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The Harm of Ableism: Medical Error and Epistemic Injustice

ABSTRACT. This paper argues that epistemic errors rooted in group- or identity-based biases, especially those pertaining to disability, are undertheorized in the literature on medical error. After sketching dominant taxonomies of medical error, we turn to the field of social epistemology to understand the role that *epistemic schemas* play in contributing to medical errors that disproportionately affect patients from marginalized social groups. We examine the effects of this unequal distribution through a detailed case study of ableism. There are four primary mechanisms through which the epistemic schema of ableism distorts communication between nondisabled physicians and disabled patients: testimonial injustice, epistemic overconfidence, epistemic erasure, and epistemic derailing. Measures against epistemic injustices in general and against schema-based medical errors in particular are ultimately issues of justice that must be better addressed at all levels of health care practice.

INTRODUCTION

Improper diagnosis and treatment due to medical error lead to tens of thousands of deaths every year (Makary and Daniel 2016). While there is a significant body of research analyzing the nature, causes, and effects of medical error, as well as the effectiveness of various error-reduction strategies (IOM 2000), the medical error literature has historically undertheorized a specific kind of error—namely, epistemic error—that is brought about by epistemic schemas linked to group- or identity-based biases rooted in categories such as race, sex, gender, sexuality, and disability. In this paper, we turn to the field of social epistemology with the double aim of filling this gap in the literature as well as better understanding the role that epistemic schemas play in the production of medical errors that disproportionately affect patients from marginalized social groups.

Our argument moves in three stages. First, we sketch dominant taxonomies of medical error, define what we mean by ‘epistemic schema’ and ‘epistemic error,’ and situate our project in the context of the larger literature on epistemic injustice. Second, we look at the socially uneven distribution of epistemic error by using ableism as a case study. Ableism, which we here explore in terms of its role as an epistemic schema, plays a pernicious role in patient–provider communication (PPC). It distorts communication between nondisabled physicians and disabled patients, subjecting the latter to various forms of epistemic injustice and exposing them to a higher risk of medical error and, consequently, harm. Our analysis of this case study will demonstrate that even though the possibility of medical error impacts everyone, it does not impact everyone *equally*. Socially vulnerable patients, such as disabled patients, are more likely to be affected by it. Finally, we contend that medical errors due to epistemic schemas rooted in prejudice, such as ableism, are issues of justice that must be addressed at all levels of health care practice. We offer this analysis in the hope of clarifying the role that epistemic schemas play in the production of medical errors and reducing the number of lives hurt or lost in their wake.

KINDS OF MEDICAL ERROR

Medical errors take many forms. To better understand them and to assist in efforts to reduce their frequency, researchers have developed various taxonomies of medical error, most of which are based on their causes or effects. For example, taxonomies that carve the joints of medical error along the lines of effect often classify errors as *fatal*, *life threatening*, *serious*, or *significant*. Meanwhile, those that track differences in origin produce rather different tables of elements. Taking this approach Aronson (2009) classifies medical errors as *knowledge-based*, *rule-based*, *action-based*, or *memory-based*.²

Taxonomies are powerful resources that help us conceptualize phenomena in specific ways and frame how we think about issues. Like all conceptual resources, however, taxonomies come with limitations. Taxonomies of medical error that focus on effects, for example, can be misleading because not all medical errors have observable consequences. “Many errors,” as Weingart et al. note, “do not produce injury; they are caught in time, the patient is resilient, or luck is good” (2000, 390). Similarly, taxonomies based on origin can misconstrue or entirely miss errors that are multi-factorial or whose source of origin is either unknown or hard to discern.

In this paper, we focus on the specific kind of error that Aronson (2009) describes as “knowledge-based.” Knowledge-based medical errors result, in one way or another, from deficient knowledge on the part of providers. As Aronson defines them, these errors involve “any type of knowledge, general, specific, or expert” (2009, 603).

It is *general knowledge* that penicillin can cause allergic reactions; knowing that your patient is allergic to penicillin is *specific knowledge*; knowing that co-fluampicil contains penicillin is *expert knowledge*. Ignorance of any of these facts could lead to a knowledge-based error. (2009, 603)

For Aronson, a central way doctors can inadvertently harm their patients is by failing to know or otherwise being ignorant about things that they ought to know at the moment that they ought to know them. This could be due to a lack of true beliefs about X or due to the possession of false beliefs about X. In the example Aronson gives, one might not know that a patient is allergic to penicillin, or one might falsely believe that a patient is not allergic to it. In the literature on medical error, knowledge-based failings such as these are typically referred to as “epistemic errors.”

Even though epistemic errors are frequently referenced in this literature, they are often equated with what we call “factual errors,” which stem from a lack or misapplication of information. Factual errors occur, for example, when not all the medically-relevant information provided by a patient is made available to all the medical experts the patient interacts with at different stages of care, when information is missing from key medical spaces at key medical moments (as when a drug container does not specify that a drug must be diluted), or when providers are ignorant of new research, methods, or protocols. We call these errors ‘factual’ because they pertain to the possession or non-possession of relevant facts and beliefs, rather than pertaining to cognitive and perceptual habits, as is the case with “schematic errors.”

The unstated assumption in much of the extant literature on medical error seems to be that if experts knew all the relevant facts, they would not make errors. We disagree with this assumption, because not all epistemic errors are factual in nature. Surely, medical errors can occur based on *what providers know*, but one of our chief claims in this article is that medical errors also depend on *how providers know*. It is a mistake, therefore, to equate epistemic errors with factual errors, since these categories are related but not co-extensive; the latter is a subset of the former. All factual errors, in other words, are epistemic; but not all epistemic errors are factual. To improve medical practices and institutions, we must attend

to the plurality of medical error types and recognize that different types of errors have different causes and effects. Epistemic errors in particular require us to look not only at the information that is available to medical providers at various moments, but also at the broader social character of medicine, because the production, operationalization, and dissemination of medical knowledge is a social and relational process that goes beyond the brute application of facts. When it comes to the epistemology of medicine, factual errors are only the tip of the medical error iceberg.

SCHEMATIC ERRORS: BEYOND MEDICAL FACTS

Over the last few decades, social epistemology has emerged as a burgeoning field of philosophical inquiry. On the whole, the field is based on the premise that knowledge is fundamentally social, which is to say, produced, shared, interpreted, and transmitted through complex human practices, interactions, and institutions. This insight, which grew primarily out of feminist scholarship on the relationship between knowledge and power, can help us make sense of those medical errors that cannot be traced to purely factual concerns and that involve *how*, rather than *what*, providers know. We call these errors ‘schematic’ rather than ‘factual’ because they are outgrowths of *epistemic schemas* that shape the larger processes, judgments, and pool of hermeneutic resources upon which providers draw. Epistemic schemas are thereby central to how medical providers position themselves relative to their patients and, as we explore below, this can have especially significant ramifications for patients who are perceived to be unlike a provider in different regards, especially patients who come from historically marginalized social groups.

The concept of a schema has been widely and variably used in linguistics, cognitive psychology, the philosophy of mind, and even the philosophy of science. In this context, we understand epistemic schemas simultaneously as “manifold cognitive structures exerting influence over memory encoding and retrieval” (Ghosh and Gilboa 2014, 104) and structures which make it possible for epistemic agents to arrive at “shared meanings or frames of reference” (Dotson 2012, 30; cf. Bartunek and Moch 1987). Epistemic schemas, then, are constellations of implicit and explicit values, norms, biases, impulses, desires, fantasies, and assumptions that condition what counts as knowledge, who counts as a knower, and how knowledge claims are interpreted, assessed, and adjudicated within a given epistemic community.³ At once perceptual, cognitive, and hermeneutical, they are structures that shape how epistemic agents participate in the life

of a community by making, sharing, interpreting, and communicating knowledge claims. And because they influence how we experience, reflect upon, and communicate information about the world we share with others, these schemas are more than simple biases or habits. Yet, like biases and habits, epistemic schemas are often implicit rather than explicit, meaning that typically most of us are unaware of the pull they exert over our thoughts, actions, and ways of knowing and the various ways in which we have been socialized into them.

Our use of the concept of an “epistemic schema” is thus related to concepts such as “body schema” and “gender schemas” that capture how networks of information are interpreted through a dynamic process of filtering and framing (Bem 1981; Johnson 1987). By definition, schemas are information-filtering mechanisms that downgrade the import of some information while amplifying and prioritizing the significance of other information. But they are not passive sieves that merely let (some) information pass. They are also meaning-making processes that present information in a certain light, that frame the information they themselves filter in sense-conferring ways. This is why we ought to think of epistemic schemas as meaning-making mechanisms that have a significant influence on how people think about themselves (personal identity dynamics) and their place in larger social formations (in-group/out-group dynamics).

Epistemic schemas can grow out of religious, philosophical, and even scientific worldviews, but the ones that interest us here are tied to social markers of identity, such as race, ethnicity, gender, sex, sexuality, class, and disability, among others. Racism, for instance, is a social, material, and political reality that profoundly affects the lives of racial minorities and shapes the larger society as a whole. It can also function as an epistemic schema in our sense of the term because it affects how differently racialized agents *think about* and communicate with one another. Racism, understood as an epistemic schema, structures how one knows, what one knows, which voices and bodies of knowledge one includes or excludes and how, and, more broadly, the ways in which one engages in the world as a knower, as an organism who gathers, processes, judges, and communicates *about* its experiences to itself and others. Although schemas such as racism and sexism do not offer an ordered interpretation of *all* one’s experiences, they can determine—and, in some cases, wildly overdetermine—how epistemic agents interact with one another as knowers, which is to say, how they interpret the meaning, validity, and force of one another’s claims. In other words, although they may appear to be domain-specific, their

impact easily bleeds into all sorts of knowing activities. And, while not all epistemic schemas are rooted in prejudices of these sorts, those that are typically lead to epistemic injustice.

One reason epistemic schemas, and especially those rooted in prejudice, are so powerful and recalcitrant is because they reinforce epistemic ignorance, which is to say, modes of knowing that *depend* upon ignorance concerning others and the world in such a manner as to maintain the privileges of the knower.⁴ Historically, philosophers have understood ignorance quite simply as the absence of knowledge. Recent work in epistemology, much of which draws heavily upon earlier feminist and anti-racist work, suggests instead that ignorance may be better defined as “the other side of knowledge” (Mills 2010; see Alcoff 2007, 18ff) because there are cases when someone’s ignorance is predicated upon, and a boon for, extant social injustices. Put simply, what one is ignorant of is no simple matter and does not absolve one from culpability. On the contrary, ignorance is shot through with ethical, social, and political choices that carry profound effects. Epistemic ignorance, this literature demonstrates, is a driver of epistemic injustice; it leads to harms against marginalized groups and individuals in their capacity as knowers. Fundamentally prejudicial epistemic schemas such as those of racism, sexism, and ableism are problems not just because of the way they lead epistemic agents to know, but also because of the way they lead agents *not* to know. Ignorance can be comparably unjust to unjust ways of knowing, if not more so.

In these cases, then, it would be inaccurate to describe ignorance as an innocent lack of knowledge and more accurate to talk about it as the controlled effect of a system of power that actively seeks to keep certain things *un-known*. Linda Alcoff writes:

The study and analysis of [epistemic] ignorance poses some special epistemological questions beyond the expected sociological and educational ones, questions having to do with how we understand the intersection between cognitive norms, structural privilege, and situated identities. (2007, 39)

In what follows, we explore the role that epistemic schemas play in fostering epistemic ignorance through the case of ableism. We demonstrate that ableism, understood as an epistemic schema, leads to medical error by fostering epistemic ignorance rooted in privilege and prejudice on the part of health care providers, and we use research on PPC with respect to patients with disabilities to illustrate our point.

CASE STUDY: ABLEISM

While the philosophical literature on social epistemology has made significant strides in exposing how systems of oppression, such as racism and sexism (Song et al. 2014), mold people's experience of medical care, this literature has paid comparatively little attention to ableism, aside from the notable exceptions we discuss below. In this section, our principal objective is to show that ableism affects the quality of care that people with disabilities receive by exposing them to a higher than average risk of medical error and, consequently, medical harm. Given that (a) people with disabilities make up the largest legally-protected minority group of health care users and given that (b) the types of epistemic ignorance associated with the schema of ableism and the epistemic injustices that result from it lead to people with disabilities being impacted by medical error disproportionately, this is a serious lacuna.

One of the chief ways that ableism brings about this regrettable state of affairs is by undermining effective patient–provider communication (PPC), which is to say, by generating communication failures between disabled patients and their typically nondisabled providers.⁵ An important caveat is in order here: Because empirical research on ableism and PPC is scarce, much of our analysis will be speculative in nature. Hence, in articulating some of the mechanisms by means of which ableism warps PPC, we take ourselves to be hypothesizing, rather than proving, a potential causal connection between these terms, and we take ourselves to be calling for further empirical research that might confirm or deny our hypothesis. More than anything, we offer this analysis in the hope of providing a research program for other medical humanists, clinical researchers, and social scientists to pursue in greater detail.

One of the reasons there is so little research on the subject of ableism, PPC, and medical error is because of the lack of dialogue between two bodies of research: the medical literature on PPC and the fields of disability studies and philosophy of disability.⁶ On the one hand, the medical literature on PPC is extensive, but comparatively little of it deals specifically with disability. That which does, however, typically does not deal with ableism understood as an epistemic schema that affects both *what* and *how* providers “know” disability and interact with people with disabilities as epistemic agents. On the other hand, since at least the 1980s, experts spanning the humanities and social sciences who work in disability studies have shown that ableism harms people with disabilities in a number of ways (see, e.g., Shakespeare 2014; Wong 2009). For example,

it harms them economically (e.g., by contributing to discrimination in employment and housing opportunities), socially (e.g., by contributing to their exclusion from public spaces and social interaction), and politically (e.g., by contributing to their denial of sound political representation and equal rights). Yet, what these experts have not documented in an equally nuanced manner is how the harm of ableism manifests itself in relation to medical error. When medical experts investigate misdiagnosis patterns, failures in PPC, and the causes of low patient satisfaction, among other things, they rarely investigate it along the lines of disability and specifically with respect to ableism understood as an epistemic schema. The result is a gap in the literature that demands rectification. This paper is a first step in tackling this lacuna by demonstrating the central and general role of epistemic schemas in poor PPC leading to medical errors and, secondly, by arguing more specifically that ableism is a significant contributor to poor PPC with patients with disabilities.

POOR PPC LEADS TO PREVENTABLE MEDICAL ERROR

Since at least the 1980s, it has been well established in the medical communication literature that PPC plays a key role in determining health outcomes (Stewart and Roter 1989; Kaplan, Greenfield, and Ware 1989; Stewart 1995). A vast body of clinical and social scientific research shows that effective communication between patients and providers leads to *better* health outcomes (Street et al. 2009)⁷ and that, conversely, poor communication harms patients, increasing the likelihood of medical error. Indeed, studies of semi-structured interviews between patients and providers (Sutcliffe, Lewton, and Rosenthal 2004) and of medical malpractice lawsuits (Beckman et al. 1994; Vincent, Young, and Phillips 1994; Hickson et al. 2002; Huntington and Kuhn 2003) overwhelmingly suggest that, while not the only variable in play, breakdowns in PPC lie at the heart of the problem of error in medicine.

Communication failure—which includes any situation in which what Alvarez and Coiera (2006) dub ‘the communication space’ of medicine is diminished, obfuscated, or obstructed—leads to medical error in at least two ways. First, whenever an encounter between patient and provider is not conducive to mutual understanding, patients are less likely to be forthcoming about their symptoms and concerns. This may be because they do not feel comfortable enough to share them with their physician or because they don’t understand what might count as medically relevant information and what might not. Either way, communicational failure

reduces the amount and quality of diagnostically-relevant information that a medical expert receives from the patient. Even in cases where patients have a condition for which an objective diagnostic test exists, diminished communication can threaten the diagnostic moment. As anyone with clinical experience will attest, not all salient information can be gleaned from diagnostic tests, and even information that can be gleaned from them cannot always be properly interpreted in the absence of patient input (Wanzer, Booth-Butterfield, and Gruber 2004; Stewart et al. 2000).

Second, poor PPC can destroy the trust that patients need to have in providers in order for the clinical encounter to run smoothly. Although many people think of the experience of going to the doctor as a one-off event that exists largely in isolation, this is rarely the case. Much of the time medical care is a protracted process that requires multiple visits to the clinic, interaction with testing laboratories, and even more encounters between the patient and what at times appears to be an interminable flow of medical knowers (nurse practitioners, residents, physician assistants, etc.). For this entire process to work, patients and providers must build a framework of trust that enables them to recognize each other as partners in a mutually reciprocal relationship. Unfortunately, poor PPC erodes this trust by making patients feel unheard and under-valued, as if the very experts on whom they depend do not see them as persons to be cared for but as names on a list to be crossed off (Neumann et al. 2009, 342). A trusting relationship between patient and provider determines the extent to which patients listen to what doctors say, whether or not they adhere to medication protocols, and even whether or not they seek out care when non-emergency medical incidents arise again in the future. Trust, in short, has a substantial effect on the quality of care and on overall health outcomes. Repairing that trust after it has been broken is no easy task (Berlinger 2005). The feelings of desperation, isolation, and frustration experienced by patients who report poor PPC eat away at the mutual trust that is the bedrock of medical practice.

Although medical error can change people's experience of the health care system for the worse and corrode their trust in this system, it also kills morale among health care providers, which research shows can further compromise quality of care (Kohn 2001). And, most importantly, it harms patients in tangible, and sometimes horrendous, ways. The medical error literature is replete with illustrations of the catastrophic effects that medical errors can have on patients, which range from intense physical and psychological suffering (on account of, say, having the wrong leg

amputated) to severe chronic illness or death (on account of, say, being systematically misdiagnosed) (IOM 2000).

ABLEISM AS AN EPISTEMIC SCHEMA

Within both social epistemology and medical error research, the concept of ableism is rarely utilized to understand the types of epistemic injustices and harms pertinent to people with disabilities. This claim is true both with respect to studies examining epistemic injustice in relation to mental illness (Crichton, Carel, and Kidd 2017; Sanati and Kyratsous 2015; Kurs and Grinshpoon 2018; Dohmen 2016) and those that discuss a wider range of disability experiences (Reiheld 2010; Ho 2011; Li 2016; Buchman, Ho, and Goldberg 2017; Tremain 2017; Scully 2018). Even in the philosophy of disability, the concept of ableism sometimes plays a secondary analytic role. For example, in *The Minority Body* Elizabeth Barnes defines ableism not in terms of an epistemic schema, but as “social prejudice and stigma directed against the disabled in virtue of the fact that they are disabled” (2016, 5).⁸ More often than not, she deploys the term as a way to understand counterfactual claims about the badness of disability in a world without ableism (2016, see especially 59, 66, 92, and 163). While ableism certainly involves prejudice and stigma, we hope to show it involves much more than that.

We argue in this section that, specially insofar as our knowledge about people invariably involves assessments of and knowledge about their abilities, ableism can regularly impact how we interact with others as epistemic agents. In other words, because ability expectations are central to the conception of any given individual, ableism serves to determine *in essential ways* how and what people know and do not know about their own experiences and that of others. It is in light of the breadth and depth of ableism’s impact that we suggest research on epistemic justice, medical error, and their connection would be improved through a greater focus on ableism and the ways in which it functions as an epistemic schema.

With respect to its role as an epistemic schema, we will use the term *ableism* to mean the assumption that forms of embodiment considered “abnormal” are necessarily experienced both differently and negatively in comparison to forms of embodiment considered “normal.” Ableism functions as a framework for preemptively knowing about the abilities and ability expectations of bodies based upon their perceived disability status, including even *what it is like* to have a particular body and mind. Ableism leads providers to “otherize” patients with disabilities.⁹ Like racism and

sexism, the concept of ableism involves both descriptive and normative aspects. Ableism is a way of understanding the quality, meaning, value, and differences of human life through the lens of abilities and ability expectations shaped via socially dominant conceptions of normality. While the idea of normality is historically and culturally variable, in modern medical contexts it takes on a far more specific meaning (Cryle and Stephens 2017; Davis 2013).¹⁰ Modern medicine invariably makes assumptions about “normal” bodily shape, size, motion, and function. It also perforce makes specific assumptions based upon statistical analyses of bodily metrics, ranging from those that determine everything from “normal” blood pressure to “normal” levels of anxiety.

Part of what is so pernicious about the way ableism functions inside of medical institutions and across various domains of medical practice is the way that it forecloses upon the vast range of meanings of disability as a fact of human life, as well as the vast range of discrete disability experiences. The term ‘disability’ is notoriously hard to define, serving to cover everything from Albinism to cystic fibrosis to Autism to Deafness to short stature to ADHD. Ableism flattens out these differences in deeply problematic ways.

Consider that since the origins of the field of disability studies in the 1980s, a core distinction has been made between medical and social models of disability. On the medical model, disability is a personal tragedy or hardship resulting from a congenital abnormality, environmental accident, or result of old age. In other words, disability is a bad thing that befalls one. On social models of disability (sometimes erroneously referred to as *the* social model), a core distinction is made between ‘disability’ and ‘impairment.’ One is impaired insofar as one’s body is different in ways that impact one’s ability to function in the world as compared to most people. One is disabled, however, insofar as one is negatively impacted by the treatment of others on account of one’s impairment, including impacts due to larger societal norms and institutions. What is crucial about social models of disability is the way they point to the social, cultural, political, and historical factors that shape how one is treated, including how one is treated by medical experts on account of one’s particular body and mind.¹¹

Ableism persists in medical contexts especially through the dominance of the medical model of disability inside of medical education, ranging from pre-med to residency to continuing education and spanning across all manner of medical institutes and centers (Iezzoni and O’Day 2006; Iezzoni 2006; Reynolds 2018). Insofar as medical providers assume

that a disabled patient is automatically a person dealing with a personal tragedy or hardship, they operate with an epistemic schema that results in them pre-judging and mis-judging their patients. The epistemic schema of ableism leads providers to not only misunderstand the lived experience of their disabled patients, but also to think that they *know* what being disabled is like.¹²

Ableism thus leads to epistemic ignorance about disability in multiple respects and to epistemic injustices as a result. As we will discuss in greater detail in the next section, it leads providers to dismiss and remain ignorant of the qualitatively distinct differences between different kinds of disabilities, to exhibit over-confidence concerning claims about disability experience in general as well as specific types of disability, and to distrust, discredit, or otherwise dismiss people with disabilities as experts about their own experiences and that of their communities. The negative effects of the epistemic schema of ableism are manifold. To better understand the effects of this epistemic schema, we will now lay out the four principal mechanisms by means of which ableism undermines PPC.

ABLEISM'S IMPACT ON PPC: FOUR MECHANISMS

Let us begin by observing that we already know: PPC failures are more common when it comes to people with disabilities (Blackstone 2015; Nordness and Beukelman 2017), and patients with disabilities suffer more misdiagnoses than non-disabled patients. For example, people with intellectual and developmental disabilities are systematically misdiagnosed (Mastroianni and Miaskoff 1997). Well into at least the 1990s, people with moderate hearing loss were misdiagnosed as “mentally retarded” (Berke 2007). Today, people with cerebral palsy “are at three times the risk of experiencing adverse events as compared with adults without preexisting communication vulnerabilities” (Nordness and Beukelman 2017, 334; Hemsley and Balandin 2014). Meanwhile, physical impairments are regularly underdiagnosed in people with intellectual disabilities (Kiani and Miller 2010), as are cognitive impairments in people with spinal cord injury (Tolonen et al. 2007). All this we know. What we need to investigate further is *how* these failures in communication and misdiagnoses come into being and interact with one another. What causes these breakdowns in PPC and produces such an asymmetrical distribution of the possibility of error along the lines of disability? We argued above that the answer turns on a dominant schema through which people without disabilities “see” and “know” disability, which is to say, the schema of ableism. Ableism brings about these disastrous effects by means of at least four mechanisms.

The first is what Fricker (2007) calls *testimonial injustice*. This is a form of epistemic injustice wherein a speaker's testimony is unfairly downgraded in credibility thanks to a prejudice on the hearer's part. Put otherwise, testimonial injustice occurs when a social agent does not take someone else's testimony as credible *because of the social identity of the testifier*. This kind of injustice treats its targets as agents incapable of contributing to a community's shared knowledge resources, an injustice which is associated with treating them as lacking the very capacity to reason—a feature typically (and problematically) held to be central to the attribution of personhood (Fricker 2007, 44; Scully 2018, 111). The social epistemology literature has produced a number of illustrations of testimonial injustice, such as the (historical) case of Black slaves whose testimony was not seen as authoritative in American courts unless “validated” by the testimony of a white man, or the case of women rape victims whose testimony is not believed by the men in their lives because those men impute onto women a credibility deficit concerning sexual violence.

Testimonial injustice occurs in medical spaces when, for example, a doctor holds a group-based belief that black people have higher pain thresholds than those who are not black (Hoffman et al. 2016). In doing so, they commit a testimonial injustice against their black patients by discounting the validity of their testimony concerning the extent and quality of pain they are experiencing. Similarly, a disabled person with a mobility impairment suffers from an arbitrary credibility deficit when medical knowers, for example, discount their testimony concerning the specific reason they entered the clinic (“I’ve got a recurring rash I think is due to an allergic reaction”), focusing instead on their impairment and tying diagnosis solely to it (“It’s probably from rubbing up against your wheelchair”). This example is not an innocent instance of misunderstanding, because the person with a disability is being “seen” through the schema of ableism. On that schema, being disabled means being *worse off* by virtue of one's disability, and so even information that is not clearly related to an impairment (e.g. a spinal cord issue leading one to use a wheelchair) can easily become a *reason* for potentially any medical issue (including a rash). By not treating the person as a fully-fledged epistemic agent, but instead interpreting them through an ableist lens, their testimony (“I’ve got a recurring rash I think is due to an allergic reaction”) is down-graded in credibility. As this happens more frequently, mistrust on the part of the patient increases. Testimonial injustice, then, is not simply a phenomenon that occurs interpersonally. Insofar as it results from epistemic schemas that track historically oppressed groups and that

depend upon prejudicial knowledge and forms of knowing, patterns of testimonial injustice can be systemic and pervasive. These patterns can become historically entrenched within the social, political, cultural, and even economic norms of a community.¹³

According to Jackie Leach Scully, medical experts often ascribe “a global epistemic incapacity to people affected by impairment” because they assume that any disability, whether cognitive or physical, manifests itself as an incapacity to engage in meaningful dialogue with non-disabled agents (Scully 2018). In one of the few, but growing number of studies of epistemic injustice in health care, Carel and Kidd contend that medical professionals frequently and presumptively attribute “characteristics like cognitive unreliability and emotional instability” to people with disabilities in ways that “downgrade the credibility of [the] testimonies [of people with disabilities]” (2014, 529).

This is confirmed by research in disability studies and the philosophy of disability. For example, in *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, S. Kay Toombs describes her experience of going to the doctor in a wheelchair with her husband (Toombs 1992; see also 1987). She reports that people would talk to her husband as if she were not there, assuming that being in a wheelchair meant she was non-verbal. This feeling of not having one’s word heard by those in positions of power is widespread among people with disabilities, which indicates that ableism brings about the regular disregard of the knowledge claims (testimony) and lived experiences (phenomenology) of people with disability. Smith (2009) claims that people from all over the disability spectrum report a feeling of invisibility in medical spaces. She writes:

Those with a disability are significantly more likely than persons without a disability to perceive that the physician does not listen to them, does not explain treatment so that they understand, does not treat them with respect, does not spend enough time with them, and does not involve them in treatment decisions. (2009, 206, cf. 213–14).

And the invisibility is not just social (i.e., feeling that medical experts do not recognize one’s presence in a shared environment), but also testimonial (i.e., feeling that these experts simply do not take one’s word as meaningful or consequential even when they elicit it directly). A good example of this is a recent study that concluded that medical experts overwhelmingly *do not* believe the testimony of people with chronic fatigue syndrome (Blease, Carel, and Geraghty 2017). This problem takes on a particularly acute

form when it comes to people with communicative disabilities (Hemsley and Balandin 2014).

A second mechanism through which ableism bankrupts PPC is what Cassam (2017) calls *epistemic overconfidence*.¹⁴ We have seen that ableism produces credibility deficits for people with disabilities, which results in an imbalance between social agents on the basis of disability status. This imbalance is compounded by another factor that is not unique to disability, but that has unique implications for it given the way that disability is often seen solely via a medical lens. This second factor is the credibility excess medical experts enjoy as a matter of course.¹⁵ We habitually extend long lines of epistemic credit to medical experts, especially physicians; we assume that they must know what they are talking about even in cases where the evidence points to the contrary. In some sense, of course, it makes sense that we would give medical experts a credibility excess in medical settings, since the reason we go to see a doctor is precisely because we assume that the doctor's knowledge of health and illness far outstrips our own.

The problem is that doctors often internalize this epistemic privilege riding on the back of their expert status to such a degree that it can mutate into epistemic overconfidence. This term refers to an excess of self-assurance about what one knows and how far one's knowledge extends. Epistemic overconfidence impedes the ability of doctors to exercise the kinds of epistemic self-monitoring we expect of them and that is expected of them by their own profession. It can lead to medical error by making experts less likely to question first intuitions, to request further diagnostic tests, to entertain alternative hypotheses, to consider referring patients to other specialists, to get a second opinion, to reflect more critically about social conditions and determinates of health, and so on—all of which can culminate in a misdiagnosis and can serve to undermine trust with a patient. In short, it produces in experts an active ignorance that blocks them from recognizing the limits of their own knowledge and its impact on care.

For example, it has been reported that epilepsy is regularly misdiagnosed among people with intellectual disabilities because doctors cannot tell the difference between epileptic events and non-epileptic self-stimulatory events (Chapman et al. 2011). Yet, the problem is not necessarily that doctors *do not know* how to tell the difference per se. The problem is that they often *do not know that they do not know* how to tell the difference, and they jump straight to a diagnosis when they should be getting a second

opinion, discussing things further with the patient, more substantively educating themselves about epilepsy as well as about various expressions of certain sorts of intellectual disability, or referring the patient to a more qualified expert.

As Cassam (2017) formulates it, epistemic overconfidence can affect all patients independently of disability status. But we argue that ableism amplifies it in particular ways. Consider the so-called “disability paradox.” This term refers to the fact that non-disabled people rate the quality of life of people with disabilities significantly lower than people with disabilities do. Albrecht and Devlieger formulate the paradox this way: “Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence?” (1999, 977). One would expect that among non-disabled people, health care providers would buck this trend since presumably their expert knowledge of medicine translates to a better understanding of impairment than the average person. But the exact opposite turns out to be true. Medical experts have an inaccurate perception of the quality of life of disabled people, and they systematically rate the quality of life *lower* than the average non-disabled person does (Basnett 2001).¹⁶ What is more, because of their expert status, medical practitioners are unlikely to call into question their own assumptions, which are continuously reinforced by the medical model of disability in which they have been reared and to which in most cases they remain committed. Research concerning the disability paradox suggests that doctors often walk into a consultation with fixed and fundamentally flawed assumptions about disability.

Bioethicist Anita Ho argues that this disability-specific overconfidence on the part of experts puts disabled patients in a dangerous catch-22 situation in which (i) they may put themselves at risk if they do not trust their doctors (given that trust correlates with positive outcomes) and, somewhat paradoxically, (ii) they may put themselves at even higher risk if they *do* trust them (since trusting an epistemically over-confident expert can lead to harm). “Trust may increase epistemic oppression and perpetuate the vulnerability of people with impairments” (Ho 2011, 113). A doctor who believes that he or she is the leading authority on disability, even when a disabled person is in the room, may put this patient in harm’s way, even if unintentionally. Ho continues:

While more empirical evidence is necessary to ascertain the multiple determinants of patients’ dissatisfaction, numerous studies show that [health

care providers] continue to hold negative attitudes and assumptions toward impairments and the quality of life of people living with these impairments. Reported negative attitudes raise questions of whether these patients can take professionals' proclaimed good will for granted. (2011, 113)

When the good will of the medical expert can no longer be taken for granted, all bets are off for people with disabilities. How could one, in good faith, ask disabled patients to put their trust, perhaps even their lives, in the hands of a provider who believes that their quality of life is poor anyways *and* who is so confident about this belief that they see no point in even putting it up for debate? This has serious ramifications not just for particular providers, but for medicine as a whole. As Grasswick (2018) has argued, when an institution such as medicine has historically failed members of a specific community, the latter have good reasons to mistrust the institution as a whole even if they do not necessarily mistrust the particular individuals who represent it.

To be clear, it may be true that a provider has more medical information about a particular impairment and rightfully considers themselves to be an expert in that sense—but medical information is wholly insufficient to understand the *lived experience* of person with a particular impairment, an experience saturated with social, cultural, political, and historical complexities typically untouched by even the best and most capacious forms of medical education. It is the transferal of confidence in medical knowledge concerning impairments to confidence in knowledge concerning the *meaningfulness* of living with a given impairment that helps produce epistemic overconfidence.

A third mechanism operative in medical spaces is *epistemic erasure*. Epistemic erasure functions by removing entire categories or swaths of hermeneutical resources from a communicative space where they would otherwise reside because the speaker's perceived social identity is erroneously thought to render those subjects categorically inapplicable.¹⁷ In the case of disabled patients, epistemic erasure vitiates communication by removing entire subjects of possible medical interest from conversation and thereby foreclosing from the outset certain avenues of dialogue that might not have been foreclosed in the absence of disability.

Consider sexual health. One of the ways in which ableism operates is by turning people with disabilities into objects of pity, which is often accomplished through the de-sexualization of disabled bodies.¹⁸ In light of this de-sexualization, many abled-bodied individuals express surprise or even shock upon learning that many disabled people have typical sex

drives and lead fully active sex lives. Healthcare providers are not exempt from this way of thinking and, like the rest of the population, tend to de-sexualize people with disabilities (Wieseler forthcoming).

This prejudice is likely to rear its ugly head in the personal lives of providers, including in the choices they make about who counts for them as a possible object of romantic or sexual interest and who does not. But this prejudice will also arise in their professional lives, as it may cause them *not to* pose certain questions, such as questions concerning sexual health, to their disabled patients, even if those questions are typically routine. For example, Shakespeare et al. note:

By assuming that people with disabilities are not sexually active, physicians may exclude them from health information or screening that non-disabled people receive as a matter of course—for example, for sexually transmitted diseases, cervical cancer, or HIV. (2009, 1816)

Of course, the de-sexualization of disabled bodies is offensive. But it is medically dangerous, too. The route from epistemic erasure to medical error is both *direct* and *indirect*. Directly, we can say that epistemic erasure does not *lead* to medical error but is itself an expression of it. Indirectly, it leads to medical error in the same way testimonial injustice does—that is to say, by limiting the information patients are called upon to provide, as well as that which they feel comfortable in providing, and, consequently, the sorts of diagnoses providers are in a position to make.¹⁹

People with disabilities often report being treated by abled-bodied individuals as objects of a violent and voracious curiosity, as “freaks” to be looked at and gazed upon (Garland-Thomson 1996). This is because ableism teaches non-disabled people to “reduce” people with disabilities to their disabilities, thereby objectifying them. In the perceptual field of one under the sway of ableism, a person with epilepsy registers simply as an epileptic object, a blind person as a walking cane on the precipice of danger, and a person in a wheelchair as one “confined” and “bound” to ever-limited self- or other-pushing. As van de Ven et al. (2005) point out, sometimes the only way to explain able-bodied people’s behavior in the presence of disability is to assume that, somehow, “they only see the disability and not the person behind it.” Disability, which is to say, ableist assumptions about disability, crowds their perceptual field so thoroughly that they are incapable of *not* looking at it, *not* talking about it, *not* being distracted by it. The tricky part, here, of course, is that it is not the disability that is responsible for producing this effect, but the way in which the disability is perceived and interpreted by the abled-bodied individual.

It is an effect of ableism as a way of knowing about the world and others. The problem lies in the gaze—and epistemic schemas—of the able-bodied.

Like all of us, medical experts are a product of their environment. Yet, medical experts are also part of an institution with a long and dark history concerning disability. Historically, medicine has played a central role in the construction of disability as both spectacle and tragedy, as something to be gawked at and pitied. This explains, in part, why the disability community tends to distrust the medical establishment and its historically teratological understanding of disability.²⁰ And while dominant social narratives of the inevitability of social progress incline us to believe that we have transcended this dark history, the ongoing experiences of people with disabilities suggest otherwise. They suggest that medical providers too often continue to treat disability as something to be poked and prodded, as a fascinating object to be stared at and squinted at.

The fourth mechanism by which ableism leads to medical error depends on this unique dynamic whereby disability becomes so visible, indeed hyper-visible, that it derails PPC from the real locus of medical concern. We call this *epistemic derailing*. Epistemic derailing occurs when the qualities and features assumed to track a speaker's perceived identity overdetermine hermeneutic space, preemptively shutting down more relevant hermeneutic resources and pathways. We here use the term 'epistemic derailing' to pick out one of effects of the medical and able-bodied gaze: It erroneously narrows the communicative space between a disabled patient and a provider.²¹ It can prevent medical experts from truly listening to what the patient has to say. By making providers assume from the start that the patient is in front of them *because* of their disability (i.e. the phenomenon that crowds the expert's field of perception), ableism derails the conversation and places an undue epistemic burden on the patient to constantly redirect the doctor's gaze back to what matters from a medical standpoint: their actual symptoms.

Let us briefly look at a case of epistemic derailing that is not directly connected to paradigmatic cases of disability: the treatment of HIV-positive people. HIV-positive patients often find that doctors cannot seem to get past the fact that they are HIV-positive and assume that whatever complaints they make are due to their status. This is why depression is severely under-diagnosed in people living with HIV (Rodkjaer et al. 2010)—doctors, held epistemically captive by the concept of HIV, may assume that patients are simply sad about having contracted HIV. Here, the over-attentiveness to HIV status interacts with other background assumptions, such as beliefs about how sad and meaningless life with HIV

must be, to create a magnetic field that pulls PPC in a specific direction and that, ultimately, leads to medical error and medical harm.²²

In summary, patients with disabilities experience this derailing effect of ableism in terms of an over-inquisitiveness on the part of providers about their disability status and a cascade of assumptions about patients with disabilities that are untethered from any concrete facts or judgments based upon the patient's actual experience. This levies a hefty "epistemic tax" on people with disabilities, who suddenly shoulder the burden of educating a non-disabled person, in this case a medical provider, about disability (Kattari et al. 2018). It also undermines the dialogue between patient and provider because the patient now understands that his or her disability takes so much space in the provider's imaginary that the latter will devote most of her or his epistemic resources to it and perhaps it alone.²³ Both of these forms of testimonial injustice or oppression can lead to what Dotson calls "testimonial smothering," wherein "the speaker perceives one's immediate audience as unwilling or unable to gain the appropriate uptake of proffered testimony" and thus self-censors (2011, 244). Dotson continues:

Testimonial smothering, ultimately, is the truncating of one's own testimony in order to ensure that the testimony contains only content for which one's audience demonstrates testimonial competence. Testimonial smothering exists in testimonial exchanges that are charged with complex social and epistemic concerns." (244)

In the contexts under discussion, a patient with disabilities may purposely limit the information they provide because they know that, if included, additional information will not be heard and may even exacerbate the epistemic and communicative issues at play. Motivated to combat this phenomenon, Shakespeare et al. (2009) draw an important distinction between "need to know" and "want to know" questions. The first category refers to questions that providers should ask; the second, to those they *tend* to ask out of ignorance and curiosity whenever disability enters the scene. The dark side of "want to know" questions is that, aside from re-enacting medicine's historical treatment of people with disabilities as freaks and monsters, they cast a shadow on "need to know" questions. When providers cannot see anything but the disability, they cannot think of anything but the disability; and when this happens, they cannot come up with the questions whose answers they really "need to know." These questions drop out of focus and, before providers realize it, their hyper-

attentiveness to the patient's disability snowballs into a situation in which patients and providers may be technically exchanging words but are not communicating in ways that will promote positive health outcomes.

ABLEISM AND CONTRIBUTORY INJUSTICE

The four aforementioned mechanisms—testimonial injustice, epistemic overconfidence, epistemic erasure, and epistemic derailing—are all functions of the ableist schema that mediates how providers think about, and relate to, their disabled patients. But what is it about providers, or the medical establishment more generally, that cultivates this ableism? We submit that at the root of these mechanisms is the medical community's lack of engagement with critical, non-medical modes of knowledge concerning disability, including and especially with respect to knowledge created by disability communities themselves, as well as bodies of work which draw directly on such knowledge, as literature in disability studies and philosophy of disability regularly does. In other words, a root cause of ableism in medicine is *medicine's own understanding of disability* as an objective lack rather than as a diverse set of phenomena that are thoroughly socially mediated. This reliance constitutes a form of what Dotson calls "contributory injustice," which turns on the willful exclusion of a certain set of hermeneutical resources from the worldview of a socially-privileged agent. Dotson writes:

Contributory injustice is caused by an epistemic agent's situated ignorance, in the form of willful hermeneutical ignorance, in maintaining and utilizing structurally prejudiced hermeneutical resources that result in epistemic harm to the epistemic agency of a knower. (2012, 31)

Contributory injustice results from histories of epistemic exclusion and entrenched relations of power. Dotson explains:

[Miranda] Fricker [in her book *Epistemic Injustice*] seems to assume that there is but one set of collective hermeneutical resources that we are all equally dependent upon. I do not share this assumption. We do not all depend on the same hermeneutical resources. Such an assumption fails to take into account alternative epistemologies, countermythologies, and hidden transcripts that exist in hermeneutically marginalized communities among themselves. [...] The agent plays a role in contributory injustice by willfully refusing to recognize or acquire requisite alternative hermeneutical resources. [Gaile] Pohlhaus calls this refusal willful hermeneutical ignorance. (31–32)

Put differently, contributory epistemic injustice results from what Dotson (2014) and Scully (2018) call *epistemic exclusions*. Scully writes:

Epistemic exclusion is the notion that social position and power align with certain forms of epistemic power, that is, power over the ways in which knowledge is accumulated within, acknowledged by, and disseminated through communities, with the result that some kinds of knowledge can be kept out of mainstream sight. (2018, 107)

Contributory injustice is thus one form of epistemic exclusion. For example, a white provider who has completed her medical education may see no reason to learn about the history of medical practice, much less the way that its history affects the differential treatments of patients along lines of racialization today. She may assume that her education, especially if it comes from a privileged institute of higher education, is sufficient. She may assume that her life experience has taught her all she needs to know about social relations. Why would the provider need to draw upon hermeneutic resources from communities of color to learn about racism and its history and contemporary role in medicine? Or, analogously, sexism? Or cissexism? Or ableism? By not attending to such bodies of knowledge, a provider commits contributory injustice. Perhaps the simplest way to think about contributory injustice is in terms of which bodies of knowledge register to people in positions of privilege as legitimate or illegitimate, and which simply fail to register at all. Contributory injustice is about the ways in which relations of oppression can be produced and exacerbated by the implicit choices we make about which hermeneutic resources matter and which do not.

As Dotson notes, one assumption of the theory of contributory injustice—and, in this regard, she differs from Fricker—is that there is no such thing as “the” pool of hermeneutic resources because not all members of a political community (say, the United States) interact with the world using the same stockpile of hermeneutic resources. Rather, different communities develop different modes of thinking about the world (or a particular slice of it) that may or may not coincide with the mode of thinking that happens to be dominant. Hence, when we witness instances of epistemic injustice, it is possible that the problem is not that a socially privileged agent unjustly doubts someone’s testimony or that the community is at a loss for the kinds of hermeneutical resources the testifier needs to shed light on an important aspect of her experience. In these cases the problem is that while there *are* hermeneutic resources that tackle the specific problem at hand, the socially privileged agents are not

familiar with them because they have no interest in learning about them, since doing so is likely to challenge their own epistemic schemas. They may in fact have a vested interest in *not* learning about them insofar as that ignorance maintains their privileges and attendant experiences in the world.

An illustration will make this clearer. Gender-affirmation surgeries (GAS) are often discussed in the medical and bioethical literatures as controversial, because medical experts disagree about whether they count as “therapy” or “enhancement” (Hongladarom 2012). But this way of thinking about GAS leaves trans individuals in a terrible double bind. On the one hand, if trans communities accept the therapeutic interpretation, then they must also accept the secondary claim that GAS are essentially a corrective, a “fix” for the condition that the DSM-V calls “gender dysphoria.” This, in turn, implies that to be trans *is* to have a “mental disorder.” As Emma Inch (2016) rightly observes, this medicalization of trans identities fuels transphobia and contributes to the ongoing marginalization of trans subjects. On the other hand, if trans communities opt for the enhancement interpretation of GAS, which is not to exclude other interpretations, including “gender euphoria,” as a way of resisting the adverse effects of medicalization, they can be left in a medically-vulnerable situation since, under contemporary medical-legal frameworks, trans people often need a diagnosis to change their names in legal documents and to offer a socially-intelligible explanation of their situation to friends and family members. In many places, a diagnosis is required for GAS.

A medical diagnosis, in addition to exercising a social control function in modern societies, can help individuals gain access to care and treatment. Gender-affirmation surgery and hormone treatments are very expensive, and the fear is that neither publicly-funded health providers, nor private medical insurance schemes will pay for treatments that are not prescribed with the intention of relieving a diagnosed condition. Some trans people ultimately view the label of disorder as the price that must be paid for access to treatment. For some, medical treatment truly is a matter of life or death, and they fear the removal of it from diagnostic manuals could have devastating consequences. Members of the WHO Working Group acknowledge this quandary and insist that diagnostic manuals like the ICD “find a balance between the competing issues of stigma versus access to care” (Inch 2016, 199).

The double bind between medical stigmatization and access to medical services is real and painful, but it may not be inevitable. This bind is only an inevitable effect of the specific hermeneutic resources the medical

community mobilizes when it thinks about GAS and trans identity, which is what makes it a good example of contributory injustice. As soon as the hermeneutic resources of the medical establishment are used to frame discussions of GAS (Is it enhancement? Is it therapy?), it becomes difficult to think about this complex phenomenon in any other way.

But the trans community—especially trans scholars working in the field of trans studies—have generated an entire body of knowledge that affords radically different understandings of what it means to be trans. The trans community, in other words, has generated its own hermeneutic resources (including concepts, questions, methods, problematics, ways of framing, etc.) to think about trans identity in ways that evade the therapy/enhancement double bind. If the therapy/enhancement double bind continues confining trans people, this is because the medical establishment continues to approach GAS using hermeneutic resources that are outmoded, ill-suited, prejudicial, and ultimately harmful—resources that have been historically produced without the direct input of the trans community itself. From the standpoint of social epistemology, the medical establishment commits contributory injustice against trans individuals by privileging a set of hermeneutic resources that are prejudiced but do not register as such and by ignoring alternate resources, including those directly from the trans community.

The same can be said in relation to the disability community. Because the medical establishment on the whole embraces the medical model of disability, it relies on hermeneutic resources that were not designed with disabled people in mind and that are often directly at odds with how disability communities understand the meaning of disability and with how disabled people experience their own lives. The four mechanisms of epistemic injustice we have outlined here result from an active ignorance on the part of providers about how disabled people understand themselves and their own experiences, not to mention how the medical model harms people with disabilities. In a world in which multiple alternative models of disability exist and the medical community has the power to access them, engage them, and incorporate them into its institutional structure, failure to do so constitutes contributory injustice because it reflects a decision on the part of the medical community that the harms its hermeneutic resources inflict on disabled patients do not matter as much as the comfort it itself takes in the continued use of these resources.

MEDICAL ERROR IN A HISTORICAL AND SOCIAL CONTEXT

We have argued that testimonial injustice, epistemic overconfidence, epistemic erasure, and epistemic derailing undercut PPC and expose people with disabilities to an unjustifiably high risk of medical error and medical harm. Of course, medical errors that terminate in suffering are always harmful insofar as they cut against the grain of the two most fundamental interests of patients, irrespective of disability status: their interest in getting better and their interest in not getting worse. While error is obviously good for no one, we argue that medical errors are *particularly* harmful when they happen to people with disabilities and other marginalized identities, because they tend to not only have first-order physical effects (e.g. suffering), but also second-order symbolic effects. Furthermore, they are particularly harmful at a first-order level insofar as they contribute to the disproportionate distribution of error against an already marginalized group.

This symbolic harm, however, can be interpreted in a different way. When a disabled patient suffers a first-order medical harm at the hands of experts because of the ableism that permeates the institution of medicine, this harm takes place not just in a historical context in which the history of medicine is implicated, but also in a social context in which the collective imaginary already conflates disability with pain and suffering. What Reynolds (2017) calls “the ableist conflation” is the persistent conflation of experiences of disability with experiences of pain, suffering, and disadvantage. That is why the most common reaction to disability is an uncritical rush to pity and an assumption of low quality-of-life. By equating disability with suffering in this way, non-disabled individuals construct in their minds an identity for people with disabilities that denies the latter agency and the possibility of a rich, meaningful life. While it is possible for the non-disabled to suffer, the ableist conflation leads non-disabled people to think it is impossible for the disabled *not* to suffer, restricting both the facts and imagined possibilities of a life. This conflation produces a pernicious “master narrative” (Lindemann 2001, 157ff) that defines what it means to be disabled from the vantage point of the non-disabled.

We have also argued that schematic epistemic errors deserve more attention in the medical error literature. While epistemic errors are frequently referenced in this literature, most of the time they are reduced to what we call “factual errors,” which are errors resulting from lack of information. But we showed that medical errors can occur not only because of *what* providers know, but also because of *how* they know. Schematic

epistemological errors pertain to “ways of knowing” that involve entire constellations of values, norms, biases, impulses, desires, fantasies, and assumptions of which we are sometimes unaware but which nevertheless shape our activities of knowing in any given milieu. It is these schematic epistemological errors, we hypothesized, that are largely responsible for the unequal distribution of medical errors.

Finally, we would like to close by suggesting that schematic epistemic errors deserve special attention in the medical error literature because of their *recalcitrant* nature. Schematic epistemic errors not only involve the ins and outs of a hyper-complex health care system, but also the ways in which epistemic agents interact with this system, with one another, and with the broader local, national, and international environments of which this system is only one component. Epistemic errors can persist despite improvements in medical education and the efforts of individual providers and teams aimed at reducing medical error. In short, they are obdurate because they are not explicit, easily localizable, or particularly amenable to change. On the contrary, they are distributed, implicit, and resistant to change. Often, they are the result of long-acquired habits of thinking and knowing that sediment and ossify with the passage of time—and these habits reflect entrenched hierarchies of social power that reinforce difficulties faced by patients from vulnerable populations. For this reason, individuals often lack the will, not to mention the ability, to uproot them. Calls to mobilize against them can even be met with collective resistance. Schematic errors can serve to undermine care even when providers are actively working to address factual-based errors and actively working to provide equal care across populations.

Schematic errors present a special problem for patients with disabilities, given the fraught historical relationship between disability and medicine. Medicine has surely contributed to improving the lives of some people with disabilities, but it has also defined disability and treated people with disabilities in ways that harm them. Medical errors due to ableism literally add insult to injury insofar as they crystallize the medical institution’s historical disregard for and disparagement of the lives of people with disabilities (Nielsen 2012).

Preventable medical errors due to ableism only fuel this conflation and further re-entrench an identity that has been constructed (with the historical aid of medicine) *for* people with disabilities, *without* them—the inverse of one of the most important maxims of the disability rights movement: *nothing about us without us*. And this forms a vicious circle.

Ableism leads to medical error. Error leads to first-order harm. First-order harm makes people with disabilities suffer. This suffering, when perceived by others under the aegis of ableism, reinforces the ableist conflation upon which ableism rests and contributes to second-order symbolic harms and damaging master narratives.

At some point, persistent medical error ceases to be a purely medical problem connected to a doctor's fiduciary and ethical duties to their patient and becomes a political problem tied to the question of justice. We can think through the connection between error and justice using a Rawlsian framework. Although Rawls's understanding of justice is traditionally framed in terms of the fair distribution of goods, such as material resources and political rights, this could easily be expanded to include the fair distribution of potential harms. Of course, no social institution can immunize itself against the possibility of accident. But all institutions should strive to ensure that the possibility of accident is not so unfairly distributed among its population that certain sub-sections of it bear all, or even most, of the brunt of it. When such an imbalance occurs, we can infer that there are deep structural problems that need to be addressed in the interest of justice, especially if we also have compelling reasons to believe that the accidents in question could be prevented with due diligence. If our analysis above is correct and the possibility of medical error is indeed not evenly distributed among all social groups in medical spaces, justice would demand that we strive to uproot the cause or causes of this asymmetrical distribution. One such cause is ableism.

NOTES

1. Each author contributed equally to the conception, research, writing, and editing of this article. For helpful feedback on earlier drafts, we thank Sandra L. Borden, Fritz Allhoff, Derek Anderson, and two anonymous reviewers.
2. Aronson presents his taxonomy specifically in relation to medication errors, but it is clear that it suitably extends to medical errors more generally.
3. For us, epistemic schemas include both epistemic elements (such as beliefs and intentions) as well as elements that traditional theories of knowledge may not consider properly epistemic (such as values, norms, and implicit biases). Schemas are conglomerations of beliefs, intentions, values, norms, and biases through which epistemic agents arrive at an ordered interpretation of their experience or of important aspects of it.
4. While here we describe the relationship between epistemic schemas and epistemic ignorance as causal (i.e. schemas cause ignorance), in reality the

relationship is dialectical. Schemas and ignorance are mutually reinforcing insofar as schemas generate various types of epistemic ignorance, which in turn reinforces the schemas by shielding them from conscious reflection and, therefore, the possibility of criticism. They are both causes and effects of one another.

5. We do not mean to suggest that ableism negatively impacts *only* people with disabilities. Though we cannot defend the point here, insofar as what counts as being “able-bodied” and “normal” intersects with assumptions about race, gender, sex, sexuality, and the like, it can have a negative impact on people who are not disabled or who do not have impairments (we here mean both ‘disability’ and ‘impairment’ in the sense of social models of disability—see pg. 12 below). We are, however, assuming that those *most* negatively affected by the epistemic schema of ableism in a medical context are disabled people.
6. The Society for Disability Studies defines disability studies as an interdisciplinary field born in the second half of the twentieth century that “encourages perspectives that place disability in social, cultural, and political contexts” (SDS 2017). There is disagreement within disability studies scholarship and disability activism across the globe concerning whether ‘persons with disabilities,’ ‘disabled persons,’ or some other such term should be used. In recognition of the underlying pluralism about ways of conceiving of the relationship between disability and personhood that these voices and ensuing disagreements represent as a whole, we will use both terms interchangeably.
7. Street et al. (2009) posit seven pathways through which communication can lead to better health: “increased access to care, greater patient knowledge and shared understanding, higher quality medical decisions, enhanced therapeutic alliances, increased social support, patient agency and empowerment, and better management of emotions.”
8. To be fair, it is entirely possible that by using the terms ‘prejudice’ and ‘stigma’ to describe ableism, Barnes was in fact thinking of something along the lines of an epistemic schema. Our only point is to show that otherwise insightful and important analyses of disability have not engaged the concept of ableism, especially with respect to its role as an epistemic schema, as fruitfully and as in depth as they might.
9. On the concept of *othering* see Shapiro (2008); Roberts and Schiavenato (2017).
10. For a fantastic study on the concept of normality and its connections to the “natural” and the “normative,” see Weiss (2015).
11. One might counter that our analysis does not attend sufficiently to the differences between intellectual and physical disability. Although our examples

are indeed taken more often than not from examples of physical disability, and although we agree that there are crucial and often substantive differences between intellectual and physical disability with respect to the topics at hand, we nevertheless maintain that our more general analysis is a boon to analyses of medical error and people with disabilities of either type (or of both together). It should also be noted that the concept of “impairment,” as well as the social models of disability more generally, have come under significant criticism from disability theorists and philosophers of disability. These debates, though important, are orthogonal to our concerns here.

12. There are many drivers of ableism in medicine. One of them, which we do not have space to discuss here, has to do with how disability becomes a synecdoche for human vulnerability as such, which ignores the fact that vulnerability comes in many forms. Scully (2013), for instance, distinguishes between “contingent” and “intrinsic” vulnerabilities. Rogers, Mackenzie, and Dodds (2012) similarly distinguish between “inherent,” “situational,” and “pathogenic” vulnerabilities. Following Scully, we hold that many dependencies, and the vulnerabilities that come with them, are not “incompatible with full autonomy” (2013, 204). There are no vulnerabilities inherently and uniquely connected with disability (or, rather, impairment) as such. Vulnerabilities emerge as a product of the relationship between an individual and his or her environment. As historians of disability and disability studies scholars more generally have shown, many of the vulnerabilities disabled people face result from environments designed to not support or which are actively hostile to them, whether due to inaccessible built environments, ableist ideologies, underdeveloped assistive technologies, or medicalized understandings of disability, impairment, and vulnerability, etc.
13. Our thanks to one of the anonymous reviewers for nudging us to reflect upon this point. With respect to sexist and racist epistemic injustices, Medina (2013) offers an illuminating analysis. With respect to testimonial injustices experienced by people with chronic illness, see Kidd and Carel’s (2018) analysis of what they call “pathocentric epistemic injustices.”
14. Jones (2012) also discusses this phenomenon in a general way. Our thanks to Derek Anderson for pointing us to this reference and those in the next footnote.
15. Among other sources that discuss credibility excess, see Medina (2013); Davis (2016); Yap (2017); Medina (2011).
16. According to Ho, in the case of people with chronic conditions, this pessimistic judgment “can inadvertently thwart physicians’ motivation to treat a patient’s other conditions aggressively on the assumption that the patient’s

overall quality of life is poor anyway” (2009, 192). Scully also notes that while the disability paradox needs to be taken seriously as an indicator of the prevalence of ableism, that impairments come along with an average quality of life “is not always the case, especially not for more recently disabled people whose impairment constitutes a significant loss and who are still struggling to adapt to their changed circumstances” (2018, 109–110).

17. With regard to both *epistemic erasure* and what we discuss shortly below as *epistemic derailing*, we take ourselves to be exploring forms of (or, depending upon precisely how they are construed in a given context, at least closely related phenomena to) what Pohlhaus (2012) calls “willful hermeneutical ignorance.” To be clear, by coining these terms, we do not take ourselves to be the first to point to these issues—on the contrary, we are using these phrases to point to experiences that we take to be well attested in disability studies writ large (as our citations throughout indicate).
18. In 2016, *InterAlia: A Journal of Queer Studies* published a two-part special issue on the subject. In the introduction to the special issue, “Let’s Talk About (Crip) Sex,” Tomasz Sikora and Dominika Ferens note that the various contributions are important reminders of disabled people’s struggle for sexual recognition. Endless narratives depict people with disabilities as either a-sexual or non-sexual, indeed as barely having sexual organs in the first place. According to Sikora and Ferens, this contributes to the oppression and marginalization of the disability community.
19. Epistemic erasure—among other types of epistemic injustice we discuss in this article—takes on a different form and can have different effects with respect to invisible disabilities. Due to space, we are limiting our discussion here primarily to visible disabilities and hope that further research in this vein will explore questions relating to invisible disabilities.
20. Clare (2009) observes that medicine played a key role in the “medicalization” of disability in the early twentieth century. One of the first tools used by medical experts to turn disabled bodies into objects of interest was the language of teratology, “the centuries old study of monsters” (2009, 97).
21. Throughout this paper, we have assumed that the medical provider in question is able-bodied. This is, of course, an assumption that leaves out disabled providers. It is sadly beyond the scope of this paper to address the specific types of challenges disabled providers might face with respect to PPC, ableism, and epistemic injustice more generally. See, e.g., Meeks (2019). Insofar as disabled providers experience ableism along the lines we discuss here, we hope that this paper may, *mutatis mutandis*, afford some insights.
22. People who are HIV-positive are not the only ones who feel this pull in the context of PPC. Overweight patients do, too. Often, when patients who are

- overweight, obese, or, as some prefer to be called, fat, show up to the clinic, they are confronted with a labyrinthine setting in which all paths lead to the same destination: “It is because of your weight.” As in the case of ableism, fatism narrows the provider’s field of vision and causes them to fail to make inferences that they otherwise would have likely made. This would explain why conditions such as mood disorders (Da Silva et al. 2015) and sleep disorders (Mears et al. 2007) are underdiagnosed among overweight patients.
23. To be clear, epistemic erasure is closely related to epistemic derailing. Keeping to our primary example, the former is when a topic of medical relevance disappears from the doctor’s perceptual field and really is *invisible*. The provider might express surprise at the patient who insists on talking about it. By contrast, epistemic derailing is a subtle deviation in the conversation where one topic slowly pulls the conversation in its direction even though the conversation begins, or should reasonably go, somewhere else. Derailing is a question of *hyper-visibility*. Each, then, are like the inverse of one another. Put more simply, erasure occurs when the epistemic schema of ableism puts patients in a situation where their impairment has the effect of hiding something from a provider that is relevant, and derailing occurs when their impairment becomes so bright, as it were, that nothing else can be seen.

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