician's perception of "excessive" or "maladaptive" response to the symptom or symptoms. Symptoms may or may not be associated with another medical condition: SSD allows for the application of a mental health diagnosis in patients with "established general medical conditions or disorders" like diabetes, heart disease

and cancer or presenting with "somatic symptoms of unclear etiology" if the clinician considers the patient otherwise meets the new criteria.

Patients with chronic fatigue syndrome (CFS) and fibromyalgia (FM), "almost a poster child for medically unexplained symptoms as a diagnosis," according to SSD work group chair, Joel E Dimsdale, or chronic Lyme disease, Gulf War illness, chemical injury and chemical sensitivity; women with potential symptoms of gynecological disease, like ovarian cancer, already often late-diagnosed, endometriosis or interstitial cystitis, or patients with vague neurological symptoms may be particularly vulnerable to misapplication or misdiagnosis with a mental health disorder under the SSD criteria.

As you no doubt are aware, despite progress in biomedical research, we still have diseases in which the cause or pathology is not completely known, but they are nonetheless clearly biomedical diseases and not psychological or psychiatric. Additionally, some diseases present with symptoms that either do not have abnormal biological tests in the early stages or which have biological tests that fluctuate.

However, the new criteria still can be – and likely will be – misapplied to those who suffer from myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), fibromyalgia, chronic Lyme disease, multiple chemical sensitivities and Gulf War illness. All of these complex multi-system dysfunction diseases include multiple symptoms and are difficult to diagnose. Since the objective biological abnormalities found in these patients are used in research but not in clinical settings, diagnosing these illnesses is based on symptoms. The Centers for Disease Control and prevention states that more than 80% of ME/CFS patients have not received a proper diagnosis.

1. Some are often misdiagnosed with depression.
2. We certainly don't want to see the DSM-5 changes exacerbate this problem.

There has been considerable opposition to the introduction of this new, poorly tested construct into the DSM-5 amongst patients, care givers, advocates, consumer organizations, mental health practitioners and clinicians and considerable concern for the implications for diverse patient populations that the Somatic Symptom Disorder category will provide a "dustbin diagnosis" for the so-called "functional somatic syndromes," for those living with chronic pain and for patients with persistent, but as yet undiagnosed symptoms of disease.

In addition to the harm done to patients, we also foresee a flood of patients with complex multi-system diseases without biomarkers overwhelming unprepared and untrained psychiatrists who will apply the wrong medication and the wrong treatments based on the patient being misdiagnosed as SSD. The frustration these psychiatrists and psychologists will feel when the patients don't respond to treatments or get worse from inappropriate treatments will be harmful to the patient / psychiatrist relationship. Misdiagnosis of these patients as having a psychiatric or psychological disorder will also lead to limitations of their disability benefits and coverage for medical tests.

The sad history of many biomedical diseases is that patients are at first not believed. Then they are misdiagnosed as having psychiatric or psychological diseases, until the science reveals the

truth of the disease. This has been true for stomach ulcers, first thought to be caused by stress but now known to be caused by bacteria; multiple sclerosis, first thought to be a type of hysteria but now known to be an autoimmune disease; and more recently, Gulf War syndrome, first thought to be psychiatric or caused by stress but now known to be a multi-system disease. Given this history, the APA should be judicious in making the criteria for psychiatric disorders with chronic physical symptoms, such as SSD, very narrow or discarding the diagnosis from the DSM until research can better define it.

The proposal for addition to the ICD-10-CM as an inclusion term during a partial code freeze should be rejected. In addition there should be no implementation in October 2015 as an inclusion term to F45.1 or to any other existing code, or with a unique code created.

Sincerely,

Michael Munoz
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Jennifer M. Spotila, JD.
Occupy CFS blog
Patient Advocate

Billie Moore
Patient Advocate

Charlotte von Salis, JD
Patient Advocate

Mary Schweitzer, Ph.D.
Patient Advocate

Mary Dimmock
Patient Advocate

References:

1. W. C. Reeves, "Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia," Population
Health Metrics, 2007.

2. J. P. Griffith, "A Systematic Review of Chronic Fatigue Syndrome: Don't Assume It's Depression," The Primary
Care Companion to the Journal of Clinical Psychiatry, pp. 120-128, 2008.