

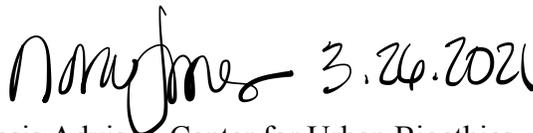
THE ETHICAL CONSEQUENCES OF MEDICAL OBJECTIVITY

A Thesis
Submitted to
the Temple University Graduate Board

In Partial Fulfillment
of the Requirements for the Degree
MASTER OF ARTS

by
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May 2021

Thesis Approvals:

 3.26.2021

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ABSTRACT

Objectivity is a valued principle in western allopathic medicine, and for good reason: it has been very effective in saving lives and improving quality of life since the nineteenth century. In recent years, however, there have been many visible accounts in social and mass media describing the consequences of disbelief by physicians, particularly from women and people from marginalized communities. This paper uses an urban bioethics perspective to examine how overreliance on the principle of objectivity can lead to violations of bioethical principles that it should be in balance with.

First, media and personal accounts of physician disbelief and misdiagnosis of patients are discussed. This is followed by a brief discussion of the historical roots of objectivity in medicine, an examination of the particular difficulty western medicine seems to have with medically-unexplained symptoms, and a closer look at specific diseases that encounter stigma in the clinical setting. From there, specific bioethical principles are analyzed. Nonmaleficence is violated when clinicians traumatize their patients through disbelief of symptoms that cannot be confirmed through confirmatory testing and when they prematurely assume a psychogenic cause of symptoms simply because the cause cannot be found with a physical examination, laboratory test, or imaging study. Solidarity, autonomy, and agency are violated through the denial of the patient's expertise in their own experience and the disempowerment of the patient in the doctor-patient relationship. Distributive and social justice are violated when the efficiency demanded of a medical system built upon reliance on objective findings disadvantages patients with difficult-to-diagnose conditions along with women and

marginalized groups. Potential solutions to the unethical overreliance on objectivity include changes to medical education and culture to be more allowing of fallibility and humility, as well as better integration of mental and behavioral health into the primary care setting, so patients' medical and psychosocial needs may be treated more holistically. Structural changes to the healthcare system allowing better physician reimbursement for clinical counseling will also mitigate dependency on objective findings for diagnosis and treatment.

Dedicated to the countless patients
inadvertently harmed by the medical system
as we all-too-slowly learn to do better.

ACKNOWLEDGMENTS

First, I would like to acknowledge my advisor, Nora Jones, PhD, for her guidance and encouragement throughout this process, along with the rest of the Urban Bioethics faculty at Temple. I would also like to acknowledge my mentor, David O’Gurek, MD, for his persistent willingness to offer advice any time it is requested, and for leading by example in how to practice medicine humanistically and ethically. Lastly, I must acknowledge my partner Sarah, my mother Jacqueline, and my dear friend Tony, who have been a tremendous support to me throughout my journey into medicine and bioethics. I have been lifted up and carried throughout my life by more people than I can mention here, and I am grateful for all of them.

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CHAPTER 1: UNEXPLAINED SYMPTOMS AND STIGMA IN MEDICINE

“Doctors don't know this but I often create a fun game for them where I strategically list my symptoms in a way that eventually leads them to the diagnosis I've already given myself because patients obviously never know what we're talking about” (tweet by @BeingCharisBlog, 2020).

Introduction

The seed for my interest in the topic of disbelief, dismissal, and discounting by physicians was originally planted by way of gradual exposure to stories from patients. It is my experience that such accounts have become increasingly visible in recent years across various forms of mass and social media, from tweets like the one above to commentaries in the popular press. Writing in *The Atlantic*, Fassler (2015) recounted his wife's experience with ovarian torsion, in which they waited for hours under the care of physicians and nurses who discounted her extreme pain as, for example, a kidney stone, ultimately resulting in the loss of her ovary. Quoting his wife, he refers to “the trauma of not being seen” that continued to haunt her after her physical recovery.

Other accounts abound. In 2019, *Buzzfeed* published “31 Stories From Women Whose Doctors Did Not Take Their Pain Seriously” (Parker, 2019). The same year, *Allure* published “The Importance of Listening to Your Body — Even When Doctors Aren't Listening to You” (Magane, 2019), describing the experience of the author, a Muslim woman, whose experience of painful menses were repeatedly misdiagnosed or dismissed as a symptom of depression before she finally found a doctor who took her pain seriously, and correctly diagnosed her with endometriosis. The issue has even been

fictionalized: in 2018 the long-running television drama *Grey's Anatomy* dramatized the account of a female physician having a heart attack, knowing full well that her symptoms were consistent with a heart attack, and being disbelieved by the physicians caring for her at seemingly every turn (Finch & Rubio, 2018).

In addition to media representations of the problem of physician disbelief, I have also heard numerous first-hand accounts from friends and family. Consistent with typical media narratives, the stories commonly have come from women, but some have also come from people of marginalized sexual orientations, gender identities, and racial categories. Themes I have heard repeatedly include experiencing dismissal of concern from healthcare providers, feeling driven to manipulate the doctor, and developing reluctance to seek care for new symptoms in anticipation of having them dismissed. Additionally, in working with individuals with addictions, another marginalized group, I have heard many stories where an individual felt that their legitimate health concerns were not taken seriously due to their substance use.

My personal experience with physician disbelief has been limited. That said, recently I was taking care of a patient with unusually severe facial and throat pain after tonsillectomy & adenoidectomy. This patient had a prior diagnosis of temporomandibular joint (TMJ) dysfunction—a diagnosis I happen to share—and it appeared the surgery, requiring her mouth to be wide open for an extended period, had aggravated the jaw pain for which she is already prone—an experience I have also shared. In presenting this patient to my attending, the diagnosis of TMJ dysfunction was met with skepticism. When I explained that I, too, suffered from the same disorder, and it was well-managed with an occlusive device worn at night and daily jaw stretches, and it had been diagnosed

and managed by orofacial pain specialists at a prestigious, university-based dental school, the attending made a reference to "ivory tower syndrome"—implying that this diagnosis is mostly in the imagination of academic clinicians without sufficient connection to the "real world."

I felt invalidated and angry at the dismissal of my lived experience. I then felt very protective of this patient, with whom I shared this condition, and whose physician was dismissing her pain. This experience, building upon hearing account after account from loved ones and strangers on the Internet alike, led me to explore the bioethical implications of this harmful occurrence in medical encounters.

All of this amounts to what Ed Yong (2020) refers to as “medical gaslighting”—the all-too common experience of patients having their symptoms disbelieved or written off as psychiatric in nature, and physicians seemingly abdicating their responsibilities to help. Although various biases, including but not limited to sexism, are certain to be at play in these interactions, I will argue that overreliance on objective findings is also to blame.

Particular Problems with Medically-Unexplained Symptoms

Although the practice of western medicine has some philosophical influences dating back to Hippocrates and other pivotal figures and movements in the healing arts from predominantly European history, medicine as it is practiced today is rooted heavily in paradigms established in the nineteenth century. This period is when germ theory gained wide acceptance, statistical methods and rigorous, controlled experimentation began being widely used, and many of the standardized physical examination practices and tools were created and adopted. This is the era in which medicine began to fully

adopt the scientific method, and shed many traditional healing methods that did not hold up to empirical scrutiny. Objectivity became a prized principle to follow, and for good reason: it worked. Medicine became unquestionably more effective and efficient through the use of empiricism and technology.

Andrew Twaddle (1968) and many others since have used a framework that differentiates *disease*, *illness*, and *sickness* as distinct concepts. For Twaddle, *disease* reflects an objective pathological state, a disruption to the structure or function of an organ or organ system—in other words, the domain of the clinician. By contrast, *illness* reflects the domain of the patient, including not only physical or psychological symptoms, but their thoughts and feelings regarding their “subjectively interpreted undesirable state of health” (Twaddle, 1993, p. 10). Lastly, *sickness* represents the social view of the individual’s experience of illness, defined by observers from outside the physician-patient dyad. This framework will be helpful as I discuss challenges encountered in the clinical setting, where a physician is chiefly concerned with the patient’s disease, while the patient is concerned with their illness, distinct terms highlighting the potential disconnect between both the goals and experience of each party.

It has been noted that medicine appears to have a particular problem with what are called medically-unexplained symptoms (MUS) (O’Leary, 2018)—patients who present with illness that evades diagnostic instruments to elicit a specific diagnosis. Certainly, some of the above examples in media are of acute and readily diagnosable biomedical diseases such as myocardial infarction and ovarian torsion, but one can also find many accounts of patients with rare and/or difficult to diagnose conditions who are similarly

written off, often for years, before a diagnosis is finally given, often to great relief of the sufferer (Björkman et al., 2016; Clauw et al., 2017; Geraghty & Blease, 2019; Magane, 2019). Clauw et al. (2017) point out that many now well-understood diseases, such as asthma, were once medically-unexplained, controversial, and even ascribed to psychological causes. Acceptance seems to come through three routes: an understanding of the pathophysiology of the disease, the development of tests for the disease, and effective treatments (Clauw et al., 2017); a common thread among these three routes is the disease gaining the veneer of objectivity.

It should also be noted that MUS is not uncommon in medical practice. O’Leary (2018) cites multiple studies placing the amount of outpatient medical encounters with MUS anywhere from 10–86 percent of all visits, with a preponderance being in the area of 50 percent or greater. Even if we accept the most modest estimation, the average family physician in the United States sees over 10 patients a day (White & Twiddy, 2017) making it likely that a doctor will encounter MUS in their practice on a daily basis. With this in mind, it is clear that any difficulty experienced by physicians in treating these patients is not a fringe problem, but one front and center, relevant to essentially all medical practice.

One explanation for this particular difficulty with MUS is that physicians tend to have discomfort with ambiguity in diagnostic approach. As Simpkin and Schwartzstein argue, while no doctor would dispute the existence of uncertainty in medicine, the training and culture of medicine reinforce a need to be decisive and definitive. “Too often,” they write, physicians “focus on transforming a patient’s gray-scale narrative into a black-and-white diagnosis that can be neatly categorized and labeled” (Simpkin &

Schwartzstein, 2016, p. 1713). Abraham Schwab discusses this difficulty with uncertainty in terms of “epistemic humility,” which he defines as “the recognition and communication of the uncertainty that accompanies [a physician’s] judgment as well as a commitment to avoid intuitive innovations” (Schwab, 2012, p. 28).

Another explanation is physician discomfort with impotence. Lorenzetti et al. write, “[w]hen the ability to improve a patient’s condition is threatened or undermined, the physician’s identity as a healer may be compromised” (2013, p. 419). Indeed, physicians sacrifice years of their youth and go into massive debt in the pursuit of learning to heal patients, and this massive investment may contribute to cognitive dissonance involving their self-image when the ability to heal meets its limits.

Additionally, Björkman et al. argue that patients, as well, can hold unrealistic mental representations of physicians as near-omnipotent, and these expectations cause them to “strike back at individual practitioners who are not able to live up to such expectations” (2016, p. 2975). Coupled with a culture that demands certainty, it is not hard to understand the identity threat that a medical mystery can present to a doctor.

Physician discomfort with uncertainty and overreliance on objectivity is nothing new, and has long been recognized for the challenges it can create. This has led to various attempts to change approaches and attitudes within medicine. One such attempt has been the “biopsychosocial model,” first proposed by Engel in 1977, challenging the notion that it is desirable or even possible to separate the biological aspects of disease from their psychological and social aspects, and calling for physicians to treat their patients more holistically. Canavera et al. (2018) insist that the biopsychosocial framework is important for destigmatizing mental health care by recognizing that mind and body are parts of an

integrated system, and to reject this approach may actually impede access to appropriate care. Geraghty and Blease (2018), however, argue that however well-intentioned the biopsychosocial framework may be, the typical result for patients with MUS is that physicians are quick to default to psychosocial explanations for the symptoms, cease medical investigation, and refer the patient elsewhere for help, due to a presumption that the symptoms do not have a biomedical component. Similarly, Redinger et al. (2018) argue that physicians will reach for psychological explanations for symptoms in the absence of known biological causes, because to continue to entertain a biological cause would imply that the physician is ignorant of that cause, despite it being within the very domain in which they are meant to be experts. With this in mind, a model that is meant to dispel mind-body dualism may instead be reinforcing it, or at least may be ineffectual in accomplishing its intended goal.

Ultimately, this reliance on “objectivity” all too commonly translates into disbelief of patients. This leads to a tension where patients with specific types of health conditions are seen as “difficult” patients (Lorenzetti et al., 2013) and ultimately are stigmatized.

Specific Diseases that Encounter Stigma

There are a number of specific diseases that are well-known to elicit stigma from healthcare providers, many of which are lumped into the category of “functional disorders.” Functional disorders are a broad grouping of diseases for which there is currently no known pathology to explain the symptoms. The concept of functional disorders comes from neurology, originally coined to describe patients with apparent neurological symptoms for which no causal neurological lesions could be identified, and

has come to serve in many cases as a more palatable stand-in term for the now-unfavored concept of “hysteria” (Kanaan et al., 2012). Specific examples of stigmatized diseases, all of which have at times been characterized as “functional” with varying degrees of controversy, include irritable bowel syndrome (IBS), psychogenic non-epileptic seizures (PNES), fibromyalgia, and myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS).

IBS is a functional disorder marked by gastrointestinal distress and changes in bowel function despite the absence of identifiable pathology. Originally named “mucous colitis” by William Osler, it has been described in medical literature since at least 1892 (Maxwell, 1997). It is commonly believed to have a psychosomatic component (Björkman et al., 2013), and notably, even Osler described many of his mucous colitis patients as “hysterical, hypochondriac, or depressed” (Maxwell, 1997, p. 1691). IBS patients interviewed by Björkman et al. (2013) often reported dissatisfying medical encounters, with their condition written off as trivial and having a psychological or stress etiology, and left with the feeling that the provider accepts no responsibility in aiding with recovery.

PNES is another functional disorder, in which sufferers have apparent seizures, but where there is no evidence of neurological dysfunction. Rawlings et al. (2017) note that past research has repeatedly shown that PNES patients frequently report experiencing discrimination from healthcare providers, and that medical professionals commonly report having poor understanding of the condition, both of which I would argue are a result of medicine’s discomfort with diseases that cannot be easily objectively measured or treated.

Fibromyalgia is emblematic of functional disorders marked primarily by chronic pain. Arguably, chronic pain conditions without readily identifiable physical causes are even more ripe for dismissal and disbelief, because the symptomatology is entirely sensory, unlike IBS or PNES, which have visible physical manifestations, even if they are given a psychological attribution. Indeed, chronic pain patients, even those with an identifiable “objective” etiology, are also commonly seen as “difficult patients” (Lorenzetti et al., 2013), and so the lack of such an etiology understandably would increase the potential stigma experienced by fibromyalgia patients. Indeed, Kool et al (2009) have found that fibromyalgia patients commonly experience invalidation from their healthcare providers.

ME/CFS has long been considered a controversial diagnosis. Its two names reflect a dispute between divergent approaches and assumptions (Geraghty & Blease, 2019); one—myalgic encephalomyelitis—implying a biomedical, neurological condition, and the other—chronic fatigue syndrome—focusing instead on the symptomatology. In other words, ME is a label of disease, while CFS is one of illness. Whatever the label, ME/CFS is characterized by a constellation of muscular, neurological, and circulatory symptoms (Geraghty & Blease, 2019), including muscle pain and weakness, fatigue, unrefreshing sleep, cognitive impairment, and orthostatic hypotension (a drop in blood pressure upon standing). Geraghty and Blease (2019) argue that physicians often write off the disease as psychosocial in etiology, despite a body of evidence supporting distinctive biological pathology in sufferers, and frequently view ME/CFS patients as difficult, demanding, and clinging to a “sick role.”

As of this writing, the SARS-CoV-2 virus continues to run rampant throughout most of the world, with mass vaccination campaigns just beginning and far from achieving anything close to herd immunity. The pandemic is barely a year old and more continues to be learned daily about COVID-19 and its long-term effects. One phenomenon that has been observed in some who have recovered from the acute disease is a constellation of symptoms that have been dubbed “long COVID,” in which sufferers contend with an indefinite post-recovery period, with numerous, varied, and often non-specific symptoms, some of which closely resemble ME/CFS.

These “COVID long-haulers” deal not only with debilitating and frustrating symptoms, but with what Yong calls “an equally debilitating comorbidity of disbelief” (2020). In a climate of extreme uncertainty, they have banded together online, in some instances utilizing networks and organizing infrastructure already put in place by sufferers of ME/CFS and other chronic diseases. While the world’s attention is on COVID-19, long COVID gives us a real-time and very public view of the spectrum of negative experiences patients frequently encounter when dealing with MUS.

Disbelief, discounting, and dismissal that results from privileging the objective is harmful to the health, well-being, and trust of patients; moreover, it is unethical. I will now turn to a discussion of the key ethical principles of urban bioethics that are violated when the individual practice of physicians and the wider culture of medicine privileges the objective.

CHAPTER 2: ETHICAL CONSEQUENCES

Violations of Nonmaleficence

Primum non nocere—first, do no harm—is perhaps the best-known guiding principle of modern Western medicine. Nonmaleficence serves the function of tempering the urge to act rashly in diagnosing and treating a patient, reminding physicians that risks must always be weighed against benefits, and that there are times when doing nothing is a better option than doing *something*.

As noted above, nonmaleficence is frequently given as the rationale for taking a restrained approach when faced with medical uncertainty. Clinicians may hesitate to take patients down an extensive diagnostic pathway with invasive and expensive tests if they believe there is low probability of yielding something that will benefit the patient. Risk of iatrogenic (medically-caused) harm, including the potential consequences of false positives, e.g. unnecessary treatments, is part of that calculus.

With that said, reluctance to over-investigate is often experienced as invalidation by patients. Furthermore, patients with MUS often experience outright disbelief from physicians, when diagnostic tests fail to yield significant findings. From the physician's perspective, in terms of what he or she can measure, there may seem to be "nothing wrong." This experience of disbelief and discounting can be deeply traumatic for patients (Stone, 2018). It may even exacerbate certain conditions: Kool et al. (2009) argue that the invalidation experienced by fibromyalgia patients is a form of social rejection, which has been demonstrated to amplify the experience of physical pain.

Stone writes: “Diseases have prestige, and suffering exists on a hierarchy of worthiness . . . A diagnosis of cancer does not have the same social meaning, access to resources, or public support as a diagnosis of depression or borderline personality disorder or MUS, even if the suffering is equivalent. Therefore, the choice of diagnosis is not ethically neutral” (2018, p. 18). A diagnosis of psychogenic illness, argues Atkins, can rob a patient of dignity, by inference that they “are either too weak to be able to withstand their emotional problems or are ignorant of their own psychological motivations (and thus not fully rational)” (2018, p. 21). In the quest for objectivity, physicians frequently fail to uphold the primary mandate of nonmaleficence and instead inadvertently do harm to their patients.

Violations of Solidarity, Autonomy, and Agency

Solidarity is a less-commonly discussed ethical principle of bioethics. It is mentioned in the UNESCO Universal Declaration on Bioethics and Human Rights as a principle “to be encouraged” (United Nations Educational, Scientific and Cultural Organization, 2005), but no further detail is given on how this is to be achieved, or even how solidarity is defined. Building on this, Barbara Prainsack and Alena Buyx have written extensively in the past decade on solidarity in bioethics, seeking both to define it, and explore its application. For Prainsack and Buyx, solidarity is distinct from charity, as the latter emphasizes the differences between donor and recipient, whereas in the former, the similarities—e.g. shared class, costs, goals, or fate—is key (Prainsack & Buyx, 2012; West-Oram et al., 2016).

I would argue that a key way in which solidarity is honored within the doctor-patient relationship is by that relationship being treated as a partnership, in which

physician and patient work together to achieve shared goals. To illustrate the nature of this partnership, let us consider the concept of signs and symptoms in the process of medical diagnosis. Signs, in medical terminology, are manifestations of disease that the physician observes in him or herself; these are considered objective findings. This is contrasted with symptoms, which refers to the patient's described experience of medical dysfunction; these are considered subjective findings. Symptoms are considered an essential part of diagnosis, and are a standard part of medical notes. In their relationship, physicians are experts in observing signs of disease, but patients are experts on the symptoms of their illness. When a patient comes to their physician with a complaint, they bring their experience of illness as a partner in the diagnostic process. Further, they come with their own unique goals of health that may not align perfectly with what the physician would independently choose for them.

With this in mind, symptoms cannot be simply dismissed or ignored when objective findings do not bear fruit. To do so discounts the patient's experience and disrupts the partnership. This has the effect of reinforcing physician power over the patient, as the only authority in the room, and as such violates the partnership mandated by the principle of solidarity. Also, when patients are "referred out" for behavioral health or psychiatry and the therapeutic relationship is terminated out of a premature assumption that symptom etiology lies outside of purview of biomedicine, this violates the "shared costs" definition of solidarity as well.

Solidarity is not the only principle threatened by the reinforcement of physician power; power dynamics are central to discussions of autonomy and agency as well. Autonomy, the ability of an individual to choose freely, is another foundational principle

of modern bioethics. The primary way in which autonomy is protected in medicine is through ensuring patients have adequate information with which to make their choices, notably through the process of informed consent, in which patients are presented with all reasonable risks and benefits around a recommended medical intervention, including the risks and benefits of refusing the intervention.

As I have noted already, when objectivity is privileged, patient's experiences are discounted. O'Leary (2018) argues that an autonomous human being is better positioned to know their first-person experiences—physical, emotional, and psychosocial—than anyone else; as such, to dismiss a patient's bodily symptoms as emotional or psychosocial in nature is a direct challenge to that autonomy.

An additional violation of autonomy occurs as a result of physician discomfort with ambiguity, with the more proximate cause being inadequate communication. Informed consent is perhaps the hallmark of physicians honoring patient autonomy. However, O'Leary (2018) argues that when a physician cannot determine a cause for physical symptoms, they will often speak authoritatively that they have exhausted all avenues of investigation in a way that masks the true uncertainty present. Further, O'Leary (2018) continues, once a physician has anchored on a psychosocial etiology of the patient's symptoms they will often nonetheless avoid framing it that way out of an intent of beneficence—or simply in anticipation of a patient's resistance to their diagnosis, as Rawlings et al. (2017) suggest; instead, argues Schwab (2018), in this vagueness they effectively strip the patient of autonomy through inadequate information. O'Leary (2018) seems to agree, and argues that this approach, sacrificing autonomy for

perceived beneficence is paternalistic and harkens back to the days of “hysteria” diagnoses when the autonomy of women was disregarded entirely.

The concept of agency builds on autonomy. If autonomy refers to the ability of an individual to freely choose, agency refers to that individual’s capacity to carry out that choice. The ability to pick an option that is nonetheless inaccessible is meaningless, and therefore barriers such as cost, time, and stigma are important considerations in medical care. Patients must also be personally empowered to fully have agency in their choices. Through the lens of urban bioethics, the classical bioethics principle of autonomy is indeed necessary, but is arguably insufficient, and respecting the principle of agency becomes essential.

As already noted, disbelief and dismissal is deeply disempowering for patients. As Swartz argues, this “testimonial injustice and silencing in doctor–patient relationships nullify the agency of the patient by failing to acknowledge an epistemically privileged position that is informed by her knowledge, values, and preference” (2018, p. 38). Further, physicians reinforce the power differential by acting as gatekeepers of diagnostic instruments; reluctance to “overinvestigate” in cases of MUS is one way in which this is perpetuated.

One way in which patients restore their agency is through banding together with other sufferers of the same illness. A web search for most of the functional disorders described above reveals dozens of information, support, and advocacy groups. Such groups serve an important function for sufferers of any disease, but I would argue that in disputed illnesses, they take on greater import for the patient, in providing information and support to re-empower the individual, as well as a community that can enable

collective actions. Indeed, it is surely no coincidence that diseases subject to high stigma and disempowerment within the healthcare milieu would have high numbers of organizations formed expressly for the purpose of patient empowerment.

Part of patients reclaiming their power, and agency, is through being “informed patients.” Patient support groups can be a major source of arming patients with information and in the Information Age there is no shortage of data, both credible and otherwise, available from any number of sources at every patient’s fingertips twenty-four hours a day. These “informed patients,” who are sometimes characterized as taking advice from “Dr. Google” (Butterfield, 2013), can be frustrating to physicians (Lorenzetti et al., 2013), who may further seek to reinforce their power through dismissal of auxiliary knowledge brought to the visit by the patient. Ultimately, this may create a vicious circle in which patients are disempowered by their physicians, re-empower themselves with outside knowledge, and are again disempowered when the physician must attempt to provide what they see as appropriate interpretation and application of the acquired knowledge.

Violations of Distributive and Social Justice

Justice, more specifically distributive justice, is the fourth classical bioethics principle, usually mentioned in the same breath with beneficence, nonmaleficence, and autonomy. In the healthcare setting, the principle of justice reminds healthcare providers to be mindful of the fair allocation of resources and to treat patients equally.

One consequence of medicine privileging the objective is that clinical counseling, a time-intensive intervention, is reimbursed inadequately. As Atkins (2018) argues, adequate and transparent communication is essential to the management of MUS.

However, the time required for appropriate clinical counseling is a luxury that is not available in most doctor-patient relationships in the US. In a 2015 survey of family medicine physicians, the American Academy of Family Physicians (AAFP) found that the average number of patients seen per week in an office setting was 73.6 (White & Twiddy, 2017). If 40 hours per week was devoted solely to patient interaction—not counting any of the documentation and other daily administrative tasks required of physicians—this would only allow a half hour per patient. Lorenzetti et al. (2013) found that time pressure was a contributing factor in the perceived difficulty of a patient encounter experienced by physicians.

The medical system in the US rewards efficiency in both diagnosis and treatment. As noted above, the current paradigm in Western allopathic medicine centering objectivity predates the US medical system and as such has been shaped by it, just as it has been shaped by economic forces. O’Leary notes that MUS represent a massive drain on healthcare resources, often without substantial relief of a patient’s symptoms. As a result, “[w]hen unexplained symptoms can be diagnosed as psychogenic, policymakers and administrators are able to conserve substantial resources for cases where established diagnosis will make them more useful” (O’Leary, 2018, p. 8). Combined with an attempt to honor nonmaleficence by avoiding the risk of iatrogenesis by unwarranted intervention, patients with difficult-to-diagnose conditions are readily deprived of distributive justice.

In a similar vein, Björkman et al. (2013) argue that functional disorders, by virtue of their not conforming to traditional biomedical models, are not only given inadequate attention in the clinical setting, but in research as well. By marginalizing certain diseases

in the research sphere, this extends beyond being a violation of justice for the presently ill, but for all future sufferers who would benefit from research.

If honoring distributive justice requires clinicians to prioritize equality, honoring social justice similarly requires the prioritization of equity. Social justice in a bioethics context, to use the words of Camisha Russell (2016), is a mandate to center the margins, and be mindful that the needs and viewpoints of the marginalized are likely not represented without expressly considering them.

It is instructive to note that women are more likely to be diagnosed with IBS (Björkman et al., 2016), PNES (Reuber & Elger, 2003), Fibromyalgia (Clauw et al., 2018), and ME/CFS (Centers for Disease Control and Prevention, 2018), and Long COVID appears to be following the same trend (Yong, 2020). It may be that there is something innate to womanhood, be it biological, psychological, or social, that makes women more vulnerable to these disorders. However, given the sexist history of “hysteria,” and its direct link to functional disorders, it is imperative that we tread lightly on assumptions that a greater number of diagnoses among women reflect actual greater prevalence in the population. Similarly, more women than men are given psychogenic diagnoses by their medical providers, and yet insufficient evidence exists that this diagnostic rate disparity reflects actual difference in prevalence (O’Leary, 2018). When physicians rely strictly on objectivity and it fails the limits of our knowledge, it is all too easy and human to fall back on innate biases.

Beyond matters of gender, we must consider impacts on racial minorities and other marginalized groups. As we have learned more about the human genome and grappled with the incredible diversity of human populations, it has become increasingly

clear that racial categories are almost entirely social in nature (Yearby, 2020). Despite this, corrections for patients' racial categories are still used for many clinical guidelines and diagnostic algorithms, carrying the veneer of objectivity despite being impacted by the subjectivity of social categorization. These corrections have real-world consequences; for example, the correction for estimated glomerular filtration rate (a measure of kidney function) for patients identified as black classifies them as having better kidney function than the same lab values would indicate for a white-identified patient, which can in turn delay referrals to specialists and listing for transplants, and potentially increasing risk of death from kidney disease (Vyas et al., 2020). There are increasing voices in recent years to do away with racial corrections in clinical medicine, but as of this writing little widespread change has happened (Gaffney, 2020).

Beyond the systemic bias built into the supposedly-objective tools that physicians use, physicians themselves are human and susceptible to bias like anyone else. Hoffman et al (2016) found that half of white medical students and residents they studied had erroneous beliefs about differences in pain tolerance between black and white patients. When physicians believe themselves to be arbiters of objectivity, they may fail to grapple with the legacy of racism and other biases within their societal and cultural background that inevitably colors their individual perceptions to some degree. This is illustrated by a recent podcast released by the *Journal of the American Medical Association (JAMA)*, in which two of the publication's editors, both white, discussed systemic racism (Antonovich et al., 2021). Although intended to explain the concept to potentially-skeptical listeners, the host himself was skeptical throughout, claiming at one point that racism was in fact "illegal" in the United States, and the tweet promoting the podcast

included the sentence, “[n]o physician is racist, so how can there be structural racism in health care?” Although the podcast and tweet were both deleted and apologized for after widespread criticism, the fact that they were published demonstrates that personal bias remains yet unexamined for prominent voices in the medical field. As long as medicine continues to treat social categorizations as biological ones, and physicians view themselves as not susceptible to bias based on those social categorizations, presumptions of objectivity will continue to harm patients.

The privileging of objectivity can lead clinicians to marginalize certain diseases, as well as to fail to center those on the margins within their patient populations. Ultimately, this leads to a failure to uphold both distributive and social justice in medical practice.

CHAPTER 3: PATHS FORWARD

If we accept that the privileging of objectivity can lead to a violation of clinical ethics, this requires that we seek solutions. In individual clinical practice, this can start with admitting and making peace with the limits of individual knowledge. As we have discussed, the process of becoming a physician, and broader cultural expectations, set up the doctor as a kind of infallible figure. However, as we have also argued, the clinical relationship is a partnership, a dyad. It is essential to always seek to narrow the gulf between the disease and the illness. Björkman et al. (2013) argue that physicians can avoid invalidating their patients' experiences in cases of medical uncertainty by simply admitting that they do not yet know the cause of the symptoms, while simultaneously acknowledging that the suffering caused by those symptoms is very real and significant.

As noted above, many of these problems are deeply rooted in medical culture. As such, steps to change the culture of medicine is necessary. This thesis is certainly part of a broader conversation happening within both medicine and, as noted in the introduction, wider society for many years now; this gives me hope that the raised consciousness on the subject is beginning to shift medical culture little by little. However, there is much more to go, and we have seen significant efforts to change it, such as the biopsychosocial model, that have been insufficient even after many years to accomplish the change that is necessary.

Much of the impetus for cultural change will need to happen at the level of medical education. Medical school and residency curricula must integrate lessons in epistemic humility. In line with this, students and residents must be adequately instructed

in the effective communication of diagnostic uncertainty, which O’Leary (2018) has argued is sorely lacking. As Schwab notes, “[t]o make an appropriately epistemically humble claim, the practitioner should not offer clarity to a patient about whether or not the patient needs biological care when the conclusions of medical science don’t support it” (2018, p. 37); in other words, physicians must learn to not default to psychological explanations merely because they do not currently have a biological explanation for a patient’s illness. In addition to epistemic humility, there is a need for the teaching of cultural humility as well, to ensure the honoring of social justice (Russell, 2016).

Through both education and practice, doctors need to hone the essential skill of saying, “I don’t know what this is, but I’m in this with you.”

This is not a call for physicians to disbelieve their objective instruments, but rather to recognize that those methods of investigation have limits, and that they cannot be relied on to the level at which doctors dismiss the experience of their patients. The harm of believing patients is vastly outweighed by the harms of disbelieving them.

There is also a place for structural changes within healthcare delivery at the primary care level, which may mitigate some of the harms resulting from medical uncertainty. The concept of the patient-centered medical home (PCMH) is one that is steadily gaining traction in primary care—45 percent of AAFP members surveyed in 2015 indicated that their practice had PCMH designation, up from only 26 percent two years prior (White & Twiddy, 2017). This approach incorporates multidisciplinary, team-based, whole-person care and typically includes behavioral health specialists within the same practice. The ability to consult and operate as a team with a behavioral health specialist rather than the traditional siloed care where specialists see patients separately

and scarcely communicate with the primary care physician, offers the promise of maintaining continuity with the patient, and not prematurely terminating the biomedical investigation even as psychosocial factors are addressed within the same therapeutic relationship (Canavera, 2018).

Beyond individualistic piecemeal changes within the US healthcare system, there must also be systemic changes. As already noted, this system evolved to its present form within the paradigm of objectivity, and this has led to violations of justice in the distribution of healthcare resources. Adequately reimbursing and otherwise allowing physicians the time to practice the relatively inefficient but essential art of clinical counseling would potentially go a long way in making care more ethical and holistic, especially for the patients discussed above. Additionally, although steps have been made to improve mental health parity, few would argue that access to mental and behavioral healthcare for most Americans is equivalent to access to biomedical care, and few would also argue that it is sufficient. Although broader healthcare reform is surely needed, prescriptions on how to best accomplish this are beyond the scope of this paper.

There is another source of hope, a beacon in the darkness of the COVID-19 pandemic: the growing awareness of long COVID is adding considerable public and medical narrative to the already growing discourse about physician disbelief and the problems posed by MUS. Just as long COVID sufferers have built their online networks utilizing existing infrastructure of ME/CFS and other disease advocates, the attention may yet reflect back on these other stigmatized diseases, which holds the promise of renewed attention in the form of research, as well as the potential to encourage the

institution of medicine to relax its unyielding reliance on objectivity at the expense of its other, equally important and essential principles.

REFERENCES CITED

- Antonovich, J., Hogarth, R., Mitchell, E., Mooney, G., Nuriddin, A., Thompson, L. M., Smith, K., Willoughby, C., & White, A. (2021, March 5). Apologies Alone Won't Solve Structural Racism: We Need a Reckoning with the Racist Roots of U.S. Medicine. *Medical Humanities*. <https://blogs.bmj.com/medical-humanities/2021/03/05/apologies-alone-wont-solve-structural-racism-we-need-a-reckoning-with-the-racist-roots-of-u-s-medicine/>
- Arnold, M. H., & Kerridge, I. (2018). Rejecting Reality and Substituting One's Own; Why Bioethics Should Be Concerned With Medically Unexplained Symptoms. *The American Journal of Bioethics*, 18(5), 26–28. <https://doi.org/10.1080/15265161.2018.1445315>
- Atkins, C. G. K. (2018). Why Bioethics Should Pay Attention to Patients Who Suffer Medically Unexplained (Physical) Symptoms—A Discussion of Uncertainty, Suffering, and Risk. *The American Journal of Bioethics*, 18(5), 20–22. <https://doi.org/10.1080/15265161.2018.1445319>
- Björkman, I., Simrén, M., Ringström, G., & Ung, E. J. (2016). Patients' experiences of healthcare encounters in severe irritable bowel syndrome: an analysis based on narrative and feminist theory. *Journal of Clinical Nursing*, 25(19-20), 2967–2978. <https://doi.org/10.1111/jocn.13400>
- Butterfield, S. (2013). Patients increasingly checking 'Dr. Google'. *ACP Internist*. <https://acpinternist.org/archives/2013/11/dr-google.htm>
- Canavera, K., Allen, J., & Johnson, L.-M. (2018). The Need for Improved Access to Mental Health Services for Youth With Medically Unexplained Symptoms. *The American Journal of Bioethics*, 18(5), 29–31. <https://doi.org/10.1080/15265161.2018.1445316>
- Centers for Disease Control and Prevention. (2018, July 12). *What is ME/CFS?* Centers for Disease Control and Prevention. <https://www.cdc.gov/me-cfs/about/index.html>
- Clauw, D. J., D'Arcy, Y., Gebke, K., Semel, D., Pauer, L., & Jones, K. D. (2017). Normalizing fibromyalgia as a chronic illness. *Postgraduate Medicine*, 130(1), 9–18. <https://doi.org/10.1080/00325481.2018.1411743>
- Engel, G. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>

- Fassler, J. (2015, October 15). How Doctors Take Women's Pain Less Seriously. *The Atlantic*. <https://www.theatlantic.com/health/archive/2015/10/emergency-room-wait-times-sexism/410515/>
- Finch, E. R. (Writer) & Rubio, N. (Director) (2018, February 1). (Don't Fear) the Reaper (Season 14, Episode 11) [TV series episode]. In D. Allen, B. Beers, Z. Clack, F. Einesman, M. Gordon, W. Harper, S. Rhimes, K. Vernoff (Executive Producers), *Grey's Anatomy*. Shondaland; The Mark Gordon Company; ABC Signature.
- Gaffney, T. (2020, July 16). Push to remove racist bias from kidney testing gains new ground. *STAT*. <https://www.statnews.com/2020/07/17/egfr-race-kidney-test/>.
- Geraghty, K. J., & Blease, C. (2019). Myalgic encephalomyelitis/chronic fatigue syndrome and the biopsychosocial model: a review of patient harm and distress in the medical encounter. *Disability and Rehabilitation*, *41*(25), 3092–3102. <https://doi.org/10.1080/09638288.2018.1481149>
- Hill, C. [@BeingCharisBlog]. (2020, December 2). *Doctors don't know this but I often create a fun game for them where I strategically list my symptoms in a way that eventually leads them to the diagnosis I've already given myself because patients obviously never know what we're talking about.* [Tweet]. Twitter. <https://twitter.com/BeingCharisBlog/status/1334147768827330560>
- Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proceedings of the National Academy of Sciences*, *113*(16), 4296–4301. <https://doi.org/10.1073/pnas.1516047113>
- Kanaan, R. A., Armstrong, D., & Wessely, S. C. (2012). The function of 'functional': a mixed methods investigation. *Journal of Neurology, Neurosurgery & Psychiatry*, *83*(3), 248–250. <https://doi.org/10.1136/jnnp-2011-300992>
- Kool, M. B., van Middendorp, H., Boeije, H. R., & Geenen, R. (2009). Understanding the lack of understanding: Invalidation from the perspective of the patient with fibromyalgia. *Arthritis & Rheumatism*, *61*(12), 1650–1656. <https://doi.org/10.1002/art.24922>
- Lorenzetti, R. C., Jacques, C. M., Donovan, C., Cottrell, S., & Buck, J. (2013). Managing difficult encounters: understanding physician, patient, and situational factors. *American Family Physician*, *87*(6), 419-425. <https://www.aafp.org/afp/2013/0315/p419.html>
- Magane, A. (2019, April 8). The Importance of Listening to Your Body — Even When Doctors Aren't Listening to You. *Allure*.

<https://www.allure.com/story/endometriosis-misdiagnosis-marginalized-women-and-medicine-experience>

- Maxwell, P. R., Mendall, M. A., & Kumar, D. (1997). Irritable bowel syndrome. *The Lancet*, 350(9092), 1691–1695. [https://doi.org/10.1016/s0140-6736\(97\)05276-8](https://doi.org/10.1016/s0140-6736(97)05276-8)
- O'Leary, D. (2018). Why Bioethics Should Be Concerned With Medically Unexplained Symptoms. *The American Journal of Bioethics*, 18(5), 6–15. <https://doi.org/10.1080/15265161.2018.1445312>
- Parker, L. (2019, October 9). 31 Stories From Women Whose Doctors Did Not Take Their Pain Seriously. *BuzzFeed*. <https://www.buzzfeed.com/laraparker/stories-from-women-whose-doctors-did-not-take-their-pain>
- Prainsack, B., & Buyx, A. (2012). Solidarity in Contemporary Bioethics – Towards a New Approach. *Bioethics*, 26(7), 343–350. <https://doi.org/10.1111/j.1467-8519.2012.01987.x>
- Preller, G., Seidlein, A.-H., & Salloch, S. (2018). Unsolicited Diagnosis of Mental Disorder: Epistemic and Normative Perspectives. *The American Journal of Bioethics*, 18(5), 34–35. <https://doi.org/10.1080/15265161.2018.1445314>
- Redinger, M. J., Crutchfield, P., Gibb, T. S., Longstreet, P., & Strung, R. (2018). Conversion Disorder Diagnosis and Medically Unexplained Symptoms. *The American Journal of Bioethics*, 18(5), 31–33. <https://doi.org/10.1080/15265161.2018.1445317>
- Reuber, M., & Elger, C. E. (2003). Psychogenic nonepileptic seizures: review and update. *Epilepsy & Behavior*, 4(3), 205–216. [https://doi.org/10.1016/s1525-5050\(03\)00104-5](https://doi.org/10.1016/s1525-5050(03)00104-5)
- Russell, C. A. (2016). Questions of Race in Bioethics: Deceit, Disregard, Disparity, and the Work of Decentering. *Philosophy Compass*, 11(1), 43–55. <https://doi.org/10.1111/phc3.12302>
- Schwab, A. (2012). Epistemic Humility and Medical Practice: Translating Epistemic Categories into Ethical Obligations. *Journal of Medicine and Philosophy*, 37(1), 28–48. <https://doi.org/10.1093/jmp/jhr054>
- Schwab, A. (2018). Calibrating Confident Judgments About Medically Unexplained Symptoms. *The American Journal of Bioethics*, 18(5), 36–37. <https://doi.org/10.1080/15265161.2018.1445313>

- Simpkin, A. L., & Schwartzstein, R. M. (2016). Tolerating Uncertainty — The Next Medical Revolution? *New England Journal of Medicine*, 375(18), 1713–1715. <https://doi.org/10.1056/nejmp1606402>
- Stone, L. (2018). Schrödinger's Disease and the Ethics of (Non)Diagnosis: The Problem of Medically Unexplained Symptoms in Contemporary Medical Practice. *The American Journal of Bioethics*, 18(5), 18–19. <https://doi.org/10.1080/15265161.2018.1445318>
- Swartz, A. K. (2018). A Feminist Bioethics Approach to Diagnostic Uncertainty. *The American Journal of Bioethics*, 18(5), 37–39. <https://doi.org/10.1080/15265161.2018.1447046>
- Twaddle, A. (1968). *Influence and illness: definitions and definers of illness behavior among older males in Providence, Rhode Island*. Brown University.
- Twaddle, A. (1993). Disease, illness and sickness revisited. In A. Twaddle & L. Nordenfelt (Eds.), *Disease, Illness and Sickness: Three Central Concepts in the Theory of Health* (Ser. Studies on Health and Society No. 18, pp. 1–18). Linköping University.
- United Nations Educational, Scientific and Cultural Organization (2005, October 19). *Universal Declaration of Bioethics and Human Rights*. United Nations. http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html
- Vyas, D. A., Eisenstein, L. G., & Jones, D. S. (2020). Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms. *New England Journal of Medicine*, 383(9), 874–882. <https://doi.org/10.1056/nejmms2004740>
- West-Oram, P. G., Buyx, A., & Prainsack, B. (2016). Solidarity in Bioethics. In *eLS*. <https://doi.org/10.1002/9780470015902.a0027021>
- White, B. & Twiddy, D. (2017). The State of Family Medicine: 2017. *Family Practice Management*, 24(1), 26–33. <https://www.aafp.org/fpm/2017/0100/p26.html>
- Yearby, R. (2020). Race Based Medicine, Colorblind Disease: How Racism in Medicine Harms Us All. *The American Journal of Bioethics*, 21(2), 19–27. <https://doi.org/10.1080/15265161.2020.1851811>
- Yong, E. (2020, August 19). Long-Haulers Are Redefining Covid-19. *The Atlantic*. <https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/>