

## **Why Bioethics Should Be Concerned With Medically Unexplained Symptoms**

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### **ABSTRACT**

Biomedical diagnostic science is a great deal less successful than we've been willing to acknowledge in bioethics, and this fact has far-reaching ethical implications. In this article I consider the surprising prevalence of medically unexplained symptoms, and the term's ambiguous meaning. Then I frame central questions that remain answered in this context with respect to informed consent, autonomy, and truth-telling. Finally, I show that while considerable attention in this area is given to making sure not to provide biological care to patients without a need, comparatively little is given to the competing, ethically central task of making sure never to obstruct access to biological care for those with diagnostically confusing biological conditions. I suggest this problem arises from confusion about the philosophical value of vagueness when it comes to the line between biological and psychosocial needs.

### **INTRODUCTION**

Biomedical diagnostic science is a great deal less successful than we've been willing to acknowledge in bioethics. While the foundations of clinical ethics have been centered on a model of medical practice involving established biological diagnosis, in

truth that model applies only in a portion of cases. Are current bioethical tools adequate for addressing the ethical complexities that arise in cases of medically unexplained symptoms?

I hope to show that they are not. While it was wise to base clinical ethics on the model of established biological diagnosis, providers, patients and policy makers are much in need of ethical guidance when it comes to the many cases where diagnosis remains elusive. Given our intense focus at this time on evidence-based practice, moreover, lack of evidence poses a substantial challenge to clinical decision-making, one it seems we can only address through ethical considerations. For these reasons, I suggest it's time for bioethicists to contribute to this central, strangely silent, area of medical practice.

Following preliminary discussions in Part 1 of the prevalence of medically unexplained symptoms and term's ambiguity, I will begin in Part 2 by framing central questions in clinical ethics that remain unanswered in this context. In Part 3, I will consider the competing demands of making sure not to provide biological care to patients with unexplained symptoms who don't need it, and making sure to provide it to those who do have a need. Evidence indicates that focus on the former task has obstructed access to biological care for patients with diagnostically challenging conditions, and I suggest we should attribute that problem to pervasive confusion about the philosophical value of etiological vagueness in this area of medical practice.

## **PRELIMINARY INFORMATION**

### **Prevalence and Terminological Ambiguity**

By some estimates, medically unexplained symptoms are significantly more common in outpatient settings, or at least in general practice, than symptoms that are medically explained – and this idea really should shake the foundations of clinical ethics as we’ve come to understand the field. One well-known study (Kroenke and Mangelsdorf 1989) offers the astonishing finding that 86% of symptoms for which patients seek biological medical care remain medically unexplained in an internal medicine setting. Findings at that high end have been echoed by several additional studies (Korber et al. 2011; Steinbrecher et al. 2011), though there are equally many that embrace far lower estimates (Swanson, Hamilton and Feldman 2010). A recent review article suggests that MUS “account for 10-15% of all general practice consultations” (Johansena and Riser 2016, 647).

In everyday practice at this time, and at the level of policy, estimates for outpatient practice generally seem to fall between these two extremes, so that the prevalence of MUS is understood as roughly equivalent to the prevalence of medically explained symptoms. The Up to Date review system settles on “more than 50%” (Greenberg 2017) because many studies and review articles offer figures in this area, (Fink and Rosendal 2015; Kroenke et al. 1994; Nimnuan, Hotopf and Wessely 2000; Oyama, Paltoo and Greengold 2007; Smith and Dwamena 2007; Warner et al. 2017). Current practice guidelines in the UK state that “on average, 52% of patients accessing outpatient services have MUS” (Joint Commissioning Panel for Mental Health 2017, 6-7), presenting this breakdown:

Figure 1: Proportions of people with MUS in outpatient clinics

Table 2. Proportion of people with MUS in outpatient clinics

| Outpatient clinic | Proportion of people with MUS                   |
|-------------------|---|
| Gynaecology       | 66%   |
| Neurology         | 62%   |
| Gastroenterology  | 58%   |
| Cardiology        | 53%   |
| Rheumatology      | 45%   |
| Respiratory       | 41%   |
| Dental            | 37%   |
| <b>Total*</b>     | <b>52%</b><br>(of which 42% are men, 57% women) |

\* From a study of 550 patients

What makes a prevalence estimate for MUS so difficult to establish is confounding ambiguity as to what the term actually means. In some contexts researchers and providers understand the phrase “medically unexplained symptoms” as a broad term that names *all symptoms for which patients seek biological care where providers do not find biological explanations* – including cases where biological causes are present but unrecognized, cases of benign self-limiting symptoms with biological origins, and cases where psychosocial distress is the primary causative factor (Jackson and Passamonti 2005; Kroenke et al.1994). In research and in practice, however, it is much more common for the phrase “medically unexplained symptoms” to name *only the specific subset of unexplained symptoms that have primarily psychosocial causes* (Johansena and Risor 2016; Oyama, Paltoo and Greengold 2007; Swanson, Hamilton and Feldman 2010). Ambiguity of this kind has far reaching ramifications in practice, and I will do my best to disentangle these as the paper proceeds.

To be very clear, from this point forward I will use the phrase “medically unexplained symptoms”, or “MUS”, in the broad sense, to name *all symptoms for which patients seek biological care where providers have not found biological explanations* – including cases where biological causes are present but unrecognized, cases of benign

self-limiting symptoms with biological origins, and cases where psychosocial distress is the primary causative factor.

Because I will consider the ethical facets of clinical decision-making about which MUS have primarily psychosocial causes and which do not, it will not work to adopt the strange, standard practice of using the term “MUS” to name both symptom groups.

Instead, from this point forward I will use the term “psychogenic symptoms” to name *the subset of MUS that have primarily psychosocial, rather than biological, causes*. In spite of this apparently dualistic language, I do take it as given that the actions of the psyche should ultimately be understood as biological, and I will discuss that issue directly in Part 3. Throughout the paper, I will use the phrase “psychogenic diagnosis” to name cases where everyday MUS are construed as psychogenic without the application of a full DSM diagnostic label, as well as cases where a DSM label is applied.

Finally, it is important to acknowledge that in 2013 the DSM-5 directly discouraged use of the term “MUS” to refer to psychogenic symptoms, and while the UK continues to use the term in that way routinely, research and textbook entries in the US sometimes avoid it. As I am using the term “MUS” in this paper, it does not refer specifically to psychogenic symptoms, but rather to the broader group of symptoms for which medical explanations remain elusive. This usage does not conflict with the DSM’s current directives.

### **What is “The Problem of Medically Unexplained Symptoms”?**

Most of us have had first hand experience with psychogenic symptoms in the form of aches and pains that take our attention for a time, but that later reveal themselves

to be driven mostly by emotional issues. Any minor ache can become the focus of anxiety and deliberation when we're facing personal discomforts in our lives, and when we do take note of the role those discomforts play in the symptom experience, that revelation can make the pain improve or even disappear. In cases of this kind it seems clear biological treatment is not in patients' best interests, and that biological testing might sometimes pose unjustified threats. And it seems on the surface that the most direct route to relief in these cases would be one that leads patients to recognize the role their psychosocial distress plays in the symptom experience – but it turns out there are formidable obstacles along that path. Things are not nearly that simple.

Since the early 1980's, when psychogenic diagnosis was first codified in the DSM-III with the category of “somatoform disorders”, practice in this area of medicine has been dictated by research in the psychiatric subdiscipline of psychosomatic medicine, though with little success. It is common knowledge that in cases of persistent MUS, physicians, and indeed mental health providers, can offer little in the way of treatment that can generally be expected to provide relief (Johansena and Risor 2017; Mayou and Sharpe 1997; Smith et al. 2003). In this first sense, “the problem of MUS” is the simple challenge of relieving symptoms.

Second, quarrels over the physical or mental nature of unexplained symptoms are more than an everyday problem in clinical settings. They are a challenge so deep and intractable as to threaten the medical enterprise from both directions, and in this sense “the problem of MUS” is the effort to eliminate exam room antagonism. Conflict of this kind has been described in research as a “tug of war”, a “duet of escalating antagonism”, and even a “medieval siege” (Stone 2014). Research suggests it is physicians' number

one source of frustration with patients (Hahn et al. 1994; Lin et al. 1991), a significant factor in physicians' reluctance to recommend their field, and a major contributor to the growing physician shortage (Stone 2014; An et al. 2009; Wileman, May and Chew-Graham 2002).

On the other side of the fence, patients' frustration with psychogenic diagnosis for MUS grows more vocal and more unified every day, as patients and patient groups are now able to compare notes online about what they understand to be mistaken refusal of medical care and support (Countess of Mar 2015; Kozachek 2016). Their concerns are now bolstered, moreover, by a rapidly expanding selection of patient memoirs that offer vivid descriptions of medical recklessness and disrespectful care to patients whose medically unexplained symptoms have been diagnosed as psychogenic (Atkins 2010; Hagberg 2014; Kamen 2005).

Third, "the problem of medically unexplained symptoms" is sometimes understood as the challenge of discerning when MUS should continue to receive biological testing, treatment and support, and when they should not. Effort to accomplish this task safely and reliably is complicated by pressure to reduce the incredible drain on resources that MUS represent, very often without significant symptom relief (Burton et al. 2011; Lee et al. 2016; Morriss et al. 2012). This side of the problem of MUS is particularly pressing for any national health service. When unexplained symptoms can be diagnosed as psychogenic, policy makers and administrators are able to conserve substantial resources for cases where established diagnosis will make them more useful.

Researchers in psychosomatic medicine have been quietly toggling criteria for psychogenic diagnosis of MUS since somatoform disorders were first established. At

this time, however, we find ourselves facing an unprecedented level of change in this area. The original conception of somatoform disorders has been largely discredited in the last fifteen years, both in the form of full DSM diagnosis and in its loose application to everyday cases (Creed and Gureje 2012; Mayou et al. 2005). The question of how to replace it is immensely important both medically and ethically, and at this time that question remains unanswered. Though the DSM-5 replaced somatoform disorders with “somatic symptom disorders” in 2013, that decision was made over the intense and very public objections of many in mental health (Carney 2012; Frances 2013; Hickey 2014), and patient advocacy (Bernhard 2012; Edwards 2013; Richards 2013). This controversy has left the World Health Organization in a state of uncertainty about the construct that should fill the slot for the new edition of the international diagnostic coding manual, ICD-11, due out in 2018.

## **UNANSWERED QUESTIONS IN CLINICAL ETHICS**

### **Informed Consent**

When a patient consents to medical care from her doctor for specific bodily symptoms, does that include consent to evaluations and recommendations for psychosocial causes if the patient has never imagined such causes might be possible? Many professionals in bioethics and in medical practice would be inclined to think that it does, based on the biopsychosocial model (BPSM). Consent to medical care, after all, is not just consent to the biological care of the body. It is consent to care for the whole person, mind and body, in whatever ways can best promote health for the whole person.

It is important to recognize, though, that patients do not necessarily share the

conceptual grounding of the BPSM with their doctors. In a very basic sense, the patient understands herself to have entered into an implicit contract with the physician where the biological medical care she seeks for her symptoms will be provided for a fee. When the physician ventures into emotional territory instead of offering that biological care, it is not unreasonable to imagine the typical patient might feel this is not what she signed up for – and this presents us with a ready explanation for the resentment patients express in response to psychogenic diagnosis. After all, in typical cases of unsolicited mental health care, patients do receive the biological care they seek *in addition to* the mental health care they do not seek, but in cases of psychogenic diagnosis patients receive unsolicited mental health care *instead of* the biological care they believe they have consented to.

On the “informed” side of the process further questions arise. Does informed consent demand that in a case of MUS a physician must fully inform a patient about the state of diagnostic uncertainty? In practice the answer to that question seems to be no. There is certainly room for debate on this point, but there are reasons for concern that physicians’ central goal in discussions with patients who have MUS is not so much to inform them about the state of diagnostic uncertainty as it is to reassure them that investigations have put to rest the question of biological disease. It seems, in other words, that in medical education there exist few guidelines for communicating with patients about diagnostic uncertainty – and given the incredible prevalence of MUS, this seems both surprising and worrisome.

And what about cases where the dual nature of the term “MUS” does lead physicians to leap directly from MUS to psychogenic diagnosis without the sort of deliberative steps that are generally expected to support a diagnostic conclusion? This, it

seems, is the most pressing question about informed consent in the context of MUS. How could a physician successfully explain, and support, that conceptual leap?

### **Autonomy**

What does it look like when a physician respects the autonomy of a patient with MUS, or a patient with psychogenic symptoms? Perhaps the issue of informed consent is as thorny as it is in this setting because diagnostic uncertainty and psychogenic diagnosis both pose challenges for our understanding of respect for autonomy.

The challenge seems to be this. An autonomous human being knows whether or not she experiences bodily suffering, and she knows whether she has significant emotional or psychosocial distress – or at least she is better placed to make these determinations from the first person vantage point than anyone could ever be from an outsider's perspective, including a physician. First person experience is defined by these forms of epistemic privilege. As we ordinarily understand these things, every autonomous human individual is the ultimate authority on her own bodily sensations and emotional states (or at least it takes complex philosophical positioning to suggest otherwise).

When a physician relays a psychogenic diagnosis for MUS, she directly challenges the veracity of the patient's first person bodily sensations, and in this sense it seems she challenges the patient's capacity to make self-governing medical decisions. Similarly, psychogenic diagnosis challenges the veracity of a patient's assessments of her own psychosocial well being. While it seems clear that all of us do learn about ourselves from the observations of outsiders, there is something decidedly strange, even still, about

the idea that a physician is in a better position than a patient to take note of the patient's psychosocial distress, particularly in the span of a few brief discussions of bodily symptoms. While it seems clear most of us do unproductively fixate at times on bodily aches and pains, our understanding of autonomy suggests it's problematic to imagine physicians can authoritatively determine, and productively assert, that patients are mistaken in their experience of biological illness.

But the most important aspect of autonomy in the context of MUS has to do with the role gender has played for centuries in diagnosis and management of psychogenic symptoms. "Somatoform disorder", after all, was a new name for the nineteenth century construct of hysteria – not a new way of understanding it, but a new way of packaging it so that patients would be less inclined to respond with resentment and resistance (Crimlisk 2001; Trimble 2004; van Gijn 2007). And as that original construct was understood by Freud, hysteria was a problem predominantly, or even exclusively, experienced by women. We continue to see a powerful gender imbalance in psychogenic diagnosis in our time, as both the DSM and ICD state that psychogenic symptoms predominantly affect women, and it's important to note that scientific evidence for that claim is lacking. There certainly is science behind the many studies that show providers do, as a matter of fact, diagnose far more women than men with psychogenic symptoms (Hausteiner-Weihle et al. 2011; Vedat 2011), but there is no science to support the claim that this practice reflects a genuine difference between women and men.

What's most problematic about the legacy of hysteria from an ethical standpoint, however, is the inextricable role that lack of patient autonomy played in diagnosis and management of that original condition. With respect to autonomy, a female patient in

Freud's time had the status of a child in our time. As a woman, a patient with hysteria was understood not to be capable of making autonomous medical decisions, so it was no stretch at all to imagine the physician was better able to discern when her experience of bodily suffering was mistaken. Like children, hysteria patients' medical decisions were made by fathers, husbands, or brothers. Moreover, their femaleness combined with the maleness of their doctors in a way that freed doctors from any concern to explain or defend their diagnostic conclusions, or indeed their treatment plans, in the context of hysteria.

Lack of ethical attention to medically unexplained symptoms is troubling on many counts, but no area of that oversight is more clearly problematic than where psychogenic diagnosis is entangled with an assumed lack of autonomy in women. Neither somatoform disorders nor any of the constructs offered to replace them has ever addressed the role of that problematic assumption in the foundational construct of hysteria. Indeed, researchers freely equate hysteria with current constructs (Broussoulle et al. 2014; Kanaan 2010), and sometimes openly advocate returning to that original notion (Stone et al. 2008), with no hint of awareness that doing so might be ethically problematic.

### **Truth-Telling**

Are physicians obligated to fully and clearly inform patients of the conclusion that MUS have been diagnosed as psychogenic? As a matter of general principle it seems they are, but research shows physicians routinely misrepresent the conclusion that symptoms have primarily psychosocial causes (Hartman et al. 2009; Kanaan, Armstrong

and Wessely 2009; Salmon, Peters and Stanley 1999; Wessely 1999).

In research and in everyday practice, the problem of exam-room conflict looms large, so large as to essentially serve as a vehicle for the problem of treatment. If patients could somehow avoid resistance to psychogenic diagnosis, research routinely implies, treatment protocols for psychogenic symptoms would be successful. This is not an unreasonable idea given that cognitive behavioral therapy is the central treatment option on the table (Kurlansik and Muffai 2016; Malins et al. 2016; Shroder et al. 2012) and, like any other mental health treatment approach, CBT will be more effective with willing participation. The most common approach to avoiding conflict, however, is to aim for ambiguity in discussion with patients. On this point, Simon Wessely's "To tell or not to tell: The problem of MUS" is especially clear (Wessely 1999, 43):

"So it is all in my mind, is it doctor?" says the patient threateningly. The correct answer from our truth telling neurologist would of course be "yes", followed by a plaintive "but psychiatric disorders really are genuine illnesses", but by that time... the patient may well have left in disgust ... There are insuperable objections to the neurologist "telling it as he sees it". The loser will be the patient, who will be denied a chance of receiving effective treatment.

Richard Kanaan considers the matter in a more directly ethical light, asking if it might be best to allow beneficence to prevail over respect for autonomy so that physicians can let go of the directive to plainly tell the truth in cases of psychogenic symptoms. He writes (Kanaan 2007, 64):

Not lying is one way in which we respect another's autonomy, but the interpretation of this has long been a subject of intense debate amongst Kantian

scholars. And any parent, or any child, can tell you that “not lying” still leaves considerable leeway.

It is important to note that Kanaan does not advocate deliberate deception, settling on a nuanced position that imagines providers might remain respectful of autonomy while avoiding the conflict that comes with direct disclosure. Still, the language of this passage is problematic, implying that patients with psychogenic symptoms are in some sense like children, while their medical and mental health providers are in some sense like parents, a paternalistic suggestion with ties to lack of autonomy in the foundational notion of “female hysteria”.

It’s important to note two considerations that make truth telling especially complex in the context of psychogenic diagnosis. First, diagnostic constructs on the psychosocial side lack the definitive boundaries of biological diagnoses, so much so that it can be hard to pin down what it would mean to tell the truth in discussions with patients. Second, the biopsychosocial model seems to positively encourage vagueness about where biological diagnosis ends and psychosocial diagnosis begins. This seems to suggest that physicians can aim for ambiguity rather than clarity without compromising their commitment to truth telling.

As I will discuss in Section 3, there is considerable confusion in medicine when it comes to the philosophical merits of vagueness about the line that distinguishes patients’ biological and psychosocial needs. In the context of truth telling, what’s most important on this score are signs that while researchers encourage etiological ambiguity in discussion with patients, they actually do mark a crisp line between biological and psychosocial diagnosis amongst themselves – a disparity that does challenge the

commitment to truth telling. For example, as explained in “The Function of ‘Functional’”, etiologically ambiguous terms for psychogenic diagnosis “conceal some of the conflict in a particularly contentious area”, offering the “advantage” of “allowing neurologists to use the same term to mean one thing to colleagues and another to patients” (Kanaan, Wessely and Armstrong 2012, 250).

## **ERROR AND OBSTRUCTED ACCESS TO CARE**

It is common for human beings to feel convinced they have a need for biological medical care when they don't, and it's important to practice medicine in a way that does not provide unnecessary biological care – that is, biological testing, treatment and support – in cases of this kind. Doing so risks iatrogenic harm and wastes resources that could be put to good use elsewhere. On the other hand, it is also common for human beings to suffer from biological illness that's hard to spot with diagnostic tests and exams, and it's important to practice medicine in a way that ensures every patient who seeks biological medical care with a need for it does receive it from her doctor. This tension is the driving force behind practice in the massive, strangely quiet area of medicine concerned with MUS.

Unfortunately – and perhaps this is due to the absence of bioethical contributions in this area – policies and practice guidelines for MUS focus almost exclusively on the first task, the effort to ensure that patients without a need for biological medical care do not receive it in error. There is significant benefit to this one-sided approach for the many patients with psychogenic symptoms because it leads researchers to develop more productive approaches to management. There is also significant benefit as a matter of

policy. Because MUS are an incredible drain on resources, often without the beneficial result of symptom relief, there is substantial financial incentive to any management policy that focuses on this side of the issue.

Ethically speaking, however, it is difficult to defend a lack of concern with that second task, ensuring that those with diagnostically challenging biological conditions do receive biological medical care when they seek it. Whatever else doctors might be able to provide to benefit patients, it seems clear they maintain a basic duty to at least provide biological care to every patient who seeks it with a need for it. Failure to do so violates our most basic understanding of physicians' duties.

### **The Strange Obscurity of the Problem of Error**

When it comes to that second task – ensuring that patients with diagnostically challenging biological conditions do receive biological care when they seek it from their doctors – the most obvious place to start would be with research that establishes how common it is for physicians to mistakenly construe medical conditions as psychogenic, and the situations where that kind of error most often occurs. Unfortunately, research of this kind is essentially nonexistent.

If we search “cancer, diagnostic error” at the National Library of Health, for example, we find over 26,000 research papers, while a search for “somatization, diagnostic error” yields 23 papers by comparison. When we take the broader search approach of “somatoform disorder, diagnostic error” we do a little better with 175 results, but the majority of those papers focus on the opposite error of misdiagnosing somatoform patients with medical conditions, including all papers published since 2007. Moreover,

when studies do set out to determine error rates for psychogenic diagnosis (de Gusmao et al. 2014; Schuepbach, Adler and Sabbioni 2002; Skovenborg and Shroder 2014), they generally adopt the strategy of following up to determine how often patients with psychogenic diagnosis “are subsequently given a disease diagnosis that, in hindsight, explained their original symptoms” (Stone et al. 2005, 989) – a process that might tell us a great deal about doctors’ reluctance to overturn a psychogenic diagnosis, and nothing at all about the actual rate of error.

On the other side of the fence, patient advocacy groups have become focally concerned in recent years about mistaken psychogenic diagnosis. Many of these groups have attempted to discern error rates through the sounder approach of determining how often patients with confirmed medical diagnoses have been mistakenly denied the biological care they need in the past. According to surveys by the American Autoimmune-Related Disease Association, for example, 51% of patients with autoimmune disease report having been told by doctors in the past that “their disease was imagined or they were overly concerned” (Ladd 2014, 1), a worrisome figure given that 23 million Americans suffer the harms of autoimmune disease (National Institute of Health Autoimmune Diseases Coordinating Committee 2005).

In addition, roughly 30 million Americans suffer from rare disorders (National Institute of Health Office of Rare Disease Research 2017), and lack of concern about access to care for diagnostically challenging conditions seems particularly threatening for this group. Studies do bear out a problem in this regard, revealing that patients with rare disorders wait seven years on average for diagnosis and treatment (Global Genes Project 2013). Moreover, for those with rare disorders, mistaken psychogenic diagnosis leads to

diagnostic delays at least 2.5 times as long, and up to 7 times as long, as those caused by mistaken medical diagnosis (Kole and Faurisson 2009, 48).

While lack of concern about error in psychogenic diagnosis is endemic within the medical community, there is growing evidence that this attitude creates a significant access to care problem for patients with diagnostically challenging biological conditions – including not just autoimmune diseases and rare disorders, but cardiac diseases in women (Maserejian 2009; Healy 1998), mitochondrial disorders in children (Eichner 2015), and the range of established conditions that can present in unusual ways.

Finally, it is important to note that public concern about error of this kind is heating up with respect to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). In the last few years, the US Academy of Medicine, National Institute of Health and Department of Health and Human Services have embraced the conclusion that it is now a “misconception” to understand ME/CFS as a psychogenic illness (Institute of Medicine 2015, 2). This dramatic reversal of opinion leaves patients, physicians and policy makers scrambling to make sense of patients’ right to access biological care in countries where researchers disagree with US authorities. Outcomes in this controversy will have a powerful impact on public debate about access to biological care for other contested conditions often construed as psychogenic, such as fibromyalgia and chronic Lyme disease.

### **Vagueness Where Bioethics Demands Clarity**

Suppose we imagine a young GP who’s struggling with the challenge of managing unexplained symptoms, and suppose she’s recognized the importance of

ensuring not just that she does not provide biological care to those who don't need it, but also that she does provide it to those with diagnostically challenging biological conditions. Suppose she sets out to review her training and update her knowledge about exactly when it's safe to channel care for MUS exclusively down the mental health track. What will she find?

Most importantly, because medical education resources tend not to offer sections or chapters on MUS, our GP will find it hard to pin down general information of this kind. Often authors recommend considerable biological caution in discussions of potential psychogenic diagnosis within symptom-specific or disease-specific chapters (Murtagh 2016, Yates 2014), but our GP's concern is broad. She's in search of general principles for ensuring that she always meets the biological needs of patients with MUS.

Macleod's Clinical Examination Handbook (Snadden 2013, 27) does offer a section devoted to MUS, suggesting that...

MUS cause similar levels of disability to those resulting from disease and are often associated with emotional distress. If such patients are not managed effectively, fruitless investigations and harm from unnecessary drugs and procedures may result.

This entry seems to assume that MUS do not, or cannot, have biological causes – an implicit suggestion that confounds our diligent GP's efforts. And though the passage offers considerable advice about making sure patients do not receive unnecessary biological care, there is little more than a sentence on protecting access to care for those with diagnostically confusing biological conditions. The same is true of the entry in the Oxford Textbook of Medicine (Sharpe 2010), where "MUS" are considered within a

chapter on psychiatric disorders, directing physicians to “seek specific treatable psychiatric syndromes” and “consider prescribing antidepressant drugs”.

When our GP searches for MUS in the “Up to Date” review system she is routed to an entry in psychiatry on somatization (Greenberg 2017), where she finds this statement: “more than 50% of patients presenting to outpatient medical clinics with a physical complaint do not have a medical condition”. Reading this, our GP will have to conclude that she should entirely let go of her concern with ensuring that those with diagnostically confusing conditions do not face obstructed access to care. Unless our GP has embraced one of the very high estimates for prevalence of MUS, Up to Date informs her that, according to general medical consensus, none of her patients with MUS should proceed along the track of biological care.

What is the basis for routine comfort with a suggestion that seems to involve so much clinical and ethical risk – that every case of medically unexplained symptoms should automatically be understood as a case where biological medical care is unnecessary? That we find ourselves asking this question is perhaps the most significant bioethical information on offer in this paper. Even before we reach for an answer, the question reveals an area of medical practice where access to care is an everyday challenge that the field of bioethics has yet to consider.

As for answers, I think it’s a mistake to imagine the source of the problem is lack of concern about patient health on the part of physicians, who base their practice with MUS on recommendations provided by research and medical education. And I think it’s a mistake to imagine that researchers or medical educators are themselves unconcerned to

protect the health of patients whose MUS are caused by diagnostically challenging biological conditions.

The source of the problem seems to be confusion about the philosophical merits of vagueness when it comes to the line between the biological and the psychosocial. Lack of terminology to even distinguish MUS from psychogenic symptoms is the strongest sign of that confusion, as if, as a matter of professional principle, it is somehow not a good idea to be specific about exactly when confusing symptoms have been attributed to psychosocial causes.

More importantly, for those who embrace a non-dualistic approach to medical practice, the biopsychosocial model seems to suggest that it's somehow a philosophical faux pas to be clear about whether a patient does or does not require specifically biological care. After all, if we do mark a clear line between biological need and psychosocial need, it seems we directly distinguish the dual territories we've set out to integrate.

Philosophically speaking, this kind of thinking is mistaken, and the error has profound ramifications for patients' access to biological care. Non-dualistic philosophers of every stripe accept without concern that we can retain language that sharply distinguishes the mental and the biological as long as we focus our attention on developing ways to make sense of that kind of talk philosophically in the end of the day. In fact, philosophical debate about the mind-body problem absolutely requires consistency with the sharp duality that distinguishes brain states from mental states. As far as philosophy is concerned, vagueness about the line between the biological and the psychosocial is not just unnecessary. If we cultivate this vagueness we make it

impossible to address mind-body challenges in a philosophically coherent way.

The conclusion we're led to here is surprising – that philosophical clarity plays a substantial role in patients' access to biological care for diagnostically challenging biological conditions. But this is the borderland between medicine and psychiatry, and in this area we should be suspicious of our willingness to allow popular ideas about “mind-body integration” to substitute for serious, well-defended philosophical reasoning. To ensure that patients receive optimal care for MUS, we must pursue not only psychiatric research but, more importantly, bioethical research, and our bioethical conclusions must be built upon foundations that are philosophically informed, and philosophically coherent.

## **CONCLUSIONS: ETHICAL THREATS ON THE HORIZON**

Medically unexplained symptoms are roughly as common in outpatient settings as symptoms with clear biological explanations, or at least that is a very common perception in practice. Recognizing this means, first, acknowledging that in clinical ethics there is work to do in the context of diagnostic uncertainty. We have yet to understand what informed consent amounts to in cases of diagnostic uncertainty or psychogenic diagnosis. We have yet to make sense of patient autonomy in cases where, through psychogenic diagnosis, physicians seem to override the authority of patients' first person bodily experiences and emotional self-assessments. We have yet to consider the extent to which it might be ethically acceptable for physicians to protect the therapeutic relationship by aiming for ambiguity in discussions about psychogenic diagnosis with patients.

Second, when we recognize how central MUS are to everyday medical practice,

we are also forced to recognize that mistaken psychogenic diagnosis creates a form of obstructed access to care that we have yet to consider. To wrestle with unexplained symptoms as a physician is to balance the twin concerns of not providing biological care to those who don't need it, while making sure to provide it to those who do have a need – and it should be disquieting for bioethicists to see how routine it is for that second task to be neglected. Addressing it requires focus on the distinction between biological and psychosocial needs, but philosophical confusion leads providers in the opposite direction, as if ambiguity about biological need is somehow in patients' best interests.

With both sets of issues we find ourselves at a crucial historical juncture. Future management of MUS will be dictated by the construct selected to replace somatoform disorders in the new edition of the global diagnostic coding manual, ICD-11. Bioethical contributions to that decision-making process would greatly improve the quality of patient care for generations to come.

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## REFERENCES

An, P.G., J.S. Rabatin, L.B. Manwell et al. 2009. Burden of difficult encounters in primary care: Data from the minimizing error, maximizing outcomes study. *Archives of Internal Medicine* 169: 410-414.

Atkins, C.G.K. 2010. *My imaginary illness: A journey into uncertainty and prejudice in medical diagnosis*. Ithaca, NY: Cornell University Press.

Bernhard, Toni. 2012. Physical illnesses may soon be labeled 'mental disorders'. *Psychology Today: Turning Straw Into Gold*. Available at: <https://www.psychologytoday.com/blog/turning-straw-gold/201212/physical-illnesses-may-soon-be-labeled-mental-disorders>.

Broussolle, E., F. Gobert, T. Danaila et al. 2014. History of physical and 'moral' treatment of hysteria. *Frontiers of Neurology and Neuroscience* 35: 181-197.

Burton, C., K. McGorm, G. Richardson et al. 2011. Healthcare costs incurred by patients repeatedly referred to secondary medical care with medically unexplained symptoms: A cost of illness study. *Journal of Psychosomatic Research* 72(3): 242-247.

Carney, J. 2012. Boycott the DSM-5: Anachronistic before its time. *Mad in America: Science, Psychiatry and Social Justice*. Available at: <https://www.madinamerica.com/2012/12/the-dsm-5-anachronistic-before-its-time-boycott-the-dsm-5/>.

Countess of Mar. 2015. "It's all in your head" psychosomatic book storm: Countess of Mar challenges author to change her mind about ME/CFS. *ME Association: Helping to Make the UK a Better Place for Those With ME/CFS*. Available at: <http://www.meassociation.org.uk/2015/06/its-all-in-your-head-psychosomatic-book-storm-countess-of-mar-challenges-author-to-change-her-mind-about-mecfs/>.

Crimslisk, H.L. 2001. Hysteria. In *Oxford Illustrated Companion to Medicine*, ed. S. Lock, J.M. Last and G. Dunea, 403-405. Oxford: Oxford University Press.

Creed, F. and O. Gureje. 2012. Emerging themes in the revision of the classification of somatoform disorders. *International Review of Psychiatry* 24(6): 556-567.

de Gusmao, C. M., R.M. Guerriero, M.E. Bernson-Leung et al. 2014. Functional neurological symptom disorders in pediatric emergency room: Diagnostic accuracy, features, and outcome. *Pediatric Neurology* 51(2): 233-238.

Edwards, L. 2013. New diagnosis risks 'it's all in your head' response to illness. *WBUR's Common Health*. Available at <http://commonhealth.legacy.wbur.org/2013/04/somatic-symptom-diagnosis>.

Eichner, M. 2015. The new child abuse panic. *The New York Times*, July 11. Available at: [https://www.nytimes.com/2015/07/12/opinion/sunday/the-new-child-abuse-panic.html?\\_r=0](https://www.nytimes.com/2015/07/12/opinion/sunday/the-new-child-abuse-panic.html?_r=0).

Fink, P. and M. Rosendal, eds. 2015. *Functional disorders and medically unexplained symptoms: Assessment and treatment*. Aarhus: Aarhus University Press.

Frances, A. 2013. The new somatic symptom disorder in DSM-5 risks mislabeling many people as mentally ill. *British Medical Journal* 346: f1580.

Global Genes Project. 2013. *Rare Disease Impact Report*. Available at: <http://www.geneticalliance.org.uk/docs/e-update/rare-disease-impact-report.pdf>.

Greenberg, D.B. 2017. Somatization. *Up to Date*, ed. J. Dimsdale and D. Solomon. Available at: <https://www.uptodate.com/contents/somatization-epidemiology-pathogenesis-clinical-features-medical-evaluation-and-diagnosis>.

Hagberg, E. 2014. *It's all in your head*. Amazon Digital Services.

Hahn, S.R., K.S. Thompson, T.A. Wills et al. 1994. The difficult doctor-patient relationship: Somatization, personality and psychopathology. *Journal of Clinical Epidemiology* 47(6): 647-657.

Hartman, T.C.O., L.J. Hassink-Franke, P.L. Lucassen et al. 2009. Explanation and relations. How do general practitioners deal with patients with persistent medically unexplained symptoms: A focus group study. *BMC Family Practice* 10(68).

Hausteiner-Weihle, C., G. Schneider, S. Lee et al. 2011. Gender, lifespan and cultural aspects. In *Medically unexplained symptoms, somatisation and bodily distress: Developing better clinical services*, ed. F. Creed, P. Fink and P. Henningsen. Cambridge: Cambridge University Press.

Healy, B. 1991. The Yentl syndrome. *New England Journal of Medicine* 325(4): 274-276.

Hickey, P. 2014. DSM-5 and somatic symptom disorder. *Behaviorism and Mental Health: An alternative perspective on psychiatry's so-called mental disorders*. Available at: [http://behaviorismandmentalhealth.com/2014/03/17/dsm-5-and-somatic-symptom-disorder-a-case-study/#disqus\\_thread](http://behaviorismandmentalhealth.com/2014/03/17/dsm-5-and-somatic-symptom-disorder-a-case-study/#disqus_thread).

Institute of Medicine Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. 2015. *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. Available at: <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>.

Jackson, J.L., and M. Passamonti. 2005. The outcomes among patients presenting in

primary care with a physical symptom at 5 years. *Journal of General Internal Medicine* 20(11): 1032-1037.

Johansena, M-L. and M.B. Risor. 2016. What is the problem with medically unexplained symptoms for GPs? A meta-synthesis of qualitative studies. *Patient Education and Counseling* 100(4): 647-654.

Joint Commissioning Panel for Mental Health. 2017. Guidance for commissioners of services for people with medically unexplained symptoms. Available at: <http://www.jcpmh.info/resource/guidance-commissioners-services-people-medically-unexplained-symptoms/>.

Kamen, P. 2005. *All in my head: An epic quest to cure an unrelenting, totally unreasonable, and only slightly enlightening headache*. Cambridge, MA: Da Capo Press.

Kanaan, R. 2007. Ethical issues in the management of somatoform disorders. *Psychiatry* 6 (2):63-66.

Kanaan, R., D. Armstrong, and S.C. Wessely. 2009. Limits to truth-telling: Neurologists' communication in conversion disorder. *Patient Education and Counseling* 77(2): 296-301.

Kanaan, R. 2010. Hysteria and the varieties of deception. *American Journal of Bioethics Neuroscience* 1(1): 55-64.

Kanaan, R.A., D. Armstrong and S.C. Wessely. 2012. The function of 'functional': A mixed methods investigation. *Journal of Neurology, Neurosurgery and Psychiatry* 83: 248-250.

Kole, A. and F. Faurisson, for Eurodis. 2009. *The Voice of 12,000 Patients: Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe*, 47-48. Available at: <http://www.ebookdb.org/reading/547128462F58332EGD1C2869/The-Voice-Of-12000-Patients-Experiences-And-Expectations-Of-Rare-Disease-Patient>.

Korber, S., D. Frieser, N Steinbrecher and W. Hiller. 2011. Classification characteristics of the Patient Health Questionnaire-15 for screening somatoform disorders in a primary care setting. *Journal of Psychosomatic Research* 71(3): 142-147.

Kozacheck, J. 2016. The sensational psychosomatic witchcraft trials: Evaluating somatic symptoms and initially unexplained pain. *The Art of Janet Kozacheck*. Available at: <http://kozachekart.blogspot.com/2016/07/the-sensationalpsychosomatic.html>.

Kroenke, K. and A.D. Mangelsdorff. 1989. Common symptoms in ambulatory care: Incidence, evaluation, therapy, and outcome. *American Journal of Medicine* 86(3): 262-266.

- Kroenke, K., R.L. Spitzer, J.B. Williams et al. 1994. Physical symptoms in primary care. Predictors of psychiatric disorders and functional impairment. *Archives of Family Medicine* 3(9): 774-779.
- Kurlansik, S.L. and M.S. Maffei. 2016. Somatic Symptom Disorder. *American Family Physician* 93(1): 49-54.
- Ladd, V. 2014. President/Executive Director's Message. *In Focus: A quarterly newsletter of the American Autoimmune Related Diseases Association* 22(2): 1-2.
- Lee, K., M.H. Johnson, J. Harris and F. Sundram. 2016. The resource utilization of medically unexplained physical symptoms. *SAGE Open Medicine* 4: 1-7.
- Lin, E.H.B., W. Katon, M. Von Korff et al. 1991. Frustrating patients: Physician and patient perspectives among distressed high users of medical services. *Journal of General Internal Medicine* 6: 241-246.
- Malins, S., J. Kai, C. Atha et al. 2016. Cognitive behavior therapy for long-term frequent attenders in primary care: A feasibility case series and treatment development study. *British Journal of General Practice* 66(651): e729-736.
- Maserejian, N.N., C.L. Link, K.L. Lutfey et al. 2009. Disparities in physicians' interpretations of heart disease symptoms by patient gender: Results of a video vignette factorial experiment. *Journal of Womens Health* 18(10): 1661-1667.
- Mayou, R. and M. Sharpe. 1997. Treating medically unexplained symptoms: Effective interventions are available. *British Medical Journal* 315(7108): 561-562.
- Mayou, R., L.J. Kirmayer, G. Simon et al. 2005. Somatoform disorders: Time for a new approach in DSM-V. *American Journal of Psychiatry* 162: 847-855.
- Morriss, R., J. Kai, C. Atha et al. 2012. Persistent frequent attenders in primary care: Costs, reasons for attendance, organization of care and potential for cognitive behavioural therapeutic intervention. *BMC Family Practice* 13(39).
- Murtagh, J. 2015. *Murtagh's general practice*, 6<sup>th</sup> Edition. North Ryde, NSW: McGraw-Hill Australia.
- National Institute of Health Autoimmune Diseases Coordinating Committee. 2005. Report to Congress: Progress in Autoimmune Diseases Research. Available at: <https://www.niaid.nih.gov/topics/autoimmune/Documents/adccfinal.pdf>.
- National Institute of Health Office of Rare Disease Research. 2017. FAQs about rare diseases. Available at: <https://rarediseases.info.nih.gov/aboutodr/pages/31/frequently-asked-questions>.

- Nimnuan, C., M. Hotopf and S.C. Wessely. 2000. Medically unexplained symptoms: How often and why are they missed? *Quarterly Journal of Medicine* 93(1): 21-28.
- Oyama, O., C. Paltoo and J. Greengold. 2007. Somatoform disorders. *American Family Physician* 76(9): 1333-1338.
- Richards, K.L. 2013. Fibromyalgia in danger of being labeled a mental disorder. *Health Central: Chronic Pain*. Available at: <https://www.healthcentral.com/article/fibromyalgia-in-danger-of-being-labeled-a-mental-disorder>.
- Salmon, P., S. Peters, and I. Stanley. 1999. Patients' perceptions of medical explanations for somatisation disorders: Qualitative analysis. *British Medical Journal* 318(7180): 372-376.
- Schroder, A., E. Rehfeld, E. Ornbol et al. 2012. Cognitive-behavioral group treatment for a range of functional somatic syndromes: randomized trial. *British Journal of Psychiatry* 200(6): 499-507.
- Schuepbach, W.H., R.H. Adler and M.E. Sabbioni. 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.
- Sharpe, M. 2010. Medically unexplained symptoms in patients attending medical clinics. In *Oxford textbook of medicine*, ed. D.A. Warrell, T.M. Cox and J.D. Firth. Oxford: Oxford University Press.
- Skovenborg, E.L. and A. Schroder. 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* 36(1): 38-45.
- Smith, R.C., C. Lein, C. Collins et al. 2003. Treating patients with medically unexplained symptoms in primary care. *Journal of General Internal Medicine* 186(6): 478-489.
- Smith, R.C. and F.C. Dwamena. 2007. Classification and diagnosis of patients with medically unexplained symptoms. *Journal of General Internal Medicine* 22(5): 685-691.
- Snadden, D., S. Potts, F. Nichol et al. 2013. History taking. In *Macleod's Clinical Examination* 13th edition, ed. G. Douglas, F. Nicol and C. Robertson, 5-39. Edinburgh: Elsevier.
- Steinbrecher, N. S. Korber, D. Frieser and W. Hiller. 2011. The prevalence of medically unexplained symptoms in primary care. *Psychosomatics* 52(3): 263-271.

- Stone, J., R. Smyth, A. Carson et al. 2005. Systematic review of misdiagnosis of conversion symptoms and “hysteria”. *British Medical Journal* 331: 989.
- Stone, J., R. Hewett, A. Carson et al. 2008. The ‘disappearance’ of hysteria: Historical mystery or illusion? *Journal of the Royal Society of Medicine* 101(1): 12-18.
- Stone, L. 2014. Managing the consultation with patients with medically unexplained symptoms: A grounded theory study of supervisors and registrars in general practice. *Family Practice* 15: 192.
- Swanson, L.M., J.C. Hamilton, and M.D. Feldman. 2010. Physician-based estimates of medically unexplained symptoms: A comparison of four case definitions. *Family Practice* 27(5): 487-493.
- Trimble, M. 2004. *Somatoform disorders: A medicolegal guide*. Cambridge: Cambridge University Press.
- van Gijn J. 2007. In defence of Charcot, Curie, and Wittmann. *Lancet* 369: 462.
- Vedat, S. 2011. Medically unexplained symptoms in women. In *Oxford Textbook of Women and Mental Health*, ed. D. Kohen, 254-261. Oxford: Oxford University Press.
- Warner, A., K. Walters, K. Lamehewa and M. Buszewicz. 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.
- Wessely, S. 1999. To tell or not to tell: The problem of medically unexplained symptoms. In *Ethical Dilemmas in Neurology*, ed. A. Zeman and L. Emanuel, 41-53. Sidcup: Harcourt Publishers.
- Wileman, L., C. May, and C.A. Chew-Graham. 2002. Medically unexplained symptoms and the problem of power in the primary care consultation: A qualitative study. *Family Practice* 19(2): 178-182.
- Yates, W.R. 2014. Somatic symptom disorders differential diagnoses. *Medscape*, ed. E. Dunayevich. Available at <http://emedicine.medscape.com/article/294908-differential>.