



PATIENT ALLIANCE FOR NEUROENDOCRINE IMMUNE DISORDERS
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DSM-5 Task Force American Psychiatric Association
1000 Wilson Boulevard Suite 1825
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Members of the DSM-5 Task Force,

In representing millions of patients with misunderstood multi-system diseases, we are submitting these comments on the proposed Somatic Symptom Disorder diagnostic criteria.

The most recent revision of the DSM-5 makes the improvement of removing the criterion of “medically unexplained symptoms.” 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 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.

All three criteria are too subjective and too broad or mimic the criteria for ME/CFS and other chronic multi-system diseases such that it is “not a valid construct” and cannot “be used reliably.” Therefore, we ask that you narrow the criteria or wait until more research is completed that will inform how to differentiate SSD from chronic multi-system diseases.

Why SSD, as it is presented in the current DSM-5 draft, should be rejected

Symptoms match other diseases:

Criterion A for the proposed SSD says: “Somatic symptoms: One or more somatic symptoms that are distressing and/or result in significant disruption in daily life.” The symptoms which the patient may describe, according to the

PHQ Somatic Symptoms Short Form on the DSM-5 website, include stomach problems, pain in the back, pain in joints or arms and legs, headaches, dizziness, chest pain or getting out of breath, feeling tired or having low energy and trouble sleeping. We note that the patient can have just one of those symptoms and receive the diagnosis if they also have criteria B and C.

According to the CDC, the symptoms of chronic fatigue syndrome include unrefreshing sleep, persistent muscle pain, joint pain, headache, and increased malaise (extreme exhaustion and sickness) following physical activity or mental exertion.³ These are part of the diagnostic criteria for chronic fatigue syndrome. The CDC says these patients also commonly experience abdominal pain, bloating, chest pain, diarrhea, jaw pain, dizziness, nausea and shortness of breath.³

Symptoms proposed to diagnoses SSD:

- Stomach problems -->
- Pain in the back ----->
- Pain in the joints or arms and legs
- Headaches ----->
- Chest pain or getting out of breath ----->
- Dizziness ----->
- Feeling tired or having low energy ----->
- Trouble sleeping ----->

Symptoms found in ME/CFS patients:

- Abdominal pain / bloating / nausea / diarrhea
- Persistent muscle pain / joint pain
- Headaches
- Chest pain / shortness of breath
- Dizziness
- Increased malaise (extreme exhaustion and sickness) following physical activity or mental exertion
- Unrefreshing sleep

The similarity of symptoms for ME/CFS, which is not a psychiatric illness, to the SSD symptom list would make one wonder if the APA was trying to confuse the two conditions. Clearly, if the intent is to aid medical professionals in differentiating SSD from complex multi-system diseases that also have varying and sometimes severe symptoms, then more work needs to be done on the SSD criterion A, or the diagnosis should not be in the DSM until research better defines SSD.

Vague behavior and thoughts description are subjective and will lead to misjudgments:

Criterion B for the proposed SSD says: "Excessive thoughts, feelings, and behaviors related to these somatic symptoms or associated health concerns: (1) Disproportionate and persistent thoughts about the seriousness of one's symptoms. (2) Persistently high level of anxiety about health or symptoms. (3) Excessive time and energy devoted to these symptoms or health concerns."

We ask you to imagine a healthy man who has a professional career with the responsibility of providing for a wife and children. Then this man catches a case of mononucleosis, but he does not recover. The symptoms continue for months and the man is so sick with fatigue and inability to concentrate that he is unable to work. This man goes to many physicians and cannot find a diagnosis. His health insurance is canceled because he lost his job due to his debilitating symptoms, yet many doubt he is really sick. His symptoms are so severely disabling that he worries that he has something progressive or deadly.

This man may spend much time researching illnesses on the Internet and going to multiple physicians in hopes of finding answers. He might even fly to other countries in hopes of finding a physician who can diagnose or treat what he has. He fears that he will lose his wife, as he has already lost his job, and he may not be approved for disability benefits as no one has given him a diagnosis that makes sense. He may be very anxious as to how his disability may lead to losing his home.

Are this man's thoughts excessive? Are they disproportionate because he thinks he may have a deadly disease? Because he spends hours trying to find out what is wrong with him, is it excessive?

This man's experience is common among those who suddenly come down with ME/CFS, which the CDC says "can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, and end-stage renal disease, chronic obstructive pulmonary disease (COPD), and similar chronic conditions." Because the disease is so disabling and impacts a person's life so negatively, and ME/CFS patients may go years or decades before they get the appropriate diagnosis, the normal response is for the person to be anxious about his health. He will go to many doctors and spend time doing his own research to find answers. This should be considered a mentally and cognitively healthy response to such a terrible situation.

An accurate determination of what is an "excessive" or "disproportionate" thought or behavior to a situation will depend on an accurate understanding of that situation. And the sad fact is that much of the medical profession does not have an accurate understanding of ME/CFS as shown by the CDC's statement that more than 80% of the patients have been misdiagnosed or are undiagnosed. This is also true of psychiatrists because they are not trained in ME/CFS treatment or diagnosis as it is not a psychiatric disorder.

Without objective measures of what is considered "excessive" or "disproportionate," the SSD criterion B will lead to over diagnosis because of medical professional ignorance, bias or simply confusion. Thus, the subjective nature of criterion B for the proposed SSD means it cannot be used reliably. Criterion B should be changed or the diagnosis withdrawn from the DSM-5 draft until more research shows how to objectively measure excessive thoughts or behavior in light of diseases with multiple and sometimes severe symptoms that are a result of a difficult-to-diagnose physiological disease that does not yet have a clinically available biomarker test.

Chronicity matches other multi-system diseases:

Criterion C for the proposed SSD says, "Chronicity: Although any one symptom may not be continuously present, the state of being symptomatic is persistent (typically >6 months)."

The CDC website says the diagnosis of chronic fatigue syndrome requires the following:

- The individual has had severe chronic fatigue for 6 or more consecutive months that is not due to ongoing exertion or other medical conditions...
- The individual had 4 out of 8 other symptoms that "should have persisted or recurred during 6 or more consecutive months of illness..." (see above list)

The CDC website also says, "The cause or causes of CFS have not been identified, and no specific diagnostic tests are available." This disease is diagnosed on symptoms and excluding other conditions that could cause these symptoms, including psychiatric and psychological ones.

But if the symptom list is almost identical and the chronicity time is the same (6 months), then patients with ME/CFS will be misdiagnosed as having SSD as no diagnostic test can be used to distinguish the two. Thus, the proposed SSD is not a workable construct for diagnosing a psychological or psychiatric disorder and distinguishing it from chronic multi-system diseases that also require symptoms to last six months before being diagnosed.

Impact of the wrong criteria:

In addition to the harm done to patients, we also can foresee a flood of patients with 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.

We feel sure the APA wants to avoid misdiagnosis and mistreatment of patients. We feel sure the APA does not want patients with normal responses to undiagnosed multi-system diseases to be sent to psychiatrists who do not have the tools or training to treat their physiological illness. So we ask the DSM-5 Task Force to provide better and narrower criteria, with objective measures, to the SSD diagnosis or do not include it in the DSM-5.

Sincerely,

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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.
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