

26 NOCEBOS TALK BACK

MARKED-BODIED EXPERIENCE AND THE DYNAMICS OF HEALTH INEQUITY

SUZE G. BERKHOUT AND
ADA S. JAARSMA

Introduction

"Nocebos Talk Back," this chapter's title, invokes a phenomenon that has in recent decades been named and embraced by biomedicine and that, despite this embracing, undermines the mechanistic and individualizing framework of medical research and practice. The "nocebo effect" is a dynamic that takes place in medical and medicalizing contexts—more like a relational exchange than a cause-and-effect mechanism—in which someone experiences a negative symptom, precisely because their bodymind expects such a symptom to emerge in and out of that very situation. "Context matters," nocebo researchers declare (Rossetini et al. 2020), drawing on experimental data in order to underscore an insight long rendered evident by feminist disability studies—namely, that the feedback loops between designs, norms, and practices of spaces and the persons moving and interacting within spaces, hold somatic import, affording exclusionary (in most cases) or accessible (in some cases) experiences that in turn shape future experiences. Although accessible and ease-filled medical scenarios that can yield the positive experience of placebo effects are a well-documented aspect of medical treatment, in this chapter we examine nocebo effects and the many forms of medical and medicalizing exclusions that can serve as nocebos. We offer the phrase "nocebos talk

back" in our chapter's title as a way to underscore the importance of the critical examination of nocebo effects for philosophy of disability and feminist disability studies.

Nocebos talk back in the form of nocebo effects, and nocebo effects express feedback loops between persons and the broader structures and practices of biomedicine. These feedback loops, in other words, can draw attention both to individuals ourselves (what "bad outcome" do our bodyminds expect, based on past learnings, that we will then experience?) and to theorists seeking to understand them (what systems and practices lead to these very expectations?). In addition, these feedback loops can implicate the vocational practices of research, as researchers might occupy positions and professions synchronized with authority and power. Indeed, we ourselves work in positions that often reinforce the very kinds of feedback loops that feminist disability studies seek to call out and resist: Suze in psychiatry and both of us in philosophy (Tremain 2020; Jaarsma and Berkhout 2022; Nishida 2018).¹ In the analysis that this chapter comprises, our own respective vocational labor-practices are on the hook in ways that should be generative for other people who likewise inhabit roles in institutions such as universities or hospitals that are inextricably entangled with structural aspects of oppression.

The term *bodymind*, a locution proposed by Margaret Price to subvert the line often drawn between "bodies" and "minds," has become an integral concept in feminist disability studies (Price 2015). This chapter focuses on "the nocebo effect" as a lived example of bodyminds-in-action, testifying (in the words of feminist philosopher Isabelle Stengers) to the myriad capacities for injury in medical contexts (Stengers 2002: 253). Like placebos, nocebos are essentially and importantly biosocial: they differ, from one context to another, and thus can afford a broad transnational examination of the relational exchanges between bodyminds, medicine, and the biosocial meanings that saturate medical contexts.

Given the importance of feedback loops for critical disability studies (Dolmage 2017; Jaarsma 2020), we look to nocebos and nocebo effects as palpable examples of the intersecting, often reinforcing, relations between medicine and harm. Feedback loops can serve as emancipatory resources, drawing attention to exclusions or injury in order to critique and resist injustices. Hence, we want to put nocebo effects forward as palimpsests of past experiences, along the lines that Price and M. Jacqui Alexander suggest (Price 2021: 261; Alexander 2006: 190). Nocebo effects, read through philosophy of disability, are tangible expressions of the "layering and relayering" of time, memories, and embodied movements (Price 2021: 261).

Harm, of course, is precisely what biomedicine seeks to avoid and evade, even as disability studies scholars document, reflect upon, and incisively

assess the many ways in which medical treatment can be inextricable from injury, even violence. As we explore in this chapter, nocebo effects are instructive indexes of the porous boundaries between “healing” (a vexed notion for feminist disability studies scholars and philosophers of disability) and harm in biomedical contexts. Even the emergence of the term *nocebo* itself signals an ever-present potentiality for harm in medical research. As we explain in what follows, nocebo effects became salient as a persistent phenomenon in the context of biomedical treatment, so much so that the term *nocebo* was coined to signify the phenomenon, sparking in turn the nascent field of nocebo studies.

Nocebos hold significance for feminist philosophy of disability, in particular, given the ways in which nocebo research can either reinforce or undermine prevailing exclusions in biomedicine, depending on the methodologies and practices of the researchers who engage in it. As we examine throughout this chapter, nocebos make manifest—through traceable and mark-able symptoms and physiological changes—the kinds of inequities that rarely become marked out as such in biomedicine. These inequities stem in part from the sedimented systems and structures of racializing colonial and settler colonialism, which continue to shape and saturate medical institutions. In this way, they align with the call of philosophers such as Desiree Valentine to attend to the processes by which bodyminds become “raced” and “disabled,” processes so entangled that Valentine offers the term *racialized disablement* as a structuring concept for engaging with these injustices (Valentine 2022: 337). These racializing and disabling injustices stem from and reflect the norms and normative practices by which some bodyminds get marked out in medical contexts, rendered otherwise from unmarked bodyminds, and, therefore, identified as in need of treatment or intervention. Thus, Valentine’s call implicitly instructs us to attend to our own positionalities as authors in this investigation: we are unmarked in certain ways and contexts—for example, whiteness, able-bodiedness—which shapes our experiences within the roles and professional practices that offer critical purchase on our analysis.

This distinction between “marked” and “unmarked” bodies is itself in need of sustained inquiry, according to Sami Schalk and Jina B. Kim, given how the field of feminist disability studies tends to employ methods and canonical texts that bear an “unacknowledged whiteness.” In our discussion that follows, we take up Schalk and Kim’s call for citational practices and theoretical framings that attend to race as an analytic (Schalk and Kim 2020: 35) by turning to Sylvia Wynter’s philosophical work on nocebos. While Wynter’s work in decolonial philosophy receives wide-ranging attention across critical race theory, philosophy, and social theory, Wynter’s attention to nocebos as an index of oppression is overlooked in otherwise

wide-ranging feminist, anti-racist, and decolonial engagement with Wynter's work. By exploring how nocebos "talk back," we bring Wynter into conversation with feminist philosophy of disability and feminist disability studies, tracking and forging the interconnections between the injuries that take place in medical and medicalizing contexts and broader systems of injustice. Wynter solicits attention to the "us/not-us . . . scripts" that animate so many of our social practices and contexts (Wynter and McKittrick 2015: 58). Nocebos and nocebo effects proffer ways to note such scripts, while demonstrating Wynter's call to reckon with the fact that "we are not purely biological beings" (34).

The testimony of nocebo effects underscores the entangled relations between bodyminds, systems and practices, and ideologies of ability, health, and (dis)ability. Schalk suggests using the term *(dis)ability* as a way to foreground "the socially constructed system of norms" categorizing and valuing bodyminds through concepts of ability and disability (Schalk 2017). As Schalk and Kim highlight, feminist-of-color disability studies often expose ideologies and discourses of (dis)ability in situations where the "aboutness" of the events or issues do not immediately appear to relate to disability (Schalk and Kim 2020). In this chapter, we forge links between the nocebo effect and medical injustices in relation to race, gender, and disability (among other identities) in order to critique the ways in which difference, to paraphrase Ehlers and Krupar, is often ontologized as biological truth (Ehlers and Krupar 2019). As biosocial and relational, nocebos, we argue, provide palpable examples of the bodied experience of health inequalities as biosocial dynamics.

In what follows, we outline a general understanding of the nocebo effect from our work tracking research in the field of placebo/nocebo studies. We suggest that, as much as anything, nocebos are a prompt that asks us to consider for whom conventional objects of care (the diploma, the clipboard, the white coat) reflect the pleasures of health versus for whom these putative objects of care demarcate pain, anxiety, and trauma. Which communities have learned—whether personally or through their collective experience—that the health-care system is *not* a place of helping or healing for them? What are the bodied effects of this cut between cure/harm? To address these questions, we consider the notion of marked versus unmarked bodyminds. Heeding Wynter's call to attend to the "us-not-us scripts" at play in concrete contexts, that is, we consider how nocebos reflect a choreography of harming when marked bodyminds attempt to navigate medical spaces. Nocebos and their talk-back effects emerge as sites to think with, especially in terms of the lived intersections between identities, (dis)ability, and the racializing violence of colonial systems.

What Is the Nocebo Effect?

The term *nocebo effect* might not be widely familiar, as it was coined only decades ago; and yet, it refers to scenarios that readers might well have experienced, firsthand. The nocebo effect involves an expectation of adverse, unwanted side effects that in spite of no biochemical or other “actual” property inhering in the treatment itself, arise through symptoms that can be observed or self-described, traced, and empirically studied. In this way, nocebos undermine the very binary between “inert” and “verum” treatments (just as placebos do), which makes them both vexing for biomedical researchers and generative for feminist philosophy of disability.

Researchers, observing that individuals in the placebo-controlled arm of clinical trials could experience adverse side effects despite not themselves receiving the treatment studied, decided to give this widespread pattern a name: the nocebo effect (Enck, Benedetti, and Schedlowski 2008; Hahn 1997; Kennedy 1961). Nocebos, in addition to serving as strange and unwanted interruptions to the protocols of biomedical research, underscore the biosocial significance of these very protocols: participants in trials who are given a placebo undergo the same protocols as participants in them who receive the verum under investigation, including the same sorts of exchanges with clinicians about potential side effects of the verum. In this way, nocebo effects, like placebo effects, make palpable—in measurable and embodied ways—how significant the many varied aspects of medical treatments can be for bodyminds, from the design of a pill to the affects of a clinician. As Elizabeth Wilson puts it in *Gut Feminism*, “having a good drug response seems to go hand in hand with having a good placebo response” (Wilson 2015: 137), so much so that attempts to firmly disentangle them inevitably fail.

The term *nocebo* is a deliberate twist on the centuries-old term *placebo*, referring to harmful, unwanted outcomes that undercut therapeutic goals of medical treatment rather than naming positive outcomes (Evers et al. 2018; Chavarria et al. 2017; Bingel and Schedlowski 2014; Kong et al. 2008). We might say, therefore, that nocebo effects are disloyal to the biomedical endeavor, given how they disrupt the overall framing of medicine as oriented toward “do no harm.” We could in addition implicate placebo effects in such disloyalty, given how they wreak havoc with bioethical assumptions about the autonomy of individuals and supposed transparency of knowledge. “Is it ever ethical to prescribe a placebo?” is a question that bioethicists and analytically trained philosophers often pose (Berkhout et al., forthcoming). Placebos, in other words, are also meaningful to think within the context of philosophy of disability, given how they complicate the liberal and humanist paradigm of bioethics. Nocebo effects might be summed up as phenomena

"whereby anticipation and expectation of negative outcome may induce the worsening of a symptom" (Benedetti et al. 2007). As we discuss later, these kinds of expectations emerge from many sources, including biomedical practices themselves. As such, nocebo effects pose a threat to the desires, found throughout medicine and every other colonial institution (including the university), for subjects to "please be successful, be pretty, be human" (paperson 2017: 56). Not only are nocebo effects unwanted ramifications of biomedical research and treatment, they draw attention to the concrete, lived injurious effects of such "please be pretty" mandates. As feminist-of-color disability scholars argue, these effects are disproportionately experienced by racialized persons, underscoring the systems-level violence of injustice that Wynter connects with nocebo effects (Wynter and McKittrick 2015: 58, 59, 65, 68).

During the COVID-19 pandemic, nocebo effects have been launched into public consciousness in relation to adverse effects described within studies of COVID-19 vaccinations. A recent systematic review of three SARS-CoV-2 vaccine trials, whose research subjects total roughly 45,000 participants, found high rates of fatigue, headache, and muscle aches and pains reported in the control (placebo) arms of these trials.² A larger review of twelve COVID-19 vaccine trials found that nocebo effects accounted for about 76 percent of common adverse reactions after the first dose and approximately 50 percent of adverse reactions after the second dose (Haas et al. 2022). These findings have been widely publicized, contributing to increased public discussion of, and familiarity with, the concept of nocebo effects.

During the pandemic, "the public," as Mel Y. Chen puts it, "has been learning how to think intersectionally" (Chen 2021: 22). Indeed, we take Chen's prompting as an invitation to focus more fully on nocebos as intersectional entanglements. A central aim of much disability activism has focused on embracing disability as valuable and desirable (Fritsch 2015), as part of human plurality (Garland-Thomson 2011: 603), and, as Joshua St. Pierre puts it, as a form of biological plurality and a critical opening in systems of power (St. Pierre 2022: 14, 11). Yet, as the work of Schalk and Kim, Ben-Moshe and Magaña, and Hamraie and Fritsch (among others) points out, untangling disability from processes of medicalization and pathologization can be fraught. Many people who are racialized, gendered, and Othered as minorities (via sexual identity, migration status, geography, or social class) experience intense disparities when they attempt to access high-quality health services, often doing so without the benefit of care delivered in spaces that are free from discrimination (Schalk and Kim 2020; Ben-Moshe and Magaña 2014; Hamraie and Fritsch 2019). Moya Bailey and Izetta Autumn Mobley point out that "having access to the healing therapies offered by the medical field is part of addressing the medical field's long disinvestment

that does not itself impact the airway, likewise generate nocebo effects: an odor that had previously been associated with increased respiratory effort will go on to produce dyspnea by expectation alone. Strikingly, it is not only a sensation of difficulty breathing that is evoked by the neutral odor—differences in neural correlates of dyspnea are also seen on functional magnetic resonance imaging (fMRI) and positron emission tomography (PET) scan (Vinckier et al. 2021).

Nevertheless, detailed study of the physiological endpoints of nocebo effects is a fraught undertaking. Not infrequently, the structure of the experimental apparatus reinforces ableist bifurcations. So-called “healthy volunteers” are regarded as the most ethical participants to willingly and knowingly engage in studies that induce distress, which is one of the reasons that pain paradigms are the most common experimental procedure in nocebo studies—pain can be straightforwardly induced in “healthy volunteers.” Inducing additional symptoms or discomfort in individuals who are already experiencing illness is more complex to justify. And although there is a certain logic to this rationale, the division between health/ill, normal/abnormal is sedimented through this structure.

Is there a meaningful takeaway from the experimental apparatus, despite these ontological challenges? Across a range of studies, functional connectivity is thought to be increased between brain areas relating to the perception of sensations inside the body (interoception), autobiographical memory, and neuroanatomical domains that correspond to the specific stimulus (Thomaidou et al. 2021; Schienle et al. 2018). We should attend to the ways in which these connections are importantly biosocial phenomena, linking memory, body sensation, physiology, and self-other relations. Not only do nocebos occur through the cues, verbal scripts, and qualities of the interpersonal interactions and the spatial context, they operate through social forms of learning as well. Observing other people experience pain, discomfort, anxiety, and difficulty to a setting and intervention can likewise produce nocebo effects (Vogtle, Barke, and Kroner-Herwig 2013). In this way, nocebo effects testify to the “basic affectability” that Kristie Dotson and Marita Gilbert argue is part of human experience: as bodyminds, all of us are vulnerable to other people and to our surrounding contexts (Dotson and Gilbert 2014), despite the myriad ways in which some of us, as individuals and as populations, receive shelter from vulnerability and many of us, as individuals and as populations, do not. Personal distress experienced by a research participant as they observe pain or difficulty in another individual similarly influences the magnitude of the nocebo pain that a particular participant themselves experiences (Bajcar and Babel 2018). As we will discuss in what follows, this phenomenon has significant implications for feminist philosophy of disability with respect to how we think about harms

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Research surrounding nocebos (and placebos) tends to describe their ontological implications as “effects”: stabilized endpoints or outcomes in a process of production, derived within experimentally controlled situations. But what we also receive from placebo/nocebo studies are stories: stories, we might say, about what we have learned regarding what heals and what harms (Yergeau 2017: 21). The story that much of allopathic medicine tells about itself is that the field comprises equal parts of the benevolent and scientific: a story of healing, affirmed within the experimental paradigms of placebos. Confidence in one’s assessment and treatment plan is meant to translate into a story of health-care providers as reassuring, masterful, and expert at controlling the entropy of disease. Another aspect of relationality, indexed by nocebo effects, is this: who is *not* treated with an expertise blanketed by warmth, empathy, and compassion? Put another way, for whom do the degrees upon the wall, the white coat, or the institutional setting demarcate trauma, suffering, and powerlessness? How does *this* relationality impact treatment outcomes and intersect with the affectability of marked-out bodyminds? As noted earlier, research studies that highlight the role that social observational learning plays in relation to nocebo effects make the field of nocebo effects research especially relevant for thinking about intersectional identities, marked-bodied experience, and the impacts of racialized disablement and systemic discrimination in health-care settings.

Marked-Bodied Experience, Health Inequality, and Nocebos

As we write in another context, “nocebos and placebos dramatize the fact that there is no generic body” (Jaarsma and Berkhout 2019) because their effects bear witness to the concrete, contextualized, embedded, and embodied interactions of specific persons. Such “witnessing” runs counter to the presuppositions, upheld by biomedical research protocols and practices, that “the human body” can be generalized, that effects “inhere” in individual persons (Valentine 2022: 337), and that assistive or adaptive technologies reflect standardizable—rather than singular—needs and capacities (Hendren 2020). Whereas the generic human, hailed by the protocols of biomedicine, is of necessity “anonymous,” the meaning-responses of nocebo and placebo effects express the scripts of culturally specific, biosocial scenarios (Berkhout and Jaarsma 2018). Nocebo effects help us recognize this tension between the universalizing aims of biomedicine and the specificity of the concrete individuals traversing medical spaces. Critical disability studies scholars often

call out this tension in order to lay claim to the resistance and solidarity that emerge out of affirming lived experiences. Alison Kafer, for example, identifies the "system marking some bodies, ways of thinking, and patterns of movement as deviant and unworthy" (Kafer 2013: 89), generating a "self-perpetuating homogeneity" (98). It is not enough, Kafer writes, to replace this system with an alternative one (102); rather, we can open up the very field of possibilities, a kind of opening that depends upon concrete and material scenarios and expressions. Nocebo effects in particular serve as a palpable kind of expression, one that demonstrates the material dynamics and processes by which inequity, injustice, and violence take place.

Kafer's use of the verb *marking* is instructive, underscoring aspects of embodiment that, by definition, often pass unnoticed. As we noted earlier, to be "unmarked," in contexts of colonial and settler colonial institutions, is to move through the world with a lived sense of ease; from first-person experience, in other words, it can seem like a comfort to be taken for granted, occupying space in ways that fit smoothly with its "homogeneity." As Aimi Hamraie explains, even architecture tends to facilitate such fitting between unmarked bodies and spaces, following design principles that heed an "ideology of ability" (Hamraie 2016: 288). In this ideology, disabled bodies are marked out, both on the level of structures (with "accessible" features added on, retroactively) and in lived experience. Disability, Hamraie points out, is cast as needing fixing or cure, in contrast to able-bodied features and movements. As Schalk argues, furthermore, recommending modification of a central term around which disability studies revolves, the term *(dis)ability* has emerged as a concept for the field in order to undermine this "us-not us" bifurcation between disability and ability (Schalk 2017).

Linguistic anthropologists use the term *unmarked* as a way to flag often-otherwise unidentified expressions of whiteness, the hegemonic backdrop of white supremacy resulting from centuries of imperialism (Urciuoli 2011). The violence by which racializing marking out reinforces the hegemony of whiteness perpetuates the power of whiteness, both in a lived sense and on a systems level. Franz Fanon famously captures this entwined violence in his writings, indicting science as one of the forces by which whiteness retains its unmarked status. "Science should be ashamed of itself," he declares (Fanon 2008: 100), given the ways that it upholds a "typical human reality" (6) that reinforces the normativity of white bodies and the exclusions of racialized bodies.

Personal experiences according to which one is marked out as Other are collectively shared, across groups, as people are minoritized by race, gender, sexual identity, socioeconomic or migration status, particularly people whose self-experiences sit in the intersections of these subjecting categories and apparatuses. Because biomedical practices reflect and reinforce systemic

patterns of marking out as Other, the lived experiences of individuals in medicalized contexts can include literal, as well as metaphorical, aspects of markedness, as Camisha Russell points out (Russell 2016). Resulting mistrust of medicine—including of the people who practice it, wearing white coats and administering protocols—reflects these injustices, which are essentially connected to colonial and settler colonial systems. Lisa Stevenson's ethnographic work, for example, demonstrates how settler states require citizens to be better patients: in colonial settings, "the patient needed not only to get well, but also to *want* to be the kind of subject or self that got well" (Stevenson 2014: 52, emphasis added), to be "please be pretty, successful, and human," in the words of paperson (paperson 2017: 56). By articulating expectancies as part of normalizing medical treatment, Stevenson prompts us to notice the connections between placebos (anticipating well-being), nocebos (expecting harm), and systems of oppression. Such connections are lived out, in the concrete experiences of bodyminds. Nomy Lamm reminds us, for example, that "the legacy of medical trauma" is a legacy that manifests in personal experiences and that therefore necessitates structural critique and resistance (Lamm 2015). And paperson points out the ever-present capacities for disloyalty, even in colonized settings: the request to be "pretty" and "human" belies the anxiety of the colonizers, imploring, "please do not fail us, reject us, betray us" (paperson 2017: 56).

Wynter brings this knot of connections together by pointing to nocebo effects. As Ashley J. Bohrer notes, Wynter's core commitment is liberation (Bohrer 2020: 529), informed by decolonial and anti-capitalist commitments. The term *nocebo effects* serves, in the critical context of Wynter's work, to demarcate the bundled relations between racializing violence, white supremacy, and lived experiences: nocebo effects refer to the harms, injuries, alienation, anxieties, and other adverse symptoms that stem from colonialism and capitalism. Nocebos are useful, for Wynter, because they cannot be separated from "palimpsestic time," as Alexander puts it (Alexander 2006: 190); tracking nocebo effects in the present turns into a practice of tracing transgenerational injustice and inherited trauma from decades, even centuries, in the past. Second, nocebos are useful, for Wynter, due to their biocultural dynamics, at odds with the attempts of "modern" science to bifurcate biology from culture (Wynter 1987).

Third, Wynter regards nocebos as useful because of their more well-known counterpart, placebos. Wynter invokes the pain-paradigm of nocebo research in order to call out lived differences that might otherwise be unrecognizable because of the unmarked forces of whiteness: notice the contrast, she writes, between whiteness (the "opiate-rewarding" placebo effects of well-being) and racialized experiences ("the opiate-rewarded blocked nocebo terms" of harm) (Wynter and McKittrick 2015: 50). Wynter's account is anti-essentialist,

refuting the pseudoscience by which “race” is synced with nonexistent genetic traits or evolutionary trajectories; at the same time, Wynter invites us to consider how we, as human primates, live out our “biology” and our “storytelling capacities” as essentially entangled aspects of who we are as a species (2003).

Fourth and finally, nocebos and placebos gesture toward “flesh and word” as liberatory interrelations. In a recent interview, for example, Wynter rehearses the story of when Frederick Douglass was told about the powers of leaves and plants by a Black person who carried African counter-belief systems over to America: recall, Wynter suggests, “what scientists have told us about neurochemical mechanisms” and consider how “the belief in that leaf giving you power would have also had that literal neurochemical effect” (Wynter, Bennett, Givens 2020: 125). It is precisely because beliefs and stories hold material traction that it matters *which* beliefs and stories enter into the looping patterns that shape our lives, interactions, and social orders.

Understanding nocebo effects as dynamic, relational enactments of harm shifts us away from the mechanizing and individualizing logics of biomedicine. Nocebos make sense of how personal and collective experiences can contribute to harmful feedback loops that further perpetuate health inequality. Simultaneous to the social context that generates inequity on multiple levels (through discriminatory practices and subsequently through the anticipation of such), inequalities in health outcome become naturalized as biology, reinforcing markedness. As Russell articulates, “the view from the margins” (of US health care and biomedicine) means that communities racialized as minorities have a distinct awareness of the historical and contemporary injustices perpetuated through abuses in medical research, reproductive abuse, and health disparities (Russell 2016). The resulting mistrust (as Russell and many scholars of racial health inequality have noted) is far from what biomedicine or philosophy might deem “irrational” (Scharff et al. 2010; Williams and Mohammed 2009). And, as the nocebo literature so clearly outlines, an individual’s level of mistrust, apprehension, or negative expectations about a given health-care encounter can be expressed through the physiology and neurobiology of the nocebo effect. Writing before nocebo studies emerged as a field of inquiry, Wynter anticipates the ways in which biochemical reward/punishment mechanisms—experienced on an individual level—reflect much broader systems-level processes: to be marked as “abnormal” is to live out the injuries and injustices of racializing violence, she explains, invoking the term *nocebo effect* to signify these bodymind experiences. Conversely, Wynter explains, to be unmarked in ways that cede to, or benefit from, “normalcy” is to live out the all-too-often unidentified whiteness of placebo effects (Wynter and McKittrick 2015: 50).

Such normalcy extends to the compulsory norms of “health” that underlie ideologies of ability.

Our understanding of nocebo dynamics is thus another way to reference the ways in which communally held stories and memories are lived as bodymind-harms for minoritized, disabled people (Clare 2017). Wide-ranging evidence of race-based health disparities can be understood in part through such disparate experiences of us/not-us within health systems (Varelmann et al. 2010). Nocebo effects, in particular, signal the likelihood that past negative experiences—the discomfort and alienation of being marked out, racialized, or stigmatized—shape the harms and injuries that take place through medical treatment and research (Friesen and Blease 2018b). The field of nocebo studies has begun to consider this explicitly, making links between nocebo effects and health inequities vis-à-vis unequal treatment on the basis of race and ethnicity, (poor) communication, medical mistrust, perceived discrimination, and racial discordance between providers and care recipients (Yetman et al. 2021; Friesen and Blease 2018b). Minoritized recipients of health care have awareness of both their own experiences of suboptimal, dismissive, or low-quality care and the experiences of others in this regard. This awareness creates expectations that, in turn, inform how subsequent interactions with clinicians will be interpreted. This awareness thus has implications for future health-related actions and impacts current health outcomes through a person’s acceptance or refusal of interventions (which hails further looping effects related to the very offer of adequate treatment) and the meaning that is made of interventions, shaping capacities for treatment adherence (Yetman et al. 2021; see also Berkhout 2014 and Green et al. 2003).

Medicine and the Choreography of Harming

The nocebo effect reminds us that medical interactions take place in normatively structured social settings. If our presumptions about the starkness of the distinction between what is *curative* and what is *harmful* hinge on our own biosocial travels, then the normative claims of biomedicine can be called out as such: that is, as normalizing ideals rather than treatments that are effective, regardless of context. The qualities of a clinical setting, the interpersonal communication between providers and receivers of care, and the dynamics between them are *themselves* constitutive of health, healing, or its converse. By highlighting how marked bodies have historically been conditioned as such and the fallacy of this naturalization

(see Ehlers and Krupar 2019: ch. 2 especially), nocebos make explicit the ontological choreography of harming. By revealing choreographies of harming, furthermore, nocebos disrupt the bifurcated logic of "us/not-us" that underpins markedness/unmarkedness, revealing material impacts of complex intersections of race, class, gender, and disability. Taking these effects of nocebos into account is especially important for thinking about the ways in which disability is perceived to be a natural site of abnormality and disabled people are disqualified on the basis of a negative ontology (Erevelles 2014).

To explore these claims further, we take up the notion of "ontological choreography" from Russell who, in turn, draws on the work of Charis Thompson. An ontological choreography makes reference to the dynamic coordination of the diverse assemblages (be they technical, scientific, gender, racial, legal, financial, kinship, etc.) that produce different kinds of being in a given setting (Russell 2018; Thompson 2005). Thompson and Russell specifically discuss this coordination in relation to assistive reproductive technology (ART). As Thompson describes, referencing ART,

The term *ontological choreography* refers to the dynamic coordination of the technical, scientific, kinship, gender, emotional, legal, political, and financial aspects of ART clinics. What might appear to be an undifferentiated hybrid mess is actually a deftly balanced coming together of things that are generally considered parts of different ontological orders (part of nature, part of the self, part of society). (Thompson 2005: 8)

Thompson suggests, furthermore, that there is an extent to which this kind of choreography takes place in all spheres of human activity. We can thus think about the ways in which negative outcomes, adverse effects, harm, morbidity, and mortality are medicalized events that likewise have a kind of choreography and, in addition, that "outcomes" such as health inequity can be better understood by attending to the imbrication of the social with the biological.

We want to flag what Thompson calls "strategic naturalizing" as a crucial insight with respect to nocebos and the ontological choreography of harming. Strategic naturalizing concerns the sorting and classifying of some things and not others as biological facts of relevance and the resulting choreography that takes place as different boundaries are drawn around narratives that delineate what is deemed cultural versus natural. Modern medical settings, writes Thompson, regularly produce extended cultural and natural biologies through the coordination of social and natural roles and facts (Thompson 2001, 2005). Relationships are constructed and

then naturalized (Russell 2018). When we attend to the particularities of nocebo effects, we can appreciate how very real, very material outcomes of discriminatory practices in health care reinscribe further bodied adverse effects, which include under- or un-treated disease, worsened pain, and death, and generated expectancies of disease, trauma, pain, and loss at the individual and community levels. These bodied adverse effects themselves coordinate with treatment algorithms, triage protocols, clinical scoring systems, and the like (Creary and Eisen 2013; Savitt et al. 2014; Roberts 2021), looping back to reinforce exclusionary politics, discriminatory practices, and palpable harms. Nocebos reveal the erasure of the social contexts that drive these feedback loops. By making apparent the individualizing of harms and demonstrating choreographies of harm, nocebos disrupt the bifurcated logic of nature/culture, mind/body, us/not-us.

At this point, a concrete example would be instructive. Consider the ways that medical rationing and triage protocols have been developed and implemented in COVID-19, as well as rightly critiqued from a health-equity perspective. Rationing refers to restrictions on medical supplies, interventions, and care—withholding potentially beneficiary treatments or interventions—from some defined segment of people (Srinivas et al. 2021). Triage protocols are the policies generated by health-care decision-makers that guide how rationing will take place. Globally throughout the COVID-19 pandemic, rationing in both critical and acute care has taken place, including: access to ventilation, to a hospital bed, to medical supplies such as personal protective equipment (PPE), and to therapeutics, particularly during surges of infection and periods of supply-chain interruption (Emanuel et al. 2020; Chen and McNamara 2020; Singh 2020). Triage protocols have been developed in many jurisdictions to address how to distribute “limited” medical resources in a consistent fashion. In some locations, these protocols have been created in reference to “crisis standards of care,” which guide how changes in usual health-care operations ought to shift to a level of care that is possible to deliver during pervasive or catastrophic events (Committee on Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations and Institute of Medicine 2012).

Disability scholars from a range of disciplines have flagged care rationing and triage protocols as enforcing discriminatory and unjust practices insofar as ableist assumptions are built into the decision algorithms. For example, the absence of disabled people from the committees that draft these protocols has been noted, as well as the lack of transparent, publicly available treatment-exclusion criteria. Other issues that disability scholars have flagged include the devaluation of disabled lives through metrics such as quality-adjusted life years (QALYs) and biases built into normative concepts such as medical futility (which themselves can be objectivized through the use of

enumeration practices) that the protocols incorporate (Chen and McNamara 2020). Underlying conditions such as chronic obstructive pulmonary disease (COPD), chronic kidney disease (CKD), hypertension, asthma, and diabetes, among other bodied experiences, increase the likelihood of worsened COVID-19 outcomes. These conditions are also incorporated into the criteria of clinical predictions related to who will most likely benefit and recover from an intensive intervention.⁴ In protocols where an institution aims toward maximizing benefit, people judged to have higher preexisting morbidity are ranked lower in priority for receiving a rationed intervention. In other contexts, even more crude markers (e.g., age alone or the presence or absence of intellectual or cognitive disability) have also been used (Orfali 2020; Bagenstos 2020). Pre-pandemic structural and institutional deficiencies are major contributors to what have been termed “preexisting conditions” in the pandemic, as well as the drivers of poorer health outcomes among disabled people compared to a nondisabled population, especially disabled people who are minoritized across additional axes of social power such as race (Sabatello et al. 2020; Yee et al. 2018). In short, triage protocols act on this inequity and further sediment it. Nocebo effects, as we described earlier, are a part of the looping of harm, biology, and difference that become further entrenched as biology when disabled people are deprioritized or refused care.

Thinking about care-rationing scenarios highlights the tension with which we engaged at the outset of this chapter: namely, between desiring disability and undermining ableist assumptions that intervention is an imperative for any disability, while also calling out the need for *more* medical access, especially to high-quality care delivered in a nondiscriminatory, equitable way. Identifying this tension *as a tension* is not meant to create a false dichotomy between the two positions but rather to draw attention to the ways in which the challenges facing disabled, minoritized individuals in health settings may be more complex than a straightforward revaluing of disability, though as our triage protocol example illustrates, valuing disabled lives *is* a central intervention into making medical spaces less discriminatory. We have named this tension (as a tension) in relation to care-rationing scenarios in order to suggest that our thinking about nocebos in reference to a choreography of harming is a way to think through the material implications of this tension and one of the ways in which it is playing out in a contemporary context.

Concluding Thoughts

As we suggest in our introduction, nocebo effects compel a kind of reflexivity within medicine and with philosophy and other critical, conceptual endeavors, particularly in relation to the ways in which intersecting axes of social power

shape roles, spaces, and practices, and how this reflexivity is (and is not) taken up in research practices more broadly. Recognizing the biosocial dynamics of nocebo effects demands, therefore, a far more relational and far less reductive view of how cure and harm work in medicine. As the field of nocebo studies expands its gaze with respect to the implications of its findings, scholarship is urgently needed that brings together insights from across critically engaged fields, such as the work happening within feminist-of-color disability studies.

As much as nocebos might be understood as dramatizing the choreography of harming in medical research and practice, they are also a call to moral and political reckoning far beyond the bounds of medicine or biomedical research. Insofar as nocebos draw our attention to concrete differences across lived experience, attending to the differences aligns with what Kim, responding to Avril Minich, identifies as a critical disability methodology that radiates scholarship outward (Kim 2017). For feminist philosophy of disability, this expansive methodology may require anchoring our work in methodological innovations that radiate our scholarship beyond what is disciplined (and counted) *as* philosophy. As Schalk and Kim note in their own discussion of method, engagement with lived experience through the stories we tell about our own bodyminds is one example (Schalk and Kim 2020). In philosophy, this expansive experiential methodology might look like transdisciplinary research practices, it might include reading more broadly beyond what is typical of philosophical analysis, or it might involve the kind of engagement with the field that Shelley Tremain offers through her long-standing Dialogues on Disability series of open-access interviews with disabled philosophers. Tremain's contributions to the field, which sit beyond the more conventional manuscripts and books/book chapters, are an instance (and there are many others) of what a critical disability methodology might look like (see Tremain n.d.). Following the work of feminist researchers who, in the words of Stengers and Vinciane Despret, find ways to "re-mark what the scientists' claim to universality makes invisible" (Stengers and Despret 2014: 29), nocebo effects invite us to "re-mark" our own methods, our own relational interactions, and our own objects of inquiry.

Notes

- 1 Shelley Tremain identifies the feedback loop between prevailing methods in philosophy and the practices of hiring committees that maintain and reinforce ableist exclusions in the discipline itself (Tremain 2017, 2020). In an open educational resource, we point to specific ways in which psychiatrists and other clinicians can likewise reinforce exclusionary dynamics within medical contexts (Jaarsma and Berkhout 2022). Akemi Nishida reminds us that academic workers

risk supporting the hierarchies of ableism and the values of white supremacy and settler colonialism (Nishida 2018).

- 2 The muscle aches and pains denoted as plausible nocebo effects were reflective of generalized myalgias, not specific injection site reactions. One would expect injection site muscle pain to be similar across trials arms given that placebo control participants would also receive an injection (sterile saline) into the deltoid muscle.
- 3 The nocebo literature suggests that the style and manner of a physician, that is, whether they are experienced as warm and competent versus as cool/distant and with low competence, modifies the extent to which expectancies about an intervention generate nocebo and placebo effects. These findings have cut across different experimental paradigms including in the study of pain as well as the impact of histamine on allergic reaction (See Necka et al. 2021; Howe, Goyer, and Crum 2017).
- 4 Notably, some underlying conditions have also been demonstrated to reflect racist discriminatory practices through the clinical scores and metrics that define when interventions ought to be offered. As Dorothy Roberts has argued (Roberts 2021), race-based correction of estimated glomerular filtration rate (eGFR) in chronic kidney disease, concretizes worse health outcomes; Elaine Ku et al. have likewise demonstrated how seemingly standard clinical evaluation metrics can result in racial disparities in relation to kidney transplantation, because of racialized assumptions built into practices of standardization (Ku et al. 2021).

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