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DSM-5 Task Force
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Members of the DSM-5 Task Force

As Executive Director of the Rocky Mountain CFS/ME & FM Association, we wish to comment on the proposals for DSM-5 and particularly on the newly created category for "Complex Somatic Symptom Disorder" (CSSD) and the category "Simple Somatic Symptom Disorder" (SSSD).

We are very concerned about the real harm that can come to patients through the misuse of the SSD and especially the CSSD in clinical practice. This is especially true for patients with ME/CFS or other diseases like Fibromyalgia, Gulf War Illness and IBS that are misunderstood, misdiagnosed and mistreated by the medical community at large. And while the DSM-5 proposal itself does not call out any specific disease, there is additional concern for ME/CFS patients because of discussions over time that have mentioned CFS specifically in the context of "somatic presentations of mental disorders" (4).

The biggest concerns are:

1. Continued stigma for ME/CFS: Despite ample evidence of the pathobiology of ME/CFS (5), patients are still subject today to the insistence by their doctors that there is nothing wrong and they are 'just depressed'. Establishing the CSSD framework that includes hypochondriacs and yet could also be easily applied to patients with real and serious medical diseases like ME/CFS only exacerbates the stigma and mistreatment that these patients have suffered for years. ME/CFS is especially subject to this because the ICD-10-CM categorizes CFS under "Signs and Symptoms/Malaise and Fatigue" and because those studying somatic symptoms of mental disorders specifically call out CFS (4).
2. Misuse and misapplication of the category: The highly subjective nature of the criteria, especially when applied to real diseases that are poorly understood by the practicing physicians, will lead to misuse of this category and the incorrect diagnosis of a psychological disorder. The "Justification for Criteria – Somatic Symptoms" (3) acknowledges that 'A key issue is whether the guidelines for CSSD describe a valid construct and can be used reliably.' Unfortunately, the document does not provide a satisfactory explanation. There are severity metrics proposed for CSSD but these do little to allay concerns when the benchmarks for normal response include healthy volunteers on the one hand and hypochondriacs on the other. How will these instruments be validated for ME/CFS, which has recently been reported to have "a greater impact on functional status and well being than other chronic diseases such as cancer" (6)

This is a huge issue for patients with diseases that are poorly understood. Every day, people who are very sick with real diseases like ME/CFS, Lyme disease, Fibromyalgia, Gulf War Illness and IBS are told that there is nothing wrong with them. It is not hard to imagine that their unwillingness to accept that diagnosis could be judged as 'disproportionate and persistent concerns about the medical seriousness of one's symptoms' by their medical doctors.

Once the physician applies a mental health label by diagnosing CSSD (whether as the primary diagnosis or as a secondary diagnosis), there will be profound implications for the patient for diagnosis, treatment, disability and insurance.

3. Inappropriate Treatments and Withholding of Needed Diagnostics: The “Justification for Criteria – Somatic Symptoms” (3), in explaining the creation of CSSD, states that “treatment interventions are similar in this group of disorders” and describes the use of antidepressant medications and CBT for “the identification and modification of dysfunctional and maladaptive beliefs about symptoms and disease, and behavioral techniques to alter illness and sick role behaviors and promote more effective coping.” It further states that “all of these disorders benefit from specific interventions with the patient’s non-psychiatric physician (e.g. scheduling regular appointments as opposed to prn appointments, limiting testing and procedures unless clearly indicated)”. We only need to look to England and the NICE Guidelines to understand the disastrous effects of such standards. In the hands of a doctor truly knowledgeable about ME/CFS, CBT and anti-depressants may sometimes be part of an effective treatment plan. But all too often, the treatments are misused by doctors who don’t understand the disease and instead believe that the real problem with the patient is his false illness beliefs or that he is just depressed. Suggesting that doctors focus on these as treatments and limit testing and procedures in such a scenario could have a disastrous impact on the patient’s life.

4. Alignment with ICD: While the DSM-5 is separate from the ICD-10 and is used primarily by mental health practitioners, there is an alignment between the two today. It appears that that will continue with ICD-11 although it is not clear at this time how that will be achieved. Instituting the CSSD in the ICD-11 would have negative implications not only for the US but also for all other countries.

We are not alone in voicing serious concern for the unintended consequences of the DSM-5 plans for SSSD and CSSD. Numerous organizations and individuals stated these same concerns in the April 2010 review cycle yet the CSSD category remains essentially unchanged. Even members of the psychiatric community, most prominently Dr. Allen Frances, the chair of the DSM-IV task force and Dr. Robert Spitzer, the chair of the DSM-III task force, have raised concerns with the process, content, direction and unintended consequences of the DSM-5 (7,8,9). Dr. Allen Frances (the chair of the DSM-IV task force) raised this issue of the unintended consequences of the DSM-5, especially around a premature “paradigm shift”. In “A Warning Sign on the Road to DSM-5: Beware of Its Unintended Consequences” (7), he states “Part of the exaggerated claim of a paradigm shift in DSM-5 is based on the suggestion that it will be introducing dimensional ratings and that this will increase the precision of diagnosis... [But] Including an ad hoc, untested, and complex dimensional system in an official nomenclature is premature and will likely lead to similar neglect and confusion”.

We urge you to seriously reconsider the inclusion of this category. For ME/CFS patients and for many other patients with other real but poorly understood diseases, those unintended consequences of implementing CSSD and SSSD could be disastrous.

Thank you for your attention in this matter,

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References

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- 5) NIH State of Knowledge Workshop on ME/CFS Video and agenda, April 7-8, 2011 (<http://orwh.od.nih.gov/CSF%202011/newsEvents.htm>)
- 6) L. Nacul et al., "The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers", BMC Public Health, May 27, 2011 (<http://www.biomedcentral.com/1471-2458/11/402/abstract>)
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