ICD-11 Beta draft Proposal Mechanism (registration required for access):

https://icd.who.int/dev11/proposals/f/en#/http://id.who.int/icd/entity/767044268?readOnly=true&action=ContentEnhancementProposal&stableProposalGroupId=eb30c64f-dd10-41a2-8edc-f254cf431d73

Comment

Suzy Chapman 2018-Apr-13 - 12:49 UTC

Declarations: This comment has been prepared by Suzy Chapman and Mary Dimmock. Suzy Chapman has no affiliations and advises ME organizations on an ad hoc basis. Mary Dimmock serves on the Board of Solve ME/CFS Initiative and also works with other ME organizations. This comment is submitted in personal capacities and not on behalf of any organizations. The authors jointly submitted a proposal for the ICD-10 G93.3 legacy entities on March 27, 2017 [1].

Dr John Grove *(Director, Information, Evidence, and Research)* has confirmed that proposals for changes to the draft submitted before March 30, 2017 are taken into account for the initial release in June 2018; that the draft is planned to be frozen at the end of May for finalization in preparation for release of an initial version of ICD-11 in June.

The proposal for addition of exclusions for the ICD entities, *Chronic fatigue syndrome*; *Benign myalgic encephalomyelitis*; and *Postviral fatigue syndrome* had met the March 30, 2017 deadline. With just a few weeks left before the draft is finalized, it is a concern that this proposal remains unprocessed.

An earlier proposal, submitted on December 30, 2014, for addition of exclusions for these three ICD entities was marked as Rejected by *"Team 2 WHO"* on November 15, 2016, with the rejection note: *"Exclusion terms must exist in the classification as entities to enable linking."* [2].

Following a period of four years' unexplained absence from the public version of the Beta platform, all three ICD-10 G93.3 legacy terms were restored to the draft by *"Team WHO"* under parent block, *Other diseases of the nervous system*, on March 26, 2017 [3]. A longstanding request for exclusions for *Chronic fatigue syndrome*; and *Benign myalgic encephalomyelitis* under *Fatigue* (in the *Symptoms, signs* chapter) was approved and implemented on the same date.

Therefore, the earlier absence of the three G93.3 legacy entities from the Beta draft is no longer a barrier for consideration of addition of exclusions for these terms.

Necessity for exclusions:

The full clinical description and diagnostic guideline texts that are being drafted for the *Clinical Descriptions and Diagnostic Guidelines for ICD-11 Mental and Behavioural Disorders* publication are not available for public stakeholder scrutiny [4]. But it is evident from the disorder Descriptions in the Beta draft, from position papers and progress reports published by the chair of the *Somatic Distress and Dissociative Disorders Working Group* [10][11] and from commentaries and comparisons in the literature, that as defined for ICD-11, the proposed "Bodily distress disorder" diagnostic construct has strong conceptual, characterization and criteria alignment with DSM-5 Somatic symptom disorder [5]. For ICD-11, Somatic symptom disorder is listed under Synonyms to Bodily distress disorder.

Thresholds for meeting criteria for a diagnosis of ICD-11's defining of "Bodily distress disorder" or for a diagnosis of DSM-5 Somatic symptom disorder are substantially lower than those of the somatoform disorders these very similar disorder constructs replace.

Frances (2013), and Frances and Chapman (2013) argue that the low sensitivity and specificity of the Somatic symptom disorder criteria - based on difficult to measure psychobehavioural responses and reliant on subjective clinical judgements as to whether a patient's response to chronic, distressing symptoms is *"excessive"* or *"disproportionate"* or whether they are devoting *"excessive time, energy and attention"* to their symptoms or health concerns - present significant potential for the application of an inappropriate mental disorder diagnosis [6][7].

In a 2013 BMJ commentary, Professor Allen Frances, who had chaired the Task Force for the drafting of DSM-IV, highlighted the particular vulnerabilities of some disease groups. Patients with chronic, multisystem diseases like chronic fatigue syndrome and myalgic encephalomyelitis, or who are awaiting a diagnosis, are considered to be particularly vulnerable to misapplication of a diagnosis of Somatic symptom disorder, or of receiving an additional "bolt-on" diagnosis of Somatic symptom disorder [8].

A misdiagnosis or a "bolt-on" mental disorder diagnosis can have far-reaching implications for patients: negatively impacting on access to medical investigations, tests, treatments and choice of service provision; on the payment of employment, medical and disability insurance and the length of time for which insurers are prepared to pay out; on the perceptions of agencies involved with assessment and provision of welfare benefits, social care, disability adaptations, education and workplace accommodations; on the perceptions of social services and child protection agencies in the case of children and young people.

WHO has conducted no field trials specifically testing the safety, validity and reliability of the "Bodily distress disorder" definition and criteria, as defined for ICD-11, in any patient populations.

With no body of evidence for the safety, validity, reliability, utility, prevalence and acceptability of the S3DWG's proposed diagnostic construct, we are not persuaded that the S3DWG has incorporated adequate safeguards for this patient population.

Our recommendation remains that exclusions are required for the entities: Chronic fatigue syndrome; Benign myalgic encephalomyeltis; and Postviral fatigue syndrome to mitigate the risk of misdiagnosis with, or misapplication of an additional mental disorder diagnosis of Bodily distress disorder.

No rationale for the S3DWG's choice of nomenclature:

Since first publishing its emerging proposals, the Somatic Distress and Dissociative Disorders Working Group (S3DWG) has proposed to call this new, single ICD category, "Bodily distress disorder."

The group is aware that this term is already used by researchers and in the field interchangeably with the diagnostic construct term, "Bodily distress syndrome," and that this has been the case since at least 2007 [21].

ICD Revision has been requested several times to provide stakeholders with the rationale for the recommendation to repurpose a disorder term which is already strongly associated with the Fink et al. (2010) Bodily distress syndrome diagnosis. ICD Revision has remained silent on this.

It is of considerable concern to stakeholders that the S3DWG group has failed to acknowledge and discuss within its progress reports the potential for confusion and conflation between its own SSD-like "Bodily distress disorder" and the differently conceptualised, Fink et al. (2010) Bodily distress syndrome construct. Nor has the working group's output discussed the implications for maintaining the integrity of its own construct within and beyond ICD-11 [9][10].

The Fink et al. (2010) Bodily distress syndrome diagnostic construct is already operationalized in Denmark and several other EU countries, in research and clinical settings. It is differently conceptualized, has a very different set of criteria and is intended to capture a different patient population to the ICD-11 "Bodily distress disorder" category.

Fink et al. (2010) consider their "Bodily distress syndrome" construct has the ability to capture the ICD-10 somatoform disorders, neurasthenia, "functional symptoms," noncardiac chest pain, chronic pain disorder, MCS and some others, but also subsume chronic fatigue syndrome, myalgic encephalomyelitis, fibromyalgia and irritable bowel syndrome *(considered by Fink and colleagues to be artifacts of medical specialization and manifestations of a similar, underlying disorder with a common, hypothesized aetiology)* under a single, unifying "Bodily distress syndrome" diagnosis [11][21].

That Somatic symptom disorder and the Fink et al. (2010) Bodily distress syndrome are differently conceptualized, have different criteria sets and potentially capture different patient populations, has been acknowledged by DSM-5 Somatic Symptom Disorder Work Group chair, Joel E Dimsdale, and by Creed, Henningsen and Fink [12][13][14].

In January 2015, the Senior Project Officer for the Revision of ICD-10 *Mental, behavioural or neuro-developmental* disorders agreed with one of the authors that there is potential for confusion with the Fink et

al. construct; that they are conceptually different; that this was not ideal; and that it would be discussed further with the working group [15].

Since no potential alternative name has been advanced and since no rationale for their specific choice of name has been provided, we conclude that the S3DWG working group has dismissed legitimate concerns for a very obvious flaw in its proposals.

We consider this unsound classificatory practice for ICD. It does not accord with the working groups' Terms of Reference and we request that the Senior Project Officer and MSAC give this their attention as a matter of urgency.

Ambiguity, confusion and conflation:

The authors have demonstrated elsewhere on the Beta platform [16] that the name which the S3DWG working group proposes to use for its single category replacement for most of the somatoform disorders has a history of usage in the literature and in the field interchangeably with that of the differently conceptualized, Fink et al. (2010) disorder construct.

One may observe frequent instances where the term "Bodily distress disorder" is being used when the disorder construct that is actually being discussed within the paper, editorial or presentation is the Fink et al. (2010) "Bodily distress syndrome (BDS)" diagnostic construct. In some cases, one also observes the conflations, "bodily distress syndrome or disorder" and "bodily distress syndrome/disorder."

Five examples:

"Bodily distress disorder" is used interchangeably with "bodily distress syndrome" in the editorial (Creed et al. 2010): Is there a better term than "medically unexplained symptoms"? [17].

In this (Rief and Isaac 2014) editorial: The future of somatoform disorders: somatic symptom disorder, bodily distress disorder or functional syndromes? the authors are using the term, "bodily distress disorder" while clearly discussing the Fink et al. (2010) BDS construct [18].

The S3DWG's proposed term is seen, here, as "Bodily distress disorder (Fink and Schroder 2010)" in *Slide #3* of a symposium presentation: An introduction to "medically unexplained" persistent physical symptoms. (Professor Trudie Chalder, Department of Psychological Medicine, King's Health Partners, 2014) [19].

In this paper: Medium- and long-term prognostic validity of competing classification proposals for the former somatoform disorders (Schumacher et al. 2017) the authors compares prognostic validity of DSM-5 "somatic symptom disorder (SSD)" with "bodily distress disorder (BDD)" and "polysymptomatic distress disorder (PSDD)" and discuss their respective potential as alternatives to SSD for the replacement of the somatoform disorders for the forthcoming ICD-11 [20]. The authors state, "the current draft of the WHO group is based on the BDD proposal." But the authors have confirmed that for their study, they had "operationalized Bodily distress disorder based on Fink et al. 2007."

In this (Fink et al. 2007) paper: Symptoms and syndromes of bodily distress: an exploratory study of 978 internal medical, neurological, and primary care patients, the authors conclude: "We identified a general, distinct, bodily distress syndrome or disorder that seems to encompass the various functional syndromes advanced by different medical specialties as well as somatization disorder and related diagnoses of the psychiatric classification." [21].

There are other examples in the literature and in the field. But these suffice to demonstrate that the term, "Bodily distress disorder" is already used synonymously with the Fink et al (2010) disorder term "Bodily distress syndrome (BDS)", that some researchers and clinicians, including Fink et al., themselves, do not distinguish between these two terms, and that as a result of the S3DWG's perversity, researchers and researcher/practitioners are now struggling to differentiate between two divergent disorder constructs.

Why did ICD Revision not identify this flaw, anticipate the potential for confusion and conflation and address this problem earlier in the development process?

SNOMED CT International:

An (undefined) Concept: Bodily distress disorder was added to SNOMED CT International for the July 31, 2017 release. It was initially assigned under Parent: *SCTID: 386585008 Functional disorder (disorder)*.

With no associated definition or descriptive text, it was important to establish what SNOMED International understood by the term, "Bodily distress disorder" and the origin of the request for its addition to the SNOMED CT terminology system.

SNOMED International's Head of Terminology clarified in October 2017 that Concept SCTID: 723916001 Bodily distress disorder (disorder) was added by the team working on the SNOMED CT and ICD-11 MMS mapping project and that the Concept was added as "an exact match" for the ICD-11* term, Bodily distress disorder.

Following a literature review, the terminology managers determined that the Concept would be more appropriately relocated under the *SCTID: 74732009 Mental disorder (disorder)* Parent, to better reflect the conceptualization and chapter placement in ICD-11. This change of Parent was effected for the January 31, 2018 Release of the International Edition.

The issue of ambiguity, confusion and conflation between these two disorder constructs was discussed with the terminology managers.

In the absence of a SNOMED CT textual definition/description for Bodily distress disorder and in the absence of the Somatic symptom disorder *Synonym* term to help clarify that SNOMED CT's Bodily distress disorder concept is an exact match for ICD-11's Bodily distress disorder, it was suggested that the inclusion of Bodily distress disorder's three severities of psychobehavioural responses might assist clinicians, coders and other end users in distinguishing the SNOMED CT/ICD-11 Bodily distress disorder concept from the similarly named, but differently conceptualized, Bodily distress syndrome, as defined by Fink et al (2010), which has just two severities.

This request was approved and we are advised that the three severity specifiers *(Mild; Moderate; and Severe)* are scheduled to be added to the July 31, 2018 release, under Children to Bodily distress disorder.

SNOMED International terminology managers had no difficultly recognising the potential for confusion and conflation; nor the implications for maintaining construct integrity that will likely result from the introduction of a new disorder category into ICD-11, which is proposed to be assigned a name historically associated with a divergent diagnostic construct/criteria set that is inclusive of a different patient population.

Our recommendation is that exclusions are required for the entities: Chronic fatigue syndrome; Benign myalgic encephalomyeltis; and Postviral fatigue syndrome under Bodily distress disorder in ICD-11 to mitigate the risk of confusion and conflation with Bodily distress syndrome, a diagnostic construct intended to subsume these ICD entities.

Will ICD Revision please give this attention before the draft is finalized in May?

Will ICD Revision also consider the implications for maintaining the discrete identity of its proposed disorder, once ICD-11 is in the hands of its end users - clinicians, allied health professionals, coders and commissioners; the statistical implications for data reporting and analysis, and most importantly, the implications for patients?

**For SNOMED CT UK Edition, Concept SCTID: 723916001 Bodily distress disorder is cross mapped in the SNOMED CT to ICD-10 mapping classification to ICD-10 F45.9 Somatoform disorder, unspecified.*

References:

1 Complex Hierarchical Changes Proposal, Other disorders of the nervous system. Submitted: March 27, 2017; Typographical edit: March 31, 2017 https://icd.who.int/dev11/proposals...lGroupId=4b26ab6a-393f-4a39-9051-4ac1d4b1a55a

2 Content Enhancement Proposal, Bodily distress disorder. Submitted: December 30, 2014 https://icd.who.int/dev11/proposals...lGroupId=16b0ba12-3e6d-4b6f-8b0c-3b6cf7094c2e

3 ICD-11 MMS, Postviral fatigue syndrome
https://icd.who.int/dev11/l-m/en#/http://id.who.int/icd/entity/569175314

4 Global Clinical Practice Network, Clinical Descriptions and Diagnostic Guidelines for ICD-11 Mental and Behavioural Disorders https://gcp.network/en/icd-11-guidelines

5 American Psychiatric Association. (2013). Somatic Symptom and Related Disorders. In Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: Author.

6 Frances A. DSM-5 Somatic Symptom Disorder. J Nerv Ment Dis. 2013 Jun;201(6):530-1. [PMID: 23719325]

7 Frances A, Chapman S. DSM-5 somatic symptom disorder mislabels medical illness as mental disorder. Aust N Z J Psychiatry. 2013 May;47(5):483-4. [PMID: 23653063]

8 Frances A. The new somatic symptom disorder in DSM-5 risks mislabeling many people as mentally ill. BMJ. 2013 Mar 18;346:f1580. [PMID: 23511949]

9 Creed F, Gureje O. Emerging themes in the revision of the classification of somatoform disorders. Int Rev Psychiatry. 2012 Dec;24(6):556-67. doi: 10.3109/09540261.2012.741063. [PMID: 23244611]

10 Gureje O, Reed GM. Bodily distress disorder in ICD-11: problems and prospects. World Psychiatry. 2016 Oct;15(3):291-292. doi: 10.1002/wps.20353. [PMID: 27717252]

11 Fink P, Schröder A. One single diagnosis, bodily distress syndrome, succeeded to capture 10 diagnostic categories of functional somatic syndromes and somatoform disorders. J Psychosom Res. 2010 May;68(5):415-26. [PMID: 20403500]

12 Medically Unexplained Symptoms, Somatisation and Bodily Distress: Developing Better Clinical Services, Francis Creed, Peter Henningsen, Per Fink (Eds), Cambridge University Press, 2011.

13 Frances Creed and Per Fink. Presentations, Research Clinic for Functional Disorders Symposium, Aarhus University Hospital, May 15, 2014.

14 Per Fink. Syndromes of bodily distress or functional somatic syndromes - Where are we heading. Lecture on the occasion of receiving the Alison Creed award 2017. Journal of Psychosomatic Research, Volume 97, 127-130 https://doi.org/10.1016/j.jpsychores.2017.04.012

15 ICD-11 Beta Proposal Mechanism Comment facility, Dr Geoffrey Reed, January 11, 2015.

16 Proposal: Bodily distress disorder, Submitted: March 2, 2017
https://icd.who.int/dev11/proposals...lGroupId=c321880e-aa46-4328-ac19-7153c5e7a364

17 Creed F, Guthrie E, Fink P, Henningsen P, Rief W, Sharpe M, White P. Is there a better term than "medically unexplained symptoms"? J Psychosom Res. 2010 Jan;68(1):5-8. doi: 10.1016/j.jpsychores.2009.09.004. [PMID: 20004295]

18 Rief W, Isaac M. The future of somatoform disorders: somatic symptom disorder, bodily distress disorder or functional syndromes? Curr Opin Psychiatry September 2014 - Volume 27 - Issue 5 - p 315–319. [PMID: 25023885]

19 Chalder, T. An introduction to "medically unexplained" persistent physical symptoms. Presentation, Department of Psychological Medicine, King's Health Partners, 2014. [Accessed 27 February 2017]
http://www.kcl.ac.uk/ioppn/depts/pm...nar-Slides/Seminar-7/Trudie-Chalder-intro.pdf

20 Schumacher S, Rief W, Klaus K, Brähler E, Mewes R. Medium- and long-term prognostic validity of competing classification proposals for the former somatoform disorders. Psychol Med. 2017 Feb 9:1-14. doi: 10.1017/S0033291717000149. [PMID: 28179046]

21 Fink P, Toft T, Hansen MS, Ornbol E, Olesen F. Symptoms and syndromes of bodily distress: an exploratory study of 978 internal medical, neurological, and primary care patients. Psychosom Med. 2007 Jan;69(1):30-9. [PMID: 17244846]