

TRUST, DISTRUST, AND ‘MEDICAL GASLIGHTING’

BY ELIZABETH BARNES

When are we obligated to believe someone? To what extent are people authorities about their own experiences? What kind of harm might we enact when we doubt? Questions like these lie at the heart of many debates in social and feminist epistemology, and they’re the driving issue behind a key conceptual framework in these debates—gaslighting. But while the concept of gaslighting has provided fruitful insight, it’s also proven somewhat difficult to adjudicate, and seems prone to over-application. In what follows, I argue that Katherine Hawley’s theory of trust can provide a useful alternative lens for looking at contested testimony. To do this, I focus on a particularly complex—but increasingly popular—application of gaslighting: the physician/patient relationship, and the idea of ‘medical gaslighting’. I argue that, even though patients can experience harm when they are disbelieved, there are nevertheless good reasons for physicians not to trust patients about at least some of their own narratives.

Keywords: gaslighting, testimonial injustice, belief, testimony, medical gaslighting, health care, medical ethics.

In Section I, I introduce the concept of gaslighting, and the issue of its potential over-application. In Section II, I introduce the idea of medical gaslighting, and the illustrative case I will focus on Section III the contested illness often referred to as ‘chronic Lyme disease’. In Section IV, I outline the basics of Hawley’s framework for trust and trustworthiness. In Section V, I argue, based on that framework, that the kinds of first-person narratives given about conditions like chronic Lyme disease give us a good illustration of why ‘medical gaslighting’ is too blunt a tool to make the kinds of distinctions we need to make. And finally, in Sections VI and VII, I discuss some of the ways in which Hawley’s model allows us to explore the social value of distrust.

I. GASLIGHTING

Recent discussions both in social epistemology and in wider culture—have placed significant emphasis on the interplay between individual testimony, belief, and shared knowledge. We can harm individuals by failing to adequately

believe them, for example, and we can harm ourselves collectively by failing to take up the testimony of particular groups. An increasingly popular theoretical framework within such conversations is the idea of *gaslighting*.

Unlike many other concepts in the area—testimonial injustice, standpoint epistemology, etc.—gaslighting originated as a concept in popular discourse before making its way (via psychoanalysis) into academic philosophy. Attempts within epistemology to give specific definitions or theories of gaslighting are thus often judged by their ability to capture the intuitive idea used in wider discourse.

Taken from the film *Gaslight*, ‘gaslighting’ refers, roughly, to situations in which a person is made to doubt aspects of their own experience over which they would ordinarily be considered an authority, and ordinarily have no reason to question. More specifically, gaslighting is generally taken to refer to instances in which another person (or persons, institutions, etc.¹) imposes their own interpretation or narrative onto an individual’s experience. In doing this, they do not treat that individual as an authority about her own experience. Calling these aspects of the person’s experience into question can then have a profound destabilizing effect on the person—it forces them to doubt whether their experiences are real, whether they can trust themselves, whether they have ‘lost their mind’, etc. And, in tandem, it gives someone else unwarranted authority over that person’s interpretation of the world.

Importantly, though, gaslighting has specific limits in its application, which can be notoriously hard to pin down. It is not automatically gaslighting if you simply doubt what someone says about their own interpretation of the world. Sometimes doubt is justified, and sometimes doubt, even if unwarranted, doesn’t connect to larger forms of systemic harm. People can be wrong about their own experience, misinterpret their own experience, or misapply their own experience. And even in cases in which they aren’t wrong, not all disagreement is gaslighting. Gaslighting arises when people are forced to doubt, in specific and destabilizing ways, things which they ought to have special first-person authority over.

In the film *Gaslight*, a woman is repeatedly caused to doubt her own perceptions by her husband as a form of psychological manipulation. He dims the gas lamps, then denies that he’s done so; it looks to her as if the lamps are dimmed, but he tells her they aren’t, and that she’s imagining things. This, then, is the paradigm instance of gaslighting. She should be able to trust her senses; she can see that the lamps are dimmed, and so to be told that they aren’t and that she can’t trust her own basic awareness of the world is utterly destabilizing.

In contrast, consider the following true scenario. We are leaving the house, and my husband says to me ‘Do you have your keys?’ I reply (hurriedly and

¹ See Pohlhaus (2012, 2017) for discussions of ‘structural gaslighting’.

annoyed) ‘Yeah, they’re in my pocket’, and he follows up with ‘Okay but do you *really* have your keys?’ This is not, given the context, gaslighting. An agent might ordinarily be assumed to know—or at least be in a better position than anyone else to know—whether her keys are in her pocket. But I am not that agent, and that is not my life. I regularly believe I have my keys, when in fact I have forgotten my keys. My husband knows this. My husband, knowing me well enough, is often a better source of evidence than I am about whether my keys are in my pocket. His follow-up question of ‘Think about it - do you *really* have your keys?’ isn’t gaslighting, in this context, even if it annoyed me and even if I was *sure* I’d picked up my keys and put them in my pocket. Based on our shared history, he’s still justified in asking me if I really have my keys. (Reader, I did not have my keys.)

Part of why this isn’t a case of gaslighting is that I didn’t actually have my keys—the original case from *Gaslight* relies on the fact that the lamps really are being dimmed. But crucially, this wouldn’t be gaslighting *even if* I had—just the once—actually managed to know where my keys are. To know that it’s not gaslighting, though, you have to understand the complexities of the context. Yes, he’s a man questioning me—a woman—about my understanding of my own experience. But he’s doing something fundamentally different from the husband in *Gaslight*, something that’s both warranted and helpful.

Obviously, a case like this is a silly example, but the broader point is not. To know whether the concept of gaslighting is well applied, we need to know more than the social position of the agents involved—we need to know complicated factors about the context, the reliability, and the first-person authority of both parties.

For gaslighting to be a useful framework, then, there needs to be a difference between gaslighting and simple scepticism or peer disagreement. Partly in response to this need for clarification, there has been a recent flurry of philosophical literature on gaslighting, with a range of different accounts put forward.² In some, the focus is on the intent of the perpetrator (the gaslighter). According to such accounts, cases of gaslighting require that the perpetrator intentionally seek to undermine the victim’s faith in her own beliefs and perceptions, and instead defer to the perspective of the perpetrator. Abramson (2014), for example, defines gaslighting specifically as a type of ‘emotional manipulation’, wherein the perpetrator actively seeks (via ‘explicit or implicit threats’) to coerce the victim into adopting the perpetrator’s viewpoint, and to view their own beliefs as baseless. Spear (2019) agrees with Abramson that some form of intentional manipulation is a necessary condition for gaslighting, but argues for additional epistemic criteria. The phenomenon of gaslighting has two key components, according to Spear: The perpetrator aims to get the victim to view herself as untrustworthy about certain aspects of her own

² Kirk-Giannini (2022) provides a useful overview.

experience, and simultaneously uses this sense of uncertainty to get the victim to defer to the judgement of the perpetrator.

A common criticism of accounts that focus on the intentions of the perpetrator, however, is that they are overly narrow.³ Ivy (2017), for example, argues that the central phenomenon of gaslighting can sometimes be enacted by people with relatively benign or even positive motivations. Gaslighting, she argues, should be understood in epistemic terms—the victim is gaslit by the perpetrator when the perpetrator fails to view the victim as an authority about her own experience, and instead insists on their own (unjustified) interpretation. Both Podosky (2021) and Stark (2019) favour a disjunctive approach, where gaslighting can be either intentional or unintentional. For Podosky, gaslighting can occur regardless of the intention of the perpetrator, so long as the victim is caused to ‘doubt her interpretive abilities’ in a way that is causally related to systematic epistemic injustice that makes her especially vulnerable to such doubt. Likewise, Stark argues that ‘epistemic gaslighting’ (in contrast to ‘manipulative gaslighting’) can occur simply when the victim is at the weaker end of a power differential relative to the perpetrator, and is caused to doubt her own epistemic capacity in a way that renders her ‘degraded as a knower’. And Kirk-Giannini (2022) argues that gaslighting arises in cases where the perpetrator seeks to persuade the victim to believe some claim *p*, such that if the victim comes to believe that *p* she will thereby have reason to doubt her own competence in the relevant domain of inquiry. For Kirk-Giannini, the perpetrator doesn’t need to have malign or manipulative intentions in trying to get the victim to believe *p*, but she must herself (whether knowingly or otherwise) lack knowledge that *p*.

And on some views—most notably Manne (forthcoming)—gaslighting both needn’t be intentional and needn’t involve specifically epistemic factors like belief or rationality.⁴ Rather, the core phenomenon of gaslighting is that ‘people are made to feel defective in certain fundamental ways—either morally or rationally—for having mental states to which they are entitled’ (p. 14).

Differences and details notwithstanding, however, a central notion at play in all such accounts is justification. What distinguishes the perpetrator of gaslighting from the mere sceptic is that gaslighting involves an *unjustified* imposition of one’s own perspective, beliefs, or interpretation onto another person, in a way that will be especially destabilizing for that person. Often, however, whether

³ For a helpful overview, see Kirk-Giannini (2022); for a sustained critical discussion of Abramson’s view as overly limited, see Spear (2019).

⁴ In another departure, Pohlhaus (2012, 2017) argues that structural features—in addition to the actions of individuals—can create situations of gaslighting. Gaslighting can occur, for Pohlhaus, in cases where ‘practices, approaches, and definitions shift attention away from the experiences of nondominantly situated persons and center (or continually recenter) the world as experienced from positions of dominance’, in a way that causes the ‘nondominantly situated person’ to doubt their own perceptions or experiences.

the parties involved are justified or unjustified, acting appropriately or acting blameworthy, failing to defer when they should defer, is precisely what is up for debate. And often, these issues depend crucially on how much authority people have about their interpretations of their own experiences.

In what follows, I'm going to look at a particularly interesting test case—so-called 'medical gaslighting'. This test case, I'll argue, illustrates ways in which Katherine Hawley's framework of *trust* can help us make progress in places where we might otherwise remain stuck.

II. MEDICAL GASLIGHTING

In recent discussions—both in the wider online world and in academic discourse⁵—the concepts of gaslighting have been applied to physician–patient encounters and patient encounters with the medical system more broadly. 'Medical gaslighting'—which has become a popular hashtag on social media—refers to situations in which physicians dismiss a patient's account of their own symptoms as unserious, perfectly normal, perhaps psychosomatic manifestations of stress, etc.⁶ And, it is also increasingly used to refer to situations in which the medical community at large downplays the physiological seriousness or diagnostic plausibility of poorly understood or 'contested' illnesses, such as Long COVID, ME/CFS ('chronic fatigue syndrome'), fibromyalgia, or multiple chemical sensitivity.

Women and people of colour are especially vulnerable to such medical gaslighting, since they are disproportionately prone to being disbelieved. But, the thought goes; the physician–patient relationship itself creates a power dynamic, as does the traditional dismissal of certain types of subjective, non-specific symptoms or contested illnesses. A middle-class straight cis White man could be subject to medical gaslighting if he goes to his doctor to talk about debilitating chronic fatigue, for example, and is told 'well, everyone's tired, that's normal'.⁷

⁵ Most such work thus far is found in the sociology of medicine—see e.g. Sebring (2021) and Au *et al.* (2022). Within philosophy, Bailey (2020) describes medical gaslighting as 'when medical professionals downplay or silence marginalized patient's self-reported experiences with illness'. And Ruiz (2020) describes the common understanding of 'medical gaslighting' as 'the interpersonal phenomenon of having one's experience of illness marginalized (including having one's self-reported or presenting symptoms downplayed, silenced, or psychologically manipulated) by a clinical provider or healthcare professional'. Ruiz, however, argues against this interpersonal approach and favours a more structural account, focusing on the harms of racial disparities in medicine.

⁶ See Moyer (2022), Booth (2023), and Kilkus (2022).

⁷ In a similar vein, Fricker's (2007) concept of testimonial injustice has also been applied to the physician–patient context. In a series of papers, for example, Carel & Kidd (2014) and Kidd & Carel (2017) argue that physician discounting of patient testimony—including testimony

The various philosophical accounts of gaslighting hinge on the idea, as Manne puts it, of ‘mental states [we are] entitled to’. Physicians have expertise and clinical experience, but the charge of ‘medical gaslighting’ rests on the assumption that patients have their own kind of expertise—they are authorities over their own experience of their body. Physicians, by nature of their job, will often seek to persuade patients to defer to the physician’s perspective, to see things the way the physician sees them and perhaps to abandon some of their previously held beliefs. Whether this is gaslighting, though, depends on whether the physician is sometimes *justified* in discounting a patient’s assessment of her own experience.⁸

What I’m going to argue is that this framing elides some important distinctions. Patients’ narratives of their own experience of illness often involve a complex mix of claims, some of which they can rightly be considered authorities over, and some of which they can’t. And because of this, ‘medical gaslighting’ is too blunt a tool to help us make progress. A broad-brush application of a concept like gaslighting to the physician–patient relationship runs the risk of substantially over-generalizing in harmful ways.

Hawley’s account of trust, however, can help us to clarify issues that might otherwise remain obscure. To illustrate this, I’m going to look at a particular case: the case of so-called ‘chronic Lyme disease’.

III. ‘CHRONIC LYME’

‘Chronic Lyme disease’ is not a diagnostic term that’s accepted in mainstream medicine. Lyme disease is an uncontroversial and common tick-borne bacterial infection. Patients with Lyme disease are acutely ill, and have objectively verifiable symptoms, such as fever and a characteristic rash. These symptoms typically resolve with a short course of antibiotics. Sometimes, patients with an initial infection of Lyme disease do not receive antibiotic treatment—either because the initial infection had few symptoms or because it was not properly diagnosed—and go on to develop more serious symptoms, such as severe joint swelling, facial paralysis, and even inflammation of the brain and spinal cord.⁹

regarding the severity and the aetiology of the patient’s illness—constitutes a distinctive kind of testimonial injustice. See also Gallagher et al. (2021) and Mikkola (2017).

⁸ Whether the physician is intentionally manipulating the patient might still be up for debate. Certainly, patients sometimes feel like they’re being manipulated and made to feel like they’re ‘going crazy’, and they feel this way as the result of things the physician says intentionally. Likewise, physicians often don’t treat patient belief as epistemically on a par with their own perspective. But a characterization like Abramson’s (2014) requires an intentional desire to control. It’s possible to think of the test case of ‘medical gaslighting’ as an argument that a more restrictive definition like Abramson’s is preferable, simply because it is better able to avoid the kinds of over-generalization I’m going to discuss.

⁹ CDC (2021).

This is sometimes called ‘untreated’ or ‘late-stage’ Lyme disease, and it can be extremely serious, potentially even fatal.¹⁰

‘Post treatment Lyme disease syndrome’, in contrast, refers to patients who, months after an initial infection of—and treatment for—Lyme disease, continue to feel unwell, but without the classic and objectively verifiable symptoms of untreated Lyme disease.¹¹ Unequivocally, these people feel unwell. There is controversy and uncertainty surrounding the cause of this persistent illness, however. Its symptoms, unlike those of acute Lyme infection, tend to be mostly subjective. That is, they are not observable or testable by a clinician on a medical exam, nor are they verifiable by objective testing (such as bloodwork or scans). Acute Lyme infection presents with fever, rash, and swollen lymph nodes. Untreated Lyme disease will often involve joint swelling or verifiable neurological damage. Post treatment Lyme disease syndrome, in contrast, typically involves things like persistent fatigue, arthralgia (that is, joint pain in the absence of joint swelling or damage), headache, ‘brain fog’, light-headedness—things that make a person feel very unwell, but which are not objectively verifiable either by clinical exam or by tests, and which don’t by themselves show objective evidence of a disease process.

‘Chronic Lyme disease’ is a term used by patients—and a few heterodox physicians—to highlight that they believe the cluster of symptoms they experience is caused by a persistent infection of Lyme-causing bacteria, even after standard antibiotic treatment. Significantly, many people who identify as having ‘Chronic Lyme disease’ (hereafter, CLD) never had an original experience of being diagnosed and treated for an acute Lyme infection.¹² The theory is that their original infection was missed or was asymptomatic, and they now have the chronic form of the disease.

Although there are some outlier viewpoints, the overwhelming consensus among infectious disease experts is that a persistent, sub-clinical infection of Lyme bacteria cannot explain the symptoms reported by patients who identify as having CLD.¹³ Moreover, data suggests that long-term antibiotic therapy for such patients is no more effective than placebo.¹⁴ And yet, a growing community of people identify as having CLD, and lobby tenaciously to have CLD recognized within mainstream medicine.

In tandem with this growing popularity is growing visibility—a handful of celebrities, social media influencers, and reality TV stars have spoken about their experiences as CLD patients in recent years, and social media hashtags

¹⁰ See e.g. Skar and Simenson (2022).

¹¹ CDC (2022).

¹² See especially Molly Fisher’s ‘What Happens When Lyme Disease Becomes an Identity?’ (2019) and Rachel Pearson’s ‘The Challenge of “Chronic Lyme”’ (2020).

¹³ Feder *et al.* (2007).

¹⁴ Lantos (2011).

like ‘#LymeWarrior’ have solidified some of the community aspects of illness.¹⁵ Alongside this, three prominent memoirs of experiences as CLD patients—Ross Douthat’s (2021) *The Deep Places*, Porochista Khakpour’s (2018) *Sick*, and Meghan O’Rourke’s (2022) *The Invisible Kingdom*—have recently been published to glowing reviews and substantial media attention. These memoirs, in addition to being intricate stories of individual suffering, are all accounts focused on testimony—a desire to be believed, frustration at not having testimony received in the desired way, and rage at the kinds of scepticism encountered. And so I’m going to focus on them as useful, specific accounts of individual testimony about illness.

As I hope will be abundantly clear, in discussing these accounts of illness I am not making any literary judgements about their value as memoirs. Nor I am, more importantly, making judgements about what illnesses the authors do or don’t have—I’m not a physician, much less a physician treating any of the authors. Rather, I want to focus specifically on the epistemic issues surrounding the first-person reports of illness that the authors provide.

Douthat, Khakpour, and O’Rourke are typical of CLD patients in many ways. By their own accounts, they never had the standard experience of an acute Lyme infection, were never diagnosed and treated for such an infection, and were only diagnosed with CLD after seeking out physicians that most would consider ‘alternative’. This came after a long process of fluctuating but debilitating symptoms, and bouncing from physician to physician, most of whom said they could find nothing wrong and many of whom suggested the problem was in some way psychogenic¹⁶ (that is, ultimately psychological in origin rather than arising from an organic disease process). They each pursue high-dose, long-term antibiotic therapy, in addition to a range of alternative therapies. They each achieve, at varying times, varying stages of recovery and relapse.

Their accounts are all stories of people who are suffering, and whose suffering is compounded by feeling that they haven’t found an adequate explanation for—or solution to—that suffering. But they are also, in various ways, stories

¹⁵ Fischer (2019).

¹⁶ A note about terminology: There is no good, uncontroversial terminology in this area to denote symptoms that are experienced as physical sensation but for which the primary driver of their persistence seems to be psychological factors (which can include beliefs, expectations, patterns of attention, etc., rather than just things like anxiety or depression) rather than physiological factors (such as tissue damage, a disease process, etc.). Such symptoms are sometimes called ‘psychosomatic’, but the implication behind this term is that the person is ‘somatisizing’—translating psychological distress into physical distress, which is not always the case. Similar points apply to the term ‘conversion disorder’ (O’Sullivan 2015). The term ‘functional’ is also used, but can be confusing because it is used inconsistently. For the purposes here, I will use the term ‘psychogenic’.

of the wrongs they feel that they—and others like them¹⁷—have experienced because they were disbelieved in systematic ways. O'Rourke sums up the idea directly in the concluding chapter of her book:

One of the bitterest aspects of my illness has been this: not only did I suffer from a disease, but I suffered at the hands of a medical establishment that . . . failed to fully credit my testimony. . . . In the throes of illness, cut off from the life you once lived, fearing that your future has been filched, what do you have but the act of witness? This is what it is like. Please listen.

IV. TRUST

Accounts of gaslighting tend to focus on the epistemic aspects of interpersonal interaction.¹⁸ You gaslight someone when you impose your own interpretation or your own narrative onto aspects of a person's experience about which they should be authoritative, in a way that causes them to doubt the veracity of their own basic perceptions. The solution, in broadest terms, is to give people the credence that is their due as authorities about their own first-person experiences. And this call for greater belief is sometimes framed in the language of *trust*: trust women, trust victims, trust patients, etc.

Katherine Hawley's framework of trust and trustworthiness offers, in this sense, an interesting alternative framework for thinking about such cases. To be clear, I don't want to suggest that Hawley's model is in conflict or competition with accounts of gaslighting. In many ways, it dovetails nicely with them. But it provides us a different lens for viewing cases of contested testimony, and because of this, I'll argue, it allows us to make progress on difficult boundary cases.

For Hawley (2019), *trust* is fundamentally a matter of keeping commitments. Suppose you regularly work from your office (rather than your home, coffee shops, etc.), and when you're in your office you leave the door open. You're friendly and have a good relationship with your students, so your students often drop in to chat. As this pattern persists, your students may come to expect and assume that you are readily available in this way. More strongly, they may come to *rely* on it—they might plan around the idea that they can run by your office in a panic about their essay and find you there, ready and happy to talk to them. But just because they rely on your generosity and availability in this way doesn't mean you've broken faith with them if you are, for whatever reason, not in your office when they come looking for you. There's

¹⁷ Struggle with disbelief is a common theme in accounts of self-identified CLD patients, to the extent that former reality TV star Yolanda Hadid titled her book about CLD *Believe Me* (2017).

¹⁸ A notable exception here is Abramson (2014).

a difference between not being in your office at a random time that students often expect they can find you there, and not being in your office when you've told students you will hold office hours, or not being in the classroom when you're expected to have class. The students expect to be able to find you in your office; they rely on being able to find you in your office. But you haven't made a commitment to them to be in your office. And because you haven't made a commitment to them, you haven't broken that commitment if you aren't there. They can be justifiably disappointed when they find your door closed, but not justifiably angry or hurt. You've contravened their expectation, but you haven't, in Hawley's sense, betrayed their *trust*.

To trust someone, for Hawley, is to assume that (i) the commitments they make, they make sincerely; (ii) they're competent to keep those commitments. And so, likewise, to be trustworthy is to (i) only make commitments you sincerely intend to keep; (ii) only make commitments you are competent to keep.¹⁹ 'Competent' here, means something like: have the dispositions to perform well, given the circumstances.²⁰ So you can do something you aren't, in fact, competent to do (you can get lucky); and you can fail at something you are competent to do (you can get unlucky). Likewise, you can lack competence because of internal features (your beliefs, abilities, dispositions, character, etc.) or because of external features of your environment.²¹

Suppose we are doing trust falls—as an imposed team-building exercise or out of a perverse sense of fun, you decide—and it is my turn to catch you. I cheerily shout out 'Ready!' and hold my arms out for you to fall. I may, with all my heart, intend to catch you. You may know and believe that I mean to catch you. But, given my own physical limitations, you shouldn't *trust* me to catch you. If you trust me to catch you, then we will both end up on the floor. I might want and intend to catch you, but that doesn't mean I actually can catch you.

Maybe I don't want to acknowledge this. Maybe I'm convinced that, by the power of positive thinking, I too can play the trust fall game. So I sincerely promise to catch you. In doing this, I am failing to be trustworthy. I'm making a promise I'm not competent to keep. I'm not blameworthy for this lack of competence. But part of being trustworthy, for Hawley, is being aware of our own limitations and dispositions. To be trustworthy, it's not enough that you

¹⁹ See chapter 4, especially pages 72–74. Hawley further distinguishes between not trusting someone and distrusting them. I don't trust you to read this paper out loud to all your friends, but that's partly because I don't interpret you as having made this commitment. I should *distrust* you—and you are not being trustworthy—just in case you make a commitment that you aren't reliably able to keep.

²⁰ Insofar as, there are degrees of competence, then there will arguably for Hawley be degrees of trustworthiness.

²¹ See chapter 2, Section 3, for a detailed discussion.

intend, as you make the commitment, to keep the commitment; you have to be competent and capable to follow through.

Hawley's account of trustworthiness is thus, at its core, about action. We're trustworthy if we keep our commitments. To trust someone is not only to *believe* that they will keep their commitments, but to structure your life in significant ways around the assumption that they will keep their commitments. Trusting testimony is, for Hawley, a more specific instance of this phenomenon (pp. 50–2). And this is something distinctive about Hawley's account. We trust people to *do* things (or not do things), and her account treats what we say as one among many aspects of what we do.

In a nutshell, testimony, for Hawley, is a promise to tell the truth.²² In order to be trustworthy, you must have the two core elements of trustworthiness: sincerity and competence. That is, you must intend to speak truly and informatively.²³ But you must also, crucially, be competent. That is, you need to know what you're talking about. For Hawley, this is more than just believing you are speaking truly and in fact speaking truly. I might believe that I can tell your future. I might sincerely be trying to speak informatively when I make a prediction. And I might get lucky—my prediction might come true. But that doesn't mean you should trust my prediction, and it doesn't mean that I was being trustworthy when I made the prediction. I'm not *competent* to tell the future, even if I believe I am and even if I get the occasional lucky guess. Competence requires more—it requires something like reliability or sensitivity to error.²⁴

In evaluating whether to trust someone's testimony, on Hawley's account, you need to evaluate two things: (i) their sincerity and (ii) their competence. Hawley's account thus allows us a framework to explain how we can distrust someone's testimony without thereby attributing deceit or bad character to that person. You might not trust what I say, not because you think I'm trying to deceive you, but because you judge that—despite my sincerity—I'm not a competent source of information. And that might not be something I'm blameworthy for.

V. TRUSTING PATIENTS

Let's return to the case of first-person testimony and illness narratives. In cases of gaslighting, people aren't given the credence that's *owed* to them—they aren't trusted as authorities over matters that they should have epistemic authority

²² See chapter 3 for Hawley's account of testimony and trust.

²³ There is not, for Hawley, a substantial difference—when it comes to sincerity—between lying and misleading. See e.g. Saul (2012).

²⁴ Hawley leaves this formulation intentionally non-specific [Hawley (2019)].

over—and harm results. A core idea of medical gaslighting seems to be that physicians (or the medical system more broadly) are not treating patients as authorities over their own first-person experience and unfairly distrust them as a result.

But should physicians trust patients, in Hawley’s sense of trust? Douthat, Khakpour, and O’Rourke’s accounts are filled with the pain of being disbelieved, and in many cases with explicit calls for greater trust from physicians. Khakpour, for example, describes her repeated interactions with physicians as ones in which she’d ‘always catch myself getting preemptively ready to argue, feeling a defensive heatedness from years of impossible experiences with so-called “medical professionals”’. And in these interactions, she characterizes herself as learning ‘to speak their suspicious, dismissive language - to let them know I was real’. Similarly, O’Rourke writes that ‘when I woke in the dark with my heart pounding, what really terrified me was my conviction that my doctors did not believe me, and so I would never have partners in my search for answers - and treatments. How could I get better if no one thought I sick?’ (p. 104) And Douthat, discussing the widespread scepticism he and others like him encounter from the medical establishment, writes that ‘The argument that Lyme disease can persist, devastatingly, despite antibiotic treatment is not bizarre or esoteric. . . It begins with patient experience, and a straightforward reading of the anecdota of Lyme victims.’ (p. 59) A recurring theme is this: If doctors would *trust* their patients as authorities about their own experiences, then everyone would be better off.

These are classic cases of what, in contemporary conversations, gets the label ‘medical gaslighting’. All three authors wonder, at various points, if they are losing their minds, imagining things, or simply over-reacting. They struggle with the question of whether their conditions are ultimately psychogenic. As such, the authors are forced to doubt and question fundamental aspects of their own experience—things they shouldn’t have to doubt—and that doubt is profoundly destabilizing. O’Rourke writes that she ‘no longer had the sense that I was a distinct person’, observing that ‘the hardest part was not being comprehended, or not believed’ (pp. 49–50). And the net effect of this is, in O’Rourke’s description, to be denied ‘the dignity of one’s own reality’ (p. 163).

I’m going to argue, however, that broad-brush application to first-person accounts of illness is a (potentially dangerous) over-extension of concepts like gaslighting. And Hawley’s framework of trust can help us to see why.

Let’s first distinguish between three types of claims that are often made in illness narratives:

- (i) Claims about the experience of suffering;
- (ii) Claims about the seriousness or significance of suffering; and
- (iii) Claims about the aetiology of suffering.

One difficult part about discussions of medical gaslighting is that people easily assume that to ‘believe patients’ or ‘trust patients’ is to believe them across the board—across every aspect of their narrative. But (i)–(iii) represent very different types of claims. And what Hawley’s model usefully allows us to illustrate are the ways in which we can distrust someone about a particular type of claim or within a particular context, without thinking that they are *in general* an untrustworthy or unreliable person. I’m going to argue, using Hawley’s framework of trust, that physicians should almost always trust patients about statements of type (i), almost never trust them about statements of type (iii), and that statements of type (ii) are a difficult middle ground. In discussions of medical gaslighting, though, all three types of claims are frequently run together, and trust on all three types of claims is often demanded as part of taking testimony seriously. But this is not only unwarranted, it’s potentially harmful.

In a nutshell, the issue is this. People’s testimony about illness very often combines a mixture of subjective and objective elements—how they feel, the biological condition of their bodies, what treatments improve their quality of life, what treatments have a causal impact on an objective disease process, etc. And while people generally have special first-person insight into—and should be seen as trustworthy sources of information about—the subjective aspects of their own experiences, they don’t generally have the same kind of insight—or the same kind of testimonial competence—into the objective condition of their bodies. Physicians, all else equal, need to trust patients about the subjective aspects of their experience of illness; but things can quickly go awry if the demand for trust extends to the objective parameters of disease.

VI.1 Trust and the reality of suffering

Absent specific reasons to doubt their testimony, it seems patients should clearly be treated as trustworthy sources of testimony regarding (i)—that is, regarding claims about the experience of suffering. We are each the world’s leading expert in our own subjective experience. This doesn’t, of course, mean we can’t sometimes be wrong—we might think we’re hungry when we’re bored, we might be looking at a perceptual illusion, etc. But we have more evidence than anyone else does about how we feel.

And each of Douthat, Khakpour, and O’Rourke’s memoirs includes highly evocative descriptions of people who are suffering. Douthat, whose experience is dominated by intense chronic pain, writes of mornings when ‘the pain was deep, layers down inside my chest, and there was nothing to do but sit with it on the cold, unheated floor’. Khakpour, for whom the first signals of a CLD relapse are usually psychiatric, describes ‘the thick burnt fog of melancholy that crept slowly, mornings when I couldn’t quite get out of bed, a sticky inability to express my thoughts, hot pangs of fear and cold dread at unpredictable times’.

She also experiences ongoing vertigo and dizziness, describing instances in which ‘I felt like the life-force was being vacuumed out of me from every opening in my body’. And O’Rourke chronicles intense, roving electric shock sensations, brain fog, and debilitating fatigue. She writes of feeling that her body ‘was slowly and inexorably failing’.

If we assume that people are generally competent to tell us about their own suffering, and we assume that they are sincere when they do, then Hawley’s criteria for trustworthiness are met. When someone tells us about how they feel, we should—physician or otherwise—generally trust them. And a fair criticism of many of the physicians that the authors encounter is that they seem to routinely distrust such testimony.²⁵ Once tests come back normal, physicians are often quick to dismiss suffering as feigned or exaggerated. O’Rourke recounts the physician who casually tells her, ‘we’re all tired’, as though she is unable to distinguish normal tiredness from her experience of illness. Douthat recalls the repeated claims of physicians that his experience was *just stress*. And Khakpour even recalls, as she leaves a visit to the ER, overhearing doctors laughing at her. This is, for O’Rourke, ‘the special horror of being not only ill but also marginalized—your testimony dismissed because your lab work fails to match a preexisting pattern.’ (p. 45)

All three encountered a sense, within medical institutions, that experiences like pain or fatigue must be backed up by objective markers of disease in order to be ‘real’. Otherwise, the patient must be over-reacting or malingering. But ‘the pain’, Douthat writes, had ‘a reality that was brutally palpable, even if I couldn’t demonstrate its existence with blood work or brain scans.’ (p. 25) As physician Rachel Pearson, writing in the *New York Review of Books* about her experience of evaluating self-identified ‘chronic Lyme’ patients, writes: ‘When medicine does not acknowledge the reality of the subjective—the thick reality of lived experience—we fall laughably short in our efforts to serve patients.’

V.2 *Distrust and the objective reality of disease*

On the other end of the spectrum, Hawley’s model can usefully illustrate why patients are not trustworthy sources of information about type (iii)—claims about the aetiology of suffering. We all have unique, privileged access to our own experience of the world, to how we feel, to the character of our own pain. But we don’t have that kind of access to the *cause* of our experience. Douthat, Khakpour, and O’Rourke all give accounts according to which a latent bacterial infection is causing their persistent symptoms. And both Douthat and O’Rourke argue at length that stories like theirs should

²⁵ As Buchman, Ho, & Goldberg (2017) discuss, the structure of evidence-based medicine can support an environment in which, once no pathoanatomical cause for suffering has been found, the patient is assumed to be exaggerating or malingering.

be part of the motivation for mainstream healthcare to consider CLD as a legitimate diagnosis.

But while individuals who experience illness can give us competent testimony about how they feel, they aren't competent sources of testimony—at least based just on their own experience—about the aetiology of that experience. Douthat should be trusted, for example, when he describes himself as 'a man unable to feel anything except the red-hot poker going through his chest' (p. 61). But he also claims that he can feel cysts of bacteria bursting in his body, or that because of the intensity of his infection he can immediately feel—if he times a cocktail of antibiotics and supplements correctly—the bacteria retreating, hiding away in his body as 'small pockets of discomfort in joints and tendons—your temples or your eyebrows or your balls'. This type of description seems like a case in which a person's narrative is layering in significant amounts of theoretical interpretation. We can have direct experience of pain, of exhaustion, of all the strange and unpleasant sensations that illness gives rise to. But we don't have special insight into whether we're experiencing the effects of a specific bacteria or the behaviour of that bacteria within our bodies. That simply isn't something we can know via introspection.

This distinction is important because we often need to be able to say that people are right (and trustworthy) about their own *experience* of illness but wrong (and not trustworthy) about what *caused* that experience. People are very often wrong about what causes them to be ill. We often think our coughing and malaise are the flu, when it's a simple cold. We sometimes think it's a simple cold when it's really pneumonia. We easily mistake the insidious signs of cancer as normal aches and pains. We easily become convinced that normal headache means we have a brain tumour. Our introspection is not, in general, a competent source of information about what is causing us to feel unwell.

Hawley's framework allows us to explain how, in a situation like this, we can say that patients aren't trustworthy without suggesting that they are somehow deceitful or malingering. Patients aren't trustworthy sources of information about the objective aspects of their health because they aren't competent, not because they aren't sincere. And their lack of competence isn't blameworthy—it's just that nobody has first-person insight into pathology, no matter how much first-person insight they have into the subjective experience of illness.

Because of this lack of competence, though, doctors *shouldn't* trust patients about claims of type (iii). Indeed, part of performing their role adequately involves questioning the patient's narrative and the patient's own interpretation. She may say the fatigue she's experiencing is 'probably just stress', but the doctor needs to be alert for warning signs that it might be something else, and potentially run objective testing to investigate further. This doesn't mean that the doctor believes the patient is lying or being deceptive, but it does mean this kind of testimony—'It's probably just stress', 'I'm sure it's nothing', 'It's probably just my allergies'—is the kind of testimony physicians, if they're

doing their job well, need to distrust, for the simple reason that it's the kind of testimony we often provide, but reliably fall short of competence as sources of information when we do.

What about group testimony? Each of the authors suggests that part of what's gone wrong in the case of CLD is that the collective testimony of the CLD community has been discounted. An individual might be wrong that Lyme disease is causing her to feel unwell. But when you consider the large group of people with shared experiences, shared symptoms, shared treatments, etc.—surely their *group* testimony deserves trust.

But when it comes to the causal mechanisms of disease, collective pooling of subjective experience doesn't seem to lead to competence. There are many similar instances (especially in online communities) of groups that have pooled collective epistemic resources in ways that go off the rails. There are groups convinced that vaccines have caused a range of diseases they experience, groups convinced that not following a specific diet (paleo, intermittent fasting, etc.) is what led them to get sick, groups convinced that all you have to do is pay Gwyneth Paltrow thousands of dollars in order to cure the ills of modern life, and so on. Group testimony might—if it's combined with biological plausibility—provide a substantial reason to investigate an etiological claim further. But it doesn't, by itself, provide trustworthy evidence.

What if instead we zoom in on more specific claims within the relatively broad category (iii)? Douthat, Khakpour, and O'Rourke might not be good sources of information about whether they have a persistent bacterial infection, but maybe they're good sources of information about narrower, related claims. They all, for example, report a dramatic benefit from taking high-dose antibiotics over an extended period of time. Shouldn't physicians trust this kind of testimony, and take it as at least *limited* evidence that some kind of infectious process is going on?

A striking feature of the three CLD narratives, read alongside each other, is that the authors attribute substantial improvement both to antibiotics *and* to a wide, divergent range of treatment modalities. Khakpour uses oxygen therapy and propolis. O'Rourke adopts a strict gluten-free, paleo diet and takes anti-malarial drugs (to treat 'co-infection'), and then travels to a private clinic in the UK to get a faecal transplant in order to support her gut health from the effects of antibiotic therapy. Douthat supplements his prescribed antibiotics with both herbal preparations and additional antibiotics that he buys himself, first from overseas pharmacies and then from pet pharmacies. He also begins treating himself with a machine, popular on CLD patient forums, that purports to use particular sonic frequencies to target specific pathogens within the body, including Lyme-causing bacteria. He describes himself as 'pinning my hopes, not on any study, but on individual testimonials'.

Again, physicians—and the medical establishment more broadly—aren't applying appropriate standards of evidence if they trust all this testimony. They

should trust that the authors really did feel better and really felt very ill before trying these treatments. But the institutions of medicine *need* to distrust medical anecdotes—partly because they’re so individualized but also because people just aren’t competent sources of information about the causal mechanisms behind their own improvement.

As Rachel Pearson points out in her article on treating patients who believe they have CLD, the double-blind trials that have been conducted on post-treatment Lyme disease syndrome found that antibiotic therapy was no more effective than placebo therapy—but, crucially, that *both* the group treated with antibiotics and the group treated with placebo reported substantial improvement.²⁶ Drug effects weren’t causing the control group to feel better, but that group felt better. Hope and expectation can do a lot of work, especially for people who have been ill for a long time. Placebo effects are real—they can change how we experience our bodies, and even what’s going on in our bodies. Whether we’ve been affected by placebo responses simply isn’t the kind of thing our own subjective experience gives us insight into.

Finally, then, what about the causal question that all three authors struggle with the most—the question of whether they are dealing with an objective biomedical disease process, or whether their illness is primarily psychological (rather than physiological) in origin. Douthat and O’Rourke both insist, at length, that it is simply not plausible that their illness could be psychogenic. And they also give compelling accounts of how devastating and destabilizing the suggestion that an illness is psychogenic can be. Douthat writes that:

Like Samuel Johnson kicking a rock to refute the philosophy of immaterialism, I should have been able to lie back, to experience the burning, the chest pain, the tingling in the extremities, and tell the *it’s all in your head doctors* “I refute you *thus*.” But I didn’t have that confidence. Night after night, day after day, my self-belief was worn away, pushing me toward submission to the medical system’s diagnoses. (p. 25)

And O’Rourke, writing of the way in which the suggestion of a psychogenic diagnosis denies the ill person ‘the dignity of [their] reality’, describes the resulting internal struggle:

It is the sick person whose worldview warps, the wounded one who absorbs the idea that the most indelible aspect of her present condition is in fact. . . a distortion of her own making. (p. 63)

And as Khakpour writes, this process of repeated questioning can itself be a psychologically damaging:

Women simply aren’t allowed to be physically sick until they are mentally sick, too, and then it is by some miracle or accident that the two can be separated for proper diagnosis.

²⁶ Pearson (2020).

In the end, every Lyme patient has some psychiatric diagnosis, too, if anything because of the hell it takes getting to a diagnosis.

Should doctors, then, at the very least trust patients—especially patients without prior history of mental illness, and who by their own lights are not currently under excessive mental stress or trauma—when patients say that their illness is not psychological in origin? Again, I don't think they should, for the simple reason that people are routinely bad at distinguishing psychogenic illness from physiological²⁷ disease processes.

To make this point, though, we have to talk openly about the reality of psychogenic illness—which for myriad reasons is something that it's not always easy to do. Patient surveys suggest that people—especially women—with complex or multi-system medical disorders often receive a psychogenic diagnosis early in their disease, along exactly the lines the authors describe, as a way of being brushed off, or because their condition is misunderstood.²⁸ And, of course, such misdiagnoses can be incredibly harmful and destabilizing to the people—again, disproportionately women—who receive them.

But this situation has led to the erroneous suggestion that psychogenic illness is only ever a label given to 'mystery' physical symptoms. O'Rourke, for example, describes the category of psychogenic illness as a 'wastepaper basket diagnosis' used to dismiss uncertainty when women present with symptoms that physicians don't understand.

While such dismissal certainly does occur, it's simply not true that psychogenic labels are only given when 'unexplained' or 'mystery' symptoms occur.²⁹ The most illustrative case for this is the family of so-called 'functional neurological disorders'—conditions in which a person experiences neurological symptoms (such as weakness, burning and tingling, paralysis, convulsions, tremors, etc.) for which the primary causal factor is assumed to be psychological rather than physiological (a 'software problem' rather than a 'hardware problem'). Although there is still a great deal about the brain and nervous system that we don't understand, we know a lot about the patterns in which they function. Functional neurological disorders are often diagnosed in cases

²⁷ I'm using 'physiological' here to refer to objective processes and functionings that occur within the body. The term 'organic disease' is often used, but is somewhat confusing.

²⁸ Dusenberry (2018).

²⁹ It's worth noting that a specific and popular instance of this charge—using the example of multiple sclerosis—appears to be erroneous. The charge—repeated by O'Rourke and brought up by an anonymous referee—is that MS was thought to be a version of hysteria until the advent of MRI allowed doctors to 'see it' and thus believe it was real. But as far as I have been able to determine, it is simply not true. There is some evidence that MS is among the neurological disorders most likely to be misdiagnosed as psychogenic, and that this misdiagnosis was more common historically than it is now (Stone *et al.* 2005). But MS has been described as a discrete disease entity since at least the late 19th century, and its female preponderance was well understood long before the wide availability of MRI. See especially Jock Murray's *Multiple Sclerosis: The History of a Disease* (2004).

where a patient has apparently neurological symptoms that *cannot* be explained by the nervous system. A person may have paralysis or extreme weakness in a pattern that is anatomically impossible. They may have what they experience as numbness, but a normal clinical exam. Or, in perhaps the most dramatic case, they may have full body convulsions and perceived loss of consciousness, but completely normal brain waves.³⁰

As neurologist Suzanne O’Sullivan explains in her book *It’s All in Your Head: Stories from the Frontline of Psychosomatic Illness*, this phenomenon—when a person has what appears to be seizures but on careful neurological examination does not have any of the signs associated with epilepsy—is not rare.³¹ And what the person is experiencing is very real, very distressing, and very incapacitating. But a person with completely normal brain waves who is unconscious and having full-body convulsions has a condition that *cannot* be explained by their physiology.

Both Douthat and O’Rourke assume that such processes can’t be occurring in their own case, because they lack the relevant emotional distress or psychological trauma. But while contemporary research suggests that trauma and psychological distress are more common in people with functional neurological disorders than in the general population, they’re not necessary to develop such a condition, and may not be present in the majority of patients.³² The aetiology of such disorders is still unclear, but there is broad consensus that the primary causal drivers are psychological, and that they are best treated by a mix of psychological/psychiatric, physical, and occupational therapies, rather than by the treatment approaches usually given to physiological disease processes of the neurological system.³³

A striking feature of such conditions, however, is that the people who have them almost always assume that their illness is physiological, rather than psychological in origin, and are often very resistant to a psychological explanation of their condition.³⁴ I want to again be very clear that I’m not in any way trying to insinuate that the illness narratives I’m discussing are psychogenic. My point is a much simpler and more mundane one. People do not, in general, seem to be reliable sources of information about the cause of their illness experience. And this extends to whether or not that illness is primarily rooted in psychological or physiological factors. People with illnesses that seem to

³⁰ See Reuber (2008) and Asadi-Pooya & Sperling (2015).

³¹ Research suggests that patients with psychogenic seizures make up roughly 1/5 of referrals to epilepsy specialists (Benbadis 2005). See also Kanner (2019).

³² O’Sullivan (2015).

³³ Espay *et al.* (2018).

³⁴ O’Sullivan (2015) describes patients dealing with psychogenic illnesses as often feeling ‘like Cassandra’—having knowledge, but doomed never to be believed. Interestingly, there is some evidence that patients with functional neurological disorders not only have the belief that they have a serious physical disease, but also that these beliefs may be part of the aetiology of their symptoms (Whitehead *et al.* 2015).

be primarily driven by psychological factors, though experienced via physical symptoms, reliably seem to assume that their illness is physiological in origin, and explain it as such. On the flip side, it's not at all uncommon for people to seek treatment for what they take to be a psychological issue like stress, only to discover that the primary causal mechanism is in fact something physiological—hypothyroidism or hypoglycemia, for example.

We are not, as a rule, reliable sources of information about whether the symptoms we're experiencing are primarily psychological or physiological in origin, which is unsurprising, given how complex the interaction between and blurry the boundary lines across such factors are. But what this means is that physicians, if they're going to investigate and treat an illness effectively, can't simply trust patients' claims that their illness is not (or is) psychological in origin.

V.3 Seriousness and suffering

This brings us to the difficult, murky case of type-(ii) claims—claims about the *seriousness* of suffering. I've argued that, for fairly straightforward reasons, patients should be seen as trustworthy about type-(i) claims (experiential claims about suffering). And for similarly straightforward reasons, they should be seen as untrustworthy about type-(iii) claims (etiological claims about suffering). In short, the idea is that individuals have introspective access to, and are competent sources of information about, the subjective aspects of their experience of illness, but not the objective causal/biological mechanisms that ground that experience. In speaking of the seriousness of illness, however, a complex mix of subjective and objective factors are often in play, making the issue of competence—and thus of trustworthiness—far murkier. Sometimes, claims of seriousness are more akin to type-(i) claims: they are reports of distress, anguish, and suffering. But sometimes, they are more akin to type-(iii) claims: they are claims about the objective biomedical aspects of a disease process. Trusting individual testimony about the seriousness of an experience of illness is especially complicated, not only because it's easy to slide between these subjective and objective readings, but also because it often seems that people don't feel fully trusted or listened to about type-(i) claims unless they are interpreted via type-(iii) claims.

In one sense of 'serious', the illnesses described by Douthat, Khakpour, and O'Rourke are clearly serious. They caused substantial limitation in their daily lives. They caused extreme distress. At various points in their narratives, each author describes despair and suicidal ideation. That suffering is significant, and matters in significant ways. Reports of this type of seriousness are closer in kind to type-(i) claims. They are claims about the nature of a person's own experience and their own suffering.

Things get trickier when we use ‘serious’ in a comparative sense. In some sense, each person who is unhappy is unhappy in their own way. Whether one person’s suffering is more or less serious than another’s is often not a useful or informative question. If someone is suffering enough to imagine death as a relief, they are suffering enough for it to matter. And we should trust them when they tell us about their own experience of distress. Likewise, we can trust people when they make comparisons based on their own experiences. A continued frustration that O’Rourke describes, for example, is that she might be confusing her extreme fatigue with the normal tiredness of a busy life, as though she doesn’t know what it’s like to be tired, and can’t tell the difference between being tired and debilitating fatigue.

But difficulty arises when the authors insist that their experience of suffering be recognized as *physically* serious—that is, as a physiologically serious disease process. The sense of ‘serious’ they often employ is the biomedical sense of ‘serious disease’, which means something like: likely to cause substantial, potentially life-threatening, and malfunctions in the body. Despite mostly normal test results, mostly normal blood work, normal clinical exams, etc., each author believes, at various points, that they might be dying. They each describe their antibiotic treatment as ‘life-saving’ and describe themselves, in the course of their treatments, as fighting for their lives. And they insist that physicians are dismissing their concerns if they don’t see them as equally *physically* serious.

But here we’ve strayed much closer to type-(iii) territory. And, again, this doesn’t seem like the kind of thing that physicians ought to trust patients about. Moreover, the narratives in question give an abundant illustration of ways in which patients, without intending to lie, can nevertheless fall short of being trustworthy sources of information. Insofar as they were dealing with suicidal ideation, all three authors may have genuinely been fighting for their lives. But by their own account, they don’t seem to have been experiencing a physical illness that was itself *life-threatening*. Long-term antibiotic treatment for CLD may have made them feel much better, and restored much of what they valued in their life, but it wasn’t a ‘life-saving’ treatment in the medical sense. The only CLD patients known to have died from complications related to the disorder are those who have died from complications of aggressive treatment.

This point is thrown into stark relief by the authors’ tendency to make direct comparison to other physical illnesses, as part of establishing the physical seriousness of their own. Even after he is fully cleared of any cardiac problems, Douthat describes his experiences of chest pain as ‘phantom heart attacks’. He also asserts that, because he’s experienced things like fatigue and shock-like sensation, he knows, if only temporarily, what it’s like to experience the symptoms of MS. Similarly, O’Rourke describes her illness as having ‘wrecked’ her immune system, concluding her book by saying ‘My illness left open a window in me through which anything can climb, at any time.’ In a *New York*

Times interview with Douthat, she remarks that ‘what we both had, Ross, were infections that also destroyed our immune systems’.

And yet, by their own accounts, neither O’Rourke nor Douthat is objectively immunocompromized. There is ‘an infection that destroys the immune system’. It’s HIV, and people who have it—unless they are giving *genuinely* life-saving drugs—will become clearly, objectively sick, and typically will die. It is also people whose immune systems really have been destroyed—objectively—that are made the most vulnerable by the over-prescription of antibiotics.

In narrating their experience of illness, the authors clearly want to establish its seriousness as rooted in the objective physiological seriousness of a disease process. But while they should be trusted about the former, it’s not obvious that they’re competent sources of information about the latter. More strongly, they’ve given us good reason to think that they *aren’t* trustworthy in this regard—that they are not accurately presenting the physiological severity of their illness. This doesn’t, of course, mean that they aren’t suffering, or that we should doubt what they say about their experience of suffering. Likewise, it doesn’t in any way mean that they are exaggerating their experience of illness or their functional limitation. Far from it. But it does mean that their *interpretation* of that suffering—the way they characterize it and contextualize it, via the language of physiological disease process—might not be trustworthy.

VI. THE VALUE OF DISTRUST

Gaslighting is both common and harmful. And patients are, doubtless, sometimes gaslit by physicians. But the over-application of the framework also has potential to do serious harm. And the wide usage of ‘medical gaslighting’—especially for a contested illness like CLD—can give a useful illustration of why.³⁵

An especially valuable aspect of Hawley’s framework of trust, I suggest, is that it allows us to explain the social value of both trust *and* distrust.³⁶ There are situations in which distrust is important and situations in which distrust plays a valuable social role. More strongly, there are situations in which distrust might hurt, disappoint, or even harm the person who is distrusted, and yet

³⁵ Byrne (2020) makes a similar case regarding the potential over-application of testimonial injustice in healthcare settings, focusing specifically on effective treatments for ME/CFS.

³⁶ Hawley discusses the potential value of distrust—and the importance of theorizing it—in her (2012), as well as (2014). As Hawley (2015) writes, specifically characterizing the doctor–patient relationship: ‘In any discussion of trust and distrust. . . it is useful to bear in mind the risks associated with miscommunication about what can reasonably be expected of either party: misplaced trust can be a dangerous thing for both truster and trustee.’

the way forward isn't obviously to find a solution for mutual trust or for more belief.

Physicians' desire to comply with their patients' wishes, especially when the cause of a patient's illness remains uncertain, is a major driver of antibiotic over-prescription, which is itself a major driver of antibiotic resistance.³⁷ And, as Rachel Pearson emphasizes in her article on CLD, antibiotic resistance is one of the greatest public health threats currently facing our medical system. In a context like this—the public health threat of such resistance coupled with the harms of antibiotic overuse—Hawley's model gives us a way of articulating the social value of distrust. Patients should be trusted about how they feel, including whether they genuinely feel better after antibiotic treatment. But trusting them too much—trusting them about what will actually provide medical improvement to them, or be a medically appropriate treatment—has the potential to do serious harm, both to them and to the wider community, especially those who are objectively immunocompromized.

Writing about the dangers of over-treatment, epidemiologist H. Gilbert Welch remarks that 'there is no more of a true believer than a patient who has undergone a major therapeutic intervention' (2016: 36). Patients often want their doctors to 'do something!', and view more aggressive treatment as better treatment, and as a sign that their condition is being taken more seriously. But patients are often wrong. Over-treatment is correlated with higher patient satisfaction, but it's also correlated with poorer medical outcomes.³⁸

There is also, I suggest, social value in distrust over patients' interpretations of their own experiences. Each of Douthat, Khakpour, and O'Rourke is at various points insulted, disoriented, and frustrated by the suggestion that their illness might be psychogenic. And both Douthat and O'Rourke argue at length that the suggestion is insulting. Their illness is far too serious—too *real*—for such suggestion to have any plausibility.³⁹

O'Rourke discusses at length the ways in which our modern understanding of psychogenic illness is rooted in the historical concept of hysteria (which is, to be fair, the term that would've previously been applied to things like functional neurological disorders). And as she explains, hysteria—or the lurking suspicion of it—is an idea that has been used to dismiss and silence women, both historically and currently.⁴⁰ It is a way, she suggests, of telling women their illness isn't real.

³⁷ See Talkington *et al.* (2017). Hawley (2015) discusses the practice of 'defensive medicine'—trying to meet patient expectations and avoid complaints—as a particular locus for distrust, and a place where trust can be over-applied.

³⁸ See e.g. Fenton *et al.* (2012).

³⁹ Similarly, Carel & Kidd discuss the application of psychogenic diagnoses as instances of medical testimonial injustice (2014, 2016).

⁴⁰ See also Dusenberry (2018).

Hysteria *is* a feminist issue. But it's not a feminist issue in the flat-footed way people so often assume.⁴¹ It is almost certainly the case that women are more likely to be diagnosed with psychosomatic illness because we view them as overly emotional. But it's also true that psychogenic illnesses—illnesses that have primarily physical symptoms, but primarily psychological aetiology—are real conditions that are relatively common.⁴² Moreover, they are disproportionately common among women, especially younger women.⁴³ Given those demographics, it's perhaps not surprising that both lay people and the medical establishment have tended to dismiss them as less worthy of compassion—even though we have ample evidence that they can be profoundly debilitating.

On the face of it, this is bizarre. We know, to begin with, that mind/body dualism is a false dichotomy. While the separation can be conceptually useful, there is not a neat divide—not the least because anything that occurs in our minds is at least partly realized in our bodies. The distinction between psychological and physical can be helpful in explaining important differences between broad types of illness,⁴⁴ including which treatment modalities might be most beneficial. But as distinctions go, this one (like so many in the biomedical sciences) is vague at best.

We also know that physical illnesses can often cause a mixture of physical and psychological symptoms, or even primarily psychological symptoms. We likewise know that primarily psychological/psychosocial illnesses can cause physical symptoms—a panic attack causes chest pain and depression often causes headaches. We don't have any problem seeing any of these manifestations as 'real'. Depression isn't any less depressing if it's caused by a low thyroid. Nausea isn't any less unpleasant if it's caused by anxiety. We're happy to accept all of this.

But when we reach the—well-established, fairly common—territory of illnesses that seem to have primarily psychosocial causes, but primarily physical symptoms, we seem to lose our bearings entirely. We immediately shift to the idea that this is 'imaginary', 'all in the head', 'fake'. And, as O'Sullivan persuasively argues, it's hard to ignore the correlation between this dismissal and the fact that this is disproportionately a way in which women—especially young women—become ill.⁴⁵

⁴¹ See especially Suzanne O'Sullivan's *The Sleeping Beauties* (2021).

⁴² Estimates suggest that somewhere in the region of 30 per cent of patients at general neurology clinics have a primarily psychogenic condition, for example, see Ropper & Burrell (2015).

⁴³ O'Sullivan (2015).

⁴⁴ As Arpaly (2005) persuasively argues to fully understand the nature of mental disorders we have to understand them qua mental entities, in ways that mark them out as distinct from purely physical illnesses—we have to, e.g. talk about the ways in which they are connected to representation, rationality, and normativity.

⁴⁵ Around 70 per cent of people diagnosed with functional neurological disorders, for example, are women. Some of this might well be due to diagnostic bias. But disorders like psychogenic

The way that illness narratives are presented often comes with a very specific interpretative slant—because they are *serious*, they *cannot be* psychogenic. Part of what it is to treat them as serious is to treat them as physiological. If we trust people on this interpretation, then we give them what they desperately want, and the type of validation they feel their experiences need.

But in doing so, we risk doing serious harm to others (as well as, in some cases, to the person giving the narrative themselves—by denying them accurate understanding of their own health condition, and access to the most effective treatments). Psychosomatic illness can have a devastating impact on people's lives.⁴⁶ And, especially given its gendered demographics, our reluctance to speak about it openly is telling. We all too easily suggest that for the illnesses of women (especially young women) to be 'real', we must explain how women become ill in the same way and along the same patterns that men become ill. But we know, empirically, that this isn't quite true. We can't fully understand the way that women suffer until we take psychogenic illnesses seriously.

It's of course understandable that patients would strongly resist any suggestion of psychogenic illness. The institutions of medicine really do dismiss such illnesses, and they really do use such labels as a way of dismissing patients. But the upshot isn't simply to trust patients that they can tell the difference between a psychogenic and a physiological illness, or to trust patients that the seriousness of their suffering means that suffering couldn't be psychogenic.

VII. MUTUAL DISTRUST

Popular discussion of 'medical gaslighting' includes many first-person accounts of obvious and harmful errors. But it's not clear what additional explanation the framework of gaslighting provides. In some cases, physicians are simply failing to practice medicine to any reasonable standard. They aren't doing their due diligence; they aren't going through a decent differential diagnosis, etc. But we don't need the idea of gaslighting to explain this—we can just appeal to the more mundane concept 'bad doctor'. Similarly, in some cases, structural prejudice is in play—physicians aren't running as many tests on their Black patients, they're assuming female patients are exaggerating reports of pain, and so on. Again, though, we can discuss the harm of such situations without appealing to gaslighting. Patients deserve—but often do not get—the same level of care regardless of race, gender, class, etc. And finally, in some instances, the stories involved seem to be simple instances of misdiagnosis—something

seizures and psychogenic movement disorders—disorders that are clearly psychogenic—are, unequivocally, disorders had disproportionately by women (O'Sullivan 2021).

⁴⁶ For an incredibly compelling personal narrative of living with a functional neurological disorder—including the difficulty and stigma with accepting the diagnosis—see FND Portal (2022).

that can be incredibly frustrating, destabilizing, and harmful, but that isn't always blameworthy, and is an inevitable reality of medicine. Sometimes, even the most conscientious doctors will get things wrong. Mistakes in diagnosis will cause harm (especially to patients), but they don't necessarily represent blameworthy lapses.

In some alleged examples of medical gaslighting, though—such as the case of CLD—it's less obvious that physicians are making mistakes. Disbelief causes patients anguish and confusion, but the upshot isn't that the disbelief is therefore unwarranted, or that more credence would be helpful. Physicians, I've argued, often have good reason to distrust patients—at least about certain claims.

But crucially, this doesn't mean that 'the doctor is always right', or that patient must always defer to physicians. Some doctors aren't very good at their jobs. Many doctors—and the institutions of medicine more broadly—are to varying degrees sexist, racist, classist, and otherwise biased in ways that affect how they deliver care. Patients often have reasons not to *assume* that their doctor is competent—they have reason to advocate for themselves, to seek second opinions, etc. They might also, given past experiences, be justified in a default distrust of doctors in general, at least when it comes to certain aspects of their care.

The net result is a situation that often works best when there is, to some degree, mutual distrust. The doctor doesn't take the patient's word for it. The patient doesn't assume the doctor is unbiased or getting things right, and is willing to advocate for herself. A doctor needs to earn her trust.

It is easy, when faced with somewhat uncomfortable situations like this, especially situations that can involve bias and can cause harm, to assume that the solution is more belief. The growing popularity of 'medical gaslighting' seems to fall into precisely this trap. Proponents insist that we trust patients, believe patient testimony, and take patients at their word—in ways that might ultimately be counterproductive. Hawley's model allows us, instead, to articulate more subtle differences—places where trust is appropriate, and places where it is not.⁴⁷

REFERENCES

- Abramson, K. (2014) 'Turning up the Lights on Gaslighting', *Philosophical Perspectives*, 28: 1–30.
 Arpaly, N. (2005) 'How It Is Not "Just Like Diabetes": Mental Disorders and the Moral Psychologist', *Philosophical Issues*, 15: 282–98. <http://www.jstor.org/stable/27749845>

⁴⁷ Thanks to Liam Kofi Bright, Ross Cameron, Anna Kietzerow, the St. Andrews feminist philosophy reading group, and anonymous referees for helpful discussion and comments. And more thanks than I could possibly express to Katherine Hawley, who was my PhD supervisor, my mentor, and my hero. It is an honour to be included in this special issue, which I'm sure she would've appreciated but also regarded as a bit too much fuss.

- Asadi-Pooya, A. A. and Sperling, M. R. (2015) 'Epidemiology of Psychogenic Nonepileptic Seizures', *Epilepsy & Behavior*, 46: 60–5.
- Au, L. *et al.* (2022) 'Long COVID and Medical Gaslighting: Dismissal, Delayed Diagnosis, and Deferred Treatment', *SSM - Qualitative Research in Health*, 2: 100167.
- Bailey, A. (2020) 'On Gaslighting and Epistemic Injustice: Editor's Introduction', *Hypatia*, 35: 667–73.
- Benbadis, S. R. (2005) 'A Spell in the Epilepsy Clinic and a History of "Chronic Pain" or "Fibromyalgia" Independently Predict a Diagnosis of Psychogenic Seizures', *Epilepsy & Behavior: E&B*, 6: 264–5.
- Booth, S. (2023) 'How to Avoid Gender-Based Medical Gaslighting', *Health*. <https://www.health.com/mind-body/is-your-doctor-gaslighting-you>, accessed 3 Jan 2023.
- Buchman, D. Z., Ho, A. and Goldberg, D. S. (2017) 'Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain', *Bioethical Inquiry*, 14: 31–42.
- Byrne, E. A. (2020) 'Striking the Balance with Epistemic Injustice in Healthcare: The Case of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis', *Medicine Health Care and Philosophy*, 23: 371–9.
- Carel, H. and Kidd, I. J. (2014) 'Epistemic Injustice in Healthcare: A Philosophical Analysis', *Medicine Health Care and Philosophy*, 17: 529–40.
- Centers for Disease Control and Prevention. (2021) 'Signs and Symptoms of Untreated Lyme Disease', Centers for Disease Control and Prevention. https://www.cdc.gov/lyme/signs_symptoms/index.html, accessed 15 Jan 2021.
- (2022) 'Post-Treatment Lyme Disease Syndrome', Centers for Disease Control and Prevention. <https://www.cdc.gov/lyme/postlds/index.html>, accessed 10 Jan 2022.
- Douthat, R. (2021) *The Deep Places: A Memoir of Illness and Discovery*. Colorado Springs, CO: Convergent Books.
- Dusenberry, M. (2018) *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*. San Francisco, CA: Harper One.
- Espay, A. J. *et al.* (2018) 'Current Concepts in Diagnosis and Treatment of Functional Neurological Disorders', *JAMA Neurology*, 75: 1132–41.
- Feder, H. M., Jr *et al.* (2007) 'A Critical Appraisal of "Chronic Lyme Disease"', *New England Journal of Medicine*, 357: 1422–30.
- Fenton, J. J. *et al.* (2012) 'The Cost of Satisfaction: A National Study of Patient Satisfaction, Health Care Utilization, Expenditures, and Mortality', *Archives of Internal Medicine*, 172: 405–11.
- Fischer, M. (2019) 'Maybe It's Lyme: What Happens When Illness Becomes An Identity?' *The Cut*. https://www.thecut.com/2019/07/what-happens-when-lyme-disease-becomes-an-identity.html#_ga=2.190676395.1870127769.1667847889-1802634515.1667847889, accessed 24 Jul 2019.
- FND Portal. (2022) 'Cadenza for Fractured Consciousness: A Personal History of the World's Most Misunderstood Illness', *Medium*. <https://medium.com/@fndportal/cadenza-for-fractured-consciousness-e9c236dc7bf2>, accessed 20 Oct 2022.
- Fricker, M. (2007) *Epistemic Injustice: Power & the Ethics of Knowing*. Oxford: OUP.
- Gallagher, S., Little, J. M. and Hooker, C. (2021) 'Testimonial Injustice: Discounting Women's Voices in Health Care Priority Setting', *Journal of Medical Ethics*, 47: 744–7.
- Hadid, Y. (2017) *Believe Me: My Battle with the Invisible Disability of Lyme Disease*. St. Martin's Press.
- Hawley, K. (2012) *Trust: A Very Short Introduction*. Oxford: OUP.
- (2014) 'Trust, Distrust and Commitment', *Noûs*, 48: 1–20.
- (2015) 'Trust and Distrust between Patient and Doctor', *Journal of Evaluation in Clinical Practice*, 21: 798–801.
- (2019) *How to Be Trustworthy*. New York, NY: OUP.
- Ivy, V. [McKinnon, R.] (2017) 'Allies Behaving Badly: Gaslighting as Epistemic Injustice', In I. J. Kidd, J. Medina and G. Pohlhaus, Jr., *The Routledge Handbook of Epistemic Injustice*, 167–74. London: Taylor & Francis.
- Kanner, A. (2019) 'The Truth About Psychogenic Nonepileptic Seizures', Epilepsy Foundation. <https://www.epilepsy.com/stories/truth-about-psychogenic-nonepileptic-seizures>, accessed 13 Oct 2019.
- Khakpour, P. (2018) *Sick: A Memoir*. New York, NY: Harper Perennial.

- Kidd, I. J. and Carel, H. (2017) 'Epistemic Injustice and Illness', *Journal of Applied Philosophy*, 34: 172–90.
- Kilkus, J. (2022) 'How to Deal with Medical Gaslighting', *Psychology Today*. <https://www.psychologytoday.com/us/blog/navigating-cancer/202209/how-deal-medical-gaslighting>, accessed 4 Sep 2022.
- Kirk-Giannini, C. D. (2022) 'Dilemmatic Gaslighting', *Philosophical Studies*, 1–28.
- Lantos, P. M. (2011) 'Chronic Lyme Disease: The Controversies and the Science', *Expert Review of Anti-Infective Therapy*, 9: 787–97.
- Manne, K. (forthcoming) 'Moral Gaslighting', *Proceedings of the Aristotelian Society*.
- Mikkola, M. (2017) 'Sex in Medicine: What Stands in the Way of Credibility?', *Topoi*, 36: 479–88.
- Moyer, M. W. (2022) 'Women Are Calling Out "Medical Gaslighting"', *The New York Times*. <https://www.nytimes.com/2022/03/28/well/live/gaslighting-doctors-patients-health.html>, accessed 28 Mar 2022
- Murray, J. (2004) *Multiple Sclerosis: The History of a Disease*. New York, NY: Demos Health.
- O'Rourke, M. (2022) *The Invisible Kingdom: Reimagining Chronic Illness*. New York, NY: Riverhead Books.
- O'Sullivan, S. (2015) *It's All In Your Head: True Stories of Imaginary Illness*. London: Chatto & Windus.
- (2021) *The Sleeping Beauties*. New York, NY: Pantheon.
- Pearson, R. (2020) *The Challenge of "Chronic Lyme"*. The New York Review of Books. <https://www.nybooks.com/online/2018/07/25/the-challenge-of-chronic-lyme/>, accessed 26 Jun 2020
- Podosky, P. M. C. (2021) 'Gaslighting, First- and Second-Order', *Hypatia*, 36: 207–27.
- Pohlhaus, G., Jr. (2012) 'Relational Knowing and Epistemic Injustice: Toward a Theory of Willful Hermeneutical Ignorance', *Hypatia*, 27: 715–35.
- (2017) 'Gaslighting, Echoing, and Gathering; or Why Collective Epistemic Resistance Is Not a "Witch Hunt"', *Gaslighting and Epistemic Injustice Conference*. Claremont McKenna College, 23 September.
- Reuber, M. (2008) 'Psychogenic Nonepileptic Seizures: Answers and Questions', *Epilepsy & Behavior*, 12: 622–35.
- Ropper, A. H. and Burrell, B. (2015) *Reaching Down the Rabbit Hole: Extraordinary Journeys into the Human Brain*. London: Atlantic Books.
- Ruiz, E. F. (2020) 'Cultural Gaslighting', *Hypatia*, 35: 687–713.
- Saul, J. M. (2012) *Lying, Misleading, and What is Said: An Exploration in Philosophy of Language and Ethics*. Oxford: OUP.
- Skar, G. L. and Simonsen, K. A. (2022) *Lyme Disease*. StatPearls Publishing.
- Sebring, J. C. H. (2021) 'Towards a Sociological Understanding of Medical Gaslighting in Western Health Care', *Sociology of Health & Illness*, 43: 687–713.
- Spear, A. D. (2023) 'Epistemic Dimensions of Gaslighting: Peer Disagreement, Self-Trust, and Epistemic Injustice', *Inquiry*, 66: 68–91.
- Stark, C. (2019) 'Gaslighting, Misogyny, and Psychological Oppression', *The Monist*, 102: 221–35.
- Stone, J. et al. (2005) 'Systematic Review of Misdiagnosis of Conversion Symptoms and "Hysteria"', *Bmj*, 331: 989.
- Talkington, K. et al. (2017) *What Drives Inappropriate Antibiotic Use in Outpatient Care? The Pew Charitable Trusts*. <https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2017/06/what-drives-inappropriate-antibiotic-use-in-outpatient-care>, accessed 28 Jun 2017.
- Welch, G. H. (2016) *Less Medicine, More Health: 7 Assumptions That Drive Too Much Medical Care*. Boston, MA: Beacon Press.
- Whitehead, K. et al. (2015) 'Differences in Relatives' and Patients' Illness Perceptions in Functional Neurological Symptom Disorders Compared with Neurological Diseases', *Epilepsy & Behavior*, 42: 159–64.

University of Virginia, USA