

The ‘medically unexplained symptoms’ syndrome concept and the cognitive-behavioural treatment model

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Abstract

The American Psychiatric Association's, 2013 DSM-5 abandoned the use of the term ‘medically unexplained symptoms’ for non-neurological disorders. In the UK, treatments for various medical illnesses with unexplained aetiology, such as chronic fatigue syndrome, irritable bowel syndrome and fibromyalgia, continue to fall under an MUS umbrella with cognitive behavioural therapy promoted as a primary therapeutic approach. In this editorial, we comment on whether the MUS concept is a viable diagnostic term, the credibility of the cognitive-behavioural MUS treatment model, the necessity of practitioner training and the validity of evidence of effectiveness in routine practice.

Keywords

cognitive-behavioural model, evidence supported treatment, IAPT, medically unexplained symptoms

Introduction

Medically unexplained symptoms (MUS) are a common phenomenon in general practice. In theory the term ‘MUS’ aggregates a diverse range of poorly understood conditions under one umbrella. MUS ‘refer to persistent bodily complaints for which adequate examination (including investigation) does not reveal sufficiently explanatory structural or other specified pathology’ and commonly include fatigue, dizziness, persistent pain, headaches and musculoskeletal complaints (Chew-Graham et al., 2017). The main differentiator of a MUS complaint from any other medical complaint is the absence of known organic pathology or other biomedical rationale for a patient’s symptoms; thus MUS covers all symptoms that are persistent and ‘unexplained’. In recent times, the

medically unexplained have been corralled into a ‘syndrome concept’. This syndrome narrative of MUS has then been led to a treatment model that hypothesises commonalities in the aetiology of ‘all’ MUS complaints with a ‘one-size-fits-all’ treatment approach of the so-called ‘cognitive-behavioural model’ (CBM; Deary et al., 2007).

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As the MUS diagnostic category is alleged to include up to one-third of all patients seen in primary care on a regular basis (Nimnuan et al., 2001), the scale of the artificially created 'syndrome' highlights the absurdity of such a conceptualisation. Evidence in support of this unifying model is derived predominantly from a small number of studies across a narrow range of disorders, principally chronic fatigue syndrome and irritable bowel syndrome (Deary et al., 2007), rather than the diverse breadth of MUS that is seen in primary care. Chronic fatigue syndrome (CFS) and irritable bowel syndrome (IBS) are the 'poster disorders' for the MUS concept in psychological medicine.

Few commentators have challenged the validity of the homogenous MUS label. Doctors in community practice understand that many patients have 'unexplained complaints', and mental health professionals understand that both psychological and physical illnesses often remain obscure and unexplained in terms of exact pathogenesis, whether that be schizophrenia or lower back pain. Our issue concerns the drive to view what is 'unexplained' as evidence of cognitive or behavioural dysfunction, as proposed by Deary et al. (2007). Reliable diagnostic criteria are an important step for research, providing a common language, but it is no guarantee that what is focussed upon has validity. The contentious scientific status of the psychosomatic approach to MUS/MECFS is examined elsewhere (Marks, 2021a).

Maes and Twisk (2010) provide a predominantly biological model to help explain chronic fatigue syndrome, rescuing it from the 'unexplained' category. Their model explains readily why immunological and endocrinological variables better predict outcome in CFS than psychological variables. By contrast, in the Harvey and Wessely (2009) model of CFS there is no specification of any key and lock mechanism that is, what precipitant, acting on which predisposing factor would usher in the said debility, nor which perpetuating factor would be pertinent to which key-lock combination. Predisposing factors include inter alia

personality traits, early childhood illness and periodic overactivity. Precipitants include viruses or stress, whilst perpetuating factors are held to include behaviours such as too much rest or excessively focussed on symptoms. There is a distinct lack of specificity in the Harvey and Wessely (2009) model. It fails to distinguish between a clinical entity and its background, such that the former is lost in a fog of alleged predisposing, precipitating and perpetuating risk factors, none of which have been shown to be causal of ME/CFS.

Invalidation, victim-blaming and treatment harms

A recurring theme among practitioners applying the CBM is the claim that dysfunctional illness beliefs (e.g. that 'symptoms are the result of a virus') are causally linked to deconditioning and a poor prognosis (e.g. Wessely et al., 1991). Attempting to induce patients into cognitive behaviour therapy (CBT) to change the way they are alleged to habitually think has not proved a successful strategy, as the revised NICE (2020) guidance has concluded. Rather than question the legitimacy of CBT and the treatment model, clinicians can attribute the failure of CBT to patients' unwillingness to change their beliefs and behaviours. Thus a recursive vicious circle is established: doctor's analysis → MUS patient's unhelpful beliefs and behaviours → CBT → failure → doctor's analysis → patients' unhelpful beliefs. This recursive victim-blaming cycle is likely to make patients with MUS feel worse, frustrated and angry (Figure 1).

The contentious nature of the CBM creates a lot of ill-feeling among the patient community. Unfortunately, people with MUS are well used to having their symptoms dismissed and to not being believed by practitioners. Some researchers refer to this phenomenon of invalidation as 'All In Your Head' (AIYH; Kool et al., 2013). Burke (2019) describes the scenario in which a practitioner communicates to patients that their symptoms are AIYH thus:

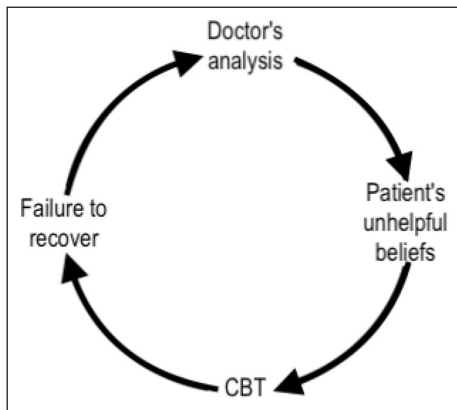


Figure 1. A recursive victim-blaming cycle between doctors and patients with the outcome that patients feel worse, frustrated, and angry.

... a typical physician-patient interaction may proceed as follows: (1) the physician provides a rundown of normal investigations, (2) the patient is told they have no known medical diagnoses, (3) a brief awkward exchange occurs and (4) little further explanation, guidance, resources or facilitation of an appropriate referral process is given. Even if the infamous phrase is not explicitly stated, this sequence leaves the patient to infer for themselves that it must be all in their head. . . The inadequate management of this segment of medicine represents a silent epidemic that is slowly eroding patient-physician relationships, perpetuating unnecessary disability and straining health care resources (p. 1417).¹

Bontempo (2021) identifies more than 25 different terms or phrases used to describe invalidation of patients and/or symptoms including: dismissed, ignored, passed off, fobbed off, not taken seriously, not believed, not acknowledged, delegitimized, discounted, discredited, disqualified, devalued, negated, rejected, trivialized and minimized. Unexplained symptoms are attributed by practitioners to psychological processes or pathology generally when symptoms are: (i) perceived by them as ‘not real’, imaginary or all in the head or mind; (ii) portrayed as reflective of neuroticism, stress, anxiety, depression, hysteria, somatization, or hypochondriasis; and (iii) as

malingering, exaggerating or overreacting to their symptoms.

The adoption of the CBM likely negatively biases how physicians approach people with MUS (Geraghty, 2020). This may explain why many MUS patients feel disbelieved and unsupported in seeking medical care. For example, in the case of ME/CFS, the CBM fails to incorporate a substantial body of evidence showing multiple biological deficits in association with ME/CFS (Marks, 2021b). Medical trainees and physicians will need significantly more training and clinical exposure to MUS patients, armed with a better awareness of misleading and unproven claims associated with the cognitive-behavioural model if they are going to succeed with treatments based on the CBM.

The dismissive approach and inappropriate treatments offered to patients with MUS can lead to patients feeling frustration and disappointment and can also do actual harm. A significant proportion of people with myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) have reported iatrogenic and treatment harms following graded exercise therapy (GET), cognitive behaviour therapy (CBT) and physiotherapy. A recent study commissioned by NICE (2020: appendix 2²) reported:

‘Many people with severe ME/CFS report anger and frustration engaging with the medical profession, a significant proportion find getting a diagnosis an arduous task and are reporting that doctors have little knowledge of the illness. . . GET ranked highest for negative responses, followed by CBT and physiotherapy. . . Participants report that pushing beyond limits, often via participating in graded exercise therapy or physiotherapy, results in some type of negative symptom response that can last from days to months and many report associated psychological distress with such relapses’ (p. 8).

One-third of a sample of 60 patients with severe myalgic encephalomyelitis (ME) reported feeling worse after GET, one-sixth felt worse after CBT and 13% felt worse after physiotherapy.

The new NICE (2020) guidance on safety is consistent with Twisk and Maes (2009) who observed that CBT and GET are potentially harmful for many patients with MECFS. Exertion is almost bound to occur with GET in patients with severe ME and is likely to produce post-exertion fatigue, which decreases aerobic capacity, increases musculoskeletal pain, neurocognitive impairment, 'fatigue' and weakness and produces a slow recovery time. Treating people with MUS in a routine manner with CBT and GET raises ethical concerns, certainly if practitioners are not fully trained in clinical/health psychology and/or general practice.

The futility of treating MUS in routine practice

The UK *NHS Improving Access to Psychological Therapies* (IAPT) service ministrations with regards to MUS take place outside the bounds of what is normally regarded an evidence-supported treatment (Tolin et al., 2015). Specifically, there have been no randomised controlled trials employing independent evaluators; there has been no evaluation in routine practice by those not involved in developing the original MUS protocols; and there has been no demonstration of effectiveness in routine practice. Whilst White et al. (2011) did not use an objective primary outcome measure, but had recourse instead to a hybrid of self-report and clinician assessment, such that the former could influence the latter, thus vitiating the standard methodological norm of blind independent clinical assessment. Indeed, a meta-analysis of the efficacy of CBT in somatoform disorders and medically unexplained physical symptoms (Liu et al., 2019) included 15 studies but none of them utilised a categorical end-point for remission. The primary outcome was the severity of somatic symptoms. But such continuous measures are measures of response not remission. They give no indication of the proportion of people no longer suffering from somatoform disorder or MUS at the end of treatment nor of the duration of recovery. Furthermore, self-report measures

are always open to expectation and demand. There was no comparison of CBT treatment with active placebo. Liu et al. (2019: 110) did conclude, 'The overall quality of evidence is relatively low due to a high risk of bias with lack of blinding of. . . outcome assessors' and 'publication bias for somatic symptoms at postintervention and follow up'. But these caveats somewhat vitiate the authors conclusions as to the efficacy of CBT for somatic symptoms. There are also major doubts as to whether there was fidelity to CBT protocols in the studies, with less than half assigning homework – a key feature of this type of psychoeducational intervention. On the surface the Liu et al. (2019) meta-analysis provides ammunition for the wider dissemination of CBT for MUS. In this context service providers and funders are likely to focus on operational matters such as numbers through the system and waiting lists.

Confirmation bias and the flourishing of treatment

In the rush to disseminate psychological treatment for MUS there is a danger that there is no check on real world outcomes that is, that the patient would recognise the 'observed' changes as clinically meaningful. In this context, dissemination efforts are likely to be legitimised on the basis of changes on self-report measures, which can occur for myriad reasons including: 'effort justification' were patients seek to justify the costs involved in undergoing treatment, or a desire to please the clinician. A self-serving, though not necessarily conscious, confirmatory bias is likely to be operated by the service providers. In the domain of MUS, independent assessors need to be aware of the possibility that treatment of MUS may be detrimental, as clinicians are advised to dissuade clients from having investigations whilst having CBT and to delay investigations, if they develop new symptoms, for 2 weeks (Chalder, 2020). This is troubling as misdiagnosis is commonplace under the umbrella term of MUS with one-fifth to one-third being at risk for incorrect provisional

misdiagnosis as MUS in, for example, neurology and cardiology clinics (Nimnuan et al., 2000). Advocates of a primarily biological model of CFS (Maes and Twisk, 2010) have suggested that interventions with cognitive behaviour therapy or graded exposure therapy are potentially harmful for many patients with CFS, since the underlying pathophysiological abnormalities may be intensified by physical stressors (Geraghty et al., 2019).

Of note, the recently published draft NICE guideline for ME/CFS has withdrawn support for these two treatments due to low quality of the evidence base and the risk of harms. Furthermore, a supportive role for CBT is proposed, rather than a curative approach (NICE, 2020). There is a pressing need for independent external audit of CBT treatments for MUS utilising the methodological standards of the last decade and not those of the previous millennium.

Conclusions

The MUS concept can no longer be accepted as a viable diagnostic term. The credibility of the cognitive-behavioural MUS treatment model has reached a nadir and can be given only an auxiliary role in treatment. An urgent necessity to provide practitioner training has been identified and the need for greater awareness of the misleading nature of poor quality evidence for effectiveness of the CBT approach in routine practice.

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Notes

1. Suzanne O'Sullivan's (2015) 'Is It All In Your Head?' was the winner of the Wellcome Book Prize in 2016.
2. The NICE commissioned the survey from the University of Manchester Centre for Primary Care with Professor Anees Esmail, Dr Keith Geraghty, Dr Charles Adeniji and Dr Stoyen Kurtev.

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