

The Blind Men and the Elephant: Mediating Conflicting Views of Controversial Diagnoses

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The fable of this essay's title offers a flexible, useful analogy for understanding how cultural and disciplinary biases—what Montgomery calls “visual field defects” or blind spots (5)—prevent lay people and experts from effectively sharing knowledge about health and illness. Researchers in medicine and the behavioral and social sciences, and critics in cultural, rhetorical, and literary studies struggle to communicate across disciplinary lines. Moreover, much of our academic work remains culturally and structurally barricaded against non-expert access. Instead, lay people are highly motivated to create their own expertise, consulting experts, one another, and the myriad, unregulated sources of popular culture to synthesize knowledge which is extensive and insightful, if not always efficient or evidence-based. As a result, experts and lay people can end up taking very different, often incompatible, approaches to the same condition, especially ones which defy easy categorization.

This article focuses on the example of controversial diagnoses, in particular, medically unexplained symptoms (MUS), fibromyalgia (FM), and post-treatment Lyme disease syndrome (PTLDS). What are they? Physiological dysfunction? Psychosomatic illness? Metaphorical expression of cultural anxiety? Political identity? How do conditions become constructed as “controversial” or “contested” among different discourse communities? A survey of expert and non-expert sources in different disciplines—research in medicine, psychology, and sociology, and popular discourses created for, and used by, lay people—reveals profoundly conflicting ideas, about the nature of medical authority, as well as the biopsychosocial, indeed, the epistemological nature of illness. As each discourse community attempts to provide meaningful definitions of controversial diagnoses, their highly divergent results tend instead to reinforce misunderstanding and provider-patient conflict.

Like many medical humanists, my critical (and personal) starting point for understanding individual and cultural experiences of illness is *the story*. We instinctively look to culturally-established patterns of quests, battles, and journeys to give shape and purpose to our experience (Hawkins). But the symptoms and course of the contested diagnosis defy

attempts to impose narrative coherence, and as much as providers and patients want to impose something like the restitution narrative, they are stuck with an “insufficient” narrative of chaos (Hydén, Frank). In fact, surveying a range of discourses about contested diagnoses demonstrates that not only is there a great deal of chaotic narrative, much of it is not meant to be narrative at all. Fact, belief, discipline-specific analysis, claims, reactions, multiple voices talking past and over one another, everyone standing too close to the problem to see it whole. No wonder experts and lay people find it so difficult to know illness, particularly of the contested variety, in the same way.

The goal of this study is to demonstrate the kind of praxis for which the medical humanities are so-well positioned, in this case, an interdisciplinary reading which unites the perspective of expert and lay person, as a step toward correcting for the blind spots which produce so much frustration when providers and patients struggle to negotiate “illness.” In the effort to correct for my own disciplinary blind spots, to step back and achieve the broadest view of the problem of the contested diagnosis, I will apply the model of rhetorical criticism defined by Judy Segal as “an intentionally underspecified procedure, with certain characteristic interests, for the study of persuasive elements, in a wide range of texts, especially in the realm of social action or public discourse” (*Health and Rhetoric*, 10). The motives of such criticism are holistic, and frankly rhetorical, that is, persuasive; we are practicing “a form of advocacy...with a will to amelioration” (Segal 16). We want our explanation and analysis to do real work that is useful, ideally applied (Segal 4-5), and definitely ethical (Wooden 275-76).

I will point out where expert and lay knowledge, which should intersect to promote wellness, is instead “incommensurate” (Barker, “Electronic Support Groups,” 23), incomplete, and unstable. Such an analysis holds the potential to help providers and patients work together towards resolving the controversy and contestation, to produce knowledge of illness and the illness experience that is co-constructed, stable, and productive of beneficial clinical and cultural interactions.

Means, Motive, and Opportunity: The Construction of Lay and Expert Medical Knowledge

In contemporary culture, the historical distinction between “lay” and “expert” status has significant effects on the average person’s experience of medical knowledge, and as much as medical education programs today emphasize the importance of a “provider-patient partnership,” the relationship remains “inherently unequal” (Montgomery 181), because the lay person has no direct, privileged, systematized access to the same medical knowledge that a provider has. Over the last century or so in North American culture, the line of demarcation between experts and non-experts has been increasingly formalized and credentialed. Education in medicine and other health sciences is an ongoing process of initiation into the mysteries of students’ chosen medical professions: the ritualistic progression from course and lab work to clinical rotations; the constant examinations; the gradual introduction to more and more privileged access to the inner workings of the body.

Students must demonstrate mastery of increasingly complex discourses, from textbooks to peer-reviewed research; through the so-called “hidden curriculum,” they are also exposed to less formal, tacit, forms of indoctrination into the culture of medicine. By

observing their teachers and more senior students, students learn the practical knowledge (or *phronesis*) that makes medicine not just a science, but an art (Montgomery 139). Students learn to think as experts: they acquire beliefs, habits of thought and reaction, attitudes, and biases, which lay people will not have (Groopman 6, Montgomery 139). They also start to imbibe an understanding of status, of their own position within the medical hierarchy, and of the limits and range of their authority and knowledge. Importantly, this is a process of differentiation, or division. Though they start to work more and more with other kinds of providers and patients, from the start of their curriculum, their knowledge, training, and testing leads them to see themselves as separate from these other groups (Montgomery 139, Segal 28).

There is nothing inherently sinister about this educational process. Any expert in any field thinks and feels differently about her knowledge than a non-expert does. Unlike many other fields of study, though, medical knowledge has become increasingly inaccessible to lay people, and medical professionals—sometimes deliberately, sometimes inadvertently—have not been very good at sharing what they know. In particular, increased complexity and specialization, combined with the establishment of medical authority, has rendered medical practice frustratingly opaque to those it is meant to serve. Practices which are meant to safe-guard medical professionalism can have the inadvertent effect of fostering paternalism amongst providers and an adversarial relationship with suspicious patients (Parker-Pope 1). Professional and cultural narratives of medical heroism contrast sharply with those instances when they feel let down: real advances in bio-science, public health measures, and diagnostic tools have not resulted in definitive solutions to medical problems both niggling (the proverbial common cold) and major (from depression to cancer); and medical errors still cause considerable injury and disability each year. Unable to contextualize the limitations of medical research, lay people hear of promising new breakthroughs every day alongside tales of malpractice and failure. Their own personal experiences teach them that as much as they *must* rely on the health-care system, they cannot completely trust it (Belling 57).

Nevertheless, lay people are inevitably driven to learn what they can about their health. According to recent Pew Research Center findings, “71% of adults in the U.S. say they received information, care, or support from a health professional...76% say they turned to friends and family, and [other non-professionals]” (Fox and Duggan, “Health Online 2013”). And lay people connect with those non-professionals largely through existing popular and social media; over 75% of North Americans use the internet, and approximately 80% use it to find and share health information (Kata, “Pandora’s Box,” 1709). When it comes to health issues, lay people have become highly accustomed to consulting far more sources than just their doctors.

Of course, there are hazards in this process of auto-didacticism. As frustrated as providers get when patients Google their symptoms and come to clinical appointments armed with their “sheaf of print-outs” (Kopelson 365), lay people *will* try to learn about their symptoms. However, the lay person who would aspire to understand her own gastrointestinal tract the way her GI specialist does, simply cannot: not only do most of them lack the necessary training in math and biology to make sense of the most current data, the average lay person cannot *get* that data without 1) access to professional, peer-reviewed research, most of which is not indexed on Google, and not available for free without

affiliation with an academic library ; 2) the skill to search for specific information in a targeted and productive way; 3) the ability to read and understand highly specialized forms of discourse; 4) the awareness of how and why information about this topic *must* be accessed through the filter of specialized discourse in the first place. According to Segal, “the democratization of health information...can include a faulty view of knowledge and expertise: the problem is not just that lay people do not know what doctors know; it is that they cannot know it” (“Internet Health,” 353). Consequently, when it comes to medical knowledge in contemporary society, lay people are uncomfortably dependent on a healthcare system that often seems much less interested in them than they are in it, and even the most well-informed non-expert is always made to feel at a disadvantage. And crucially, the well-informed non-expert is in the distinct minority. According to a recent report from the US Department of Health and Human Services, only 12% of English-speaking adults in the US have “proficient health literacy skills” (“Health Literacy” 4). Due to a variety of socio-economic, political, and structural problems, low levels of literacy and numeracy in English mean that the average lay person has no choice but to rely on whatever health care information he can understand, let alone access.

Not surprisingly, lay knowledge varies considerably from that of the experts. As Segal has observed, the lay person’s use of factual information and argument (*logos*) is always strongly influenced by belief, assumption, and emotion (*pathos*): “... and fear is the most salient of these [emotions]” (363). Fear of what a known, or dreaded, illness will do to one’s body, one’s mind, one’s relationships, and one’s self breeds suspicion: that experts are missing something, are wrong, are holding something back, are not taking the patient seriously. Some of these suspicions are not unfounded. The expert response to the “trespassing” of lay people—the effort of patients to take an active and informed role in the care of their own bodies and minds—is generally unproductive, varying from indifferent, to patronizing, to helpless, to dismissive (Shattock et al 252). Kopelson finds that physicians are very protective of their own authority and resistant to sharing it with their patients. They are skeptical that patients can effectively educate themselves about their own health, and concerned that the partially-informed patient will de-rail the clinical encounter, wasting time and resources. And when they do concede the value of the educated (compliant) patient, it is to co-opt them as “ideal patient subjects” who will re-inscribe medical authority as they act it out. Most strikingly, Kopelson’s assessment of physician attitudes and practices reveals how medical authority and knowledge is discursively constituted, protected, and reproduced, at the cost of patient autonomy and true patient-centered care (387). Moreover, as Segal suggests, this unequal access to knowledge and power, constituted through discourse, changes the very nature of what that discourse is “about” (Segal 352). When we make a survey across and between multiple discursive viewpoints, what we like to think of as shared, stable conceptions of “health” and “illness,” are anything but.

Fact, Belief, Bias, Knowledge: Experts and Lay people Clash Over Controversial Diagnoses

This problem is most strikingly divisively in the instance of controversial diagnoses. The names and symptoms for contested diagnoses vary, overlap, and depend heavily on cultural and discursive setting or point of view. Medically unexplained symptoms (MUS), fibromyalgia (FM), post-treatment Lyme disease syndrome (PTLDS), chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS), hypochondria: these might be several

discrete disorders, or one, or none. These conditions are a source of distress to both patients and providers because they are simultaneously poorly understood, resistant to treatment, chronic, and potentially debilitating. Physical symptoms include extreme fatigue, pain, and neurological and/or gastrointestinal dysfunction. Many of these symptoms are not easily measured by lab tests, imaging, or physical exam. Patients suffering from multiple, unexplained physical symptoms also report other, complicating factors: anxiety, depression, difficulty coping with social and professional roles (Barsky et al 904). Depending on who is making the diagnoses, these symptoms account for anywhere from 15-50% of primary care visits (Ring et al 1505).

No-one, lay people or any variant of expert, would claim that the individuals presenting with the above symptoms are not unwell, that their health is not impaired. The controversy arises over *cause*. It is unsurprising that lay people would experience frustration in the clinical encounter, when they experience a degree of certainty (not knowing what is causing their symptoms becomes a driving force of their distress, but they *know* that they feel physically unwell) that is absent amongst the experts they consult. Within the realm of expertise on contested diagnoses, there is, in fact, a wide variation of approaches.

The problem begins in the initial clinical encounter, when patients, experiencing bodily pain and distress, identify their illness as physiological, and seek care from physicians who might have neither the training, resources, nor, unfortunately, sympathy to provide the holistic care that the patient needs (Shattock et al 252). Depending on whom they see, patients might receive multiple, conflicting diagnoses, many of which deny patients' authority to name their own distress, and give the impression that the available experts either cannot or will not help them. When physicians cannot find anything "wrong" with a patient, that could mean that her¹ symptoms are not "genuine" and that she is "faking" (Shattock et al 251), malingering (Merkelbach and Merten), or experiencing some kind of allostatic overload, where an out-of control stress response has caused systemic damage (Luyten and Van Houdenhove 15); that she has not developed "mature capacities for distress and affect regulation" (Landa et al 718); that "ill-attuned caretakers" have failed to help her develop healthy "mentalization" and her fragile ego, unable to process distress, causes her to manifest her dis-ease in an embodied form (Katz 443); or that she is suffering from a physiological problem in the body that is not yet known or understood, potentially including pain, a dysregulation of the brain-gut axis, or an infection with one or more pathogens.

Many of the symptoms of contested illnesses have long, deeply-rooted cultural and clinical associations with mental illness, neurasthenia, hysteria, and hypochondria.² Elusive diagnoses have been complicated by the burden of unexamined stereotypes about class and gender, moral and physical strength. The history of stigmatization surrounding these symptoms has long influenced both providers and patients, driving both groups to prefer a physiological diagnosis, offering the promise of clear-cut etiology and treatment, relatively free of moral judgments, to the diagnosis that is ambiguous, complex, and shadowed by suspicions that the patient is somehow "making herself sick" or that the provider refuses to take her seriously (Dimsdale et al 227).

In recent decades, academic researchers in medicine, psychology, and sociology have found that Engel's multi-dimensional, *biopsychosocial* model of illness and health offers both

methodological and discursive space for a more nuanced, comprehensive, and de-stigmatizing understanding of the distress caused by syndromes such as MUS, FM, or PTLDS. For the most recent revision of the American Psychiatric Association's *Diagnostic and Statistical Manual (DSM-5)*, published in 2013, researchers in medicine and psychology spent years debating the status of these conditions, studying syndromes (collections of symptoms), trying to decide where to draw the line between physiological symptoms that have no observable biological explanation (MUS), functional or somatic symptoms with both physiological and psychological components (which can include CFS, IBS, Fibromyalgia), and other psychological conditions with physical manifestations, or effects. The resulting criteria for the category of somatic symptom disorder (SSD) in the *DSM-5* notably take a "holistic," biopsychosocial approach which is more respectful of the patient's experience: "This change in emphasis removes the mind-body separation implied in *DSM-IV* and encourages clinicians to make a comprehensive assessment and use clinical judgment rather than a check list that may arbitrarily disqualify many people who are suffering with both SSD and another medical diagnosis from getting the help they need" ("Somatic Symptom Disorder Fact Sheet"). The *DSM* revisions were meant to provide greater diagnostic clarity for both providers and patients. But the new criteria for somatic symptom disorder, and the extensive clinical and theoretical research that went into them, are inevitably reflective of a process of experts talking to other experts. Gone is the explicitly dismissive and paternalistic tone of the previous edition (*DSM-IV-TR*), which advised that "somatizing" patients exaggerate and make "inconsistent historians" ("Somatization Disorder" 486). But the diagnostic criteria are distilled from specialized research that does not, and methodologically cannot, easily incorporate the lived, subjective experience of lay people. Nor is the manual, or any of its supporting research, made readily accessible to a lay audience. Consequently, the "bible" of psychology and psychiatry is ubiquitous amongst experts and yet practically invisible to lay people.³

While many physicians are increasingly likely to categorize the symptoms and etiology of contested diagnoses as straddling biology, psychology, and social situation, many others have learned from the hidden curriculum of medical culture that MUS and somatic symptoms are imagined, not "real" illnesses (Shattock et al 253). Biases against the "difficult patient"—the hysteric, the hypochondriac—persist (Ring et al 1506). Even if providers have a more informed, biopsychosocial understanding of contested diagnoses in theory, it can be difficult to apply the model in clinical practice. Medical researchers and physicians, just like their patients, are uncomfortable with the ambiguity, and interpretive doubt that accompanies contested diagnoses. In fact, Montgomery suggests that when it comes to the tension between certainty and indeterminacy, medical culture has an intractable, and possibly-necessary, "visual field defect" or blind spot (135) that hinders clinicians from acknowledging either the limitations or the flexibility of medical knowledge, a perspective they reinforce amongst their patients (Montgomery 39-40). As a result, when a patient's symptoms elude categorization and remedy, when a physician is forcibly confronted with the limits, the fallibility of her knowledge and authority, both parties leave the consulting room deeply dissatisfied (Barsky et al, 903-4). Lacking a diagnosis recognizable to either patients or their friends and family, the person who knows she is sick is denied recognition and acceptance, and instead encounters moral judgment (of making herself sick, of making it all up, of being a hypochondriac, of malingering) (Nettleton 1170), which in turn produces

defensiveness and anxiety. The provider-patient “relationship,” which should be therapeutic, becomes adversarial.

Thus patients and providers, having incommensurate evidence and training, and very different kinds of authority as a result, are at a constant impasse in treating contested diagnoses (Barker, “Support Groups” 23). Each group is motivated by the best intentions to reduce distress and increase wellbeing. And yet each discourse community is barricaded from the others. The interplay of knowledge and power reinforces difference and separateness; the inability of each discipline to communicate effectively with the other perpetuates conflicting, unstable, meanings and—in concrete terms—hinders the effort to relieve patients’ suffering.

Perhaps more troubling, as much as the varied experts are all talking about the lay person, they are not talking *to* the lay person. Patients might be asked about their experiences, but they do not have much control over how they are asked, or what might be done with the results. This situation is partly methodological, partly cultural, and partly epistemological: medical and psychological researchers have to be careful about how they handle the subjective, the anecdotal, and the narrative (that is, what is often the most meaningful and essential material for memoirists, novelists, poets, artists, and other patients). Because lay knowledge is not credentialed or authorized as expert, it can serve as vital *qualitative* data, but what makes it useful is its perceived flaws and limitations. Even when researchers are exhorting their colleagues to take patient values and beliefs into account, such categorization automatically minimizes and subordinates “values” and “beliefs” as insufficient to constitute reliable, valid information.

Meanwhile, lay people, in general, have little access to this research (let alone cultural and rhetorical critique such as the present study). Instead, they are assembling their knowledge as best they can, drawing on the facts and hypotheses which filter from academic study to blend with the values and beliefs circulating within popular culture and their social networks. Willis explains that lay people use what they learn from these various cultural and social sources, in a “generative” way, “by observing and modeling others’ behaviors” (2). Often, lay people can learn a great deal about specific conditions, particularly ones the etiology and treatment of which are well-studied, not particularly controversial, and have a long history of direct coverage in the media.

The Non-Expert Autodidact: Information, Media, and Health Literacy

When it comes to contested diagnoses, however, it is much harder for patients to generate accurate knowledge. The unprecedented proliferation of electronic media would seem to be the key to unlocking the disciplinary and cultural barriers which have long thwarted lay people’s attempts to educate themselves about health. Yet several significant obstacles immediately present themselves. First, lay people form their initial impressions about medical conditions from encounters with clinicians, others in their social circle, and from the narratives about medicine and illness available in popular culture. For entertainment, we generally prefer acute, heroically-treatable illness and injury in the plots of medical melodrama or reality television. We find hypochondria, or Seinfeldian “germaphobia” hilarious in sitcoms. But unless they appear as false leads in the solving of

medical mysteries (Farkas), medically-unexplained symptoms, illness anxiety, and chronic fatigue are not—cannot be—incorporated into popular fictional narrative. Their intractability and chronicity makes them unsuitable for the kinds of “restitution” narratives which popular culture recognizes and reproduces (Shapiro 69). Resistant to narration, they become resistant to observation, to notice.

For similar reasons, wellness journalism (magazines, health programs like the *Dr. Oz Show*, even reporting in major outlets like *The New York Times*) tends to mis-represent contested diagnoses. The parameters of these conditions are nebulous, and the expert discourse of academic researchers does not translate well to the narrative terms which are the framework of popular discourses (Mnookin, 215). When combined with the demands for timely, engaging reportage that non-expert audiences will find accessible and “relatable,” peer-reviewed data and theories become oversimplified and distorted. Popular health journalism tends to use the diagnostic labels, concepts, and assumptions circulated by politicized lay advocates who are more vocal and media-savvy than academic researchers (Knudsen et al 5). Instead of a comprehensive survey of expert sources, nonacademic researchers use the information most accessible through a search engine like Google, mixed in with the testimony of “victims” and the claims of self-appointed experts, to create inspiring or pathetic human interest stories appealing to the widest audience:

Journalists might be more prone to present novel information, and thus ignore more established forms of treatment...Even if the results of scientific research or complicated treatment trials are presented to the media, journalists may find them more difficult to summarize into a readable format compared to case stories or strong statements from alternative therapists. Many journalists admit finding it difficult to comprehend some health issues, to place health news in context, and to interpret statistics. (Knudsen et al 5)

When it comes to contested diagnoses, symptoms, experiences, and stories are conflated, terminology applied inconsistently, less engaging concepts left unmentioned, un-named. That is, contested diagnoses are either badly represented in lay discourse, or not visible at all. The lay person can work very efficiently with what she has, but cannot educate herself about something that she is glimpsing in pieces—or has no reason to suspect even exists. Lay people are figuratively working blind, trying to create knowledge in a state of *anosognosia*—not knowing what they do not know.

For example, a Google search of Medically Unexplained Symptoms provides many useful, reliable sources, from a well-constructed Wikipedia entry to academic research. In fact, the Google search results are so reliable that there are no popular sources on the first page, indicating that no-one *but* experts talk about MUS. So where would a lay person hear about MUS, and its place within the controversy amongst specialists about somatic symptom disorder, in the first place? By contrast, a lay person will have heard about fibromyalgia and Lyme disease from social and popular culture sources. If she looks up fibromyalgia treatment on *WebMD*, she will find entries un-controversially in line with current research (recommendations to use appropriate medication for pain, manage stress, and get a good balance of rest, exercise, and nutrition). But the site avoids mention of the condition’s controversial clinical status (other than a link to “Common Fibro Misdiagnoses” on *WebMD*).

She will not find much nuanced discussion about possible psycho-social components of these conditions, nor will she find direct mention of medically-unexplained symptoms or somatic symptoms disorders. She will not learn about the role of pharmaceutical companies or activist groups in shaping popular and professional responses (Barker, "Listening to Lyrica"). When the mandate to provide helpful information about fibromyalgia and other contested diagnoses exists in conflict with the profit motive, strategic inoffensiveness harmfully distorts objectivity and neutrality (Wolfe 675).

While the information about contested diagnoses which is available electronically is overwhelmingly abundant, the way it is organized, and the ways in which people initially access it, make certain kinds of information practically invisible. As a corollary, lay researchers reasonably infer that visibility equates with approval and reliability. These are the conditions for the second obstacle: while lay people cannot easily access expert sources, and while popular health discourse functions in very indirect (often contradictory) relation to academic research, the interactive, social nature of electronic media means that lay people have direct, unlimited, and undifferentiated access to experts of varying degree of authority (including self-appointed ones) *and* one another. As Kata has observed, the internet creates a connectivity of voices and perspectives that can be beneficial, when it puts lay people in touch with evidence-based expertise—or very harmful when it gives a platform to self-appointed experts from the fringes. It is easy for lay people, motivated by uncertainty and fear about their health, "to fall into a trap of self-referencing and mutually reinforcing links that can fool users into believing there are many who share their beliefs, when in reality it may only be a small committed group" (Kata, "Anti-Vaccine Activists," 3779). The internet "flatten[s] truth," Kata explains, and "places carefully scrutinized evidence next to the opinions of crusaders, critics, and conspiracy theorists, potentially weakening messages from qualified experts" (3779).

Recent studies have found that, regardless of educational background or degree of health and information literacy, once lay people form strong beliefs about their health, they become very intractable to contradictory information: "As a result, corrective information about controversial issues may fail to change factual beliefs or opinions...In some cases, corrections can even make misperception worse" (Nyhan et al 836). Lay people and experts are highly motivated to conflate belief with certainty, especially when it comes to health (and politics); confirmation bias then leads us to be open to information that accords with our beliefs, and extremely closed-minded to anything that challenges them. We are all uncomfortable with uncertainty, especially when it comes to our health; both experts and lay people are "susceptible to [the] unconscious emotions and personal biases" which make us "more likely to make cognitive errors" (Groopman, 5). As Nyhan et al have observed, lay people are also particularly vulnerable to the influence of health information when it is presented through "emotive stories": the human interest accounts which provide a common framework for health information when it is presented in popular journalistic sources, or in personal accounts that are available everywhere on the internet. There is a "danger priming effect" from "dramatic narratives" which increase misperceptions and make people less receptive to corrective information (840).

Doctor-in-the-Box: The Influence of Pop-Culture Medical Authority on Health Literacy

Lay people looking for solutions to the medical mysteries posed by contested diagnoses are drawn to join self-selecting, symptom-specific discussion groups (fostered by everything from commercially-sponsored patient information sites such as *WebMD*, to medical tv programs such as *Dr. Oz* or *Mystery Diagnosis*, to Facebook pages). Not surprisingly, such groups function somewhat as echo chambers, where in addition to exchanging information, patients exchange their stories, using personal narrative as a shared medium in which they can recognize and validate one another's experiences. Such discourses, as Barker has found, tend to reify incomplete beliefs about contested diagnoses, the nature of illness, and the nature of medical authority ("Electronic Support Groups" 27). In such discourse environments, lay people share accounts of personal suffering, exacerbated by a perceived lack of concern from "mainstream" medicine. In the effort to supply certainty, participants exchange advice and explanatory theories, which only amplify the "danger priming effect" (Nyhan et al), reinforcing distorted perceptions of risk, belief in unproven alternative remedies, suspicion of conspiracy on the part of mainstream medicine and the pharmaceutical industry, and a conviction that doctors are not only unsympathetic, but poorly trained (Kata, "A Post-Modern Pandora's Box" 1714).

WebMD's fibromyalgia page has links to patient forums, where the "fibro" community actively discusses the challenges of living with the symptoms of the condition, particularly the adversarial provider-patient relationship. On the thread "When It's Time to Ditch Your Doctor," patients share stories of being condescended to, disrespected, and simply not given the help they seek. As Barker has found, "nearly all fibromyalgia sufferers endure invalidating and discrediting experiences" which drive them to search for

the ideal doctor—one who unquestioningly acknowledges patient expertise; and they attribute [physician] non-compliance to doctors' lack of knowledge. There is an expectation that doctors will concur with patients' (i.e., consumers') definition of the situation (i.e., they have a discrete physical illness) and the definition of the solution (i.e., they need a fibromyalgia diagnosis and access to the host of medical treatments recommended by fellow sufferers). Discrepancies between their embodied expertise and medical expertise conceding the existence or character of fibromyalgia are swiftly and consistently dismissed. ("Electronic Support Groups" 28-29)

And yet, lay people do not dismiss mainstream biomedical explanations. In fact, even as they may be pursuing a variety of alternative remedies on the basis of their acquired lay expertise, they long to have their condition recognized in "strictly orthodox medical terms" (29). Lay discourse tends to "reinforce the very mind-body dualism through which medicine negates the 'reality' of patients' suffering. Rather than critiquing scientific medicine's core assumptions (i.e., 'real' illnesses are demarcated by observable pathophysiology), participants simply challenge the competence of particular doctors...[T]he strong desire to frame one's suffering within scientific medicine's core assumptions demonstrates that medical discourse still garners significant cultural authority" (29).

And as many lay people have found, one immediately-available source of medical authority even makes house calls: Dr. Oz. Mehmet Oz, trained as a cardio-thoracic surgeon,

and on the faculty of Columbia University and New York Presbyterian Hospital, began his media career as the expert Oprah would summon to her program to answer the audience's questions about common illnesses. Since 2009, *The Dr. Oz Show* audience has come to count on him to spend more time with them than their own doctors do. In general, Oz dispenses reasonable advice which focuses on good preventative care: stress management, a healthy diet, exercise. He also has a knack for theater, and attracts and persuades his audience with the strategies common in popular health journalism from women's magazines to evening news programs, by presenting himself as the non-conformist who has access to miracle cures (for weight loss) and will tell them what their own providers will not: "Myths That Your Gyno Believes," "The Disease Your Doctor May Miss: Fibromyalgia," "Are Parasites the Real Reason Your [sic] Sick?" Oz, of course, is not simply Oz, but "Oz"—the front man for a team of writers and producers all intent on providing health information that also makes for good television. Like Oprah, he has attained the status not simply of expert, but also of guru; he has established a powerful rapport with his audience which allows him to inform them *and* influence their beliefs about illness, including the repeated suggestion that many health care providers cannot or will not *share* vital information.⁴

In a recent 6-minute segment, Oz refers several times to Lyme Disease as "the disease your doctor misdiagnosed." Patient-viewers describe their symptoms (pain, fatigue, rash) and share the experience of seeing multiple doctors (17 in one case) all offering different diagnoses, including that "it's just all in your head"; Oz says, "even though a simple blood test can detect it, a lot of docs can miss this diagnosis..." and "you're at far greater risk than you think" of getting Lyme ("Lyme Disease"). In the segment, Oz provides useful information about preventing this increasingly-prevalent tick-borne disease, and—with the use of a giant rubber insect, a 3-foot long pair of tweezers, and audience participation—demonstrates how to safely remove ticks. He also provides an overview of symptoms from the initial days after a bite to months and years afterwards. In his overview of Lyme disease diagnosis and treatment, he does not emphasize that most people recover from the disease (most within a few weeks); and he does not explain that months after evidence or memory of a tick bite are long gone, the symptoms that many people ascribe to post-treatment Lyme disease syndrome (PTLDS), such as neurological problems, neuropathy, or short term memory loss, could be caused by many conditions, including Lyme, somatic symptom disorder, or pain disorder ("Steere Interview"). Oz is the only expert the viewers get, but in the process of simplifying his explanation for a non-expert audience, he misleadingly, dangerously blurs details, cites no sources, and does not include any other researchers or physicians to supplement (or contradict) his instructions.

In the comments section on the accompanying Dr. Oz blog site, several participants dismiss this information, instead exhorting Dr. Oz to provide more thorough coverage of the condition, focusing on PTLDS as the culprit for a range of chronic-fatigue and fibromyalgia-like symptoms. They emphasize the need to find "Lyme literate" doctors (the non-conformists who will take patients seriously) to prescribe antibiotics for months and years, a treatment which neither the Centers for Disease Control (CDC) nor the National Institutes of Health (NIH) recommends ("NIAID: Lyme Disease"). One participant asserts that sources such as the CDC are "not up to date" and provides a link to the advocacy group, the International Lyme and Associated Diseases Society (ILADS), not to scrutinize research, but "to talk to other people" ("Reader Comments"). The ILADS overview on Lyme argues that

the CDC's research is biased, and fails to show that antibiotic therapy is ineffective for Lyme, but provides no links to any sources, including the "numerous European studies," which support their claims ("ILADS: About Lyme").

Thus: the lay person who feels unwell without any formal explanation, might catch Dr. Oz's show, recognize the non-specific symptoms he mentions, identify with the patients' struggles with providers resulting in few answers and little empathy, feel vindicated in her suspicions that someone has missed something, and end up by tracing her way through sources from the Dr. Oz website to far-less-reliable ones. She may end up convinced that she has PTLDS, without understanding the scientific and political controversies surrounding the diagnosis. More importantly, she may very well experience continued ill-health, as the commitment to PTLDS might prevent her from getting more appropriate care. Along the way, she will find encouragement from others like her who have learned from the exchange of experiences that it is hard to "find physicians who are as knowledgeable" as Dr. Oz's audience, after viewing the segment, because "mainstream medicine is truly lacking in knowledge, awareness, and aggressive action" ("Reader Comments").

As we have seen, the overall health literacy of lay people is quite low; according to Pew research, most lay people get their news, including health reporting, from popular, accessible, increasingly-networked sources like Dr. Oz, patient-oriented websites, social media, and Yahoo ("Changing News Landscape"). But even sources targeted at a more health-literate audience are vulnerable to the same kinds of constraints and mis-directions which inevitably influence lay efforts to acquire comprehensive medical education. For example, unlike print or online magazines which tend to focus on weight loss, anti-aging strategies, stress reduction, and relationships, and which segregate news by sex, the *NYTimes.com* "Health" page covers all of those issues, plus the business of health care, pharmaceutical research, treating and living with various conditions, caring for the ill or elderly, and the practice of medicine in general. Reporters regularly relay findings published in academic journals to a lay audience. The popular feature, "Think Like a Doctor" provides readers with case notes, labs, and imaging comparable to what a doctor might have—hundreds of readers contribute to solving the medical mystery. But while the "Health" section is a good site, it is not perfect; after all, it is part of a publication made by lay people for other lay people, the larger purpose of which is to provide timely news at a profit. The medical information here might be reliable, it might come from expert sources, but it changes in the process of translation; it is no longer expert information.

Take, for example, a discussion of the controversy over so-called post-treatment Lyme disease syndrome (PTLDS), published in the "Personal Health" column in the summer of 2013. Author Jane Brody, an experienced and popular reporter, employs a very typical article structure, developing a narrative of the issue framed by one patient's personal experience. She relies primarily on two other sources (a book by a researcher, and an interview with an infectious disease specialist) for her medical information, a limited selection given the amount of both peer-reviewed research and activist opinion available. Her treatment of the patient's situation is affecting and engaging, but not at all objective; one patient makes a very small sample from which to draw any conclusions. Her description of PTLDS contains some contradictory information, particularly since she does not seem to realize that the condition is extremely controversial. Brody, who has written for the paper

for decades, is not known as a polemicist; here, rather than attempting to stir up controversy, she seems simply to be attempting to provide coverage of a timely issue with the information most readily available, concluding with uncontroversial advice about the importance of avoiding ticks in the first place.

Brody's article generated a conflicting, adversarial discussion between close to three hundred doctors, patients/victims, advocates for alternative treatments, and proponents of conspiracy theories (the pharmaceutical industry and CDC in cahoots to withhold a vaccine). But the reader trying to learn about Lyme disease, and the controversy over PTLDS, will not learn much here about epidemiology (including social and environmental factors such as climate change or the effect of human development on ecosystems); or about the process not only of developing vaccines, but also of making a case for their efficacy, safety, and profitability. Nor will readers get a nuanced tutorial on the differences between opinion, weak evidence, and strong evidence—differences which depend on a complex system of accountability and peer review that is meant to be relatively transparent within academic discourse, but which is also nearly invisible to audiences unable to access such sources. Readers will understand that there is some kind of controversy here, but this lay source, as reliable as it is, cannot easily or simply encapsulate the full complexity of PTLDS as part of the larger biopsychosocial phenomenon which is the contested diagnosis.

Authority, (Non)Adherence, and Patient Autonomy: The Need for a Biopsychosocial Approach to Controversial Diagnoses

It is important to emphasize that the lay person who consults the “Health” section of the *New York Times*, and Dr. Oz and *WebMD*, and the myriad other sources and commentators available *is* engaging with a highly complex set of information. It just might not be quite what the experts expect (or prefer). When lay people educate themselves about their health—and, having both the right and the obligation to do so, they will—the process they go through bears important resemblance to that of the experts. Explicitly, they acquire information; implicitly, the availability and construction of that information provides a hidden curriculum which teaches lay people how to think, critically and skeptically. They learn, for example, that knowledge is fluid, and that interpretation is a vital skill in constructing and reading health care narratives. At the same time, they learn that the “experts” are not infallible, and that the authorial role is not a privileged one accorded only to “the experts.” Lay people have to, and can, become experts in their own health. Like the experts, lay people learn to approach information (and the people who dispense it) in particular ways. And, just as the experts learn, this is a process of differentiation and division, wherein each group's sense of identity and separateness inevitably affects its relationship to knowledge (Montgomery, 139). When people do not feel well, they want to find a way to feel better; at a minimum, they want to know *why* they feel ill. It ought to strike us quite forcefully that lay people study and practice such a wide range of treatments because they *matter*.

Consequently, the knowledge that the self-educated lay person ends up with is not only a product of the available information. It depends heavily on the habits of thought, the identity, and the claim to authority that she has acquired as well. Inundated with details, opinions, and narratives employed for every rhetorical purpose, presented with diagnoses

and treatment which seem to fit their symptoms, and with more access to the support and encouragement of “fellow-sufferers” than to sympathetic or helpful doctors, patients come to understand their illnesses as political and social identities as much as medical conditions (Barker, “Electronic Support Groups” 31).

As much as many lay people embrace medical self-education as empowering in contemporary society, doctors see it as a risk factor for poor patient adherence. But not only is the concept of patient adherence inherently paternalistic, “a form of social control premised on the unquestioning acceptance of medical authority” (31), it represents a failure on the part of the medical establishment to truly understand what drives non-expert behavior. As Kopelson has found, clinicians are still not comfortable with a patient identity that is not *passive* (363). Providers prefer to be the ones setting the parameters for how lay people interact with medical knowledge and authority. When patients present with easily-diagnosed symptoms, that traditional relationship continues to prevail, and the blind spots which hinder understanding between lay people and experts are not particularly noticeable or bothersome. If lay people and experts can get to the point where they agree on what to call a problem, that point of discursive contact establishes recognition, certainty, and a degree of trust that allows both groups to work together *somehow*. When the illness is resolved, everyone moves on. But when the illness cannot be resolved—as occurs too often in the case of contested diagnoses such as MUS, fibromyalgia, PTLDS, or the many other biopsychosocial syndromes—the resulting frustration and distress underscore the real harm that can be done when medical “knowledge” differs so much depending on who “knows” it. As we can see when we look at how discourses fail to constitute a coherent, shared knowledge about contested diagnoses—those blind spots are there.

Conclusion: The Role of the Medical Humanities in Mediating Contested Diagnoses, and Contested Knowledge

There is no single, easy solution to bridging the disciplinary, epistemological gaps which divide experts and lay people. But the point of this study, and of others like it, is to demonstrate that gaining the perspective to see those gaps is a move toward ameliorating them. This is where cultural critics and rhetoricians working in the medical humanities attempt to usefully intervene. Our perspective is inevitably interdisciplinary and holistic, if not completely objective. As lay people, we are excluded from the most specialized realms of medical knowledge, but we are driven to make meaning anyway. As experts, we leave the bio-medical explanations to colleagues in other disciplines, and do what we are trained to do: we focus on pattern and meaning in a wide array of texts, including, very crucially, lay discourses about the illness experience, and interpret these discourses in the context of larger social and institutional forces. Such analyses often provide more insight into elusive conditions than bio-medical approaches can. Without always being aware of the term, the biopsychosocial focus of humanists and social scientists can illuminate the blind spots that make it so hard for providers and patients to understand one another.

Unfortunately, the kind of nuanced analysis that we practice in the medical humanities—where we read the body-as-text, and illness-as-narrative to elucidate stable and unstable meanings—has yet to find a clinical application. We are certainly not immune to the shared faults of the other expert and lay disciplines that we study; that is, we do not

always realize how our own discursive construction of knowledge encodes its separateness from others. The very interdisciplinarity that makes our work so valuable also inevitably comes with limitations: disciplinary bias, access to knowledge/training, and, simply, access to audience. Our critique of biomedical and lay discourses might be well and comprehensively researched. But because we come at the topic from the standpoint of literary, cultural, or rhetorical criticism, the same holistic breadth that makes our work interdisciplinary simultaneously limits its visibility to audiences outside our discipline; we are at once overly, and insufficiently, specialized. Within the context of textual and cultural criticism, we practice readings of illness narratives which impose satisfying coherence on the otherwise terrifying incoherence that is the fear of getting, or the fear about being, sick; we assert the post-modern position, that the “the condition of doubt” is a normal condition of existence (Belling); and our nuanced, abstract position may not line up at all with either the lived experience of patients, or with the practices and beliefs of their health care providers. As Montgomery and Kopelson have observed, clinicians are strongly acculturated to practice a *phronesis* which privileges certainty—of knowledge, of relationships, of identities. The nuance and ambiguity that we medical humanists privilege in our own *phronesis* is so incompatible with traditional biomedical knowledge that the difference can provoke explicit antagonism: the work of the medical humanities seems characterized by “obscurity and overspecialization”; its theories and methods are anti-scientific, full of impenetrable jargon, smug, pretentious, and variously useless and “potentially harmful” (O’Mahony 611, 614).

Such outright, pointed hostility is rare; it is the implicit manifestation of disciplinary incompatibility which presents the real obstacle. Quite simply, the experts and lay people that we study are largely unaware of that work, and they are not studying us in return. The work of medical humanists to analyze, and correct, the disciplinary biases which get in the way of effective communication and therapeutic action have had subtle, limited impact outside of our own discipline—because we exist in a blind spot of our own. Our research has been in some ways the most comprehensive and yet the least visible of any group of experts or lay people concerned with medical knowledge.

But the work is good, and useful; now, our project must be to disseminate it. And as a still-emerging discipline, we do not have to be constrained by any traditional disciplinary boundaries; we can choose to speak more directly to our audiences, to participate more actively in the discourses they *have* to use. The point would not be to intrude, or pedantically correct; research shows that would not work (Nyhan et al). Rather, we can speak as experts to the other experts, targeting our academic study to researchers in medicine and psychology. And we can distill our findings into popular discourses, not necessarily to argue or persuade, but, more importantly, to establish a presence, a voice that can more directly reach lay audiences. This study has been a demonstration of the kind of praxis we need, reading “illness” as a problem of knowledge construction, writing about “illness” to synthesize, and attempt to resolve, conflicting viewpoints. But it needs to go further: we must adapt our work to the kinds of discourse communities we study. Having surveyed both lay and expert concerns and the contested knowledge which arises in their blind spots, we must now participate in the discourse communities that we study, to provide what insight and guidance we can, to nudge everyone towards a shared construction of knowledge about health and wellness.

Notes

¹ Researchers have found that the majority of patients (self) identified as suffering from contested diagnoses is female. Barker notes that both the illness identity and stigma associated with hysteria are highly gendered; in her study of direct-to-consumer advertising of the drug Lyrica, she observes that the pharmaceutical company uncritically constructs a set of non-specific symptoms as “fibromyalgia”—and the typical FM patient as female.

² For a more extensive treatment of biomedical and cultural constructions of hypochondria, see Belling’s *A Condition of Doubt: The Meanings of Hypochondria*.

³ The retail price of DMS-V is \$106.18 (US) in paperback.

⁴ In June 2014, Oz came under very public scrutiny in a Senate subcommittee on Consumer Protection, Product Safety, and Insurance hearing; he was unable to provide a convincing response to charges that he uses his considerable public influence to shill bogus health and weight-loss claims.

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