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From: Diane O’Leary, PhD

**RE: Comments on proposals, September 18-19, 2013 meeting of the ICD-9-CM
Coordination and Maintenance Committee**

November 14, 2013

As an advocate for diagnostic rights, I strongly oppose the addition of DSM-5’s Somatic Symptom Disorder to ICD-10-CM.

I am a philosopher and author who speaks and writes on behalf of medical patients unable to secure medical care because of confusion about somatoform, or “somatic”, symptoms. The mere fact that there is a place for me in our culture is evidence of immense frustration with diagnostic practice.

We are standing at a crossroads that will define the future. Patients have grown angry about the recklessness of somatoform diagnoses and our mental health diagnostic manual has taken steps to loosen criteria even further.

We are left wondering whether our medical coding system will systematize that radical error or take a stand that forces its revision. While progress on ICD-11 chugs along at its slow pace there are difficult decisions to face. On a continental level we can adopt the DSM-5’s mistake of “Somatic Symptom Disorder”, or we can accept a significant disparity between the DSM and the ICD. Neither situation is desirable, but it is not overstating to say the viability of the patient-physician relationship hangs in the balance.

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The Purpose of a Definition for Somatoform Disorders is Ignored

Whatever flaws there might be in the complex, overlapping criteria for Somatoform Disorders, it’s clear that diagnosis aims to assist physicians in determining whether patients’ symptoms have psychiatric causes. Whatever else we might say about its replacement, Somatic Symptom Disorder, it’s clear that diagnosis *does not* aim to assist physicians in determining whether patients’ symptoms have psychiatric causes.

That is hardly an insignificant oversight. The DSM-5’s entry for Somatic Symptom Disorder centers on the phrase “somatic symptoms” from its very first sentence, but this is a phrase it never attempts to define. Though they’ve never said so, it seems the APA believes medical doctors are sufficiently clear about which symptoms are somatic and which are medical, but that is a highly controversial and truly indefensible position.

It is the responsibility of the APA to overtly establish a definition for “somatic symptoms” that doctors can use safely and uniformly in practice – that is the primary purpose of this diagnostic category. The repeated presence of the word “somatic” reveals a blatantly circular approach that cannot possibly serve this aim.

A Central Aim of the Revisions is Ethically Indefensible

The category of Somatoform Disorders has been revised largely to make somatoform patients “easier to manage”, to minimize the anger patients express when they receive the diagnosis. I submit that the APA’s revisions are in no way designed to address the concerns patients universally voice on this issue – substantial concerns about practices that are actually very difficult to defend.

Instead, they are designed for the expressed purpose of obscuring the doctor’s leap from the medical to the psychiatric in a direct attempt to circumvent the need for defense. That purposeful manipulation is a direct violation of every patient’s right to full disclosure, and it is paternalistic in the extreme.

Patients have a right to know in which specialty their diagnosis falls. That is not debatable and it is not a right that wavers with physicians’ comfort levels.

The Problem of Being Too Broad is Ignored

Every diagnostic category in medicine and in mental health faces the twin risks of being too narrow and being too broad. Every soundly devised diagnosis addresses these twin risks in a responsible way.

In the case of somatoform diagnoses, being too narrow creates a problem of access to needed mental health care. This is a concern the APA has made an important effort to address with SSD.

At the same time, in the case of somatoform diagnoses, being too broad creates a problem of access to needed medical care. This is a concern the APA has entirely ignored.

If SSD were purely a mental health diagnosis there could be some situations in which exclusive focus on the threat of being too narrow would be warranted. But SSD is a diagnosis that straddles the divide between psychiatry and medicine. That means being too broad threatens consequences of much greater import than any pure mental health diagnosis could possibly match.

Being too broad in this unique category means denying access to medical care for patients in need of medical care. We might debate about different approaches to addressing that problem but there can be no debate about its central importance.

No candidate to replace somatoform disorders can be viable that does not attempt to minimize the number of medical patients denied access to medical care.

ICD Has Medical Responsibilities that DSM Does Not Share

The distinction between the DSM and the ICD is not wholly one of jurisdiction, of national applicability as opposed to continental or worldwide applicability. More importantly, it is also one of scope, of the restricted purview of mental health care versus the broader framework of medical care.

Accordingly, the question of adding new DSM diagnoses to the ICD must centrally involve evaluation of mental health constructs within the larger framework of medicine.

It is the responsibility of the North American contingent of WHO to act as a filter in this way and that means the problem of being too broad cannot slip under their radar as it has with the APA. Continental editions of the ICD cannot responsibly deny the general aim of improving access to medical care any more than international editions could.

In the context of WHO the problem of error in somatoform diagnoses has the same outcome

as racial or socioeconomic discrimination - denial of access to available healthcare - and it must be accorded the same vigilant concern on every level. Every single time a somatoform diagnosis is made in error a patient in need of medical care is denied access to care. That is an outcome all editions of the ICD are pledged to avoid.

Statistics Prove Radical Over-Diagnosis of Somatoform Disorders

A survey by the American Autoimmune-Related Disease Association reveals that 40% of patients with autoimmune diagnoses were wrongly denied medical care in the past because of mistaken diagnoses of somatoform disorders. In the US alone that's 22 million patients at this very moment, all of whom were indefinitely denied access to medical care for serious illness because criteria for somatoform disorders were too broad.

It is well known that woman having a heart attack in the US is 7 times more likely to be mistakenly sent home from the ER than her male counterparts, a fact unquestionably tied to the presumption that somatoform diagnoses apply almost exclusively to women. Largely because of this problem women in the US are statistically twice as likely to die of heart attack at men.

Even if we set aside the immensely disturbing trend of gender bias in these figures, they force us to face an unconscionable problem. Reckless diagnosis of somatoform disorders is alarmingly pervasive, causing quantifiable suffering and threat of harm. Even if we had reasons to believe that the problem extends only to these two diagnostic categories – and of course there are no such reasons – that would be more than sufficient cause to reject any revisions to the somatoform category that might worsen this problem.

Prevalence Rates are Staggeringly Incommensurate

Physicians are trained to expect a prevalence of 25-75% for somatoform diagnoses in general practice. How do the prevalence estimates of the NIMH stack up against the medical estimate?

We would find significant cause for alarm if, by comparison, the NIMH estimated the prevalence of somatoform disorders at, say, a mere 25%. That would mean that, on a middle-of-the-road view, physicians make somatoform diagnoses twice as often as they should. At the high end it would mean physicians apply the somatoform label three times as often as they should. Knowing that every mistaken application of the label results in denial of medical care to a medically ill patient, a disparity of that magnitude this would be extremely worrisome.

The reality of the actual disparity between doctors' estimates and those of the NIMH is far, far more alarming. The NIMH estimates the prevalence of *all mental health disorders* at 25%.

Otherwise put, the group of patients diagnosed with somatoform disorders in general practice is two to three times larger than the group of all people with mental health disorders in the US, according to the NIMH.

These figures are horrifying and it is staggering that the medical community could have failed to take note of them. For ICD-10-CM to make even a tiny contribution to worsening this problem would be grotesque. It is negligent to fail to take action against it.

Care in Evaluation Must be Proportionate to Number of Patients Impacted

The category of somatoform disorders is arguably the most frequently used tool in the medical toolkit. Inaccurate as they are, doctors' prevalence estimates tell us that every patient at the GP's office is a candidate for somatoform diagnoses.

If somatoform diagnoses were like other medical diagnoses, leaving patients who wrongly receive the label with the wrong kind of medical treatment, the sheer number of patients impacted by somatoform diagnoses would indicate a need for significant effort in the evaluation of every aspect of revision.

The fact is, though, that this unique category leaves patients who wrongly receive the label with no medical care for medical problems, drawing them out of the medical arena to a field where their untreated ailments cannot possibly be considered. That means this one unique category threatens the majority of patients at the general practitioner's not just with medical misdiagnosis, but with a significant risk of losing medical care for medical problems.

This combination makes evaluation of this diagnostic category more important than any other activity the North American contingent of WHO could engage in. Shuffling it into an unconsidered heap of new diagnoses would be medically negligent in the extreme.

The Suffering of Rare Disease Patients is Not Inconsequential

Rare disease patients are directly targeted whenever criteria for somatoform diagnoses are too broad, and in this sense they are the most effective litmus test for success.

Criteria for SSD could not be more troubling in this regard, because a recent survey by NORD reveals that most rare disease patients wait at least 3 years for diagnosis, with 20% waiting an unfathomable ten years or more.

That kind of delay might be acceptable if the prevalence of rare disease patients, or "zebras", was quite low – but it is not low. It is actually very high. 1 in 10 Americans has a rare disease, according to the Office of Rare Diseases Research of the NIH: roughly 30 million people. That's 30 times more than the number with HIV/AIDS (according to the CDC), and 6 times more than the number with Alzheimer's (according to the National Institute on Aging). It is more than double the number of cancer patients, including all those in remission (according to the American Cancer Society).

That is to say that most of a group of patients twice the size of all cancer patients has been forced to accept a diagnostic and treatment delay of at least three years. 20% of this group – that's 6 million people – suffer for 10 years or more without treatment or medical support. During those horrific years, they will certainly present their doctors with "C. Symptoms persisting six months or more", as well as "A. One or more somatic symptoms that are distressing or result in significant disruption of daily life".

Most importantly, the majority of this mammoth population of patients will present their doctors with "B. Excessive thoughts, feelings or behaviors related to somatic symptoms", because without verification of their suffering in the form of explanatory medical tests, doctors will mistakenly conclude their symptoms warrant no thoughts or behaviors at all.

This is an army of patients suffering from serious medical problems that have remained untreated not for days, weeks or months, but for years. They will certainly have "persistent thoughts about the seriousness of their symptoms". They will have "high levels of anxiety about health or symptoms", and they will spend large amounts of "time and energy" on their health concerns, making them not just potential candidates for mistaken diagnoses of SSD, but dead ringers for "Severe SSD" in every single case.

Diagnostic criteria for SSD very precisely describe the majority of rare disease patients, who struggle to cope with at least three years of diagnostic delay. Each one of SSD's diagnostic criteria has a role to play in unanimously dismantling the hope of rare disease patients. Each criterion will independently chip away at patients' prospects for accurate diagnosis, lengthening the delay at every turn.

Even if there were important mental health gains earned by the construct of SSD it would be unconscionable to earn them without even bothering to comment on the cost, the extended medical suffering of such an enormous group of patients. In reality the mental health gain is trivial – essentially a doubling up on labels for a common source of anxiety – and that is an atrocity.

There can be no defense for callously marginalizing such a massive population of medical patients in need. It is inconceivable that the North American contingent of WHO might consider condoning such reckless disregard for a problem of this magnitude.

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The problems I describe here are inching their way toward general public awareness. SSD so radically worsens the reckless over-diagnosis of somatoform disorders that it has created a burgeoning international conversation among patients.

To put it very bluntly, the peasants are about to storm the gate. If that were not the case I would not have a job.

Controversy about SSD, and proposals for the ICD's "Bodily Distress Disorder", have forced us as a culture to turn and look squarely at what supports the offhanded denial of medical care to such a massive proportion of the patient population day in and day out.

What we see there is simply not acceptable. We have come to blithely accept a general diagnostic practice that cannot possibly be defended, a practice that directly threatens the physical well being of every patient, an approach that forces us to systematically ignore years of unnecessary suffering for a population twice the size of all cancer patients.

Doctors make mental health determinations that purport to explain physical symptoms without safety nets of any kind, without protocols or standard guidelines on the medical side or the mental health side, entirely without acknowledgement of even the possibility of human error.

They are encouraged to do this – trained to do it – at an absolutely alarming rate, a rate that cannot possibly be supported by any definition of somatoform disorders, and every single time they do it in error someone in need of medical care must suffer without it.

Doctors are diagnosing somatoform disorders at a rate two to three times higher than mental health practitioners are diagnosing anything. Refusal to acknowledge and address that as a problem is an atrocity on the scale of genocide.

It is not typical for the North American arm of WHO to have to consider such massive shifts in policy and awareness, but the fact remains that a new diagnostic category has presented itself from the mental health field that seems to threaten the general population to such an extent that it must be carefully considered.

It is certainly not pleasant to openly investigate the possibility of a significant medical threat now intrinsic to standard diagnostic practice, but that is what systematic, rational consideration of SSD must lead us to. There is no mature, ethically responsible approach to the question of SSD that does not force us to take action against our own preexisting biases.

There can be no morally tenable grounds for including SSD in the ICD-10-CM. There can be no morally tenable grounds for failing to organize an international campaign to root out reckless diagnosis of somatoform disorders.

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