

Medically unexplained symptoms: exacerbating factors in the doctor–patient encounter

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This paper proposes that well-intentioned actions by medical practitioners can exacerbate or maintain medically unexplained symptoms (MUS)—i.e. physical symptoms that are disproportionate to identifiable physical disease. The term is now used in preference to ‘somatization’.¹

Although research has gone some way to explain the predisposing and precipitating causes of MUS, there is little information on the factors that maintain such symptoms and resulting behaviour. We conducted a search of the Medline and Psychinfo databases using ‘iatrogenesis’ and ‘medically unexplained symptoms’ or ‘somatization’ as keywords; however, the yield of references was disappointing, so we supplemented these with papers that included relevant data even if not explicitly about iatrogenesis.

MUS are common. In one study, 30% of new patients attending general medical outpatients had no medical diagnosis to account for their symptoms, whilst a further 22% had a doubtful medical diagnosis.² Among frequent attenders at secondary care clinics the prevalence of MUS is high,³ and the greater the number of reported symptoms the more disabled the individual is likely to be.⁴ MUS may or may not be associated with anxiety and depression. Patients with the highest number of MUS are likely to fulfil the psychiatric criteria for somatization disorder—at least 2 years of multiple and various MUS, with persistent refusal to accept advice and reassurance from doctors; functioning impaired. In patients attending general medical clinics the prevalence of either somatization disorder or hypochondriacal disorder is as high as 12%²—in contrast to a community prevalence of 0.1–0.7%.⁵ The medical specialties employ shorthand descriptions for particular clusters of MUS including irritable bowel syndrome, non-cardiac chest pain, fibromyalgia, chronic fatigue syndrome and repetitive strain injury. They are diagnosed on the basis of symptoms which overlap considerably and have no clear organic aetiology.

Factors predisposing to MUS are female gender,⁶ childhood experience of parental ill-health (particularly

paternal),⁷ childhood abdominal pain⁸ and lack of care in childhood.⁹ High rates of ‘life events’ occur in the period predating the onset of MUS in a pattern similar to that seen before the onset of depressive illness.¹⁰ In those with somatization disorder there are high rates of personality disorder.¹¹

What are the factors that lead to persistence of MUS in some individuals? Examples of possible precipitating events include chest pain induced by hyperventilation¹² and muscle ache after unaccustomed exercise.¹³ Some of these mechanisms may become chronic. Additional psychosocial factors may be ‘secondary gain’¹⁰ (for example, when chronic pain spares a parent the burden of caring for a difficult child) or maladaptive psychological coping strategies.¹⁴ In this paper, we focus on the adverse effects of medical interventions at various stages of the doctor–patient encounter.

REFERRAL

In the UK, the general practitioner (GP) is the primary medical contact for patients. Faced with a patient with persistent and disabling MUS, a GP will often feel under pressure to refer to specialist services. Sometimes a patient will be attending several secondary care departments at once, for various symptoms, either because the GP has arranged this or because of interspecialty referrals.³ These consultations are likely to focus on the system of specialist interest, so that a rheumatologist may pay particular attention to musculoskeletal symptoms and apply the label fibromyalgia.¹⁵ Consequently a patient who sees several specialists may receive conflicting messages. The expert consensus is that, once an organic cause for symptoms has been excluded, further examination and investigation should only be initiated if a new symptom develops.¹

Occasionally the GP or specialist will decide to refer the patient to a psychiatrist. This is neither simple nor straightforward. As one expert notes, ‘It is a commonplace clinical observation that somatising patients—more than any other group—resent psychiatric referral or at least are very sceptical of its purpose’.¹⁶ With MUS psychiatric referral is a difficult matter to raise with the patient, and close liaison between the physician and the psychiatrist is desirable. Poorly prepared referrals can be interpreted as

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invalidating the illness experience long before the patient has even seen the psychiatrist. However, techniques have been described for introducing the idea in a non-confrontational way.¹⁷ The referrer should preferably have some knowledge of the patient's psychosocial background, and should strive to avoid any implication that the symptoms are being made up. A joint meeting with physician, patient and psychiatrist is ideal. The worst strategy is to refer the patient without saying that the specialist is a psychiatrist: the patient may feel deceived and misunderstood, and as a consequence become more deeply entrenched in the biomedical model.

ASSESSMENT

When presented with a patient who has symptoms that cannot be explained organically, doctors often respond negatively. If the patient has already been extensively investigated and the results are not supportive of physical illness, doctors tend to lower their estimation of the severity of the symptoms (e.g. pain or disability); this happens even if the doctor has not yet met the patient.¹⁸

Kouyanou *et al.*¹⁹ undertook a comparative study of 125 patients with chronic pain, of whom 58 were considered to have medically unexplained symptoms (cases) and 45 to have clear organic symptoms (controls); the remaining patients were not included in the analysis. When asked about past advice from doctors, the group with medically unexplained symptoms were significantly more likely to recall being told their pain was all in the mind. The patients with MUS were more likely to be dissatisfied with their GP and with the thoroughness of investigation.

An earlier cross-sectional study by the same group had aimed to identify possible iatrogenic factors in the persistence of pain.²⁰ 47% of the chronic-pain patients had received more than five types of treatment for their pain (regarded as overtreatment) and 39% had been given at least one inappropriate explanation. Qualitative evidence shows that patients with MUS can experience medical assessment as hostile and adversarial.²¹ Once a patient feels discredited, the opportunity to explore psychosocial factors is lost. In a specialist chronic fatigue syndrome (CFS) clinic the patients who were dissatisfied with their medical care were those who judged their doctors dismissive or sceptical or ignorant about CFS.²²

Irritable bowel syndrome (IBS) is one of the most common medically unexplained syndromes. Evidence from secondary care clinics shows that, at initial consultation, doctors and patients have different expectations of the medical encounter.²³ Moreover, a 'positive' doctor-patient interaction at the first visit seems associated with fewer subsequent visits.²⁴ Positive medical factors include exploration of the psychosocial history, reassurance about

the diagnosis, and discussion of test results. The implication is that a poor doctor-patient interaction in IBS and kindred illnesses may lead to repeat consulting. Other work has shown that, over a series of routine consultations with a single doctor, patients with IBS can make positive changes to their illness attributions²⁵. Published advice on how to handle the assessment of MUS^{26,27} includes: taking a careful history at the first assessment (including an exhaustive list of symptoms), probing for life 'stresses', and physical examination.

INVESTIGATIONS

Doctors sometimes use investigations as a means of reassurance to patients. Physicians and psychiatrists have somewhat different views on investigations in the patient with MUS: physicians tend to believe that negative results allay health anxieties, although there is some evidence to the contrary.²⁸

For patients with MUS, the sensory experiences leave scant room for doubt about physical causation, and tend to outweigh the negative results of a doctor's examination or investigations.²⁹ Thus one sees how the cycle of excessive investigation can begin. When, after reassuring words, the doctor orders some investigations, the patient may suspect that the doctor has missed something or is uncertain.³⁰ Pre-existing health anxiety seems to be a factor: in patients undergoing gastroscopy, the news that there was no organic disease gave immediate reassurance but in those with high health anxiety the worries about illness quickly returned.³¹ Seemingly, most people are reassured by normal investigations, but those with pronounced psychiatric or psychological comorbidity are not reassured in the same way and may even be made worse.³² This issue is currently being addressed in a randomized controlled trial of magnetic resonance imaging in chronic headache.³³ A further difficulty is that, if enough investigations are performed, minor and irrelevant abnormalities will be detected and themselves become hypothesis-generating.

REASSURANCE

Reassurance is particularly important with patients who are hypochondriacal or have MUS. Some qualitative work has looked at the experience of patients with MUS.³⁴ Patients' accounts of their doctor's explanations were categorized into three types—rejecting, colluding and empowering. The authors suggest that empowering explanations—i.e. explanations that make patients feel they have some influence over their symptoms—are most beneficial individually and to the health service.

'Breaking bad news' is a part of the doctor-patient encounter now incorporated into the undergraduate medical curriculum, but techniques for reassuring patients

who have negative investigations or examinations have been given less attention.³⁵ With MUS the message will often have an element of uncertainty: there is no clear explanation for the symptoms though sinister causes have been ruled out.³⁶ Note that, before trying to reassure the patient, the doctor must establish what the patient thinks is wrong.

LABELLING

The adoption of a label such as IBS, fibromyalgia, CFS or repetitive strain injury affords the sufferer legitimacy, avoids the stigma of a psychiatric illness and ensures that dysfunction is not seen by others as imaginary—in other words, it allows entry into the ‘sick role’.³⁷ Thus patients often gain relief when their disabling symptoms are given a name.^{21,38} Labelling can make sense of debilitating and often chronic symptoms, and the external acknowledgment that the condition is ‘legitimate’ is both reassuring and enabling.

However, the conferring of an illness label is not a neutral act, since specific labels are associated with specific beliefs and attitudes. In CFS, for example, the name itself generates vigorous debate;³⁹ use of this term or the alternative ‘myalgic encephalomyelitis’ implies underlying assumptions about aetiology and treatment for both patients and doctors.⁴⁰ That a label can have long-term implications was shown by a study published in 1967. Bergman and Stamm⁴¹ looked in detail at 93 children who were thought by their parents to have heart disease. 81% of these did not have any evidence of heart disease at the follow-up, yet nearly half had had their physical activity restricted by their parents because of concerns about the heart. The authors felt that the label of ‘congenital heart disease’ or ‘rheumatic heart disease’ had led to changes in the family’s approach that were largely unnecessary. A key factor in the parents’ approach to their child’s apparent condition was the advice given to them by the diagnosing physician.

Even when organic illness is certain, the illness label can result in adverse behaviour changes. The doctor, too, may behave differently to the patient once the symptoms have been accorded a label.⁴³

So, there is conflicting evidence on whether labelling is helpful or not for the individual with MUS.⁴⁴ Medical labels are the product of a complex overlap of social and historical factors including input from the sufferers themselves.⁴⁵ Doctors need to consider the implications of labelling in the individual patient, though the various terms have value and should continue to be used.

TREATMENT

Most treatments have the potential for side-effects, and decisions on risk and likely benefit are particularly difficult

when the diagnosis is controversial or there are few evidence-based treatments. Those which are instigated so as to get the patient out of the consulting room or make the doctor feel less helpless are likely to do harm, and patients with chronic or multiple MUS are particularly likely to be treated for illnesses that they do not have. In a retrospective study by Fink,⁴⁶ patients with persistent MUS had worryingly high rates of unwarranted surgery and medical interventions during admissions to hospital. Not surprisingly, the treatments usually failed to relieve the symptoms.

Lyme disease is an infection that has been overdiagnosed in the USA, largely because of confusion about the diagnostic criteria and media misinformation. This has produced great anxiety among people who live in endemic areas.⁴⁷ Misdiagnosis means not only that the ‘true’ diagnosis has been missed (be it psychiatric or physical), but also that patients are burdened with potentially harmful treatments and an inaccurate prognosis. In one study of referrals to a specialist Lyme disease clinic,⁴⁸ 60% of patients had no evidence of ever having had active disease. Yet many had received inappropriate treatments such as antibiotics, and 55% reported at least one adverse drug event. Those who had been given an inappropriate label of Lyme disease by a physician fared particularly poorly, needing additional consultations, using more antibiotics and with a higher prevalence of depression. A substantial proportion of those who had their Lyme disease label ‘removed’ by the clinic remained unconvinced and many sought further medical opinion.

There is some emerging evidence to suggest that harm occurs also at the hands of non-medical practitioners in medically unexplained syndromes such as ‘multiple chemical sensitivity syndrome’. One study pointed to harm when non-medical practitioners colluded with patients’ abnormal illness beliefs or suggested that the patient adopt avoidance techniques or use inappropriate therapies.⁴⁹

SOCIAL

Clinical iatrogenesis refers to the direct ways in which doctors and other health practitioners cause or prolong disease in their patients. Social iatrogenesis has been suggested as a term for illness caused or prolonged by wider sociopolitical inputs.⁵⁰ Patient support groups have evolved to the point where they have an important role in propagating information about illnesses as well as offering support to the patient and family. However, this support is not always unbiased, and sometimes the views propagated by these groups can encourage inappropriate illness behaviour.⁵¹ In two studies, membership of a patient organization was associated with poor prognosis.^{52,53} Even

if this does not prove cause and effect (since membership of a self-help group is not randomly allocated) the finding can still raise the possibility that aspects of group culture are maladaptive—perhaps promoting emotional support and legitimacy at the expense of continued disability.

The medical profession has come under fire from both the media and special interest groups for failing to diagnose conditions such as repetitive strain injury in Australia⁵⁴ and seronegative Lyme disease in the USA,^{47,55} and even researchers have been subject to damaging pressure from groups who disagree with their findings.⁵⁶ If sections of the media advocate an exclusively organic model, as has happened with CFS in some parts of the English-speaking world, the biomedical model may become firmly enshrined for patients and families at the expense of broad-based psychosocial models. This would matter less if broad-based rehabilitation strategies were not currently the most successful management approaches.

CONCLUSION

Patients with MUS are an important and expensive group. The aetiology of their symptoms is still poorly understood but this paper has identified points within the doctor–patient encounter where MUS may be iatrogenically maintained. Clearly there are implications for the way doctors are taught to assess and treat these patients. Although the management of patients with MUS is commonly challenging and even frustrating, many of the difficulties can be overcome by use of appropriate interview techniques. We anticipate that these same techniques could reduce the likelihood of iatrogenic damage. At the very least, doctors in all clinical specialties must be wary of causing physical harm by unwarranted investigations and treatments.

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