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Ethical Management of Diagnostic Uncertainty: Response to Open Peer Commentaries on “Why Bioethics Should Be Concerned With Medically Unexplained Symptoms”

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INTRODUCTION: THE CHALLENGE OF “MEDICALLY UNEXPLAINED SYMPTOMS”

Commentaries on my target article, “Why Bioethics Should Be Concerned About Medically Unexplained Symptoms,” offer a range of valuable perspectives on the unconsidered ethical territory of medically unexplained symptoms (MUS). In what follows, I briefly review the article’s central points, then hone in on three central challenges that arise in the commentary: the suggestion in Canavera that physicians should not focus on carefully distinguishing biological and psychosocial symptoms, the suggestion in Kanaan that psychogenic diagnosis rarely errs, and the suggestion by Preller and colleagues, and by Sankary and Ford, that a risk/benefit analysis for patients with psychogenic symptoms supports the current status quo. Finally, I explore a suggestion that can unify most of the commentary, the idea that the best path to improving care in this area is truthful humility about diagnostic uncertainty.

Before I can pursue those tasks, however, it is important to acknowledge that in the effort to develop bioethical discourse on medically unexplained symptoms (MUS), we face a substantial methodological challenge. Because the term “MUS” has long maintained confounding duplicity in practice, disambiguation doesn’t quite stick in discussions. As I clarify in the article, the term “medically unexplained symptoms” (MUS) is often used in practice to name the wide range of “symptoms for which patients seek biological medical care where providers do not find biological explanations” (O’Leary 2018). The term is also used, however, to name a specific subset of that larger group, “psychogenic symptoms,”

which I have defined simply as symptoms with primarily psychosocial causes.

I had hoped that with a crisp distinction throughout the article between MUS and psychogenic symptoms, discussion might develop from it that could finally give careful consideration to the distinct needs of these two patient groups—but it is not so easy to do away with ambiguity in common usage. Though most of the commentaries directly accept the importance of this distinction, many then proceed as if the challenge of MUS can be addressed with a discussion of psychogenic symptoms, or a discussion of contested conditions that are assumed to be psychogenic. Others proceed as if MUS must be either psychogenic symptoms or rare medical conditions. Several commentaries actually ignore the article’s central distinction entirely, assuming without clarification that all MUS are psychogenic.

In what follows, as in the original article, I understand debate about MUS to be debate about management of diagnostic uncertainty, recognizing that, as Schwab aptly points out in his commentary, “uncertainty is the constant companion of medical practice” (Schwab 2018). Diagnostic uncertainty can arise across the entire spectrum of symptoms, including not only psychogenic symptoms, but also benign self-limiting biological symptoms, rare disorders, contested conditions, everyday medical conditions that present themselves in unusual ways, more serious medical conditions that are diagnostically challenging (such as autoimmune diseases), and very serious medical conditions that have not yet made their seriousness apparent. We do not consider ethical management of MUS unless we recognize the

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whole range of symptoms that can lead to diagnostic uncertainty.

CORE CONCLUSIONS

How, then, should practitioners proceed when “I don’t know” is the end result of a medical diagnostic inquiry? I suggest in the article that ethical management of diagnostic uncertainty should address two distinct areas of concern, and that in both areas current research and practice guidelines offered by the field of psychosomatic medicine fall short.

First, ethical management of diagnostic uncertainty must consider the unique challenges that arise with MUS when it comes to core concepts in clinical ethics. Research in this area fails to consider the ethical implications of advocating deliberate ambiguity about psychogenic diagnosis in discussion with patients. Moreover, while “it is debatable whether informed consent is possible when making a psychogenic diagnosis for MUS, and such an act may infringe upon a patient’s autonomy” (Preller et al. 2018, 35), the challenge of informed consent has not been considered in current research. Most importantly, researchers have failed to note that in the original Freudian construct of hysteria that forms the basis for current practice, patients, as women, were understood to lack autonomy. As originally conceived, the construct of hysteria depends deeply on an absence of autonomy in patients, and it is concerning that psychiatry continues to work with hysteria as if that fact poses no ethical dangers. Commentary by Swartz begins the important exploration of autonomy in this area, suggesting that the model of relational autonomy is more appropriate for patients with MUS than autonomy as traditionally conceived (Swartz 2018).

Second, ethical management of diagnostic uncertainty must balance two competing tasks: avoiding unnecessary medical care, and making sure to provide medical care to those who do need it. There are hazards on both sides. On the side of unnecessary medical care, Arnold and Kerridge (2018) rightly point out that because “medical systems and healthcare practitioners abhor uncertainty and are often loath to admit to any failures,” practitioners are led to “overdiagnosis, overtreatment, and the abandonment of clinical reasoning” (27). They note that

ignorance of the relevance of the sensitivity and specificity of tests, post-hoc interpretation of epiphenomena identified by inappropriate testing and misapplication of increasingly granular genetic information may lead to spurious diagnoses and unwarranted treatment and conflate predisposition with disease via “dispositionalism” (Arnold and Kerridge 2018, 27).

On the other side of the fence, however, when physicians fail to provide medical care to patients in need,

they challenge the foundations that define medical practice. Medicine’s fundamental beneficence assumes—and should be able to assume—that patients in need of medical care can trust they will receive it when they seek it from their doctors. It is a serious matter, both clinically and ethically, for mistaken judgment to obstruct access to medical care for patients who seek it in need.

I have suggested that current practice guidelines fail to balance these competing challenges, and it is this point that has drawn the greatest share of commentary. Because the term “medically unexplained symptoms” names both the whole group of symptoms unexplained for any reason, and the specific subset of that group where symptoms have psychological causes, diagnosis of psychogenic symptoms often occurs without diagnostic criteria and reasoning. In practice, that is, when a physician notes that a patient suffers from “medically unexplained symptoms,” she does not merely remark on a lack of diagnostic clarity. She actually names a diagnosis in the category of psychiatry.

This truly remarkable ambiguity—this conflation of “I don’t know” with “I know, and symptoms have psychological causes”—drives a single-minded focus in research on the goal of avoiding unnecessary medical care, and a profound lack of concern in practice guidelines about avoiding error in psychogenic diagnosis. Guidelines encourage practitioners to embrace the assumption that all cases of diagnostic uncertainty are cases of psychogenic symptoms, and it is reasonable to imagine that the lack of caution in that assumption is related to practitioners’ tendency to overttest, overtreat, and overdiagnose. Because parameters for psychogenic diagnosis seem inadequate to protect patients with unrecognized medical needs, it is reasonable for practitioners to conclude that they should take responsibility for that task themselves.

THE PROBLEM OF ERROR: SCHWAB AND REDINGER VERSUS CANAVERA AND KANAAN

My concern with lack of attention to error in psychogenic diagnosis is aptly supported in commentary by Arnold and Kerridge (2018) through Schwab’s original definition of epistemic humility as “a characteristic of claims that accurately portray the quality of evidence for believing (a) claim to be an accurate one” (Schwab 2010). Schwab’s own commentary on the target article then clarifies exactly why epistemic humility is so important in cases of MUS:

Psychogenic diagnoses should carry with them low levels of confidence. Whenever a practitioner considers a psychogenic diagnosis there is an as-yet unquantified risk of a false positive—a psychogenic diagnosis for symptoms that have biological causes. In cases of MUS, practitioners will not be able to avoid this risk. Because the robust

support for a psychogenic diagnosis will always be lacking, the diagnosis is always provisional in a more fundamental way than most other diagnoses in medical practice. (Schwab 2018, 36)

Based on the logic of psychogenic diagnosis, Redinger and colleagues (2018) reach similar conclusions in their commentary, arguing that while “physicians often infer psychogenic causation when confronted with MUS ... the inference to the best explanation is unjustifiable because it fails to meet the specific conditions required by this type of inference” (31). Redinger and colleagues are particularly concerned about *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5), revisions to conversion disorder (now “functional neurological disorder”), which, in eliminating requirements for psychological evidence, fall victim to those same logical errors. “DSM-5 authors,” they warn, “were overconfident in their colleagues’ ability” to reliably distinguish psychogenic symptoms from symptoms of medical conditions.

Because error in psychogenic diagnosis is so rarely discussed in current research on MUS, it would be helpful to find a direct discussion of it in commentary on the target article by professionals working in this area. What’s needed, really, is a defense of current practice that acknowledges the importance of accurately distinguishing psychogenic symptoms from biological conditions and shows, through evidence or reasoning, that current practice is successful at that goal. Unfortunately, no analysis of that kind has been presented. In fact, in commentary by Canavera and colleagues (Canavera et al. 2018), and by Kanaan (2018), we find, by way of example, stronger evidence of a problem with error than I was able to provide in the article.

Though Canavera and Kanaan aim to present strong challenges to my conclusions, both commentaries ignore the article’s central distinction, proceeding from start to finish as if all cases of MUS are cases of psychogenic symptoms. The result is a very useful example of routine conflation of MUS and psychogenic symptoms in psychiatry, but the conflation is both confusing and concerning as a response to the target article. Conceptually speaking, because neither commentary uses terminology as it’s defined in the article, and neither clarifies its usage in the article’s terms, neither can engage with the article’s central points about MUS versus psychogenic symptoms.

Whether for terminological reasons or as a matter of professional hubris, it is not uncommon for professionals working in this field to avoid acknowledging that many cases of MUS do not involve psychogenic symptoms. As a result, and as we see with both of these commentaries, research in this area proceeds without a sense of responsibility for the decision-making process that brings medical care to an end in cases of uncertainty. Canavera and colleagues, for example, emphatically advocate deliberate

ambiguity about determinations of medical pathology in cases where diagnosis is uncertain:

By delineating a clear distinction between biological and psychosocial needs, access to mental health services will become even more stigmatized and limited for a population already sensitive to negative perceptions surrounding the use of psychotherapy. (Canavera et al. 2018, 30)

From a perspective that recognizes the ubiquity of diagnostic uncertainty, and the profound importance of managing it ethically, this recommendation is alarming. As a group of professionals working in the field, it seems Canavera and colleagues are unaware of, or unconcerned about, the weighty responsibility that determines the course of care in 52% of cases where people seek medical attention from their doctors. While it is theoretically possible to show that psychogenic diagnosis safely excludes biological disease in current practice, it is not practically possible as long as authors fail to recognize the nature and vital importance of that task.

IS IT TRUE THAT PSYCHOGENIC DIAGNOSIS RARELY ERRS?

In spite of persistent conflation of MUS and psychogenic symptoms, Kanaan does comment directly on the question of error, directing our attention to controversy over Eliot Slater’s work in the late 20th century (Kanaan 2018). A practicing psychiatrist, Slater developed a concern that his hysteria patients were actually suffering from undiagnosed medical conditions, devoting himself to research that could uncover hidden diseases. He concluded:

Looking back over the long history of ‘hysteria’ we see that the null hypothesis has never been disproved. No evidence has yet been offered that the patients suffering from ‘hysteria’ are in medically significant terms anything more than a random selection The diagnosis of ‘hysteria’ is a disguise for ignorance and a fertile source of clinical error. (Slater 1965, 1399)

According to Kanann, Slater’s research “has been substantially dismantled” because research shows that “for the great majority the diagnosis is not overturned” (Kanaan 2018, 23). Though I addressed this kind of reasoning directly in the target article, Kanaan’s commentary, and questions in commentary by Schwab, suggest that further clarification would be useful.

To evaluate the hypothesis that all swans are white, we can take two distinct approaches. First, we could search for a large number of white swans, and second, we could search for black swans. As a foundational point of evidence-based research, only the second sort of effort can establish the truth or falsity of our hypothesis because we cannot prove an idea by setting out to verify

it. We prove it only when we make a rigorous effort to falsify it and fail to do so. In the well-known words of Karl Popper, “No matter how many instances of white swans we may have observed, this does not justify the conclusion that *all* swans are white” (Popper [1935] 1992, 4).

If we want to evaluate the hypothesis that psychogenic diagnosis rarely errs, what approach should we take? First, we could search for patients with psychogenic diagnoses that have not been overturned by subsequent medical diagnoses, noting that they far outnumber those whose diagnoses have been overturned. This is the approach of the study cited by Kanaan (Stone et al. 2009), and nearly all of the scant research on mistaken psychogenic diagnosis, but this is not an approach that can verify the hypothesis. To accomplish that, researchers must proceed as Slater did, intently seeking black swans—not patients with psychogenic diagnoses, but patients with known medical conditions that have been diagnosed as psychogenic in error.

Outside of psychosomatic medicine there has been quite a lot of effort to falsify the hypothesis that psychogenic diagnosis rarely errs. As I point out in the article, surveys by the American Autoimmune Disease Association find that 51% of patients with autoimmune disease report a history of obstructed access to medical care based on mistaken psychogenic diagnosis (American Autoimmune-Related Disease Association 2014). To scientifically verify that psychogenic diagnosis rarely errs, then, researchers could readily perform studies that definitively establish whether those survey results are accurate. Similarly, studies by Eurodis suggest that the problem of diagnostic delay for patients with rare disease is tied to error in psychogenic diagnosis (Kole and Faurisson 2009). It would not be difficult to help verify, or finally refute, the hypothesis that psychogenic diagnosis rarely errs through research that determines rates of mistaken psychogenic diagnosis for patients with rare diseases.

It is both strange and telling that there exists no research to establish rates of mistaken psychogenic diagnosis for patients with known medical conditions. Commentary by Eichner (2018) ably highlights the seriousness of this problem for children with MUS and their families. With increasing frequency, when parents insist on continued medical care for children with serious unexplained symptoms, they face the prospect of medical child abuse (MCA) diagnosis. As Eichner points out, however, research has never been performed “that establishes the validity of the ... diagnostic process” for MCA. As a result, the process “fails to adequately screen out children with rare medical conditions” (Eichner 2018, 25). Though this problem has gathered enough public concern to warrant an opinion piece in the *New York Times* (Eichner 2015), bioethics has yet to step into the fray.

Eichner is certainly right to point out that without scientific evidence that diagnostic criteria successfully exclude those with medical conditions, “we cannot know that the diagnostic process is accurate—and neither can the physicians who make these diagnoses” (25). Until diligent effort has been made to find cases where psychogenic diagnosis and MCA diagnosis are made in error, there will be little basis for professional faith that either diagnosis is generally reliable.

SUPPOSE CURRENT PRACTICE IS OPTIMAL FOR PSYCHOGENIC SYMPTOMS? WHAT THEN?

Several commentaries offer critiques of the article’s conclusions from a perspective that does carefully distinguish MUS from psychogenic symptoms. Preller and colleagues (2018), for example, argue that when physicians offer a psychogenic diagnosis for symptoms, they “prevent a loss of health, without necessarily making a sacrifice of equal value.” I do agree with Preller and colleagues that “if a thorough, stepwise diagnostic procedure is followed”, obstruction of necessary medical care “will be minimal” (35). The target article centrally argues, however, that no such procedure exists in practice, that psychogenic diagnosis is encouraged without criteria of any kind, without any evidence at all of mental illness. More importantly, while Preller’s risk/benefit analysis is clear and accurate, and I see little reason to disagree, it can only affirm current practice for those who suffer from psychogenic symptoms. Nothing in Preller and colleagues’ analysis considers the risks and benefits of current practice for the larger group of patients with MUS.

Along these same lines, Sankary and Ford offer a very refined, very insightful analysis of the challenges of MUS in practice, based on a crisp distinction between MUS and psychogenic symptoms (Sankary and Ford 2018). They convincingly show that the boundary between diagnosis and therapy is vague in this area of practice, that “treating empirically” is routine, and that it often leads (as Arnold and Kerridge have suggested) to overtesting, overtreatment, and an array of iatrogenic harms. Most importantly, Sankary and Ford walk us through the murky area where patients with known medical conditions also suffer from psychogenic symptoms, so we are able to see how impossible it can be to distinguish psychogenic symptoms from biological medical conditions.

This discussion is immensely valuable for future efforts in this area, and yet, as with Preller and colleagues, it leaves off too early, assuming that what’s best for patients with psychogenic symptoms is best for patients with MUS. That is not the case—or at least it is not reasonable to assume that it is. While the ambiguity of current practice might well be optimal for patients with psychogenic symptoms, there is nothing in Sankary and Ford’s discussion that considers that benefit in light

of the risks it might create for the larger group of patients whose conditions lead to diagnostic uncertainty.

We are led here back to where we started. Because the term “MUS” has been ambiguous for so long, even those who recognize the importance of distinguishing MUS from psychogenic symptoms can lose focus on that bigger picture in the analysis. If we want to sort out how best to manage MUS, we must develop diagnostic and management parameters that are in the best interests of all of patients whose symptoms result in diagnostic uncertainty, including not just those with psychogenic symptoms, but also those with benign self-limiting biological symptoms, rare disorders, contested conditions, everyday medical conditions that present themselves in unusual ways, more serious medical conditions that are diagnostically challenging (such as autoimmune diseases or rare disorders), and very serious medical conditions that have not yet made their seriousness apparent. This is the nature of the problem, that practice must proceed in spite of uncertainty about the wide range of explanations that could possibly be correct.

CONCLUSIONS: ALIGNING APPARENTLY DISPARATE POSITIONS

We can unify most of the perspectives we find in commentary on the article if we aim for a deeper acceptance of uncertainty as a valid diagnostic result, and a deeper commitment to truthfulness about uncertainty. “Medical culture makes it hard to accept... the ‘gray-scale space’ of diagnostic uncertainty,” note Preller and colleagues (2018) (quoting Simpkin) (34). “The task for bioethics ... is to encourage ... acceptance of uncertainty and to critically excoriate the various forms of professional and epistemic hubris,” write Arnold and Kerridge (2018, 28). Similarly, Sankary and Ford (2018) conclude:

If clinicians too quickly attribute symptoms only to either psychogenic or to biological diagnosis, they will overlook important aspects of their duty to treat patients as a whole. (17)

While this suggestion seems to be offered as a point of dispute with my article—as are similar points by Canavera, Atkins, and Schwab—in truth I emphatically agree now, as I did in the original article. Though the line that determines medical need is always of primary clinical and ethical importance in practice, we gain little by pretending to draw the line successfully in cases of diagnostic uncertainty. This really is the article’s primary point: that it is problematic for current practice to conflate diagnostic uncertainty with certainty about psychogenic diagnosis. There is no more value to the pretense of certainty on one side of the line than on the other.

When it comes to communicating about uncertainty, Atkins suggests “the culture of medicine needs to evolve” so that, as a matter of everyday practice, patients

are aware “of the possibility that their doctor may not be able to discern exactly what is wrong with them” (Atkins 2018, 21). Similarly, Schwab suggests “practitioners should incorporate strategies for communicating about uncertainty” (Schwab 2018, 37). This, it seems, is a clear step for improving practice: dissolving the everyday expectation of diagnosis for patient and for doctor (and indeed for the culture at large), and developing guidelines for discussion of uncertainty that prepare patient and practitioner for collaborative decisions going forward.

Along these lines, it is important to note that Canavera, Atkins, and Sankary and Ford emphasize the integrated, biopsychosocial model of care, and express concern that the holistic model might be threatened if practitioners endeavor to be clear about the presence of biological pathology in every case of diagnostic uncertainty. This concern is misplaced. Uncertainty does not weaken the primary obligation to provide biological medical care to every patient who seeks it in need, not even when it makes the task impossible. And continued effort to resolve uncertainty poses no greater threat to holistic practice than effort to understand symptoms the first time they are presented. There is nothing about diagnostic uncertainty that transforms diagnostic effort into a dualistic enterprise.

When we accept uncertainty as a valid result of diagnostic inquiry, and we embrace a humble, truthful approach to managing it, we are better able to see how philosophical confusion leads practice off course. We do not integrate mind and body when we instantly leap from lack of biological explanation to causes in the mind. An integrated practice model requires that we allow uncertainty to be what it is, that we make space within the diagnostic coding system for practitioners to conclude that they do not know, and space within the exam room for patient and practitioner to grapple with uncertainty, as uncertainty, in the context of the whole person.

Finally, Kanaan (2018) emphatically writes, “The strongest evidence that there is a bioethical problem in the realm of medically unexplained symptoms is the presence of angry patients” (22). Kanaan seems to understand this as a point of dispute, though, again, it is a conclusion I emphatically accept, and one that can be addressed with deeper acceptance of, and truthfulness about, diagnostic uncertainty. The truth is that we do not have criteria for psychogenic diagnosis that patient or practitioner should fully trust. Practice guidelines proceed as if this is not the case, as if patient and practitioner should accept psychogenic diagnosis as they’d accept biological diagnosis confirmed by labwork. That expectation is prideful and untruthful, and it is reasonable for patients to be angered by it.

Surprisingly, the strongest directive we can find for attention to humble, truthful management of diagnostic uncertainty comes from within the psychiatric community, from Eliot Slater, whose adamant change of

heart about hysteria nearly topped the field of psychosomatic medicine just before it staked its first claim in DSM-III:

The diagnosis of "hysteria" is all too often a way of avoiding a confrontation with our own ignorance ... In the main the diagnosis of "hysteria" applies to a disorder of the doctor-patient relationship. It is evidence of non-communication, of a mutual misunderstanding. (Slater 1982, 40)

Slater does not suggest here that psychogenic diagnosis is always mistaken. Rather, he suggests that it is a pathological response to uncertainty. The remedy for this "disorder of the doctor-patient relationship" is truthful humility about the limits of diagnostic science, and a clear set of parameters for ethical practice in the many cases where it fails.

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