

Proposal on the New Construct, “Bodily Distress Disorder” as a Replacement for “Somatoform Disorders” in ICD-11 Beta Draft

Diane O’Leary, PhD
doleary8@uwo.ca

Submitted March 2017

I am a bioethicist and philosopher with strong concerns about the adoption of BDD to replace somatoform disorders. I believe the task of developing a construct like BDD (and the alternative, most recently dubbed “bodily stress syndrome”) is chiefly ethical rather than medical or psychiatric, and that, on ethical grounds, BDD cannot be defended.

Before I begin, two preliminary points. First, I want to express concern that while field trials for the BSS construct (a slight variation on Denmark’s “bodily distress syndrome”) have taken place[1], there exists no public forum where comments on that alternative might be offered and considered. As it’s clear that two constructs are under consideration, I think it’s clear the public should be involved with both at this point.

Second, I think it’s useful to explain that at the start that I am a philosopher with a professional interest in the mind-body problem. This is not an area I will delve into in these comments – largely because the language of BDD as it’s presented here clearly hopes to avoid philosophical concerns - but I raise it to ward off the charge of dualism. It is common for professionals in this area to suggest that when we aim to eliminate dualism we must work to eliminate from our discussions all signs of a distinction between patients’ biological needs and their psychosocial needs. That suggestion is mistaken. Philosophers, including non-dualists of every stripe, not only accept the viability of apparent distinctions between the mental and the biological, they understand them as necessary to any coherent discussion of the mind-body problem (as, for example, with the vital distinction between mental states and brain states). In what follows I will work with a distinction between patients’ biological needs and their psychosocial needs, as a non-dualist, based on an understanding that in the end of the day language of this kind can readily be aligned with a non-dualist position.

1. The purpose of the construct

Whatever else we might say about the empty slot that now presents itself where somatoform disorders used to be, it is clear the construct that ends up here “serves as a decision node or a working diagnosis on which treatment, further investigations and conclusions on the absence of serious disease are based”[2]. Providers will primarily use the construct in this slot as a tool for distinguishing bodily symptoms best managed along a mental health track from those that require further biologically-oriented testing and treatment, and this is the case even when an established medical diagnosis explains symptoms to some extent.

There are many conceptual reasons for resisting a very black and white characterization of this kind, but the fact remains that this is the central role played by the core idea of somatization over the last thirty years, and (alongside somatic symptom disorder for those with focus on the DSM) it is the central role that BDD will play if it is adopted. In practice, physicians understand the category in these terms: when confronted with patients whose bodily symptom experiences lack biological explanation, I can apply criteria for [insert the new construct here] to safely and reliably determine whether mental health diagnosis is appropriate for those symptoms.

2. The tools it offers

Understanding the purpose of the construct in this way, it's important to be very clear about the nature of the tools the construct offers to accomplish the task. First, the vast majority of the descriptive language for BDD applies equally well both to a symptom experience that should be explained biologically and one that should be explained with a mental health diagnosis. I'm speaking here of persistent bodily symptoms, symptoms that are distressing, repeated contact with medical providers, significant impact on important areas of functioning, and failure to become less concerned after reassurance. In terms of the everyday need to determine which symptom experiences should be explained on the medical side and which should receive a diagnosis in the category of mental health, none of this language will be useful in any way because it applies equally well to both kinds of symptom experiences.

Second, the only language in the construct that does help physicians accomplish the central task they need to accomplish is the word "excessive", and this is the case for somatic symptom disorder in DSM-5 as well (though that construct spells out some very minimal additional requirements). The one and only tool offered by BDD for the task at hand is the notion that mental health diagnosis will be appropriate when "excessive attention [is] directed toward the symptoms", or when "the degree of attention is clearly excessive in relation to [a medical condition's] nature and progression".

In evaluating the success of the construct, then, in terms of the central purpose for which it will be used, we need to focus on the usefulness of the notion of "excessive attention directed toward symptoms" as the one tool that would be offered in the ICD to help physicians distinguish unexplained bodily symptoms that should be classified in mental health from those that should receive continued biologically-oriented care.

3. Three problems with "excessive attention"

First, what's most important about the idea of "excessive attention" is that it's a matter of subjective opinion rather than a scientific specification. In some ways this is an advantage. By focusing on a subjective marker, BDD gives physicians very broad discretionary power on the matter of which bodily symptom experiences should and should not be explained as mental health disorders.

On the other hand, given that this entry in the mental health category will chiefly be put to use in medical practice – not just now and then, but as a matter of everyday routine – it is concerning that the core idea of the construct is so subjective. It's not just that it's difficult to specify how much attention is required to meet a standard of "excessive"; it's that no objective determination could possibly exist for this concept. Given the incredible power that BDD would wield as the central tool physicians use to determine when bodily symptoms should receive a mental health diagnosis, I think it's inappropriate for its core concept to be deeply subjective.

Second, there are strong reasons for questioning whether physicians' training gives them the expertise to make reliable determinations as to whether attention to symptoms is excessive. This is problematic in itself, because reliable determinations in this area are so immensely important (an issue I will take up again shortly). But it is also problematic in terms of its impact on the patient-doctor relationship. It is genuinely unclear whether a doctor's determination of excessive attention is credible – and that means it is unclear whether the doctor herself is credible when she makes the determination. Given the intractable problem of exam room conflict over diagnosis of this kind, I think it's unwise to adopt a construct that so clearly adds to the problem of doctors' credibility in this area.

Third, and this is by far the most obvious problem with both BDD and SSD, as an explanatory model it begs the question. BDD cannot possibly succeed at the task of distinguishing bodily symptoms that should receive a mental health diagnosis from those that require further biologically-oriented care because its central tool can only be used when providers have already made a determination on that point.

Is this patient's attention to symptoms excessive? To answer that question a provider will have to have reached a conclusion as to the cause and severity of the symptoms in question. That is, to answer the question that determines whether a patient's symptoms should be diagnosed as BDD, a provider must have already decided whether the symptom experience is caused by a biological problem that warrants significant attention or by a mental health problem that generates attention unnecessarily. But of course if the provider has already made that determination, there is no value at all to the process of applying BDD criteria.

This problem is catastrophic. While it's notoriously difficult to find an empirical scientific basis for providers' decision-making in this area, providers can continue to make a claim to evidence-based practice as long as their diagnostic decision-making is based on careful, logically successful reasoning – but the BDD construct fails that test. Because, as a matter of basic logic, it forces providers to assume the central conclusion they use the construct to support, diagnosis of BDD fails the standards of evidence-based practice.

As with the second problem, this is concerning not just in itself, but in terms of the patient-doctor relationship. Not all patients have the personal skills or interests that would lead them to recognize a logical problem with the construct that defines their condition, but because this logical problem is so glaring, it is one that will intuitively lead

patients to reject the diagnosis. Indeed it is one that should lead them to reject the diagnosis.

Finally, this problem has ramifications outside the exam room in terms of the credibility of the professional area of psychosomatic medicine. In the absence of clear empirical standards for determining when patients' bodily symptom experiences should receive a mental health diagnosis, the field itself can make a claim to credibility only if its central decisions are based on sound reasoning. By offering the construct of BDD to the world to replace somatoform disorders, the field presents itself as incapable of taking note of very basic circular reasoning.

4. The ethical bottom line

This area of diagnostic practice is notoriously difficult, and I think that's centrally because of insufficient attention to the ethical side of the task.

There is nothing more important in health care than making sure to provide biologically-oriented medical care to every patient who seeks it from her doctor with a biological need. This minimal form of beneficence is what defines the field of medicine and that means the stakes with diagnosis of this kind are profoundly high, frustrating as that may be. In every case where a physician uses the tool that fills this slot in error, she violates the ethical obligation that defines the practice of medicine – because she reaches a conclusion that either compromises or fully obstructs access to medical care for a patient in need.

Professionals in this crossover area of medicine and psychiatry may be convinced that it's rare for physicians to mistake bodily symptoms that require biological medical care from those that belong on the mental health track, but it is a terrible mistake to develop this category as if patients, physicians, or the general public share your view on that point. There exist no broad studies, after all, that establish the rate at which known biological medical symptoms are mistakenly construed as having been caused by psychosocial distress[3], and it is a gross scientific error to imagine that any study does establish this when it discerns the rate at which physicians have been willing to overturn mental a health diagnosis for bodily symptoms[4], [5], [6].

Moreover, patient groups publicly express concern about this issue with increasing intensity – and many now publicly track the development of this category to discern whether steps are being taken that protect access to medical care for patients with unexplained symptoms who actually do need it. Surveys show, for example, that over 50% of patients with autoimmune diseases report having been denied the medical care they need in the past on the basis of mistaken mental health diagnosis for their symptoms[7]. And those with rare disorders now wait an appalling seven years on average for diagnosis[8] - this in the era of brand new access to a searchable rare disorder database. Further, studies show that mistaken mental health diagnosis for the symptoms of rare disorders leads to delays in accurate diagnosis that are at least 2.5 times as long, and up to 7 times as long, as delays caused by mistaken medical diagnosis[9]. Given that

one in ten Americans suffer from rare disorders[10], this is a serious problem that needs to be addressed.

The diagnostic construct that fills this category needs to quell growing public concern that insufficient attention has been paid to the ethical bottom line of protecting access to biological medical care for every patient who seeks it from her doctor with a biological need – because public concern on this point vocalizes the concerns of individual patients in the exam room, and indeed the concerns of physicians, who continue to feel fearful that standards in this area might lead them to overlook disease[11], [12]. More than anything else, the construct that replaces somatoform disorders needs credibility – not professionally assumed credibility, but the public credibility that can only be earned with an overt central focus on ensuring that patients with a need for biologically-oriented medical care are protected from mistaken mental health diagnosis for their symptoms.

For these reasons, I urge you to go back to the drawing board, resisting pressure to adopt BDD (or any form of Denmark’s “bodily distress syndrome”, which, on these points, is far worse than BDD). It is a slap in the face to patients, to physicians, and to the credibility of the field of psychosomatic medicine to present the world with such sloppy standards for a distinction of such immense ethical importance to medical practice.

Diane O'Leary, PhD
Kennedy Institute of Ethics
Georgetown University
do271@georgetown.edu

1. Goldberg DM, Reed GM, Robles R, Bobes J, Inglesias C, Fortes S, de Jesus Mari J, Lam TP, Minhas F, Razzaque B, Garcia JA, Rosendal M, Dowell CA, Gask L, Mbatia JK, and Saxena S. (2016). Multiple somatic symptoms in primary care: A field study for ICD-11 PHC, WHO's revised classification of mental disorders in primary care settings. *Journal of Psychosomatic Research* 91, 48-54.
2. Rask TM, Anderson RS, Bro F, Fink P, and Rosendal M. R.S. Andersen, F. Bro, P. Fink and M. Rosendal. (2014). Towards a clinically useful diagnosis for mild-to-moderate conditions of medically unexplained symptoms in general practice: a mixed methods study. *BMC Family Practice* 15:118, 68.
3. I know of only one current study that pursues (though as a finding outside the study’s chief area of concern) the question of how often established biological symptoms are mistakenly construed as having been caused by psychosocial distress. Nimnuan et al showed that 17% of UK patients who seek secondary care for biological bodily conditions are mistakenly construed in their first visits as suffering chiefly from psychosocial distress, a result that should be medically concerning, and ethically alarming. Nimnuan C, Hotopf M, Wessely S. (2000). Medically unexplained symptoms: How often and why are they missed? *Quarterly Journal of Medicine* 93:1, 21-28.

4. Skovenborg EL and Schroder A. (2014). Is physical disease missed in patients with medically unexplained symptoms? A long term follow-up of 120 patients diagnosed with bodily distress syndrome. *General Hospital Psychiatry* 366:1, 38-45.
5. Schuepback WM, Adler RH and Sabbioni ME. (2002). Accuracy of the clinical diagnosis of 'psychogenic disorders' in the presence of physical symptoms suggesting a general medical condition: A 5-year follow-up in 162 patients. *Psychotherapy and Psychosomatics* 71:1, 11-17.
6. de Gusmao CM, Guerriero RM, Bernson-Leung ME, Pier D, Ibeziako PI, Bujoreanu S, Maski KP, Urion DK, and Waugh JL. (2014). Functional neurological symptom disorders in pediatric emergency room: Diagnostic accuracy, features, and outcome. *Pediatric Neurology* 51:2, 233-38.
7. American Autoimmune-Related Disease Association. (2014). News Briefing 2014: The Status of Autoimmune Disease," at <http://slidegur.com/doc/96420/viewthe-power-point-presentations>.
8. The Global Genes Project. (2013). Rare Disease Impact Report, at <http://www.geneticalliance.org.uk/docs/e-update/rare-disease-impact-report.pdf>
9. Kole A, and Faurisson F. (2009). Eurodis: The Voice of 12,000 Patients: Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe, at <http://www.ebookdb.org/reading/547128462F58332EGD1C2869/The-Voice-Of-12000-Patients-Experiences-And-Expectations-Of-Rare-Disease-Patient>, at 48.
10. Office of Rare Diseases Research, Office of Rare Diseases Research (ORDR) Brochure. 2009. [August 4, 2010], at http://rarediseases.info.nih.gov/Wrapper.aspx?src=asp/resources/ord_brochure.html.
11. Warner A, Walters K, Lamahewa K, and Buszewicz M. (2017). How do hospital doctors manage patients with medically unexplained symptoms: A qualitative study of physicians. *Journal of the Royal Society of Medicine* 110:2, 65-72.
12. Rask TM, Anderson RS, Bro F, Fink P, and Rosendal M. R.S. Andersen, F. Bro, P. Fink and M. Rosendal. (2014). Towards a clinically useful diagnosis for mild-to-moderate conditions of medically unexplained symptoms in general practice: a mixed methods study. *BMC Family Practice* 15:118, 68.