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Short communication

Syndromes of bodily distress or functional somatic syndromes - Where are we heading. Lecture on the occasion of receiving the Alison Creed award 2017

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1. Background

Bodily symptoms not attributable to any known medical condition are very common in the general population and in any medical setting [1]. The severity of such symptoms range from everyday bodily sensations to severe disabling and persistent symptoms. In severe cases, the conditions are costly for the health care system (diagnostic testing, fruitless treatment attempts) as well as for society (disability, lost working years). Also, patients risk being exposed to iatrogenic harm [2,3]. The conditions have always been a diagnostic challenge due to lack of objective signs of disease and the unspecificity of the symptoms.

Against this background, it is difficult to understand why diagnosis and treatment of these conditions are under-prioritised compared to other illnesses.

The patient group is trapped in a limbo between different medical specialties as to diagnostics, treatment and research, and no medical specialty takes full responsibility for these conditions.

A broad range of syndromes or diagnoses have been introduced, and most medical specialties have at least one 'specialty-specific' syndromal diagnosis such as non-cardiac chest pain, fibromyalgia, irritable bowel syndrome (IBS), chronic fatigue syndrome (CFS or myalgic encephalitis. ME), somatoform disorders and recently the 'somatic symptom disorder' (SSD) [4–6]. Diagnoses in this area are almost entirely based on consensus. A recent example of this is the new criteria for CFS/ME called systemic exertion intolerance disease [7,8]. The poor evidence for most of the functional somatic syndromes has fuelled a prolonged discussion on whether they are all the same or many different conditions, which hampers their clinical use.

Research attempting to comply with scientific principles for establishing diagnostic categories and testing different diagnostic constructs simultaneously however suggests that despite different names, the syndromes may not be different clinical phenotypes, but different permutations of the same underlaying phenotype or related phenotypes [4,5,9]. The discussion is thus not "either one or many", but should be "one and many". Functional somatic syndromes may thus partly be an artefact of medical specialisation, i.e. developed and tested in highly selected patient populations and only including symptoms of interest for differential diagnostics between diseases within a certain specialty, and therefore overlap in syndromes has not been in focus.

In the multisymptomatic patients, the absurdity of classification becomes obvious as they may receive a plethora of different diagnostic labels depending on the specialty of the department at which they are seen in a diagnostic hunt that may go on for years. The broadly defined pain diagnoses fit poorly. The somatization disorder diagnosis may apply for some, but a mental cause for the condition is not evident in many patients. Furthermore, non-psychiatric doctors, that see the vast majority of patients with bodily distress are often reluctant to use psychiatric diagnoses, and hence the diagnosis is not made.

A further challenge is that we cannot agree on a common name for the phenomenon [10]. In this paper, I use the term 'bodily distress' as it is a neutral, descriptive name avoiding the mind-body dichotomy and it is aetiologically neutral.

2. Prevailing concepts in the classification of pathological bodily distress

In the classification, basically 3 different major characteristics are prevailing: 1) a focus on the physical symptoms or symptom patterns (patient complaints), 2) a focus on cognitions, emotions and behaviour related to the symptoms/ailment and 3) a focus on the cause or the attribution of the symptoms (Table 1).

Regarding patient complaints: in its most simple form, the condition is defined by a symptom such as pain or dizziness. This approach may have merits in mild cases with few symptoms which may be difficult to delineate from normality. Symptom diagnoses are often used in primary care.

The dimensional somatic symptom count approach has been widely used for decades - probably because of the popularity of symptom screening questionnaires in research (e.g. SCL-90 somatizating subscale and PHQ-15) [11,12]. The scales include symptoms that are common in the general population and not symptoms specific for functional disorders, and hence the symptoms may be caused by a well-defined medical condition or be "medically unexplained".

Patients with multiple unspecific symptoms more likely belong to

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Table 1
Differences and similarities in criteria and concepts between different diagnostic constructs.

Bodily distress syndrome[a]	Somatic symptom disorder DSM-V[b]	Somatoform disorders DSM-IV or ICD-10	Functional somatic syndromes
Defined by physical symptom pattern	Defined by emotional and behavioural symptoms/characteristic	Defined by physical symptom pattern including emotional and behavioural symptoms/characteristics and exclusion of organic basis	Defined by a primary symptom, or a symptom pattern or/and assumed attribution (depending on the FSS)
Organic (CNS) based bodily symptoms	Bodily symptoms of any aetiology	Symptoms without organic basis (medically unexplained)	Organic based (CNS or peripheral)
Emotional or behavioural symptoms not necessary for the diagnosis but are prevalent and may be important for the treatment	Emotional or behavioural symptoms are crucial for the diagnosis	Includes worrying and preoccupation with physical health and bodily sensations	Emotional or behavioural symptoms not necessary for the diagnosis but are prevalent and are assumed secondary to physical ailment
Medical and psychiatric differential diagnoses have to be excluded	No requirement of exclusion of a medical diagnosis, but of psychiatric differential diagnosis	Organic explanations and other mental disorders have to be excluded	Unclear relations to differential diagnoses, multiple FFS diagnoses possible
Suffering from symptoms of BDS	Suffering from emotional and behavioural trouble related to bodily symptoms or sensations	Suffering from medical unexplained symptoms and emotional/behavioural trouble	Suffering from symptoms of FSS
Cause unknown but emotional or physical stress and dysfunction in the CNS likely to be involved	Health anxiety and misinterpretation of bodily symptoms	Stress, emotional conflicts etc.	In some cause is unknown. Some FFS are defined by an assumed cause, (like Multiple chemical sensitivity)
Challenge the mental/physical dichotomy thinking of medicine	A mental disorder	A mental disorder	A non-psychiatric disorder
Based on empirical studies	Consensus driven	Poor empiric basis, most consensus driven	Consensus driven, poor empiric basis with a few exceptions

[a] May apply to the ICD-11-PC Bodily Stress Disorder draft as well.
[b] May apply to the ICD-11 (psychiatric chapter) Bodily Distress Disorder as well.

the functional spectrum as only few, well-defined medical diseases are indeed multi-symptomatic. The number of symptoms are also associated with severity of the conditions - whether due to a well-defined medical condition or not [13]. This symptom count approach may thus have some merits for screening purposes and in epidemiology, but the scales cannot be used for defining clinical cases as they have little diagnostic and differential diagnostic power.

The symptom pattern approach suggests that symptoms belong to a distinct disorder. The somatization disorder of the DSM-III is an early example of this phenotype approach. The diagnosis origins from the Briquet's syndrome which was an early attempt to apply scientific principles in development and validation of diagnostic constructs. Unfortunately, the criteria were developed in a highly unrepresentative population of 39 women admitted to a psychiatric asylum with the diagnosis of hysteria and are thus hampered by methodological error, and the criteria have been shown not to be valid [12,14]. More recent studies exploring a broader range of symptoms across different populations and using different methods (questionnaires or diagnostic interviews) have identified the same symptom clusters or profiles, i.e. gastrointestinal (IBS), musculoskeletal (widespread pain or fibromyalgia), cardiopulmonary (chest pain), and a general unspecific symptoms group (fatigue/CFS/ME) clusters [5,9,12]. Furthermore, these symptom profiles are not entirely independent distinct conditions but share a common basis, and a multiorgan bodily distress syndrome has been detected [5,9,15].

This approach is in a modified form adapted in the ICD-11-PC (primary care) draft but under the name bodily stress disorder (BSD) [24].

An advantage of the symptom pattern or illness picture recognition approach is that it is familiar to non-psychiatric doctors as this is also the way you diagnose appendicitis, rheumatoid arthritis etc.

Regarding cognitions, emotions and behaviour: a broad range of psychological symptoms and behavioural characteristics have been shown to be associated with patients disturbed by bodily symptoms not attributable to a well-defined medical condition, but except for health anxiety (previously hypochondria), using these symptoms for diagnostics has not been successful [16,17].

The DSM-5 somatic symptom disorder (SSD) is an example of a diagnosis that is mainly based on psychological and behavioural characteristics. The SSD pays very little attention to somatic symptoms; only one disturbing somatic symptom of any aetiology - including symptoms of cancer! - is required to qualify for criterion A of the diagnosis. This will include most patients seen in both primary and secondary care. The condition is defined by health anxiety, preoccupation with symptoms or that the patient devotes excessive time and energy to symptoms. The diagnosis has little in common with the diagnosis of somatization disorder that it is supposed to replace, and it is rather a permutation of the hypochondria diagnosis.

The SSD supports the mind-body dichotomy as it is clearly defined as a mental disorder, and it is of no differential diagnostic value for a doctor in distinguishing between a well-defined medical condition and bodily distress etc. The ICD-11 bodily distress disorder (BDD) draft seems to be much in the line with the SSD thus having the same problems [18].

Regarding the focus on the cause or the attribution of the symptoms: some of the functional somatic syndrome diagnoses are based on an *assumed cause*. For instance, in whiplash associated disorder the cause is an assumed late complication following a neck sprain and in multiple chemical sensitivity the condition is assumed to be caused by a non-measurable chemical toxic or smell [19].

The suggested central sensitivity syndrome (CSS) may also be included here, i.e. that an inherited or acquired central sensitivity in the CNS is a common cause for FFS [20]. Although appealing, the hypothesis is currently not supported by substantial evidence.

Throughout history, such new syndromes have emerged, and recently an epidemic of assumed adverse effects of the human papilloma virus (HPV) vaccine has emerged in Denmark [21].

We have little knowledge about the mechanisms behind the primarily layman-driven diagnoses and about patients' attribution of their symptoms despite it can be a major challenge in treatment.

3. Stigmatization

Even today, patients with BDS are met with negative attitudes in the health care and social security systems as well as in society in general. They do not feel understood and taken seriously by doctors, they feel accused of not being genuinely sick and they face difficulties in getting disability benefits or compensation from insurance companies because

Table 2
Misconceptions and myths in syndromes of bodily distress.

Assumption	Reality
The patients misinterpret normal physical sensations as indication of severe disease	The case in health anxiety but not in BDS. The patients have their symptoms
Preoccupation with their physical health and bodily sensations	Suffering from symptoms. Most people with disturbing symptoms would be preoccupied with their health.
High health care use – frequent attenders	The patients cannot get any help or explanations. Rather a problem of the health care system than a characteristic of the patient
It is a chronic illness	The same spectrum as in other disorders/diseases
Unresponsive to therapy	Quite good treatment results even in the chronic group, but not all respond
The symptoms represent a (disguised) mental disorder	The problem is physical symptoms. It is a distinct disorder of its own, but a high psychiatric comorbidity is evident.

their diagnosis is not recognized.

Mental illness is still plagued by prejudice which unfortunately is reflected in the diagnostic criteria of somatoform disorders and now the SSD and BDD draft in the psychiatric classification chapter. The mind-body dualistic thinking is strongly founded in Western thinking, both among laymen and health professionals, making it difficult to change.

Stigmatization can be counteracted in several ways, but the most important is to change doctors' views on the condition by updating their knowledge and eliminate misunderstandings by introducing a modern understanding of the condition (Table 2) [22].

An additional challenge is the small but very active patient groups that aggressively spread misinformation on the social media. In some cases, they also try to undermine doctors and researchers with whom they disagree. Unfortunately, it seems to have some impact on research. The Institute of Medicine in the US report on CFS/ME avoids including any studies on psychological factors or treatment by stating that this is a medical condition and not a psychiatric one [7,8].

This can only be counteracted by authorities, layman information on the internet, in books etc., and doctors must be aware of the scientific basis of medicine.

4. A new way forward

The situation today is that we have a profound conceptual and diagnostic confusion, hampering research and communication between medical specialties and making rational treatment and teaching of colleagues difficult. We therefore need to bridge the body and mind gab in understanding this phenomenon between medical specialties.

A first step would be to recognise that bodily distress syndrome/disorder is a distinct disorder of its own, but with different subtypes. Like in depression, it has both a dimensional quality - we all have bodily signals everyday as we all we have a mood - and a categorical aspect, i.e. it is a disorder in its severe forms, that can be diagnosed and differentiated from other medical or psychiatric disorders. The recognition of this is of paramount importance and may lay down the avenue for a diagnostic system that is acceptable across medical specialties and for the patients. The bodily distress or stress syndrome/diagnosis and even the CSS may aspire as a candidate for this. The BDS (or BSD) diagnosis is one of the few diagnoses in this field that is empirically- and research-based and has high utility [5,9,23,24]. Especially a diagnosis of BDS multiorgan type is very needed as we do not have any diagnostic options today for this.

To include the BDS/BSD diagnosis and all the relevant functional somatic syndromes in a separate chapter in the ICD-11 would have been optimal, but the WHO has rejected this option.

Unfortunately, the DSM-V classification and the ICD-11 psychiatric draft rather seem to broaden the gap between medicine and psychiatry instead of bridging it. The exclusive focus on the emotional and behavioural symptoms in SSD and the BDD draft diagnosis may seem bizarre and offending to the patients as these do not reflect the patients' bothersome problem, namely bodily symptoms.

We have to bear in mind that most of the patients with BDS are primarily diagnosed and treated in non-psychiatric settings, and therefore a diagnosis for positive identification and with differential diagnostic power is important.

We all hope in the future to have aetiological, biological or psychological diagnostic markers for BDS that can be used for classification and diagnostics, but we are not there yet. An avenue ahead would be to agree on European research criteria for syndromes of bodily distress that could form the basis for further research.

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