

For the attention of the Somatic Symptom Disorders Work Group: Chair Joel E. Dimsdale, M.D.

*Submitted by Suzy Chapman, advocate and parent/carer of young adult with chronic illness.
Website owner of <http://dxrevisionwatch.wordpress.com> formerly
<http://dsm5watch.wordpress.com>*

Submission in response to J 00 Somatic Symptom Disorder

I note that at June 14, APA has published no report on the results of the *DSM-5* field trials. The majority of stakeholders wishing to provide feedback on this third release of draft proposals have no information on the make-up of the SSD study groups, the numbers studied within each of the three arms or the resulting data.

- **Stakeholders have been obliged to submit comment without the benefit of scrutiny of field trial results to inform their submissions. This is not acceptable.**

For the first and second release of draft proposals, a 7 page "*Disorders Description*" document and a 14 page "*Rationale/Validity Propositions/Justification of Criteria*" document accompanied proposals and expanded on the website *Proposals, Criteria, Rationale* and *Severity* content for this category section. In the case of the latter, this included five pages of references to published and unpublished papers, including a number of papers authored or co-authored by members of the SSD Work Group. With the release of this third and final draft, no updated versions of these two documents were published that reflect significant revisions to SSD criteria between the second and third draft. The unrevised versions have been removed from the website.

- **Stakeholders have been denied access to the more expansive rationales and validity propositions set out within these two documents, the research papers that have been relied on and more detailed explanations for the revisions made to criteria between the second and third iterations in response to field trial results and internal/external input. If the Work Group considered these documents essential background information for the first and second drafts it is unreasonable not to have provided stakeholders with updated versions for this third draft.**

The "*Rationale/Validity Propositions/Justification of Criteria*" document (as published May 4, 2011, for the second public review) states:

"...It is unclear how these changes would affect the base rate of disorders now recognized as somatoform disorders. One might conclude that the rate of diagnosis of CSSD would fall, particularly if some disorders previously diagnosed as somatoform were now diagnosed elsewhere (such as adjustment disorder). On the other hand, there are also considerable data to suggest that physicians actively avoid using the older 6 diagnoses because they find them confusing or pejorative. So, with the CSSD classification, there may be an increase in diagnosis.

"The B-type criteria are crucial for a diagnosis of CSSD. These criteria in essence reflect disturbance in thoughts, feelings, and/or behaviors in conjunction with long standing distressing somatic symptoms. Whilst an exact threshold is perhaps arbitrary, considerable work suggests that the degree of functional impairment is associated with the number of such criteria. Using a threshold of 2 or more such criteria results in prevalence estimates of XXXX in the general population, XXXX in patients with known medical illnesses, and XXXX in patients who may previously have been considered to suffer from a somatoform illness. {text in development concerning impact of different thresholds for criteria B- from Francis}..."

An article by Woolfolk RL, Allen LA. Cognitive Behavioral Therapy for Somatoform Disorders. *Standard and Innovative Strategies in Cognitive Behavior Therapy* states:

"...To receive a diagnosis of complex somatic symptom disorder, patients must complain of at least one somatic symptom that is distressing and/or disruptive of their daily lives. Also, patients must have at least two [SC: now reduced to "at least one from the B type criteria" since evaluation of the CSSD field trials] of the following emotional/cognitive/behavioral disturbances: high levels of health anxiety, disproportionate and persistent concerns about the medical seriousness of the symptom(s), and an excessive amount of time and energy devoted to the symptoms and health concerns. Finally, the symptoms and related concerns must have lasted for at least six months.

"Future research will examine the epidemiology, clinical characteristics, or treatment of complex somatic symptom disorder as there is no published research on this diagnostic category."

"...Just as for complex somatic symptom disorder, there is no published research on the epidemiology, clinical characteristics, or treatment of simple somatic symptom disorder."

The following major changes to proposals are noted for the third draft for the "Somatic Symptom Disorder" category: to merge CSSD and SSSD; to drop the adjective "Complex"; to reduce the threshold for the B type cognitions from "at least two" from the B type criteria to "at least one"; to include three new optional Severity Specifiers: Mild; Moderate; Severe.

That the "B type" criteria are considered highly subjective and problematic has been discussed in previous submissions. There are now particular concerns that the Work Group is proposing to lower the B type threshold.

- **Whilst it is welcomed that the SSD Chronicity criteria of > one month has been removed with the merging of SSSD with CSSD, it is of considerable concern that in order to accommodate SSSD within the CSSD criteria the B type threshold has been reduced from "at least two" to "at least one," thereby potentially increasing prevalence.**
- **It is of considerable concern that no data on prevalence estimates were available for the second review; that no data on impact of different thresholds for the B type criteria and prevalence estimates has been published with the third review; that there is no published research on the epidemiology, clinical characteristics or treatment of this new construct "somatic symptom disorder."**

The group is proposing to operationalize an entirely new construct of its own devising, using highly subjective criteria for which no significant body of research into reliability, validity and safety has been published, that will capture adults, children, adolescents and elderly people with diverse illnesses.

The SSD Work Group's framework *"...will allow a diagnosis of somatic symptom disorder in addition to a general medical condition, whether the latter is a well-recognized organic disease or a functional somatic syndrome such as irritable bowel syndrome or chronic fatigue syndrome."*

"...These disorders typically present first in non-psychiatric settings and somatic symptom disorders can accompany diverse general medical as well as psychiatric diagnoses. Having somatic symptoms of unclear etiology is not in itself sufficient to make this diagnosis. Some patients, for instance with irritable bowel syndrome or fibromyalgia would not necessarily qualify for a somatic symptom disorder diagnosis. Conversely, having somatic symptoms of an established disorder (e.g. diabetes) does not exclude these diagnoses if the criteria are otherwise met." [1]

According to Dr Dimsdale's presentation to APA Conference, May 2012, 15% of the "diagnosed illness" arm of the field trial study (cancer, malignancy and severe coronary disease) met the criteria for SSD when *"one of the B type criteria"* was required; if the threshold was increased to *"two B type criteria"* about 10% met criteria for dual-diagnosis of cancer + *"Somatic Symptom Disorder."*

For the 94 "functional somatic" study group, said to comprise patients with irritable bowel and "chronic widespread pain" (a term used synonymously with fibromyalgia) about 26% were coded when one B type cognition was required; 13% coded with two cognitions required.

If these proposals are approved they have the potential for bringing millions of patients under a mental health banner and greatly increasing application of psychiatric services, anxiolytics, antidepressants and behavioural therapies like CBT, for the *"modification of dysfunctional and maladaptive beliefs about symptoms and disease, and behavioral techniques to alter illness and sick role behaviors."*

- **In light of these field trial findings, it is of considerable concern that the SSD Work Group has yet to publish any projections for prevalence estimates and the potential increase in mental health diagnoses across the entire disease landscape.**
- **It is also of concern that the Work Group has not published on the projected clinical and economic burden of providing CBT and similar therapies for patients for whom an additional diagnosis of "Somatic Symptom Disorder" has been coded across the entire disease landscape.**

In a counterpoint response to Dr Allen Frances' May 12 New York Times Op-Ed piece, APA has stated:

"...There are actually relatively few substantial changes to draft disorder criteria. Those that

have been recommended are based on the scientific and clinical evidence amassed over the past 20 years and then are subject to multiple review processes within the APA."

The "*Somatic Symptom Disorders*" section is one section for which substantial changes to existing disorder criteria are being proposed.

The group reports that preliminary analysis of field trial results shows "*good reliability between clinicians and good agreement between clinician rated and patient rated severity.*" In the field trials for new category proposals, CSSD achieved mediocre Kappa values of .60 (.41-.78 Confidence Interval).

Kappa reliability reflects agreement in rating by two different clinicians corrected for chance agreement – it does not mean that what clinicians have agreed upon are valid constructs. Radical change to the status quo needs grounding in scientifically validated constructs and a body of rigorous studies.

- **It remains a considerable concern that there is *no substantial* body of independent research evidence to support the group's proposals for this new construct.**

During the Q & A session at the end of Dr Dimsdale's APA Conference presentation, a questioner raised the issue that practitioners who are not clinicians or psychiatric professionals might have some difficulty interpreting the wording of the B type criteria to differentiate between negative and positive coping strategies.

Dr Dimsdale was asked to expand on how the B type criteria would be operationalized and by what means patients with chronic medical conditions who devote time and energy to health care strategies to try to improve their symptoms and their level of functioning would be evaluated in the field by a very wide range of DSM users and differentiated from patients considered to be spending "*excessive time and energy devoted to symptoms or health concerns*" or perceived as having become "*absorbed*" by their illness and whose preoccupations were felt to be "*disproportionate.*"

By what means will the practitioner reliably assess an individual's response to illness within the social context of the patient's life and determine what should be coded as "*excessive preoccupation*" or indicate that this patient's life has become "*subsumed*" or "*overwhelmed*" by concerns about illness and "*devotion*" to symptoms? By what means would a practitioner determine how much of a patient's time spent "*searching the internet looking for data*" (to quote an example provided by Dr Dimsdale) might be considered a reasonable response to chronic health concerns within the context of this patient's experience?

I am not reassured from Dr Dimsdale's responses that these B (1), (2) and (3) criteria can be safely applied outside the optimal conditions of field trials, in settings where practitioners may not necessarily have the time nor instruction for administration of diagnostic assessment tools, and where decisions to code or not to code may hang on arbitrary and subjective perceptions.

Implications for a diagnosis of SSD for all patient populations

Incautious, inept application of criteria resulting in a "bolt-on" psychiatric diagnosis of a "*Somatic Symptom Disorder*" may have far-reaching implications for all patient populations:

- Application of highly subjective and difficult to measure criteria could potentially result in misdiagnosis with a mental health disorder, misapplication of an additional diagnosis of a mental health disorder or missed diagnoses through dismissal and failure to investigate new or worsening somatic symptoms.
- Application of an additional diagnosis of "*Somatic Symptom Disorder*" may have implications for the types of medical investigations, tests, treatments and procedures that clinicians are prepared to consider and which insurers are prepared to fund.
- Application of an additional diagnosis of "*Somatic Symptom Disorder*" may impact payment of employment, medical and disability insurance and the length of time for which insurers are prepared to pay out. It may negatively influence the perceptions of agencies involved with the assessment and provision of social care, disability adaptations and workplace accommodations.
- Patients prescribed psychotropic drugs for perceived unreasonable levels of "*illness worry*" or "*excessive preoccupation*" with somatic symptoms may be placed at risk of iatrogenic disease.
- For multi-system diseases like Multiple Sclerosis, Behçet's syndrome or Systemic lupus it can take several years before a diagnosis is arrived at. In the meantime, patients with chronic, multiple somatic symptoms who are still waiting for a diagnosis would be vulnerable.
- Patients who have already received or are in the process of being assessed for an additional diagnosis of SSD may be reluctant to report new and troublesome symptoms for fear of adding to "symptom counts" or of being labelled as "catastrophisers."
- The B type criteria allow for the application of a diagnosis of "*Somatic Symptom Disorder*" where a parent is considered excessively concerned with a child's symptoms [1]. Families caring for children with any chronic illness may be placed at increased risk of wrongful accusation of "*over-involvement*" with a child's symptomatology.

Where a parent is perceived as encouraging maintenance of "sick role behaviour" in a child, this may provoke social services investigation or court intervention for removal of a sick child out of the home environment and into foster care or enforced in-patient "rehabilitation." This is already happening in families with a child or young person with chronic illness, notably with Chronic fatigue syndrome or ME. It may happen more frequently with a diagnosis of a chronic childhood illness + SSD.

Although the Work Group is not proposing to classify Chronic fatigue syndrome, ME, IBS and fibromyalgia, per se, within the "*Somatic Symptom Disorders*", patients with CFS – "*almost a poster child for medically unexplained symptoms as a diagnosis,*" according to Dr Dimsdale's presentation – or with fibromyalgia, irritable bowel syndrome, chronic Lyme disease, Gulf War illness, chemical injury and chemical sensitivity may be particularly

vulnerable to misapplication of or misdiagnosis with a mental health disorder under these SSD criteria.

- **There is considerable concern that this new "Somatic Symptom Disorder" category will provide a "dustbin diagnosis" into which the so-called "functional somatic syndromes" might be shovelled.**

In his journal article *Medically Unexplained Symptoms: A Treacherous Foundation for Somatoform Disorders?* [2] Dr Dimsdale discusses the unreliability of "medically unexplained" as a concept and acknowledges the perils of missed and misdiagnosis:

"...On the face of it, MUS sounds affectively neutral but the term sidesteps the quality of the medical evaluation itself. A number of factors influence the accuracy of diagnoses. Most prominently, one must consider how thorough was the physician's evaluation of the patient. How adequate was the physician's knowledge base in synthesizing the information obtained from the history and physical examination? The time pressures in primary care make it difficult to comprehensively evaluate patients and thus contribute to delays and slips in diagnosis. Similarly, physicians can wear blinders or have tunnel vision in evaluating patients.¹ Just because a patient has previously had MUS is no guarantee that the patient has yet another MUS. As a result of these factors, the reliability of the diagnosis of MUS is notoriously low..."

For DSM-5 then, the Work Group proposes to deemphasize "medically unexplained" as the central defining feature of this disorder group and instead, shift the focus to the patient's cognitions – "excessive thoughts, behaviors and feelings" about the seriousness of distressing and persistent somatic symptoms which may or may not accompany diagnosed general medical conditions – and the extent to which "illness preoccupation" is perceived to have come to dominate the patient's life.

Dr Dimsdale concludes:

"Patients present with an admixture of symptoms, preconceptions, feelings, and illnesses. The task of psychiatric diagnosis is to attend to the patient's thoughts, feelings, and behaviors that are determining his/her response to symptoms, be they explained or unexplained."

In proposing to license the application of an additional mental health diagnosis for *all illnesses* if the clinician considers the patient also meets the criteria for a "bolt-on" diagnosis of SSD, Dr Dimsdale and colleagues appear hell bent on stumbling blindly from the "treacherous foundation" of the "somatoform disorders" into the quicksands of unvalidated constructs and highly subjective, difficult to measure criteria.

Has the Work Group projected for potential increase in law suits against clinicians and APA members for missed diagnoses, misdiagnoses, misapplication of inappropriate treatment regimes and iatrogenic disease that may result from incautious and inept application of its proposed criteria?

- **It is a considerable concern that no clinicians from medical specialties beyond psychiatry and psychosomatics and no general practitioners were invited to sit on the Work Group to input into considerations for the clinical and medico-legal implications of the group's proposals.**

As an advocate, I have received disturbing accounts over the years of patients diagnosed with poorly understood chronic illnesses who have met with contempt and dismissal when presenting in A & E departments following accidents or medical emergencies, or sent home with symptoms uninvestigated. Broken ribs, initially dismissed as "catastrophising," where the patient has had to plead for X-rays to be carried out. Severe, disabling back pain, initially dismissed as "catastrophising" and for which CBT had been prescribed but where eventual scans identified insult to the spinal chord putting the patient at risk of paralysis had surgery not been carried out.

As the patient herself wrote, *"If someone is very ill and in pain is it not normal to feel distressed? How much distress is too much? Who decides what the right amount of distress for any given situation is? What does 'disproportionate' mean in such a situation?"*

What barriers to appropriate care and investigation might patients encounter when presenting for primary, specialist or emergency assessment with an additional diagnosis of "SSD" on their medical records?

Dr Dimsdale concedes his committee has struggled from the outset with these B type criteria but feels its proposals are *"a step in the right direction."*

Patients deserve better than this; science demands rigor.

In the absence of a substantial body of independent evidence for the SSD construct as a reliable, valid and safe alternative, I urge the Work Group not to proceed with its proposals for the reorganization of the "Somatoform Disorders" categories in favour of the status quo, or to dispense altogether with this section of DSM. There can be no justification for replacing one set of dysfunctional, unreliable and unsafe categories with another.

References

[1] *Justification of Criteria - Somatic Symptoms*, May 4, 2011 for second DSM-5 stakeholder review.

[2] Dimsdale JE. Medically Unexplained Symptoms: A Treacherous Foundation for Somatoform Disorders? *Psychiatr Clin N Am* 34 (2011) 511–513
doi:10.1016/j.psc.2011.05.003