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Post-Diagnosis: A Networked Framework for Narrative Reassemblage

Kristen Gay

Clemson University, kngay@g.clemson.edu

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POST-DIAGNOSIS: A NETWORKED FRAMEWORK FOR NARRATIVE
REASSEMBLAGE

A Dissertation
Presented to
the Graduate School of
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by
Kristen Gay
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Accepted by:
Dr. Todd May, Committee Chair
Dr. Cynthia Haynes
Dr. Steven B. Katz
Dr. Sarah Winslow

ABSTRACT

This dissertation examines the relationship between diagnostic communication practices and deliberative rhetoric through the lens of Actor-Network theory and feminist theory. Specifically, I argue that Bruno Latour's Actor-Network Theory (ANT) provides a generative framework for tracing diagnostic networks as it accounts for uncertainty, dispersed agency, community stakeholders, and nonhumans. The chapters explore how a networked approach to diagnosis opens up opportunities to reform doctor-patient relationships, expands our conceptions of diagnostic actants, suggests ways to respond to patients living at risk for disease, and broadens our understanding of ethos in healthcare contexts. Furthermore, I also consider how a networked framework can help us comprehend how public misdiagnoses happen so we can prevent them in the future. I conclude by advocating for healthcare providers to reform diagnostic communication practices to account for the agency and expertise of non-specialist stakeholders, particularly patients. I also explore methods for intervening within global health networks and addressing the intersectional problems they collaboratively solve.

DEDICATION

To my parents, my first teachers.

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This clash of contexts pits the doctor's impulse to reduce against the patient's impulse to multiply. Medicine's reductionism narrows its gaze, eliminating that which proliferates around the biological phenomena of sickness in a patient's always generative and teeming life. – Rita Charon

Popular representations of diagnosis, in television shows such as *House*, commonly depict the diagnostic process as a doctor (usually male) and his trainees looking down at test results or a lab report that reveals the problem. *Cancer. Kidney failure. Multiple Sclerosis.* The doctor usually experiences relief and sometimes pride because he or she has cracked the case. In real life, though, diagnosis is much messier. A patient waits for over an hour with trembling, sweaty palms in a stark, white office that smells like Latex gloves and hand sanitizer, and she listens anxiously to her doctor's greeting for hints as to what will come next. When she hears the news, she will either breathe a heaving sigh of relief because she is safe— but only for now—or she will face a new reality, one to be haunted by incomprehensible medical terminology, pokes and prods by needles, stethoscopes and laser rays, and potentially most troubling, her own mortality.

In response to the divide between the two presentations just described, one of cool rationality in the face of illness, and one of the confusion, pain, and chaos that illness can engender, scholars within the medical and health humanities have posed a series of challenging questions in recent years: how can doctors most ethically respond to patient's needs for emotional as well as physical support? (see Nancy Mairs and Ann Jurecic); who should get to tell narratives of illness? (see Arthur Frank and Rita Charon); and what do patients deserve in communication about their health, and where do doctors fall short in delivering on these rights? (see Lisa Sanders and Kathryn Montgomery Hunter).

This dissertation adds to such questions by considering how acknowledging the rhetorical and intersectional dimensions of diagnoses might enable doctors to more ethically account for (1) the complex factors that constitute illness and (2) the narrative agency of patients. More importantly, I will examine how this shift in framework might enable patients to find a sense of meaningfulness within an illness experience that can significantly alter one's sense of self. Contemporary rhetorical accounts of diagnosis tend to cast the encounter as a static process wherein the doctor is granted ultimate narrative authority. In "Diagnosis: A Biocultural Critique of Certainty," Lennard Davis highlights the roots of the term diagnosis itself: "*Dia* means both 'through' and 'thorough [knowing]" and "*Gnosis*, as knowledge, implies the certainty of religious knowledge" (85; emphasis original). He argues that diagnosis serves two key rhetorical functions: it grants doctors the status previously held by priests, who could make determinations about a person's spiritual health, and it also renders diagnoses ostensibly a-rhetorical, or incontestable. Similarly, *in Every Patient Tells a Story*, Lisa Sanders argues that in diagnostic encounters, the doctor plays the role of detective and the patient plays the role of the "passive bystander to the ongoing crime" (6). Within this detective work, according to Rita Charon, the patient loses even her ability to control the form that her narrative of illness will take: "Instead of listening silently while a patient makes the countless narrative decisions that must be made in conveying anything, the doctor spoils the patient's narrating by forcing it into medicine's preferred outline and sequence" (99). Such a move on the part of the physician to control both the form and content of the patient's narrative means that "information of the most valuable sort" is lost (99).

Significantly, these views of diagnosis limit the patient's agency (narrative and otherwise), ignore sociocultural factors that cause and contribute to illness, and fail to account for the complex network of actants involved in any illness or diagnosis. Perhaps Judy

Segal, in *Health and the Rhetoric of Medicine,* most clearly establishes this static view of diagnosis when she takes an Aristotelian approach to medical rhetorics by defining rhetoric as persuasion (1-2). While of course many medical encounters involve persuasion, such a definition fails to account for the dynamism of diagnosis, the uncertainty it engenders, and the multiplicity of actants involved in molding illness narratives and their meaning.

My thesis is that shifting from an Aristotelian view of diagnosis to a Latourian (networked, rhetorical) framework will promote a more relational practice that accounts for various actants, narratives, social and structural factors, and objects that shape diagnosis, specifically, and illness, in general. I'm interested in an Actor-Network Theory (ANT) approach to diagnosis because networks enable us to trace complex situations and follow the movements of every actant so that we might intervene and respond to what we find. As opposed to the static model of diagnosis, which solely considers the doctor and patient (who remains powerless), ANT suggests that diagnostic networks are vibrant, ever evolving, and constitutive of our worlds, but most importantly, they can always be reassembled if actants redistribute into other, better chains of associations. Thus, such a method serves well as a framework for medical rhetorics because it reflects the dynamism of medicine, the relational qualities that are inherently apart of caring for patients, and the reassemblage of practices and theories that no longer serve patients' needs. Such a framework might empower patients to navigate the various narratives that haunt their illness experience rather than simply accepting a diagnosis that reduces their complex identity into a singular narrative of patient hood. I also hope that such an approach will counter the stigmatization and blame that often accompany contemporary diagnoses by contextualizing illness within a Western framework of racism, sexism, homophobia, poverty, and ableism. For example, such a rhetorical framework might take into account the extent to which poor minority women living near

waste sites are more likely to develop breast cancer, and this analysis might shape the diagnosis so as to assign blame to the social factors that influence disease. It is not enough for medicine to define or even treat illnesses; it must respond to the structural sources that disproportionately cause them. To the extent that diagnoses serve to categorize the healthy and the sick, the normal and the abnormal, the self-governing and the dependent, ignoring such rhetorical dimensions that inform diagnosis is irresponsible and deeply unethical.

Beyond speaking to more healthy power dynamics between doctors and patients, such a rhetorical rethinking of the practices and assumptions particular to diagnosis represents a vital way for medicine to reclaim its significance in a time when Google, Web MD, and other medical websites sometimes offer cheaper, faster, and more empathic interactions than doctors do (Topol 26). If doctors fail to acknowledge the rhetorical and networked elements of medicine and diagnosis, then they will further undermine their own relevance by limiting their role to the interpretation of test results. Ann Jurecic reminds us that doctors offices and hospitals have replaced churches as the foremost place wherein people face questions of life, death, pain, and suffering, and since this is the case, healthcare providers must account for this growing need that people have to make meaning in medical spaces (10). Medical rhetorics is a field that must engage with the most painful type of uncertainty, mortality, and this means that medicine as a rhetorical enterprise must recognize patients as agentive participants in the diagnosis and treatment of illness. Charon claims that, "Nothing will ease patients' uncertainty in the face of illness, but perhaps their doctors can help them to articulate the uncertainty and thereby live less painfully with it" (30). And perhaps the field of medical rhetorics remains uniquely poised to support such efforts by advocating for patients, opening up forums for listening to their narratives, and considering the intersectional and networked actants that cause and inform illness.

Actor-Network Theory

       Before I shift to a more specific analysis of the diagnostic problems to which Actor-Network Theory might respond, I want to first discuss what Actor-Network theory does, and then provide an example of what such a framework might look like in practice. In *Reassembling the Social*, Bruno Latour introduces his method(ology) of Actor-Network Theory, which he uses to trace connections between actants (he prefers this term to the more humanist "actor") under the umbrella of a particular social institution, sociology in his case. ANT's key slogan is to "follow the actors themselves," or "to try to catch up with their often wild innovations in order to learn from them what the collective existence has become in their hands, which methods they have elaborated to make it fit together, which accounts could best define the new associations that they have been forced to establish" (12). To put it most simply, networks *are* action, and the researcher who adopts an ANT framework must follow this action to see the linkages and assemblages they (re)form. Latour notes that while definitions for ANT have proliferated, there are three "tests" that may be applied to see if a given study can accurately be dubbed ANT. First, an ANT method will grant to nonhumans the role of "actors and not simply the hapless bearers of symbolic projection" (10). ANT dramatically reconceives of the agency of non-human actants, which are now seen as not only agentive but "vibrant," in the words of Jane Bennett. Furthermore, another test is to check whether the assemblage being considered (such as science, diagnosis, or sociology) is treated as static and stable. "If the social remains stable and is used to explain a state of affairs," says Latour, "It's not ANT" (10). Or, to translate Latour, ANT remains highly suspicious of efforts to present any assemblage as inevitable or explain away an assemblage by pointing to a "hidden social force" responsible for a particular event (11). Finally, the most difficult test is to "check whether a study aims at reassembling the social or still insists on dispersion and

5

deconstruction" (11). Latour's ANT aims to eschew the iconoclasm or critique in favor of a method that builds something new and reassembles actants into a more healthy chain of associations. Rather than critique, Latour introduces the word "gather" to serve as the project for the 21st century ANT practitioner, who must undertake "a multifarious inquiry launched with the tools of anthropology, philosophy, metaphysics, history, sociology to detect how many participants are gathered in a thing to make it exist and to maintain its existence" ("Why Has Critique Run Out of Steam?" 246). Thus, Latour's version of ANT demands a commitment to active tracing of associations, attempts to reassemble unhealthy or malfunctioning networks, and recognition of all actants as engaged and agentive.

Within Rhetoric and Composition, Latour's ANT has been embraced as revival of rhetoric, a way to not only open up rhetorical inquiry to nonhumans but to recognize that deliberation occurs in response to complex negotiations amongst human and nonhuman actants. In their "Introduction" to *Thinking with Bruno Latour in Rhetoric and Composition*, Paul Lynch and Nathaniel Rivers put it simply: "Rhetoric's new thing is, in fact, things" (40). Despite the misleading "new" moniker, however, ANT stresses the limitations that have *always* haunted human deliberators: "Latour dramatically increases the number and kinds of deliberators. The truth is made but not solely by humans. In Latour's agora, *everything* is nervously loquacious. There is not a 'society' but rather a 'collective'" (4). The serious question that Latour puts to rhetoric—how can a discipline that has "historically defined itself in terms of human language and expression adequately account for the persuasive contributions of nonhuman agents?"—has serious implications for agency, ethics, and policy formation, to name just a few key areas of rhetorical study (Scot Barnett 81). Not only do we co-create truth and knowledge with nonhuman actants, but we rely on them even to create occasions for speaking.

For example, in her dissertation, *Relational Agency, Networked Technology, and the Social Media Aftermath of the Boston Marathon Bombing*, Megan McIntyre argues that agency can no longer be considered a possession of a single actor but rather something co-created through a relationship among actants, a shared power to act. She explains, "agency is not the property of any single actant but the product of the relationship between actants. Or, perhaps, more importantly, agency becomes a product of the work of what Latour calls mediation and translation undertaken by actants to improve the strength of their networks, which is, at its core [...] a rhetorical endeavor" (73). For McIntyre, we have no choice but to embrace such a conception of agency and to negotiate with nonhumans as we come to decisions together. She also acknowledges that the stakes are quite high: "By layering dependent and networked visions of agency, we might come to a more complex vision of agency, one that privileges the relational over the autonomous and the dependent over the independent" (73). Such a conception of agency, as ushered into rhetoric by ANT, better responds to the problems facing many disciplines—from rhetoric to science studies—as it promotes relational and collaborative decision-making.

Of course, medicine is also one such discipline that stands to benefit from ANT's method of tracing assemblages and relational agency. ANT has recently been adopted as a method for studying medical environments, interactions, and even illnesses themselves. In *The Body Multiple*, for example, Annmarie Mol, an ANT practitioner, argues that disease can never be isolated as a single object—it is instead a dynamic series of "practices" involving "the body, the patient, the disease, the doctor, the technician, the technology" (4-5). She explains, "The 'disease' that ethnographers talk about is never alone. It does not stand by itself. It depends on everything and everyone that is active while it is being practiced. The disease is *being done*" (31-2). Whereas rhetorical ANT practitioners emphasize agency's dispersal, Mol

emphasizes that illness itself is dispersed, relational, and uniquely uncertain. Others have emphasized that ANT serves as a productive method for deliberating within medical contexts of uncertainty. In *Illness as Narrative*, Jurecic wonders how stakeholders might best respond to illness narratives if we exchange the critical project, which haunts the study of illness narratives, for Latour's concept of gathering. She asks, "Does prioritizing concerns about risk, pain, human vulnerability, and the uncertainty of the future alter the critical project? What might the study of narratives about illness look like if the critic's task were to create intellectual arenas for the gathering of ideas, and to address matters of concern with care and compassion?" (17). Jurecic wonders if accounts of medical events can unhinge the critical project of debunking fact and fiction by creating a different task for the stakeholder within an illness event: a commitment to care. In fact, Latour himself speaks to the need to reconceive of illness, among other complex figures including God and art, apart from critique when he writes: "I know, for instance, that the God to whom I pray, the works of art I cherish, the colon cancer I have been fighting, the piece of law I am studying, the desire I feel, indeed, the very book I am writing could in no way be accounted for by fetish or fact, nor by any combination of those two absurd positions" ("Why Has Critique Run Out of Steam?" 243). ANT's value within medicine, at least in part, is its ability to open up alternative ways for responding to illness that are actively constructive and responsive to other actants.

While further sections of this introduction, and later chapters, will perform ANT and more fully articulate its value to medical rhetorics, generally, and this dissertation, specifically, I want to shift to an example of what Latour's theory might look like when used as a method for tracing an illness experience. In *Exile and Pride: Disability, Queerness, and Liberation*, Eli Clare approaches the issues of environmentalism and disability in conjunction

with his emotional and mental problems: "body-deep terror, grief, and confusion" (36). Rather than treating these issues from a purely psychological standpoint, he generates an intersectional approach to identity-generation through what he calls "multi-issue politics," or an attempt to invite political and personal unity regarding issues that affect us all (xi). Primarily, Clare organizes this approach by focusing on the loss of home—the body as home and his backwoods logging community in Oregon as home. As he reflects, he is "exiled" from both due to his borderlands identities. He writes as a queer "supercrip" from a "redneck," working class family (36-8). He writes of his homesickness for a place that he cannot return to because of the physical danger associated with being queer in the backwoods of Oregon (35-6). As he explains, "If I moved back to Port Orford, the daily realities of isolation would compete with my concerns for safety" (35). Thus, the loss of home involves a physical separation from his working-class, rural roots, which remain at odds with his sexual and political identities.

Clare also writes of being exiled from his body, which has been repeatedly abused, tortured, and raped by his father and other men in his community throughout his childhood. "Being a queer is one piece of this loss, this exile," he writes, "Abuse is another" (36). Beyond the extreme trauma Clare experiences based on past violations of his body, Clare lives in the world as a queer person who must navigate societal demands that he identify as a male or female. He writes of a desire to maintain his "long history as a girl" in conjunction with his current state of living "as a man, even while my internal sense of gender is as genderqueer, neither man nor woman" (xiii). Significantly, Clare's complex identities lead him to think of issues within mainstream feminist and queer studies and environmentalism from an intersectional perspective. For example, he chastises queer theorists for maintaining classist stereotypes about working-class "rednecks," and treating

them as if they are not intelligent enough to engage in conversations about homophobia, racism, sexism, and other forms of structural and interpersonal violence (37). He also argues that environmentalists need to think carefully about the lives of those who might be affected if logging towns are shut down—as he emphasizes, caring for the environment might mean putting entire towns of people out of work (67).

Most importantly, perhaps, Clare highlights the extent to which his personal traumas associated with being exiled from home require structural and multi-faceted changes. He explains, "My displacement, my exile, is twined with problems highlighted in the intersection of queer identity, working-class and poor identity, and rural identity, problems that demand not a personal retreat, but long-lasting, systemic changes...I want each of us to be able to bring our queerness home" (48). As I consider my project of adopting an ANT approach to diagnosis, I am reminded of Clare's story and his intersectional approach to the personal and political problems that haunt him. In Latourian terms, Clare's narrative is a tracing of an assemblage, a lively (re)construction of a series of identities, and an exploration of the varying factors that have shaped them. Whereas the terror, grief, and confusion could have been diagnosed as a particular illness that shaped his story, Clare takes another approach —one that reiterates the many narrative threads that inform him and rejects the idea that one simple explanation can suffice. In what follows, I will explicate what I mean by this method of narrative (re)assemblage, and I will explain why I find it so meaningful in the contexts of healthcare and diagnosis.

As Clare probes the intersectional nature of his life problems, he discovers that none of his problems can be neatly allocated to medicine—they are rather hybridized results of trauma, location, class, politics, and many other factors. As this example illustrates, medical rhetorics needs a hybridized approach to diagnosis to account for all of the factors that

intersect to cause illness and shape a person's response to it. While some have considered the intersections of medicine and rhetoric in relation to intake forms (see Allan Peterkin's "Adult Intake Form,"), public conversations about abortion (see Bernice L. Hausman's "Public Fetuses"), and death and dying (see Felicia Cohn "When the Doctor is Not God"), among many other issues, few have questioned the overlapping purviews of rhetoric and medicine in relation to diagnosis. In response to the need for a theory that can adequately account for complex experiences of illness, this dissertation interrogates the intersections of rhetorics of diagnosis, theories of narrativity, selfhood, and meaningfulness, and networked theories of human and nonhuman attachments.

In what follows, I will more fully articulate these three key areas of inquiry and their intersections. Following a Latourian method of tracing assemblages, I will begin by discussing a few problems within the rhetorics of diagnosis, and I will then consider how ANT responds to such problems and opens up possible solutions. While later chapters will explore these issues in greater depth, my aim here is to highlight what is at stake in a rhetorical, networked view of diagnosis, and to establish the connection I see between ANT assemblages and diagnostic encounters.

Problems with Contemporary Diagnosis

I am most concerned with the extent to which diagnoses have come to dominate conversations surrounding illness today. For example, many argue that "reckless and misleading drug company marketing" leads to the over-diagnosis of particular illnesses (notably childhood Bipolar Disorders) (Frances 5), and about ten new disorders are added to the *Diagnostic Statistical Manual of Mental Disorders (DSM)* annually (Davis 85). I acknowledge, of course, that diagnoses are oftentimes necessary for patients to seek treatment

and insurance coverage; most patients, after all, see a doctor because they want to know what is wrong or affirm the belief that they are healthy. The problem lies, then, not primarily in diagnosis itself, but in a tendency to overly emphasize its importance in relation to the assemblage of stories that comprise a person's identity, her illness, her culture, her triggers, and many other factors that cannot be captured in a DSM number. In "Diagnosis: A Biocultural Critique of Certainty," Davis defines diagnosis as "a complex process in which a person's behaviors and thoughts, capable of being seen in many registers, are transmuted into the register of symptoms" (84). As Davis highlights, diagnosis involves reducing a set of complex, oftentimes confusing experiences with illness to a set of symptoms that must be objectively determined and matched to a diagnostic label. As I will suggest in what follows, this overemphasis of diagnosis can limit the significance of the narratives generated by patients, diagnosticians, and other stakeholders. While diagnoses can provide explanations for *what* is causing a person's illness, they can be less helpful when patients seek to answer questions regarding *why* they are sick and *how* they might cope.

Furthermore, the tremendous inflation of certain illnesses in recent years suggests a sort of faddish approach to diagnosis, in which common illnesses are overly diagnosed because they are conveniently memorable or seem to be the illness du jour. More specifically, Allen Frances cites research by Ronald C. Kessler et al. that illustrates this inflation: their study found that "half of Americans will meet the DSM-IV disorder criteria sometime in their life, with first onset usually in childhood or adolescence" (Kessler et al. 593, Frances 5). Beyond these problems of presuming that half of the population might be disordered given the current criteria, many physicians fail to communicate diagnoses to patients. According to Shergill et al., in "Communication of Psychiatric Diagnosis," in their study of 126 patients, only 53 percent were informed of their diagnosis, although most patients revealed that they

wanted to know (32). Furthermore, only 75 percent of patients agreed with their diagnosis (32). This speaks to the ethical dangers of viewing diagnostic encounters as arhetorical; at times, when the diagnosis is seen as indisputable, some physicians may feel that it doesn't warrant a conversation with the patient. Worse than a limited view of a diagnostic encounter as only being rhetorical to the extent that its persuasive is the view that the diagnostic encounter does not require any dialogue at all.

In other cases, particularly within medicine, diagnoses may be ineffectively communicated to patients in ways that increase their suffering or confusion. In Nancy Mairs' *Waist High in the World*, she recounts her experience of visiting a student health center with complaints of a limp and weakness on her left side. After she waited for a few days while her doctor made phone calls to neurologists, she was finally told that "I had to worry about a brain tumor. [...] The weakness on my left side, coupled with a history of headaches, pointed to a tumor, which a battery of tests could confirm" (25). In response to this diagnosis, "electrodes were pasted to my scalp, my spine and groin were punctured, dyes were injected and X rays taken, and in the event there simply was no brain tumor" (26). The doctors effectively shrugged their shoulders over this failed diagnosis, and Mairs remembers that it was only when she recognized her symptoms in a *Parade* magazine article months later that she asked her doctor if she had Multiple Sclerosis. "Probably," he told her, "But only time [will] tell" (27). This lack of clear communication about diagnosis, while partially understandable given the lack of tests available for MS at the time, still contributed to added stress and grief on the part of Mairs, who had to wait eighteen more months before her diagnosis would finally be confirmed by the onset of more symptoms.

Beyond these problems associated with diagnosis, there remains the problem of how patients can account for their suffering post-diagnosis. According to Arthur Frank, "Whether

ill people want to tell stories or not, illness calls for stories" because they must explain their experiences to various audiences including "medical workers, health bureaucrats, employers and work associates, family and friends" (53-4). The demands placed on patients by the need for insurance coverage, Social Security benefits, employer understanding, and even the concern of friends and family places the patient in the position where she must be able to name and speak about her illness. She must be a responsible rhetor post-diagnosis, so why is she not considered a key informant and participant in the diagnostic process itself? After all, it is she who must give an account for her illness—and in many cases, such as for insurance coverage, defend the legitimacy of her condition and the extent to which she is impaired by it (if she wants to "claim" disability).

In all of the above examples, a few major stalemates within the field of medical rhetorics are invoked that I wish to more fully explore in the following sections. In particular, I want to shift away from a static view of the actants involved in diagnosis, the construction of illness, and the post-diagnosis account of illness and towards a Latourian framework that imagines all actants—from the patient herself to her X-Ray images—as active and engaged in the process of diagnosis and its attendant meaning. In what follows, I will consider three major stalemates within medical rhetorics surrounding diagnosis—shifting from the patient vs. doctor to the assemblage, from critique to reassemblage, and from listening to tracing— and the ways in which ANT opens up new possibilities for responding to them.

Diagnosis and Actor-Network Theory

From Patient vs. Doctor to the Agentive Assemblage

The tendency to view a diagnostic encounter as solely involving two rhetors, the doctor and patient, remains a key issue within medical rhetorics because of the way in which

it denies patients agency. Trish Roberts-Miller, whose research focuses particularly on political deliberation, defines rhetoric as the "art of communities coming to decisions together in a context of diversity and uncertainty" ("Research"). This definition, and its emphasis on communal decision making, informs this research because of its emphasis on navigating diverse and uncertain contexts, which applies perfectly to the complex and multifaceted diagnostic experiences my project will cover. This definition also remains significant because a major tension within medical rhetorics is the question of how best to balance power relations between doctors and patients in a technologically-savvy time when, according to Eric Topol, many would rather visit Google than their local doctor's office when they fall ill (26). As Roberts-Miller's definition suggests, taking a rhetorical approach to diagnosis will involve moving past the model that pits doctors against patients to invoke a community of actors who decide together. This question of how best to balance the authority of patients, doctors, technologies, and other stakeholders such as family members, nurses, and hospital administrators remains crucial to conversations surrounding ethical decision-making in healthcare settings.

In response to this tension, some have suggested that doctors must find better strategies to convince their malleable patients to work with and trust them. For example, Sanders is critical of attempts to rely on medical expertise to diagnose illness while ignoring the patient's agency and testimony. However, she insinuates that paying attention to the patient's agency is most useful for persuading her to trust the doctor and even obey him or her. She writes:

> Studies have repeatedly shown that the greater the patient's understanding of
> his illness and treatment, the more likely it is that he will be able to carry out
> his part in the treatment [...] Patients who understand their illness are far

more likely to follow a doctor's advice about how to change their diet and how to take their medications than those who do not. It's understandable. Taking medications on a regular basis isn't easy. It requires dedication on the part of the patient. Motivation. A desire to incorporate this inconvenient addition into a life that is already complicated. Greater understanding by the patient has been shown to dramatically improve adherence. This is where getting a good history—one that provides you with some insight into the patient and his feelings about the illness, his life, his treatment—can really pay off. (14-15)

While Sanders encourages doctors to help their patients "understand" their diagnosis and invite them to participate in conversations about their treatment, her emphasis remains on the doctor's orders that must be followed. The process of letting patients speak about their feelings abruptly becomes "getting a good history," and Sanders notes that it can "pay off"—but for whom?

Similarly, Segal also defines rhetoric as persuasion in *Health and the Rhetoric of Medicine,* which implies that the doctor and patient have very different functions in the diagnostic encounter. More specifically, she argues that doctors must not merely rest on their ethos but must effectively persuade patients to comply with their advice and/or demands within kairotic moments of illness. Patients, she argues, are "an audience, addressed but also interpellated and constituted by the physician" because "each time [they] are addressed, [they] are invited, sometimes irresistibly, to take the shape of a particular audience" (39). Not only are patients generally limited to the rhetorical role of being convinced by their doctors and dutifully following their advice, they are called into (rhetorical) existence by their physicians. In being addressed by a physician, patients are asked to be a particular type of

patient, a particular type of audience. Physicians, too, are bound to the work of interpretation rather than rhetorical invention, within Segal's framework. "The text to be read," she writes, "is not the person but the disease" (27). For Segal, doctors are limited to the role of interpreting the disease (commonly through tests and technologies that speak for the person) and to convince patients that the diagnosis is correct and that they should therefore pursue the recommended treatment options. While such a belief suggests that the patient and doctor are active participants in the diagnostic encounter, it problematically assumes that patients are called into rhetorical existence only as an audience to the doctor's persuasive tactics and that doctors are rhetors who may not create meaning but only interpret facts.

Segal's view of medical rhetorics is echoed in Kathryn Montgomery Hunter's *Doctor's Stories*. As the title suggests, Hunter also privileges the doctor's function within the rhetorical exchange of medicine. She adds that "It is interpretive work that the physician is doing, not original composition, nor even (except in rare cases) co-composition. Physicians who attend the funeral of one of their patients have this brought home to them in a striking manner. The discovery that neither the physician nor the disease has been the strongest force in a patient's life comes as a surprise and relief" (12). I would suggest that what surprises and relieves physicians, in this case, is the undeniable sense that their patient was a person, a rhetorical being that existed and acted apart from their control as the authoritative rhetor. Hunter goes further with this idea by labeling the doctor as a detective and the patient as the bystander to the illness crime, suggesting that diagnosis is not rhetorical (in the sense of coming to a collaborative decision in an uncertain context, a la Roberts-Miller) as much as a challenging but surmountable interpretive act (Hunter 11, Sanders 6). Within Roberts-Miller's conception, the rhetorical encounter might fail. For Hunter, there is no room for error: the

doctor's role is reading the patient's body and solving the case by locating the culprit behind the problem.[1] The patient's job is to open herself up to interpretation by a doctor and her instruments while accepting that she will, within such a framework, inevitably be both the victim and perpetrator of the crime.

On the other hand, feminist physicians and therapists reframe the diagnostic encounter as more egalitarian, and they argue that patients should reclaim authority over their bodies and illnesses. In particular, Laura S. Brown, who self-identifies as a feminist therapist, argues that in an egalitarian model of diagnosis, "therapists are charged with the responsibility of acting in such a manner as to earn clients' trust, thus offering to clients the power to decide as to the therapist's trustworthiness rather than having the therapist declared trustworthy simply by virtue of occupying that role in the exchange" (50). Physicians must *earn* a client's trust, then, not simply to reify their authority, but to encourage patients to engage in the rhetorical exchange with them. Brown notes that feminists tend to "avoid [diagnosis] when possible" because it commonly "reifi[es] an objectification of the client and pathologizes her or his pretherapy strategies for increasing personal power by whatever means available" (51). When diagnosis is necessary, however, for medical or financial reasons, Brown advocates for an alternative model of diagnosis wherein the patient actively contributes to the diagnosis, and wherein the constructed qualities of the diagnosis are discussed. "Thus," Brown explains, "in the worst case scenario where a diagnosis is written down, it is not given by the therapist but arrived at collaboratively and known to the client because she or he has taken part in deciding which [diagnosis] is a best fit" (51). Whereas Sanders wants to engage

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[1] Such a metaphor raises obvious ethical questions when we consider the rhetoric of war that circulates within conversations about illness, which Audre Lorde spoke out against in her *Cancer Journals*. As Lorde highlighted, such a metaphor causes patients to look at their own bodies as an alien enemy, rather than directing their warlike aggression and concomitant anger towards the environmental, social, and political factors that contribute to their disease.

patients in the rhetorical diagnostic exchange solely to persuade them to listen to the doctor, Brown offers a refreshing alternative that might assert the patient's right to name and own her illness.

Such a debate about whether the doctor's authority or the patient's agency should be emphasized is troubling for two major reasons. First, the stakes are quite high when patients are left to be read and "solved" by their detective doctor. Sanders notes that much information about illness will be overlooked, possibly leading to an incorrect diagnosis and medical error, when physicians fail to engage patients as co-creators of knowledge within the medical encounter. She notes, for instance, that doctors need to listen to the patients rather than asking the questions that are solely important to them; the patient's own testimony about her illness will reveal the correct diagnosis up to 70 percent of the time (57). Such an approach might also save patients the time and money that extensive testing requires and the distress of being viewed by their doctor as an object. Furthermore, this stalemate also casts the doctor as either an absolute authority figure who objectively diagnoses illness or a detective who must distrust her patient as an unreliable witness and the perpetrator of a crime that she must solve. Perhaps such options for a doctor's relationship to her patients and to illness can account, in part, for the disproportionately high rates of depression and suicide amongst physicians in training. According to Louise B. Andrew, a survey of physicians found that "1 in 16 had experienced suicidal ideation in the past 12 months, [and] only 26% had sought psychiatric or psychologic help" (n.p.). For medical trainees, the rates were even higher, even accounting for less ability or willingness to share given the extremely competitive nature of residency programs. For trainees, one study revealed, "9.4% of fourth-year medical students and interns reported having suicidal thoughts in the previous two weeks" (Goebert et al 238, Andrew n.p.). While many factors undoubtedly contribute to

physician and trainee depression and suicide, a better model for understanding diagnosis, and the doctor-patient relationship, might open up alternative ways for doctors and patients to work together rather than at cross-purposes as they confront illness. Improving doctor-patient relations might reduce stress and isolation for both parties.

A networked framework for diagnosis shifts the conversation previously explicated away from an emphasis on the adversarial relationship between doctors and patients and towards an assemblage model. Rather than fighting for authority and privilege within the diagnostic process, patients and doctors might recognize their mutual expertise that they bring to bear: for patients, their embodied experience of illness and their personal history with it, and for doctors, their generalized knowledge of the illness and its complications. As co-creators of knowledge about illness and its attendant meanings, doctors and patients might come into a more healthy relationship as nodes on a diagnostic network rather than rhetorical adversaries. For example, Rita Charon implores doctors to better attune themselves to the health care divide that exists between themselves and patients. She, too, describes the fraught power struggle inherent within diagnosis, albeit in different terms:

> Despite the complexity and consequences of the events that unfold in the doctor's office, the participants are often ill prepared for that meeting. They speak different languages, hold different beliefs about the material world, operate according to different unspoken codes of conduct, and are ready to blame one another should things go badly. Many patients feel abandoned by their doctors, dismissed in their suffering, disbelieved when they describe their symptoms, or objectified by impersonal care [...] Sadly, patients have come to reconcile themselves to a forced choice between attentiveness and competence, between sympathy and science. At the same time, many doctors

feel aggrieved by the extravagant hopes patients have come to hold for the

powers of medicine. They feel unable to measure up to the patient's inflated

expectations and demands that medical treatment will reverse the results of

unhealthy behaviors, poor health choices, or random and unfair bad luck.

Realizing how 'slow' are their true fixes, doctors prepare to disappoint

patients or to be sued for not being as effective as everyone seems to think

they are. (21)

In this passage, Charon captures the frustration of patients, who feel they must either trust a

cold, distant, but effective doctor or a sympathetic, patient, incompetent one, and the

feelings of inadequacy that doctors experience when they are seen as ultimate authorities,

invincible healers. The framework that presents doctors and patients as rhetorical adversaries

ultimately fails both doctors and patients, since it leaves them both feeling (often secretly)

vulnerable and helpless.

Another key value of the networked method is that it moves us past a focus on these

two actants alone and brings in other areas of expertise—that of the tests that generate

knowledge about illness rather than just interpret facts for doctors, that of the nurses who

spend intimate moments caring for the patient and therefore have their own insights, that of

the objects in the patient's room that shape her relationship to her illness, that of the family

members who will advocate for the patient based on their emotional connections, and that of

the larger community which shapes conversations about illness, treatment, and what it means

to be a patient. Within a networked framework, no single actant is privileged more than any

other, so the narratives of the patient and the doctor, the technology and the location, the

nurses and the family members, and the social circumstances and the history of the patient,

would all be accounted for within the rhetorical encounter of diagnosis and coming to

decisions about treatment options. Graham Harman sums up this position nicely in "The Road to Objects," where he writes:

> There can be no better example of a perfectly flat ontology than the early philosophy of Bruno Latour. At that point in Latour's career, all human and inhuman things, all chunks of physical matter and people and cartoon characters, are equally *actors*. What makes all things actors, despite the vast differences between them, is that they have an effect on other things. As Latour puts it as recently as 1999 in *Pandora's Hope*, to be real means "to modify, transform, perturb, or create" something else. Reality is defined not by what it is, but by what it does. Not everything is equally *strong*, since the Chinese government affects more things than does a stick figure drawn in the notebook of a Chinese schoolboy, but everything is equally *real*, since even that stick figure has *some* faint emotional resonance in the boy's mind and is therefore not just an empty hole of non-being, while the mighty effect of the Chinese government on its citizens is different only *in degree* from the stick figure, even if that degree of difference is huge. Reality for the early Latour means having an effect on other things. And just as for Aristotle all humans are equally humans and all trees equally trees, for the early Latour all actors are equally actors. (177-8)

Within healthcare contexts, interestingly, objects and nonhumans—such as tests and scans—have come to be more credible actants than humans themselves. Some doctors find that relying on tests is more comfortable and accurate than listening to the stories of patients, their bodies, and the other actants within the diagnostic assemblage. However, networked diagnosis would bring the expertise of all such actants to bear on difficult cases and would

draw on their collective authority in responding to the most challenging and painful of all uncertainties: how to regain health or face death.

From Critique to Reassemblage

Another stalemated debate within medical rhetorics to which a networked framework might respond is the problem of critique. Previously, I mentioned that some scholars within medical rhetorics have tried to locate alternative ways of responding to illness experiences and narratives that evade the distrust and iconoclasm of critique. Such techniques are undoubtedly inappropriate for experiences of illness that can devastate a person's identity and life. But feminist writers and disability activists have also been particularly, and rightly, vocal in speaking out against disparities within healthcare settings and encounters, such as disproportionate access to compassionate care, abusive practices that harm rather than help patients, and neglect of the elderly, in particular, in long-term care facilities. While I align myself with such critiques, as will likely become apparent in the analysis that follows, I also recognize the importance of moving beyond critique and towards an active reassemblage of the very medical networks of which we're apart. As Latour claims in "Why Has Critique Run Out of Steam?" critique on its own can result in compassion fatigue, frustrated abandonment of difficult conversations, and stakeholders pointing fingers at each other from opposite sides of the room (I might add, hospital). Perhaps the most common example of such an overemphasis on critique can be seen in discussions surrounding mental healthcare, where some attempt to shore up their field's ostensible objectivity by citing the authority of such tools as the *Diagnostic Statistical Manual of Mental Disorders*, while others rally against these disempowering justifications for labeling (primarily) minorities as "ill." In what follows, then, I will focus on mental healthcare rhetorics as I consider ways in which a networked approach

would more fruitfully address the need to hold those in power accountable while it opens up

ways to reconstitute traditional methods for diagnosing people with mental illnesses.

Perhaps the most commonly critiqued practice within mental healthcare rhetorics is

the use of the *DSM* to diagnose mental illness. In 2013, in fact, the National Institute of

Mental Health revoked support for the *DSM-V*, the most recent version of what some

affectionately call the "Bible" of mental disorders, noting that they would no longer support

research projects that relied on or studied *DSM* criteria. Christopher Lane, in "The NIMH

Withdraws Support for DSM-5," calls the decision a "humiliating blow" to the American

Psychiatric Association, particularly since the NIMH explained that "The weakness of the

manual is its lack of validity" (n.p.). This significant move comes in the wake of much dissent

about the manual's validity, usefulness, and misuse. For example, in *Making Us Crazy*, Herb

Kutchins and Stuart Kirk argue that the groups most likely to be designated as mentally ill

are already vulnerable populations, such as women, minorities, and LBGTQ+ individuals.

For example, the "illness" of homosexuality remained a mainstay in the *DSM* until the

1970s, and several "illnesses" have surfaced within the *DSM*'s history that attempt to

pathologize women's interest in sex. Furthermore, Frances notes that many physicians fail to

even double-check *DSM* criteria when making a diagnosis, and that when he quizzed them

on the basic guidelines for diagnosing common disorders, most of the physicians were

stumped. He argues that a tool is only as useful as its implementation, and that the *DSM*'s is

most useful at instigating overdiagnosis of illnesses like depression or anxiety because of their

popularity or because new drugs are being pushed by pharmaceutical companies. Relatedly,

others have criticized the small group of (mostly) white, male physicians who have

traditionally served as the *DSM* editors for allowing drug companies to influence their

categorization of illnesses. For example, the diagnosis of depression exploded in popularity

following the invention of Prozac, which drug companies marketed directly to doctors and consumers. As this all-too-brief analysis illustrates, critiques of the *DSM* from many stakeholders—including psychiatrists and NIMH leaders—proliferate.

Other prominent criticisms of diagnosis within mental healthcare circles come from feminists who challenge the authority of psychologists to label some "ill" and others "well" based on a reductive criteria. For example, Joan Jacobs Brumberg challenges diagnoses with eating disorders by demonstrating that, since the Victorian period, women's appetites have represented sexual appetite, drudgery (such as housework and extensive meal preparation), and aggressiveness. She cites historical stigmatizations of female desires and appetites as the underlying cause of eating disorders rather than a pathological state on the part of the woman who suffers. She writes, "even when an illness is organic, being sick is a social act" that responds to contemporary circumstances (8). "Among affluent young Victorians," she adds, "food and eating were at the center of a web of associations that had a great deal to do with gender and class identity. The same is true today, but broad social and cultural forces, particularly the intensification of messages about the female body, have promoted the urgency of appetite control and generated a new experience of the disease" (8). For Brumberg, DSM criteria describe symptoms of a larger cultural disease that affects particular vulnerable populations more accurately than they describe the disease itself. Susan Bordo echoes Brumberg's analysis and extends it to argue that anorexia nervosa, as a common example of a disease that cannot be reduced to a DSM diagnosis, represents not a rejection of the "ideal" female body but a hyperbolic enactment of it. The disproportionately high incidence of eating disorders in women during periods of gender change leads her to suggest that these disorders tell us what is wrong with Western culture rather than what is wrong with self-starving women. The contemporary anorectic, for Bordo, "experiences her life as

well as her hungers as out of control," and due to cultural messages that tell her that this is wrong, she becomes "hooked on the intoxicating feeling of accomplishment and control" that eating disorders can supply (149). This feminist approach levies blame at representations of female bodies in advertising, cultural ideas that women should be thin and without appetite, and expectations for women to focus on controlling their appearance rather than becoming politically engaged. While I am quite sympathetic with such critiques of the DSM, in particular, and constructions of mental illnesses that affect vulnerable populations, more specifically, I want to suggest that they might be more powerful when enacted with an eye to reassemblage of these troubling paradigms.

A networked framework for shifting from critique to reassemblage would involve generating alternative narratives about mental illnesses and other methods for responding to them in addition to critiquing structural inequities and abuses within medicine. For Latour, reassemblage is additive in the sense that, "The social that makes up society is only one part of the associations that makes up the collective. If we want to reassemble the social, it's necessary, aside from the circulation and formatting of traditionally conceived social ties, to detect other circulating entities" (*Reassembling the Social* 233). What other actants are circulating that might be added to this assemblage to strengthen it? Digital support groups offer excellent examples of patients and concerned stakeholders coming together to support each other, rally for their rights to insurance coverage and to define their illnesses on their own terms, provide advice to those who have recently fallen ill, and respond to injustices within healthcare settings (see Kristen Gay, "Unbearable Weight, Unbearable Witness"). These groups oftentimes critique problems that they've witnessed, but they also construct an alternative space wherein patients might tell their stories and reclaim their subjectivity from stigmatizing mental health diagnoses. Such an active reassertion of what is missing in medical

discourse for many—the unique identities of individuals that cannot be encapsulated by a diagnosis—speaks to the empowerment that a network reassemblage might foster. Furthermore, for researchers who want to engage in networked critique, they might follow the lead of Becky W. Thompson in *A Hunger So Wide and So Deep*, who interviewed many Black, working-class, and lesbian women with eating disorders and found that nearly all named experiences with sexual abuse as the cause. While she firmly levies a critique against assumptions that eating disorders are a superficial "white girl" illness, for example, she goes a step further by suggesting a new way to label eating disorders without stigmatizing those who suffer: eating problems. Problems, she suggests, indicate the complex narratives that interweave to create a troubled relationship between a woman and her body in contrast to disorder, which implies that the woman is somehow responding inappropriately to a traumatic experience. Beyond adding this new word to the network, she also adds new voices; she writes that, "scholarship on eating problems is not particularly behind in its lack of attention to race, sexuality, and class. Unfortunately, it mirrors health scholarship in general" (6). Rather than simply critiquing such an omission, which has led to misdiagnosis and lack of treatment for women of color, she fills this gap, in part, with the voices of the women she interviews, who reassemble what it means to be a woman with an eating problem (12). While there is still room for critique within and against diagnosis, Thompson's method for also assembling something new might empower patients, enliven conversations surrounding a particular illness, and lead to more structural changes by inviting conversation with multiple stakeholders.

As I hope my extended example of critique and reassemblage in the literature surrounding eating disorders has illustrated, ANT's commitment to adding new voices and listening to those who have been excluded offers a compelling alternative to the critical

project. The trick, for Latour, is not to reassemble our networks to account for all of the isolated voices that must be heard but to be able to negotiate with them in concert—after all, when we trace a chain of associations, the actants to who we are responsible only grows. In "Where are the Missing Masses?" he writes, "Students of technology are never faced with people on the one hand and things on the other, they are faced with programs of action, sections of which are endowed to parts of humans, while other sections are entrusted to parts of nonhumans. In practice they are faced with [...] the only thing they can observe: how a negotiation to associate dissident elements requires more and more elements to be tied together and more and more shifts to other matters" (174). The work of reassembling networks is never done because the network is never stable or complete but ever evolving, like a swarm of ants attacking a piece of food, carrying pieces away, eating the food, and making new shapes as they go. Furthermore, what can initially look like a small chain of associations will eventually reveal, in the tracing of them, a complex system of humans and nonhumans that have never stopped moving. For diagnosis, critique falls flat because it ultimately reinscribes the very hopelessness and frustration that simplistic diagnoses engender. On the other hand, a reassemblage project that adds new actants to the diagnosis being considered (and actants here might be anything from the poverty affecting a young woman with an eating disorder to the diet pills she abuses), opens up new ways to conceive of the problem, new sources of the problem to consider, and new ways to intervene in the assemblage.

From Listening to Tracing

As previously discussed, when doctors consider their role to be that of persuading patients to listen to them or interpreting their bodies and symptoms, all members of the

diagnostic network suffer and diminish their agentive capacities. Furthermore, when researchers and theorists respond by critiquing such practices without creating alternatives, they fail to open up conversations about revising them. A final debate wherein a networked framework for diagnosis might be preferable to the current, static framework is within the characterizations of diagnostic encounters as hinging on silencing vs. listening. Countless debates within medical rhetoric stem from a concern about whether patients are being silenced or listened to, and in fact, such concerns often inform alternative practices like narrative medicine. I want to consider what a shift to tracing, in addition to listening, might do to move this conversation into a third space of active reconstruction of networks. In this section, I will discuss several prominent voices within this debate before I explicate why tracing might be a helpful complement to listening practices.

In Thomas Couser's *Recovering Bodies*, he argues that the professionalization techniques that doctors have adopted function more to shore up their own authority than to serve patients and their needs (20-1). For example, he highlights problems surrounding the diagnostic interview, and mentions that doctors are highly likely to interrupt patients, especially Black female patients, during this process (20). As patients tell the story of their illness, doctors might tell them to stick to the facts or only answer their questions, or they might abruptly cut patients off and ask a particular question that they deem important. Couser also mentions that fears surrounding identification with a patient who might be ill or dying leads to a depersonalization of medical care, while concerns that their authority might be undermined can lead doctors to withhold information or even a diagnosis from patients. Beyond not listening to patients, the fear doctors experience of identifying with patients and their unsettling mortality has led some to adopt a language that downplays their personhood altogether. Thus, Couser writes, a man with liver failure might be referred to as "the liver in

201" (26). Similarly, Couser refers to Perri Klass, who highlights the language used when a patient's treatment isn't going well: "You never say that a patient's blood pressure fell or that his cardiac enzymes rose. Instead, the patient is always the subject of the verb: 'He dropped his pressure.' 'He bumped his enzymes.' [...] When chemotherapy fails to cure Mrs. Bacon's cancer, what we say is, 'Mrs. Bacon failed her chemotherapy'" (*A Not Entirely Benign Procedure* 73-4). Such issues within the diagnostic process, far from simply reiterating doctors' insecurity about their authority to speak for illness, also highlight the routine silencing of patients as they try to speak about what pains them, what they fear, and what might be wrong. Patients aren't merely silenced; they are even grammatically blamed for their illness, since the disease has happened in their body, and they must thus be a co-conspirator with it. Couser sums up these problems by noting, "Thus discourse between patient and doctor occurs in a way that may be at odds with the root meaning of *communication*, the making common of information" (20-1).

As if to highlight the silencing of patients on the part of doctors—and to reinstill the sense that it's somehow the patient's fault if the doctor ignores them—Barbara M. Korsch and Caroline Harding authored the *Intelligent Patient's Guide to the Doctor-Patient Relationship* to ostensibly teach patients to "lear[n] how to talk so your doctor will listen," as the subtitle promises. While Korsch and Harding attempt to put patients in doctors' shoes to help them better appreciate the struggles and demands they face, the text comes off as defensive. For example, they write that "Ideally, we all would like our physicians to be completely dedicated. In the best of all worlds, our doctors would cater to all our needs and we would no longer have any complaints. Although that sort of an arrangement does sound alluring, it doesn't work. When physicians consistently go beyond what should realistically be expected of them, they become less responsive to their patients" (128). What cannot be

realistically expected of physicians—what chafes too much against time restrictions and compassion fatigue—is apparently the commitment to listening to patients, hearing what concerns them, and reassuring them that they will do something about it together.

In response to such methods for interrogating, rather than engaging, patients during the diagnostic encounter, Charon and others have created an alternative narrative medicine practice that shifts from silencing patients to listening to them. Charon advocates for enabling patients to not only tell their stories but to do so on their own terms; in her experience, the ability to control the way the story is told is as important to patients as the ability to speak. Her process involves listening carefully to patients, asking open-ended questions that allow them to elaborate as they wish, and letting them open up about uncomfortable topics such as their fears of death, what it might mean to be terminally ill, or how their bodies might change through treatment. She explains that her process "begins simply with the invitation to 'tell me what you think I should know about your situation,' and is followed by a commitment to listen and not—at least at the start—to write or even to speak. When I first started doing this, I had to literally sit on my hands to prevent myself from writing in the chart or calling up the patient's computerized medical records" (187). As the patient recounts her story, Charon listens intently, avoids interrupting unless its absolutely necessary, and pays attention "as I sit there at the edge of my seat, absorbing what is being given—to metaphors, idioms, accompanying gestures, as well as plot and characters represented for me" (188). Once the patient has told her story, a process that tends to take twenty or thirty minutes, she then begins the physical examination, keeping in mind the patient's experience of her illness, the language and idioms she used to describe it, and her fears and concerns. She refutes the idea that such a process is too time-consuming to be useful as she notes that the time she spends listening to her patients early on usually saves her

time later as she more quickly comes to a diagnosis and can more easily generate treatment plans with patients once she has earned their trust. She elaborates, "Unfortunately, sickness does not travel in straight lines, and we who care for sick people have to be equipped for circuitous journeys if we want to be of help. Although many health care professionals worry that they do not have the time to listen for stories, many of us who have incorporated listening into practice find that time invested early is recouped quickly" (67). While Charon's process is both more ethical and compassionate than the type of "care" previously described by Couser, Korsch, and Harding, I want to suggest that it could be taken a step further by incorporating a Latourian concept of tracing a network. Rather, the kind of work within which Charon engages, while it can aptly be called listening, also serves an important function of inviting the patient to trace her illness experience in collaboration with the doctor.

As Charon acknowledges in her practice, for Latour, tracing is a necessarily slow process, one that requires care and precision. He writes that when tracing one must "Instead of cutting the Gordian knot [...] struggl[e] to follow the gestures of those who tie it together" (*Pandora's Hope* 87). Rather than trying to separate interwoven problems, then, one who traces must look at where the problems intersect and follow the actants as they navigate their networks. As McIntyre puts it, "Tracing is a painstaking process that requires adherents to follow nonhuman and human participants from network to network and trial to trial" (21). Just as Charon experiences when she listens to her patients trace their experiences with intersecting problems, the time invested in listening often yields more fruitful ways to approach treatment and healing since tracing emphasizes intersectionality.

For example, Charon recounts the experience of working with Mr. Ortiz, a patient who described not only his symptoms but "the recent shift from construction work to part-

time clerking in a clothing store because of physical inability to do strenuous work, and his current shame at being unable to support his family without accepting welfare" (185). In treating Mr. Ortiz, she treated the physical symptoms of his coronary artery disease, but she also discovered that "his sadness and shame have by no means gone away. He continues to have joint pain, fatigue, trouble with his son, bursts of intolerable but uncontrollable anger" (185). Charon notes that she listens "as an internist—deciding to get knee films, for example, and to start anti-inflammatory medicine for his joint pain" but also "for his story of himself" (185). She concludes by writing, "He finds comfort and strength in the telling and finds himself remembering things from childhood and making connections among his emotions, his past, and his physical symptoms" (185). Ultimately, such disclosure enables Mr. Ortiz to seek talking therapy with Charon, who asks a colleague in medical social work to be her mentor as she develops her skills in this area. "It feels right," she says, "for me to commit this work myself instead of referring Mr. Ortiz to a separate psychotherapist because his emotional pain is intimately tied to his physical situation. It would feel disruptive of his integrity as a self-with-a-body to pull apart those two aspects of his suffering, apportioning the discouragement and depression to the social worker and keeping the chest pain and shortness of breath for myself" (186). While Charon does not assume full responsibility for the care of Mr. Ortiz—and she reiterates later that "bearing witness requires community"— she does refuse to disentangle the Gordian knot of the patient's sources of pain to preserve his integrity as a complex but whole person (197). For Latour, similarly, "ANT claims that it is possible to trace more sturdy relations and discover more revealing patterns by finding a way to register the links between unstable and shifting frames of references rather than by trying to keep one frame stable" (*Reassembling the Social* 24). Thus, Charon's listening can be seen as

a kind of Latourian tracing, a practice for medicine that is preferable to a dynamic of listening to or silencing patients.

Furthermore, tracing is also invaluable for medical rhetorics because, although Sanders allows that while in simple cases doctors can easily tell "whodunit" due to advances in medical technology, difficult cases offer a chance to revert to diagnosis as an art, since they suspend the doctor's automatically assumed authority to speak for disease. As the medical advisor to the popular television show *House,* she estimates that up to 15 percent of patients are given the wrong diagnosis, and that incorrect diagnoses cause many of the adverse effects associated with illness (xxii). Far from blaming the patient for failure to be "read" properly or to comply with the doctor's instructions, Sanders blames the diagnostic interaction, as recommended by Segal, that values technology over touch, testing over discussing, speaking over listening. In "Overconfidence as a Cause of Diagnostic Error in Medicine," Eta S. Berner and Mark L. Graber corroborate Sanders' assertion while they argue that doctors' pride itself is commonly to blame for inaccuracies. They assert that physicians tend to generate an automatic hypothesis when examining patients, and once they have (often prematurely) made this educated guess, they automatically limit the range of available causes of illness. This creates a "general tendency on the part of physicians to disregard, or fail to use, decision-support resources" because "physicians do not think they need diagnostic assistance" (57). Berner and Graber attribute this tendency to overconfidence, at least in part, to the demands placed on physicians to be absolute authorities, to eschew uncertainty, and to present themselves as competent professionals—even in the face of fatal or complex illnesses (Timmermans and Mauck 18, Katz 35). Lest I sound too critical of physicians, it's important to note that this process generally works—more often than not, such a process is adopted because of its general efficacy in limiting an enormous range of illnesses to a few likely

"culprits." However, the relatively high rates of inaccurate diagnosis for common illnesses such as Bipolar Disorder (wrong diagnosis in 69 percent of patients), breast cancer (missed in 21 percent of patients), endometriosis (missed in 18 percent of cases), and pulmonary embolism (diagnosis was incorrect in 55 percent of fatal cases) suggests that perhaps this model doesn't work well for all illnesses, or in all situations (Perlis, Beam et al, Buchweitz et al, Pineda et al). Perhaps doctors and patients need other ways to trace problems particular to pain and illness that move beyond the antagonistic or paternalistic models so common in the medical literature. Perhaps, more to the point, they need each other.

From Certainty to Meaningfulness

The suggestions here of the implications of networked diagnosis are by no means comprehensive, as there are both other fruitful benefits of adopting such a framework and potential consequences to consider, such as the allotment of resources and medicine's values of efficiency and timeliness. If I at times come across as particularly critical of doctors, I want to acknowledge too that they face very real constraints when diagnosing patients. For medical doctors, a patient's risk of death or other health complications (like a stroke) might urge them to quickly and perhaps brashly move forward in pursuit of an answer rather than considering their patient's need to tell their story. For mental health practitioners, fears that their patients might take their own lives or endanger others if they don't adopt a paternalistic role within the diagnostic encounter can foster detrimental but nonetheless understandable psychologist-patient dynamics. I also acknowledge that my project challenges a key value within medical or psychological diagnosis: the ability to be certain. As previously mentioned, Davis argues in that the very roots of the term diagnosis speak to the intricate relationship between certainty and medicine. However, as I hope this analysis highlights, coming to a

certain knowing of a patient's illness may not only be impossible in some cases, it may not be enough to satisfy their need to make meaning out of a death-inflected or life-altering diagnostic experience. Thus, I want to conclude by suggesting that a networked approach to diagnosis might finally move us past the rigid pursuit of certainty and towards a striving for meaningfulness.

Ann Jurecic, in *Illness as Narrative*, says that if folk explanations for illness and religious justifications for suffering no longer hold sway in our contemporary moment, then doctor's offices become the new space wherein people ask these questions "human fragility and significance" (10). The failure of doctor's offices, both in general medicine and psychology, to answer these questions or to even entertain them has been well-documented, as the recent increase in autobiographical accounts of illness in digital and print spaces suggest. But as long as patients will be diagnosed with terminal illnesses, as long as everyday persons will suddenly have to open themselves up to medical authority because of a dot on an X-ray, and as long as doctors will serve as patients' guides in their journey towards better mental health, it will not be enough to definitively tie down a diagnosis for a given person. People want to be cured, but they also want to be healed. And a networked approach to medicine, as it opens up alternatives to the diagnostic process that decenter medical authority, enable revisionary practices, and instigate tracings of complex illness experiences, might more effectively heal people by inviting them to make meaning within their networks.

Chapter Overview

The chapters that follow develop and qualify my claim that diagnostic practices are out of sync with the narratives diagnoses foster. As I will argue, ANT provides a generative framework for diagnostic deliberation as it more fully accounts for uncertainty, dispersed

agency, community stakeholders, and even nonhumans. In what follows, I will further tease out an alternative approach that better reflects diagnostic narratives authored by doctors, patients, and community stakeholders.

In Chapter 2, I conduct qualitative research on Dr. Lisa Sanders' interactive *New York Times* "Diagnosis" column and explore an alternative definition for medical rhetorics. Whereas medical rhetorics has traditionally been defined as persuasion, interpretation, or identification, I argue instead that Sanders' diagnostic narratives point to a more complex work for rhetoric: assembling actants together to solve a problem, enlisting new actants, and maintaining connections. I pay particular attention to the actants responsible for solving the diagnostic "cases": the doctor and/or other healthcare providers, the patient and other actants (including family and community members), and chance. As these narratives reiterate, diagnosis is much messier than many doctors and patients would like to recognize; in fact, many of the cases are solved through random happenings, such as doctors agreeing to work late or a doctor deciding to run a challenging case past a greenhouse employee. This chapter highlights the need for a rhetorical approach to medical assemblage that might better enable us to account for and respond productively to uncertainty rather than being paralyzed by it.

Chapter 3 tells a more cautionary tale of what can happen when a network misdiagnoses patients, which occurred in 2015 for asymptomatic Ebola nurses who were forced into involuntary quarantine. The chapter focuses on methods for intervening in networks when they fail and holding all actants accountable. I focus particularly on Kaci Hickox, or the so-called "Ebola Nurse," who was involuntarily quarantined by Chris Christie. I offer a rereading of the Hickox network through the lens of ANT, arguing that Christie and Maine governor Paul LePage attempted to exclude Hickox from the public health network and reinforce a myth that U.S. healthcare networks are safe from outside

influence. I also serve as a moralist in Latour's sense by arguing that we must reincorporate several actants back into the collective if we are to confront future Ebola outbreaks more effectively. In particular, I reincorporate nonhumans (such as destroyed habitats and bat populations in Africa), perspectives of African aid workers, and conservative politics as they contributed to Hickox's quarantine and the breakdown of the Ebola network.

In Chapter 4, I return to Chapter 2's emphasis on uncertainty to argue that non-Western theories of deliberation might better equip patients and doctors to navigate uncertain diagnostic contexts. In particular, I will consider the activities of two enigmatic communities. First, I will analyze the phenomenon of bug-chasers, or a subgroup of gay men who intentionally try to contract HIV because — among other reasons — they'd rather know they have it than live in constant fear. Then, I will highlight the experiences of people at risk for genetic diseases who choose not to take predictive tests, primarily because they would rather live with uncertainty than know for certain whether they will develop a particular disease. Such cases point to a dangerous fixation on certainty within Western medicine, which values outcome generation and knowledge of one's health status even when such efforts may not help — and may actually harm — patients. I draw on Arabella Lyon's research in *Deliberative Acts: Democracy, Rhetoric, and Rights* and explore how a shift towards Chinese deliberation practices (which closely resemble ANT practice) might better enable patients to dwell with uncertainty. Such research might also contribute to Western rhetorics an appreciation for alternatives to outcome-driven and hierarchical deliberation.

Finally, in Chapter 5, I argue that medical assemblages can contribute to rhetorical scholarship a more complex understanding of *ethos*. Drawing on both examples of networked *ethoi* in diagnostic practice and theories of networked *ethoi* from feminist ecological rhetoricians, I will consider how such a framework might enable rhetoricians to ethically

respond to the needs of multiple stakeholders. The view of medicine—and rhetoric—as an assemblage means grappling with pressing questions regarding which stakeholders should be prioritized and why. Diagnostic networks perform a kind of "calibrated" *ethoi*, to borrow a term from Annmarie Mol, wherein the expertise of doctors, patients, healthcare providers community members, insurance companies, family members and friends, and nonhumans must be shared. I will conclude by exploring the implications of such a model of *ethoi* for rhetoric and composition.

CHAPTER 2:

DIAGNOSING MEDICAL RHETORICS

Socrates wants to replace pistis with a didacticism that is fit for professors asking students to take exams on things known in advance and rehearsed by training and rote exercises, but that is not fit for the trembling souls who have to decide what is right and wrong on the spot. - Bruno Latour

In April 2016, a CFP began circulating for an edited collection entitled *The Rhetoric of Health and Medicine as/is: Theories and Concepts for an Emerging Field*. Editors, including Lisa Meloncon, Scott Graham, Jenell Johnson, John Lynch, and Cynthia Ryan, called on readers to propose chapters that "[would] explore how scholars in the rhetoric of health and medicine use rhetoric in theoretical and practical ways to examine the discourses of health and medicine and how those discourses create meaning within a wide variety of scientific, technical, practical, and political sites" (Ryan "Re: CFP"). They charged those submitting proposals with the hefty task of defining what it means to take a rhetorical approach to studying medicine and healthcare. More specifically, they asked for submissions to address what rhetoric as/is medicine means:

> Let's take the concept that is part of the field's name, "rhetoric." For many years, scholars in rhetorical studies and rhetoric and composition have argued that rhetoric is a way of analyzing existing discourse as well as providing a framework for creating it. *As* provides us an entryway into thinking about different concepts as theoretical underpinnings. *Is* provides us an entryway into thinking about how theories can potentially be applied in practice. We definitely want to nudge and even push scholars in the rhetoric of health and medicine to appraise what it is that we do and examine what sets us apart from other related fields. This endeavor means taking a critical stance to

determine what is at stake when we say that we are rhetoricians of health and

medicine. (Ryan "Re: CFP")

Aside from delineating theoretical foundations for the field of healthcare rhetorics, the CFP

raised a deceptively simple question: what *is* medical rhetorics? Perhaps it should be no

surprise that such a question be posed by those attempting to further establish a growing

field, since it directly echoes another question that scholars since Plato have attempted to

answer: what is rhetoric?

The CFP is merely the most recent example of an attempt to explore the intersections

of rhetoric and medicine and locate what makes studying them in concert so compelling.

According to Stephen Pender in "Between Medicine and Rhetoric," medicine and rhetoric

have been linked since at least the fourteenth century since "both rhetoric and medicine are

pragmatic and interventionist: one devoted to the body, the other to the body politic" (40).

The study of medicine's rhetorical dimensions initially served the needs of physicians who

needed to categorize complex medical and bodily phenomena. Pender argues that rhetorical

inquiry has also informed the ways in which physicians are able to generalize medical

findings based on particular cases and data; rhetorical theories of probability and best

practices have shaped medical inquiry. "For physicians struggling with the variable,

conflicting medical theories and a frangible, uncertain practice," he writes, "rhetoric offers

methods for reducing phenomena to their common forms, for placing these forms within

emergent systems, and for practical intervention devoted to agitation, comfort, or cure" (41).

Because rhetoric has so heavily influenced the way medicine is conceived and practiced,

Pender concludes: "[M]edicine cannot be immured from the pressures and pulsions of

rhetorical inquiry" (64). Since rhetoric provides us with tools for analyzing situations,

categorizing types of situations, and acting in a decisive and informed manner, Pender

suggests, it is indispensible to the art of medicine. Indeed, each of the famed ancient rhetoricians and philosophers—from Plato's Socrates, to Aristotle, to Quintillian, to Cicero —spoke to the relationship between the two.

Reinvigorating rhetoric's and medicine's ancient affinities, the area of study labeled "Rhetoric of Health and Medicine" or the "Health Humanities" more recently developed as a subgenre of the "Rhetoric of Science" and Science and Technology Studies (Segal 12-14). Barbara Heifferon and Stuart J. Brown note that the emergence of Writing Across the Curriculum (WAC) programs in the 1970s influenced a renewed interest in medicine on the part of rhetoric and composition scholars, since the WAC movement "turned attention to textual production in other disciplines" (3). Although Kenneth Burke had long before "opened up rhetoric to science" just as Thomas Kuhn "opened up science to rhetoric," it wasn't until the 1980s that the field of rhetoric and composition began to rhetorically study scientific processes and texts (Segal 10). In part, the downplaying of "humanistic origins and impulses" in Western biomedicine contributed to the resurgence of studies that linked rhetorical theory and science studies / medicine (Heifferon and Brown 3). In response, the 1990s "saw a return to humanities training and an understanding of the role of language in both medical school curricula and health practices" (3). In the 1990s, the narrative therapy movement (see Michael White and David Epston's *Maps of Narrative Practice*) began to thrive, and in 2000, Rita Charon founded Columbia's Program in Narrative Medicine, later theorizing her alternative philosophy and method in *Narrative Medicine: Honoring the Stories of Illness*. The 1990s also saw the relative proliferation of scholarly texts dealing with rhetorical approaches to medicine, including Celeste Condit's *Decoding Abortion Rhetoric*, Kathryn Montgomery Hunter's *Doctor's Stories: The Narrative Structure of Medical Knowledge*, Lennard J. Davis' *Enforcing Normalcy: Disability, Deafness, and the Body*, Arthur W. Frank's

The Wounded Storyteller, and Marc Berg's and Annemarie Mol's *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*, among others. As these titles suggest, topics ranging from medical practices, scholarship and writing to the constructions of bodies / ability were explored through the lenses of rhetorical theory, literature, philosophy, communication studies, and sociology.

In 2000, *Technical Communication Quarterly*'s special issue on medical rhetoric seemingly sealed medicine's place within rhetoric and composition scholarship. In their "Guest Editor's Column," co-editors Heifferon and Brown mention that the special issue is the first to invite submissions pertaining to "medical rhetoric," but they also note the historic roots of their project: their goal for the collection is to reverse Plato's splitting of rhetoric and medicine by reuniting them and designating their union as an area of study (247). Heifferon and Brown define medical rhetoric loosely as "how we communicate healthcare concerns," and highlight its evolution from the first time an ancient cave person "turned to the person next to him/her and tried to describe a pain" to contemporary healthcare policies and attempts to theorize the body (247).

Jessica Masri Eberhard's "An Annotated Bibliography of Literature on the Rhetoric of Health and Medicine" provides an especially detailed review of key texts within this area of study from 1973 (Foucault's *Birth of the Clinic*) to 2011 (Joan Leach's and Deborah Dysart-Gale's *Rhetorical Questions of Health and Medicine*). By the time of Eberhard's writing in 2012, the compilation of sources for an annotated bibliography on medical rhetorics scholarship proved a "daunting task" given "The various methodologies, objects of interest, critical lenses, disciplinary affiliations, and overarching conversations [that] have spread and now overlap to a large extent" (n.p.). Since 2012, the study of medical rhetorics has continued to flourish in terms of technical communication, narrative theory, healthcare

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education, and public health discourse, among others (see, for example, Therese Jones',

Delese Wear's, and Lester D. Friedman's *Health Humanities Reader* for a vibrant display of

such scholarship).

This tracing of the recent history of rhetorics of healthcare and medicine brings us

back to the CFP for scholarship that defines the boundaries and foundations of the field of

medical rhetorics. How might we define medical rhetorics *now*—8 years after Heifferon and

Brown—and what might we change about their early definition to better reflect

contemporary circumstances? In "Recognizing Differences and Commonalities: The Rhetoric

of Health and Medicine and Critical-Interpretive Health Communication," John A. Lynch

and Heather Zoller revert to an even older definition in response to my question:

> Like rhetorical studies generally, rhetoric of science, technology, health, and
>
> medicine identify Aristotle's *Rhetoric* as its foundational text. Rhetorical
>
> studies of health and medicine, like the rhetoric of science and technology,
>
> usually emphasize the situatedness of discourse, consider stylistic components
>
> (i.e., metaphor, trope) as key to persuasion, and culminate with a judgment
>
> about the rhetorical practice(s) being considered (Condit et al., 2012, Depew
>
> & Lyne, 2013, Prelli, 2013; Segal, 2009). (500)

This approach to defining medical rhetorics in Aristotelian terms presumes that medical

rhetoric means studying the available means of persuasion in healthcare contexts. While

Lynch and Zoller are not alone in this presumption (about which more later), I want to

suggest that continuing to define rhetoric in general, and medical rhetorics in particular,

based on Aristotle's limited purview means failing to account for contemporary theories that

better represent the complexity (rhetorical and otherwise) of medical encounters. Of course,

some aspects of medicine are inherently persuasive—doctors must persuade their patients to

trust them; in some cases, they must persuade patients to take their medicine, and in other cases, they attempt to persuade them that a particular course of treatment will best suit their needs. However, as I will argue in this chapter, persuasion alone cannot account for all that is communicated and all that happens in rhetorical encounters surrounding medicine.

The idea that rhetoric in medical contexts always takes the form of persuasion fails to reflect the uncertainty of day-to-day medical encounters, in particular. The proliferation of narratives written by doctors, surgeons, medical residents, and other healthcare providers has revealed the extent to which doctors are often not in a position to persuade patients regarding what to do since they are unsure themselves. In Atul Gawande's *Complications: A Surgeon's Notes on an Imperfect Science*, he emphasizes that doctors are constantly uncertain as they make informed life-and-death decisions, despite years of training, education, and specialization. He writes:

> Medicine is, I have found, . . . a disturbing business . . . We drug people, put
> needles and tubes into them, manipulate their chemistry, biology, and
> physics, lay them unconscious and open up their bodies to the world. We do
> so out of an abiding confidence in our know-how as a profession. What you
> find when you get in close, however—close enough to see the furrowed
> brows, the doubts and missteps, the failures as well as the successes—is how
> messy, uncertain, and also surprising medicine turns out to be. (4)

Gawande's book makes a compelling case for viewing medicine as a science with limitations and doctors as humans with vulnerabilities, despite technological advances and medical discoveries that have generated an alternative narrative of medical perfection. For Gawande, notwithstanding the "habit, intuition, and sometimes plain old guessing" that medicine entails, there is still the need to "act decisively," to make decisions in the moment with

people's lives on the line (7-8). In contrast to the view that doctors are authorities who must persuade patients to accept their diagnoses and comply with a treatment plan, Gawande views the doctor-patient relationship as a dynamic and fragile one wherein the doctor must act decisively yet with full knowledge of his/her limitations. Gawande's response to the idea that rhetoric within medical contexts is persuasion might echo Jake's infamous quote in *The Sun Also Rises:* "Isn't it pretty to think so?" (251).

However, Gawande implicitly speaks to the value of studying what rhetoric means for/within medicine when he writes, "[W]hat seems most vital and interesting is not how much we in medicine know but how much we don't—and how we might grapple with that ignorance more wisely" (8). In this chapter, I will extend Gawande's question by considering how rhetorical theory might help healthcare providers contend with uncertainty and ignorance more productively. I'm primarily interested in how medical practitioners might grapple with diagnostic uncertainties more effectively because, as Gawande notes, diagnosis often looks less like "plug[ging] it all [test results and patient information] into a formula [to] calculate the result" and more like "us[ing] . . . clinical judgment [and intuition] . . . to decide" (42). Diagnosis, perhaps more than any other rhetorical interaction within medicine, is haunted by uncertainty, and the stakes are high since doctors can only effectively treat patients once they've accurately determined what's wrong. As Lisa Sanders points out in *Every Patient Tells a Story*, "[A]s treatment becomes more standardized, the most complex and important decision making will take place at the level of diagnosis" (xv). In contrast to the definitions previously proposed, I define rhetoric as collective decision-making in contexts of uncertainty and diversity (as adapted from Trish Roberts-Miller's definition, see Chapter 1), I wonder what such a conception of rhetoric might illuminate within diagnostic encounters. My goal is not to offer physicians a new way to conceive of their work but to trace diagnostic

processes and their rhetorical events as they unfold within real-life scenarios. Furthermore, I do not hope to offer a "once-and-for-all" definition of medical rhetorics but to rather see what the lens of this definition can reveal about medical decision making surrounding diagnosis.[2]

In what follows, I will first trace tentative definitions for rhetoric within diagnostic contexts before I elaborate on my own definition, as informed by Bruno Latour and Nathaniel Rivers. I will then perform an analysis of narratives written by Dr. Lisa Sanders for the *New York Times'* "Diagnosis" column to consider what rhetorical interactions are taking place, and what they reveal about the intersections of rhetoric, medicine, and diagnosis. In particular, I will pay attention to the actants responsible for solving a diagnostic "case," such as the doctor, another healthcare provider, the patient and other actants (including her family members), and chance.

How is Medicine Rhetorical?

As I consider how key figures in medical rhetorics define their area of study, I am struck by the resonances of their definitions with classic definitions for rhetoric. Thus, in what follows, I will highlight three ancient definitions for rhetoric now adopted by medical rhetoricians to describe their practice: medical rhetorics as persuasion, interpretation, and identification. While all of these rhetorical interactions occur within medical rhetorics, I find it restricting to reduce the complex and multi-faceted interactions between healthcare providers and patients to one type of rhetorical event. I will thus adopt what I find to be a more encompassing and versatile definition for medical rhetorics via Latour and Rivers.

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[2] It's also important to note that the meaning of medical rhetorics will change depending on the type of medicine and type of medical situation being studied. A surgeon will likely conceive of rhetoric's role differently than a pathologist would, for example.

These scholars bridge two major areas of study: new materialism and rhetorical theory; they are thus well-suited to generate a multi-faceted conception of medical rhetorics that resonates with the uncertainty of medicine that Gawande highlights.

First, as previously discussed, persuasion continues to be perhaps the most popular definition for medical rhetorics in contemporary scholarship. Judy Z. Segal's foundational text, *Health and the Rhetoric of Medicine*, espouses this definition: rhetoric is persuasion, especially in medical contexts. As Segal notes in the introduction, "The premise of the book is that rhetorical study—essentially, the study of persuasion—is a good means of illuminating and recasting problems in health and medicine" (1). By conflating rhetoric and persuasion, Segal uncovers a myriad of provocative relationships between health and rhetoric; for example, she writes of hypochondriacs that they "have become persuaded in the absence of an organic precipitating cause that they are ill" (74). But more pressingly, Segal focuses on the extent to which persuasion saturates the doctor-patient relationship. In her 1994 article "Patient Compliance, the Rhetoric of Rhetoric, and the Rhetoric of Persuasion," Segal emphasizes the usefulness of persuasion for understanding the problem of patient (non)compliance with taking medications as prescribed, which was labeled the most pressing problem facing medicine at the time of its publication (90-1). How is it, she wonders, that doctors can effectively persuade patients to take their medicine as prescribed? And what goes wrong when they fail to convince their patients? However, Segal's useful insights ultimately lead her to go too far in suggesting that rhetorical criticism is solely "the study of persuasive elements . . . in a wide range of texts, especially in the realm of social action or public discourse" (10). Although she expansively highlights the value of Burkean and Kuhnean versions of persuasion within medical situations pertaining to compliance, Segal overstates

her case by assuming that *all* rhetorical interactions within medicine are persuasive—thus failing to anticipate other rhetorical relationships.

Even Segal's previous work undermines her book's argument, as she suggested in an earlier essay that imbalanced power dynamics and asymmetrical relationships within medicine may prevent doctors from persuading patients. In short, she posits that communication breakdowns between doctors and can oftentimes be attributed to a failure to find common ground.. She explains:

> Within this rhetorical view, persuasion is predicated on the existence of at least a shared language and shared values—both of which are absent to varying degrees within biomedicine's physician-patient relationship. In fact, with its focus on the discourse community as a context and necessary condition for rhetoric, rhetorical theory so clearly predicts the failure of physician-patient persuasion within the current medical model that the more interesting question (though one I will not attempt to answer) is probably not why so many do not comply with medical advice, but why so many do. ("Patient Compliance" 97)

Because in Segal's view effective persuasion must involve both rhetors speaking the same language and caring about the same things, doctors cannot truly persuade patients, or, at best, they can do so only in rare circumstances. Segal's later assertion, in *Health and the Rhetoric of Medicine*, that rhetorical persuasion must involve "a contact of minds," while idyllic, fails to account for her own point regarding the divisions between doctors and patients: linguistic barriers, differing expertise, and, perhaps most significantly, varying levels of health (17). Thus, the view that medical rhetorics need always hinge on persuasion fails on Segal's own criteria.

Other scholars, most notably Kathryn Montgomery Hunter, define medical rhetorics in terms of Renaissance-era hermeneutics, of which Augustine is perhaps the most famous practitioner. For Hunter, rhetoric's function within medicine lies in its interpretive power, particularly in regards to diagnosis. She likens diagnosis to a process of active reading wherein the patient is a text and the doctor is a critical reader, thus reinforcing stereotypical and paternalistic relationships between doctors and patients. She writes:

> [T]he investigative procedures of medicine resemble the act of reading far more closely than they do the laboratory process that has customarily been regarded as scientific. Diagnosis is interpretive; therapeutics is interpretive; and the care of the patient includes the interpretation of what is regarded as brute fact: the symptoms, the test results. 'Your pain is bursitis,' the doctor says; or, 'The biopsy indicates that that lump is malignant.' Patients enter the doctor's office sick; they have come for interpretation of their signs and symptoms. (9)

The diagnostic process then, for Hunter, occurs when a patient willingly presents her body as a text to be read and interpreted by an expert. Hunter carefully distinguishes the work doctors do from invention, since she argues that the view that patients and doctors co-create narratives of illness "accords the physician a much too central role in the life drama of the person who is ill" (12). She adds, "It is interpretive work that the physician is doing, not original composition, nor even (except in rare cases) co-composition" (12). While Hunter claims that doctors play an integral role in interpreting patients' bodies as texts (apparently passively inscribed with symbols and codes to be deciphered), she simultaneously denies that doctors participate in the creation of such texts. In effect, Hunter denies that diagnosis and interpretation are rhetorical events at all in that she sees them as a process of inputting data

to gain the correct answer (a view that Gawande explicitly rejects, as previously demonstrated).

Beyond the issue of physician agency, Hunter's offers a disempowering theory of patient identity in diagnostic contexts. A patient who fails to be read by a doctor, for Hunter, hardly exists at all as a rhetorical being. She explains:

> As a medical construct, the patienthood of the sick person requires a physician-reader for its existence in a way that illness and suffering do not. Indeed, the physician's reading as it is recorded in the patient's chart or presented at morning report transforms the ill, unknowable person into a knowable, narratable, and thus treatable medical entity. Interpretation is in itself not a method that leads to good or ill. The medical reading ideally does no violence to the person and does not intervene in or alter the illness. (12)

To reiterate: *the patienthood of the sick person requires a physician-reader for its existence*. A person does not become a patient until a physician reads her—and yet it is not an agentive role that the physician holds. Hunter's conception of diagnosis as a static interpretation of illness casts both the physician's reading and the patient's body/text as passive, a-rhetorical objects. Within Hunter's framework, all that matters is treatment (wherein patients attempt to re-embed a diagnostic interruption into their ongoing life story) and attempts to standardize the identification and categorization of each illness, regardless of the individual who suffers. She posits that "[M]edicine awaits the day when the anomalous character of each malady will disappear, and with it the need for all narration" (105). Or, put another way, a perfect medicine would need no rhetoric.

In contrast to Hunter's a-rhetorical approach to medicine, and in response to the problems previously described, the narrative medicine movement proposes an alternative

definition for medical rhetorics, particularly surrounding diagnosis: identification. In "The Reader's Response and Why It Matters in Biomedical Ethics," Charles M. Anderson and Martha Montello describe identification via Plato's *Gorgias*: "Rooted in what rhetorician Kenneth Burke describes as the natural inclination of persons to 'identify' with others, Socrates' greatest form of friendship seeks 'consubstantiality,' which is the recognition that, despite significant differences, I am of the same substance as you, we share interests, experiences, and we value each other accordingly" (88). Such an approach prefigures any ethical rhetorical interaction, for Anderson and Montello, because Socrates' version of consubstantiality enables readers to "imaginatively experience [and inhabit] the narrative realities" he proposes and to thereby "return to the present moment to consider in a more critical, more analytical way the knowledge gleaned from the experience" (89). The process of identification, then, becomes a way of destabilizing the self to enter the "rhetorical power of the narrative" and experience "the relational impact of the friendship shared by participants in the conversation" (89). Such a method serves bioethical deliberation, too, since Anderson and Montello envision patients and doctors engaging in a similar exchange as they experience the patient's story.

For example, Anderson and Montello describe a woman named Mrs. Green, who meets an "appalled" and "harried" medical student who takes her "case" when she is hospitalized for end-stage diabetes (91). The student "accidentally opens a door onto the narrative of the patient's life" by inquiring into her history of growing cotton as a child; the patient responds by opening up to the medical student about her life and the challenges she has faced (92). This moment of narrative exchange alters the relationship—or rather creates one—between Mrs. Green and the medical student, who "finds himself transformed by the

narrative consubstantiality they share" and "resists and finally discards the normative medical narrative" of her deteriorating health (92). The medical student's response is powerful:

> As he enters the world her story offers him, he meets her authentic, historic self and understands that she and he, as different as they might seem, are indeed of the same substance at the deepest levels of human experience and value. He is empowered by that knowledge to deliver effective, efficient medical care that brings about significant improvement . . . medical care he simply could not deliver had he not so fully participated in the narrative events in which her story engages him. (92)

Such an approach enables the patient to receive better treatment and the medical student to achieve greater personal satisfaction from his work, as he identifies with the patient's story and sees her as a human being.

Identification seems crucial to the process of viewing a patient as a human being with individual needs and life stories. However, I worry about the wholesale and uncritical adoption of a practice that enables doctors to feel like they can fully understand a patient by listening to their stories. While doctors taking the time to listen to patients and hear their needs represents progress, the claim that they can fully understand the needs of a patient that may—in many cases—lead a less privileged life than they do based on a single narrative is naïve. Imbalanced power dynamics cannot simply be erased when a physician empathizes with a patient. Furthermore, what happens to patients with whom doctors cannot identify? Will they receive less effective care, less empathy, or less attention from their physician? While identification may occur in some cases, to the mutual benefit of doctors and patients, it cannot be counted on to guide rhetorical relationships in medicine.

All of the above definitions for medical rhetorics fail to fully account for the diagnostic process—what is rhetoric's function in this medical situation? While doctors may need to persuade patients to receive a particular treatment, it is uncommon for patients to actually reject a diagnosis that can be substantiated with evidence (as most diagnoses are), which renders persuasion an improper definition for medical rhetorics in diagnostic cases. Doctors must certainly interpret test results, their patient's story, and their bodies in order to diagnose, but does this cover the decisions that doctors must make to determine which tests to order, which elements of the patient's story to focus on, and which bodily symptoms to pay attention to? Finally, while identification may enable doctors to provide more empathetic care, it can actually prevent diagnoses from occurring when it obscures important information—in the cases that follow, despite their ongoing relationships with patients, primary care physicians often miss a diagnosis that a new doctor immediately catches. A more fitting and encompassing way to conceive of medical rhetorics—particularly in regards to diagnosis—can be found in bringing together the work of Latour and Rivers since it accounts for deliberating in complex situations that encompass a range of actants.

Toward A New Definition for Medical Rhetorics

In contrast to the previous definitions offered for rhetoric (persuasion, interpretation, identification), Rivers offers an alternative definition for rhetoric via Latour; rhetoric "is the glue or the work of gluing together relationships" and "the art or science of living together" ("Introduction" n.p.). Lest anyone imagine that "relationships" or "living together" applies only to humans, Rivers speaks to the value of Latour's work for rhetoric: its assertion that we must also "account for the glue between humans and nonhumans and maybe even between nonhumans and nonhumans" (n.p.). The shift then is away from a conception of

rhetoric as static and occurring between two actors (speaker and audience) and towards a dispersed view of rhetoric occurring within a collective of actants, many of them nonhumans. "The term 'collective,'" Latour clarifies, "does not mean 'one'; rather . . . it means 'all, but not two'" (*Politics of Nature* 94). Whereas Latour refrains from defining rhetoric, as he famously prefers to watch what something does rather than posit what it is, I suggest that, based on his framework, rhetoric *assembles*. For Latour, assembling occurs as actants move and shift in and out of networks that together form such concepts as the social, reality, rhetoric, and, I might add, medicine. An assemblage within medicine, for example, might involve a doctor, patient, nurse, X-Ray, family member, the patient's prescriptions, her body, the conditions in her history or environment that caused her illness, among many others. While the only way to trace an actant's movements is to watch it act, Latour carefully reminds readers that no actant ever acts alone. He explains that "Action is not done under the full control of consciousness; action should rather be felt as a node, a knot, and a conglomerate of many surprising sets of agencies that have to be slowly disentangled" (*Reassembling the Social* 44). While networks will continue to assemble regardless of our intervention, Latour does allow that the ANT practitioner should "trace social connections using the unexpected trails [traces] left" behind when they shift or mutate into new associations (*Reassembling the Social* 43).

Thus, rhetoric can be understood as having two key functions within ANT assemblages. First, as Rivers points out, rhetoric operates within networks as "the glue" that holds actants together. Assembled actants use discourse to enlist actants into the collective, negotiate their communal actions, and bind themselves together. The work that networks do is rhetorical in that actants (human and non-human) must be persuaded to join forces within a network and maintain the assemblage using discourse, though this does not always take the

form of written or spoken language. The work of network (re)composition is also rhetorical in that ANT practitioners use rhetoric to trace associations, intervene in networks as they shift, and determine which actants have been excluded and need to be reconsidered (about which more later). At the level of network tracing, ANT practitioners employ rhetoric to reshape networks to most effectively meet the problems requiring our collective attention.

While Latour does not speak directly about rhetoricians, he addresses a group he calls the "moralists" in *Politics of Nature* as he redefines the roles that scientists, politicians, economists, and moralists will share in the new collective. Rather than defining the world in terms of nature vs. society (or fact vs. value), Latour proposes a new system wherein experts would solve the same problems using their own expertise "Like fairies . . . offer[ing their] own particular gifts" (137). While a full analysis of the new collective is beyond the scope of this chapter, it's important to note that Latour explicitly tasks scientists with the responsibility to "detect scarcely visible phenomena very early" and, using their specialized tools, skills, and ability to see (through their instruments) through multiple points of view, to take into account the imperceptible propositions demanding to be heard" (138). Scientists, then, are tasked with listening to a range of actants and attuning themselves to their demands. On the other hand, Latour tasks moralists (who I read as rhetoricians and/or ethicists) to "equip the entities that have been set aside with the *right to appeal* that they can use when, in order to fulfill the requirement of closure, they are driven out of the collective" (156). Thus, while scientists must hear the actants that are apart of the assemblage, moralists/rhetoricians must constantly ask who has been excluded from it. These excluded voices cannot be left out forever but will "*have to be* reintegrated, at some later point" when the network needs them, at which point, "Those who have been excluded from the collective are going to come back all the more quickly to knock on the door, to the extent

that the moralists will . . . *go looking for them* outside the collective, in order to faciliate their reentry and accelerate their insertion" (157). While moralists and scientists work in concert with economists and politicians, I want to emphasize the complementary roles Latour assigns to scientists and moralists—the work of listening to the imperceptible, tracing its movements, considering the problem from multiple points of view, asking which actants have been prematurely excluded, and bringing these actants back into the network when necessary. Put another way, Latour sees scientists and rhetoricians as intervening in assemblages to observe actants at work and add to the assemblages when actants previously considered insignificant stand to reshape the collective in beneficial ways.

As the above analysis attempts to make clear, the work of assemblage serves well as a definition for what medical rhetorics looks like in diagnostic situations. When a doctor diagnoses a patient, she must be able to trace associations amongst actants, listen to the actants as they speak—even and especially the scarcely perceptible ones—and she must constantly ask herself which actants have been overlooked or excluded as insignificant that might illuminate the problem. Only once she has traced all of the actants within the assemblage, often in conjunction with a variety of other actants that comprise her own professional network, can she intervene in the illness's network and revise it to remove dangerous actants and add healthier links. Networks are never static but ever evolving, which results in a vibrant and always uncertain work of following them without being certain where one of going; such a point resonates with diagnoses because, for Sanders, "Uncertainty is the water we swim in" ("Unexplained Illness" n.p.).

In the analysis that follows, I demonstrate that in addition to generating an alternative framework for diagnoses, the ANT assembly frame better describes what is already happening. I hope that such a view might offer physicians and patients a more livable

framework for inhabiting diagnoses—for understanding the uncertainty that haunts them, the randomness with which some diagnoses occur, and the networked actants that make both illness and diagnosis possible. Thus, in what follows, I briefly describe the "Diagnosis" column by Sanders, and I then shift to an analysis of 75 diagnosis narratives to more fully develop my claim that Latour's practice of assembly serves as a productive framework for understanding rhetoric's function within diagnostic scenarios.

Sanders' "Diagnosis" Column

Sanders created the *New York Times* "Diagnosis" column back in 2002, and her column's focus on mysterious illnesses and elusive diagnoses inspired the popular television show *House* several years later. Each column generally begins with a patient being brought to the hospital or suffering from a medical emergency, getting evaluated by a physician, and, eventually, getting treated for his or her illness. Strikingly, the diagnostic revelation generally comes at the end of the column rather than the beginning—this is not the story of recovery but the story of discovering what's the matter with a patient. Most narratives, of which there are 75 total, have three sections—Symptoms, Investigation, and Resolution—with the diagnosis generally occurring within the Resolution section. When the column's 47th post was published in 2011, readers were suddenly invited to respond to the mysterious story (and each subsequent one) and post their diagnostic hypothesis. Later, Sanders would update the post, highlight the range of answers submitted by readers, and congratulate the readers who guessed correctly (the first person to guess the correct diagnosis also wins a signed copy of her book, as of 2009). The invitation for readers to participate in diagnosis creates what Sanders calls a kind of "crowd sourced medical conversation" amongst healthcare providers, medical students, and laypersons ("The Girl with Unexplained Hair Loss"). Her overall goal in telling

these mysterious diagnostic stories, she explains, is to "put you, the reader, in the front line, in the shoes of the doctor at the bedside—to know that feeling of uncertainty and intrigue when confronted with a patient who has a problem that just might kill him" (*Every Patient Tells a Story* xxv). The payoff is not just for doctors, who need to be better informed about strange diagnoses so they can catch them in their own patients, but for patients themselves, who might better grasp their agency in diagnostic situations once they've studied her column. Sanders notes, "As physicians become more open about what we do, we make it easier for patients to understand what they can do to more fully participate in their own care" (xxvi). Thus, Sanders turns diagnosis into a kind of networked game wherein everyone can participate—albeit with varying levels of expertise and different roles.

To analyze the 75 narratives, I created a list of common ways in which the diagnosis occurred based on the primary actant responsible for the diagnosis—the doctor, another healthcare provider, the patient/others, and chance. Within these four major categories, I created a list of subcategories based on the more specific way in which the diagnosis occurred and calculated how many narratives fit each subcategory. For the first category, Doctor Solved the Case, I created the following subcategories: doctor's observation of an episode (3), doctor just figures it out (4), doctor runs through a list of possibilities (1), reading the patient's past history reveals the problem (2), linking symptoms rather than viewing them separately (4), doctor remembers something / notices a new factor (4), problem diagnosed during a physical exam (5), test reveals the problem (14), and creating a hierarchy of problems / isolating one factor (2). For the second category, Another Healthcare Provider Solves the Case, the subcategories were as follows: a medical blog provided the answer (1), Google provided the answer (2), the doctor missed the diagnosis (4), another doctor solves the case (9), and a resident or medical student solves the case (3). For the third category, the

Patient/Others Solved the Case, the subcategories were as follows: the patient solves her own case (5), a family member solves the case (4), a non-expert solves the case (1), and the patient's story provides the answer (3). Finally, for the Chance category, wherein the diagnosis was discovered through a random series of events, the subcategories were as follows: chance (3), disease had to progress (3), the problem was discovered during an operation (2), an object in the patient's room revealed the problem (2), and an effective treatment demonstrated the problem (1). In a few cases, because the diagnosis involved two actants working together, I allowed for the diagnosis to fit within two subcategories, and I also excluded two columns from my analysis because they dealt with diagnosing fictional characters.

In what follows, I will analyze key narratives using my major categories to explore what rhetorical interaction entails in diagnostic encounters. While these 73 narratives are by no means comprehensive, they nonetheless highlight key tensions and connections between rhetoric and medicine. The narratives also highlight tensions within assemblages between doctors, patients, their families, and random occurrences / nonhuman actants, and they emphasize the shared agency these actants demonstrate as they initiate and support diagnostic deliberation. The three sections that follow are based on three key actants (doctors, patients/others, and nonhumans/chance), but as my analysis will prove, such actants are often dispersed and complexly interwoven rather than solitary and stable during diagnostic encounters.

Doctoring the Network

The narratives in Sanders' "Diagnosis" column commonly emphasize that doctors fail to diagnose patients on their own; in general, they rely on a network of other physicians,

friends, and web resources to help them come to an accurate diagnosis. In part, this might be attributed to the fact that no doctor can remember all diagnoses, so a network of fellow doctors is needed to expand their collective bank of possible illnesses. Furthermore, as the forthcoming narratives highlight, doctors often rely on others to pick up on the clue that hides in plain sight. Just as a person solving a puzzle might be stumped by a missing piece only to have a friend come by and immediately find it, doctors often need other doctors to help them see the problem from a new angle, thus revealing the problem (in many cases).

Such a networked approach to diagnostic decision-making is emphasized in a post called "A Red Scare," where a patient is mistakenly diagnosed with poison oak, even though she disagrees with this diagnosis. Although the patient insists that her rash doesn't itch, as it generally does when a person has been exposed to poison oak, her admission that she's "visited a friend's farm and picked Swiss chard" recently "cinch[es]" the diagnosis for the doctor (n.p.). When she returns with darkening welts on her skin, the doctor admits that it is "time to call in reinforcements," in this case two younger colleagues who are invited into the patient's room to see her rash. "After a long moment," Sanders writes, "one of the partners, Dr. Michael Adler, broke the silence. He asked the patient whether she had eaten any shiitake mushrooms recently. The question surprised her. 'How did you know?' she asked" (n.p.). The younger partner immediately identifies the rash as a response to consuming undercooked or raw shitake mushrooms, which the patient revealed she had done recently when offered a sample at a local grocery store. When asked how he was able to diagnose the patient so quickly when two visits to the primary doctor had failed to yield the diagnosis, he attributed it to luck: "He had read a case report of a patient who developed this crazy-looking rash after eating shiitakes. The picture in the journal was so striking that as soon as he saw the patient, it all came back in a flash" (n.p.). This example illustrates the importance of having a range of

physicians involved in solving each diagnostic case, as each collects informational fragments and memories of diseases such as this that will aid them in identifying rare illnesses or unusual presentations of common illnesses. "That's what is so great about working in a group," the younger partner explained, "When you get stumped, you just call for help, and chances are, one of these guys will know the answer. It's like doing the crossword puzzle with a friend. With any luck, the other guy fills in your gaps in knowledge. This time I got to be that guy" (n.p.). The younger partner reiterates the collaborative nature of diagnosis and the need for doctors to share the responsibility of solving challenging cases in order to most effectively treat patients, thus undermining conceptions of doctors working in isolation to immediately diagnose patients with no outside help. The younger partner's successful diagnosis also highlights the larger context within which both illnesses and diagnoses arise; the network involved in the patient's sudden rash included mushrooms, a truck that carried the mushrooms to a grocery store, the store, an employee who improperly prepared the mushrooms, and the pans and ingredients she used. The network involved in her diagnosis is just as complex, since it involves a string of doctors with various forms of expertise, journal subscriptions, past memories, and educational experiences. In this case, the woman's case was solved because the diagnostic network was able to trace her illness network in a way that highlighted the connections between actants.

Such collaborative diagnostic decision-making seems especially important in urgent cases where patients may not have time to wait for a doctor to sort through all possible causes of illness. In "Losing Consciousness," for example, a woman presents to the hospital after two episodes of passing out in public with excessive rectal bleeding, which is caused by her blood's inability to clot. Because the patient is in danger of bleeding to death, her doctor, gastroenterologist Dr. Susanne Lagarde, immediately recognizes that "this patient needed a

diagnosis before whatever it was that already happened twice happened again" (n.p.). Lagarde is stumped by the tests she's conducted, so she thinks of a respected colleague who might be able to shed some light on the case—and using a different medical specialty. Sanders writes, "Lagarde immediately thought of Dr. Thomas Duffy. Duffy was one of the smartest doctors she knew, and he was a hematologist. When Lagarde reached him, she quickly outlined the case: a middle-aged woman with two episodes of low blood pressure and a temporary loss of the ability to form blood clots. Did that bring anything to mind?" (n.p.). Duffy explores several options before concluding that the patient has systemic mastocytosis, a rare disease stimulated by certain drugs where huge amounts of histamine are dumped into the blood, which results in the failure of blood to clot. When the patient confirms that she had started a new antidepressant prior to her episodes, a chemical combination that likely led to the excess histamine, the diagnosis is accepted. Despite years of formal training and access to specialized resources, Sanders concludes by noting: "For doctors, perhaps the most powerful diagnostic tools available are a phone and a friend" (n.p.). In this case, too, it's important to note the significance of doctors with different areas of expertise working together—a gastroenterologist may see some of the problem through her lens, but a hematologist may see other important information through his. Additionally, this case unexpectedly involves the pharmaceutical industry in that prescribed antidepressants had potentially lethal effects on the patient, which only a collaboration between doctors could uncover.

In other cases, when groups of doctors are stumped by challenging cases, they might turn to an additional actant within their diagnostic network: a computer. In "The Heat of the Night," Sanders recounts the story of a patient who awoke with strange fevers during the night, experienced significant weight loss, and had a mass on his liver. His doctors found no clear explanation for what was causing his ongoing illness, so the patient called an old college

friend who was now a practicing internist. Because the friend was stumped himself, he suggested a novel approach to his old friend: posting his friend's case in an online forum and inviting physicians from around the world to participate in solving the case (a process that resonates, of course, with Sanders' own project). Sanders writes, "That afternoon Schumann put the case on a blog . . . he was writing and contacted Kevin Pho, who has a popular medical blog . . . who then posted it, too. Within hours, a dozen comments were posted in response. Several pointed to a series of reports similar to this very case: patients with large hemangiomas and persistent nightly fevers. In several cases, simply removing the tumor stopped the fevers" (n.p.). The patient's doctor arrived at the diagnosis without seeing these online contributions through a "more traditional route" of asking a colleague, a gastroenterologist, to help. This colleague immediately recognized the problem. After the removal of the tumor healed the patient and stopped his strange fevers, the diagnosis was confirmed. Sanders concludes by noting the significance of the extended network of healthcare providers the Internet provides: "In medicine, doctors accept that no one knows everything. Our knowledge is shaped by experience, training and personal interest. We all reach out to our community of doctors when we are stumped. Usually it's to our friends and colleagues, but the Internet offers the possibility of a broader community — a sea of strangers linked by our medical curiosity and by our keyboards" (n.p.). Given the importance of assembling diagnoses in concert with other physicians with different areas of expertise and unique experiences with treating and studying illnesses, the Internet represents an especially helpful forum for solving challenging cases with experts around the globe. Rather than relying on their network of immediate friends and colleagues, physicians can now open up their diagnostic queries to the entire medical field.

When doctors do diagnose patients more independently, they often do so by linking symptoms together rather than viewing them in isolation—thus forming a networked version of illness. In some cases, doctors must be able to see how the symptoms relate to one another rather than simply paying attention to the most prominent or strange symptom. For example, in "Sleepless," Sanders recounts the story of a patient who hadn't gotten a decent night's sleep in a decade—he was unable to sleep for more than 90 minutes at any given time and often fell asleep during the day. He was also being treated for sleep apnea, chronic allergies, high blood pressure and cholesterol, adult onset acne, poor teeth alignment, and weak bones. The patient visited a new specialist to see if he could find an answer where so many other doctors had failed, and indeed, the new specialist noticed a striking symptom: the patient was physically large. Sanders describes how the specialist was able to identify a symptom missed by all previous doctors: "As he examined the patient, Helfrich was again struck by how massive he seemed. Not obese but big, really big. 'Have you always been this large-boned?' he asked the patient. The patient joked that he was thinner years ago — but weren't we all? Helfrich looked carefully at the man's face. His lower jaw and chin seemed broad and unusually square," (n.p.). On a hunch, the doctor ordered blood work, which revealed that the patient was producing excessive growth hormone—the result of a tumor in the pituitary gland. The doctor ordered surgery to remove the tumor, which immediately helped his hands, feet, and face to shrink back to their normal size.

But everyone was shocked when the other symptoms which he'd complained about were also healed—the patients allergies were never allergies but the result of swelling tissues in the face caused by the disease, the high blood pressure was reduced to normal given the lack of excess growth hormone, and the patient's sleep apnea was cured. Sanders asks, "How come not one of the dozens of doctors — including an endocrinologist — that he saw over

the nearly 15 years of interrupted sleep and other symptoms figured out that he had acromegaly? Perhaps because the various symptoms of his tumor were, for the most part, common problems: insomnia, high blood pressure, allergies and acne. They developed separately, years apart, and each was addressed by a specialist. It would take an act of imagination to link these symptoms. The patient never made that leap, and neither did any of his doctors" (n.p.). The division of the illnesses' symptoms and their separate treatment by various specialists resulted in an inability to see the overarching cause of illness—and all of its attendant symptoms. In this story, the process by which doctors determine what they do and do not see as significant in diagnostic cases becomes an actant, as a string of seemingly minor complaints actually comprise the network of a major medical event. The rhetorical work of diagnosis, then, involves being able to see the way various problems relate to each other—to unite a group of symptoms and puzzle over what could cause all of them to occur. Sanders adds that such an ability to "[cast] a wide net to see the whole picture" is especially important when "the complaint that brings the patient to medical attention is commonplace, like insomnia" (n.p.). In such cases, the patient may suffer when his symptoms are considered as individual problems to be treated by specialists who don't communicate with each other about their patient's health.

A similar case is explored in "Perplexing Pain," where a patient opens the narrative by telling her new doctor, "They took out my ovaries" (n.p.). After revealing that she has had thirteen exploratory surgeries to help doctors determine the cause of her chronic abdominal pain and fever, she tells her doctor that she has been living a "nightmare" (n.p.). The woman is referred to Dr. Chelimsky, a neurologist, when she begins to lose feeling in her hands and feet, and she explains that her ever-shifting symptoms felt like "the arcade game her children played, whack-a-mole — you get rid of one problem, but then it would pop back up, along

with another and another" (n.p.). Dr. Chelimsky began to focus on the patient's nervous system, and he finally hypothesized that "Many of her other symptoms — the rapid heart rate, being unable to urinate, abdominal pain with no visible cause, even her constipation, which had been so severe that six months before much of her colon was removed — could be caused by damage to the autonomic nervous system" (n.p.). Dr. Chelimsky suggests to the patient that she might have porphyria, and recommends that she consult with her regular doctors about this possible diagnosis. Desperate for answers, the patient and her husband (a pediatrician) immediately take to his medical library to read up on the illness, and the Sanders reveals, "[I]t was as if she were reading her own medical history: her entire life seemed to be there on the page of these old medical textbooks. All the strange and terrible symptoms she suffered through, had surgery for, been considered crazy for, were there on the pages she read. Tears flowed down her face. Her husband cried, too. They had, she felt certain, finally found the answer" (n.p.). Although it takes the patient three weeks to get confirmation of the diagnosis, Sanders puzzles over what enabled Dr. Chelimsky to figure out in a short time what so many doctors had not despite multiple invasive surgeries and years of familiarity with the patient. She rationalizes, "Porphyria is a disease of the nervous system. Thus, everything in the body is affected. The patient's hardworking doctors had been chopping down the trees one by one, treating each ailment in isolation. Dr. Chelimsky, a neurologist, was finally able to step back and see the entire forest" (n.p.). Because the illness affected the entire body, it was difficult for the patient's doctors to notice that each symptom was linked to one key problem with her nervous system. Thus, rhetoric can function within such situations to form a conglomerate of symptoms that doctors can trace to see how they fit together—and what common thread or problem glues them together.

Such a rhetorical goal of uniting symptoms rather than isolating one factor or another is also at play in "Abdominal Attacks," the first ever post in the "Diagnosis" column. In the narrative, a patient presents with unbearable abdominal pain that recurs and then recedes after a few days. He tells his gastroenterologist, Dr. Sachdev, "I can't go on this way" (n.p.). After a few tests come back normal, the doctor decides that this won't be an easy case and that it will require her to take an alternative approach. Sanders clarifies that there are two distinct processes for diagnosis—one involves "pattern identification — you see a patient, recognize the signs and symptoms of some known disease and make your diagnosis" (n.p.). But for other patients, she explains, "the ones with symptoms that don't match any of the patterns you know" doctors develop their "own hierarchy of possible diagnoses based on what they consider the patient's most prominent symptom. It's a personal hierarchy developed through individual experience, the experiences of their teachers and what they have read" (n.p.). In this case, though, the doctor finds the answer to the patient's problem not by isolating one prominent symptom (the patient's extreme abdominal pain) but in asking herself how it relates to the patient's other symptoms. The doctor notes that "Whatever [the patient] had, it was going to be unusual. She thought about his strange allergies, the swelling of the hands and feet, which she had previously assumed were unrelated to his stomach problems. Could they be linked? Were all these symptoms caused by hereditary angioedema, a rare genetic disease that can cause allergylike swelling? The swelling is usually found in the hands or feet but can also occur in the GI tract, which results in abdominal pain" (n.p.). Testing confirms that the patient did in fact have this rare disease, which the doctor only identified because she was able to link the symptoms rather than separate them. The doctor was ultimately able to cure the patient by asking what each of his symptoms had in common rather than focusing on one vague symptom.

Perhaps the best illustration of a doctor's need for a network of other actants to support her diagnostic process is the fact, as represented in the "Diagnosis" column cases, that doctors often miss diagnoses. Sanders admits, in "Missed Signals," that her failure to notice a patient's illness almost led to his death. She recalls that she had been treating him for about a year and "He was doing well, so I was shocked when I got word from the E.R. that my patient was dying. And the doctors there weren't sure why" (n.p.). The patient's heart was beating very slowly, and the doctor on call in the E.R. suddenly realized why—his kidneys weren't functioning, and his potassium was dangerously high. When the doctor attempted to test the patient's urine, he realized that the patient couldn't urinate, so he instructed a nurse to insert a catheter into the patient's bladder. When the nurse was unable to do so, it became even more obvious why the patient was so ill—he had an enlarged prostate gland that was blocking his bladder and shutting down the kidneys. Sanders chastises herself for failing to have the patient undergo a yearly rectal exam, which is a process that would have enabled her to prevent the patient from all of these complications: "When I heard that the prostate was the cause of the life-threatening bradycardia, I felt as if I had been punched in the chest. This was something I should have caught and didn't. An internist's job is to diagnose and treat acute illness and screen for and prevent additional disease. I joke with the residents I teach that it is our responsibility to keep our patients healthy and out of the hospital. If so, I had failed" (n.p.). Sanders attributes her failure to an inability to balance the patient's acute needs with his long-term healthcare goals. While she had been treating and responding to his immediate complaints, she hadn't probed him for information about additional concerns (such as his trouble urinating) and she hadn't insisted on routine preventative exams. "Practicing medicine is a balancing act," she writes, "weighing immediate and long-term good. His case was a vivid reminder of what can happen when that balance is lost" (n.p.).

Although Sanders sought forgiveness from her patient, and received it, her tale cautions us to grasp the importance of continually seeking what has been left out and excluded from a diagnostic assemblage. If the diagnostician must constantly attune herself to what *is* happening, she must also be able to ask herself *what else*?

Doctors can also fail to accurately diagnose patients when the need to solve a challenging case leads them to prematurely decide on a likely cause of the patient's problems. In "An Elusive Agony," Sanders tells the story of a 9-year-old girl experiencing attacks of excruciating stomach pain. When a series of tests ruled out the most likely culprits, the girl's doctor referred to her as "his little mystery and continued to search for the answer" (n.p.). Unsatisfied with the doctor's inefficacy, and determined to help her child, the mother began to research possible causes of illness herself; she "trolled the Internet and described her daughter's symptoms to every doctor she knew" (n.p.). Ultimately, when "she outlined the symptoms to her own internist . . . he said right away, 'Sounds like familial Mediterranean fever'" (n.p.). When she returned to her daughter's doctor to ask if this might be the answer they'd been searching for, he quickly dismissed the idea, and noted that based on his experience training in Israel and his familiarity with the disease, it was unlikely that her daughter had it. When the doctor referred the child to yet another doctor, the mother again raised the possibility that her daughter was suffering from familial Mediterranean fever. This time, the doctor took the possibility seriously and a blood test revealed that the mother was right. Sanders writes, "I asked Levy [the child's original doctor] why he had been so certain that the child didn't have F.M.F. Until recently, he explained, F.M.F. had been a clinical diagnosis — one made based on the patient's symptoms and the physical exam. The identification of the gene and the subsequent development of the test — which had only just become available at the time of this patient's diagnosis — changed doctors' understanding of

the disease" (n.p.). He added, "'What we learned from the test was that there was a whole spectrum of disease . . . Before, we were only able to pick up what we now know were the most extreme forms of the disease — the tip of the iceberg. Now we can find all the rest" (n.p.). Thus, for Levy, his training to only identify the expected presentations of a disease led him to disregard unusual presentations, such as that of the little girl. He failed to see that the little girl's symptoms also fit for the disease because they didn't match the usual criteria and severity of symptoms for FMF. Again, this situation speaks to the importance of constantly shifting paradigms within medicine and asking what other actants within an assemblage might be contributing to a problem.

As these cases highlight, doctors must constantly solve diagnostic problems within networks of other actants, collaboratively share their areas of expertise to pinpoint the problem, view illnesses as complex assemblages rather than isolated illnesses, and link symptoms rather than isolating the most prominent one. To return to the view of diagnosis as assembling, we can see that such a process always hinges on tracing connections between multiple actants—or, as Rivers put it—using rhetorical tools to find the glue that holds an illness together. Such a framework contrasts with the view of a doctor as an isolated actant pinpointing a single factor that reveals the illness. As these cases emphasize, doctors' work is messy and chaotic, and they must often follow multiple possibilities before they arrive at the right answer. The rhetorical work that doctors engage in as they locate a diagnosis is not simply persuasion, interpretation, or identification, but a work of assembling a diagnostic network and tracing the network of illness to account for the problem.

Self-Diagnosis and Patient Advocacy

While the analysis of "Diagnosis" cases has thus far highlighted the doctor's networked rhetorical work within diagnostic situations, much remains to be said about the role that patients play. Far from being passive texts inscribed with meaning to be interpreted by doctors, or arhetorical beings called into existence only through the doctor's authority, the "Diagnosis" narratives reveal an alternative type of patient: one who is engaged, active, and responsible for her own health. In many of the cases, in fact, the patient actually solves her own case. In "Flower Power," for instance, a patient (who is also a doctor) experiences high blood pressure and acute psychosis. Her physician, a colleague, is horrified when she begins to speak and the words are meaningless. The doctor tests his friend for abnormal thyroid hormones, abnormal blood chemistry or an infection, and illicit drug use. But when all of the tests come back normal, "After four days, the patient recovered, and she was discharged, her diagnosis still unknown" (n.p.). The patient, once home, resumes her normal gardening routine, and is surprised to find a strange but beautiful flower growing in her garden. She wonders, "Before it had flowered, could this plant have been mistaken for lettuce and ended up in her salad? She pulled the plants up by their roots, put them in a baggie and drove to a nearby nursery. As she pulled the plants from the bag to show the owner, the woman exclaimed: 'Don't touch those! They're highly toxic. That's jimson weed'" (n.p.). The patient learns that the root has long been associated with temporary female madness, and she had likely accidentally consumed some before she became sick. The patient's perceptiveness—and her ability to consider unusual factors—ultimately led her to solve her own case, a move that echoes the rhetorical assemblage that doctors engage in themselves. Her refusal to be satisfied with no diagnosis, and her ability to enlist new actants into her network (such as the nursery owner), also serve as a reminder that it can be challenging to accurately diagnose a patient

when their symptoms resolve on their own or come and go. In such cases, patients may have to rely on their own investigations to determine what has caused their episodes.

Other cases present examples of physicians suddenly becoming patients and diagnosing themselves collaboratively with their doctor. In "Patient is a Virtue," an 81-year-old man (also a physician) suddenly loses feeling in his right leg. When he's rushed to the E.R., he immediately begins to ask the doctor if he might be having a stroke. The doctor insists that they must be sure what's going on before they treat him, but all of the tests are unrevealing in terms of the nature of the man's problem. When a surgeon explains his confusion to the patient, he's struck suddenly with another idea. Sanders writes, "As he [the surgeon] moved toward the door, the doctor-patient couldn't resist adding one more possibility to the list: 'Could I have dissected my aorta?' he asked" (n.p.). The resident argues that it's unlikely given that most of the patients he's seen with a dissected aorta are younger and writing in pain. However, while it "was unlikely given the patient's age and the absence of chest pain" the resident finally decides that "if he had torn his aorta, anticoagulation could cause the patient to bleed to death. She sent the patient back to get a CT scan of his chest and abdomen" (n.p.). The CT scan reveals that the patient has a huge dissection in his aorta and that he needs immediate surgery. Sanders concludes by mentioning that the dissected aorta is one of the most difficult diagnoses in medicine and that it's often not even considered as a possibility. "In the case of this elderly patient," she muses, "it was the very hardest kind of diagnosis — an unusual presentation of an unusual disease . . . In spite of that, two physicians reached this diagnosis coming at it from two different perspectives — that of an E.R. doctor who conscientiously made sure that she first did no harm and that of a patient who couldn't stop himself from thinking like a doctor" (n.p.). Here, Sanders makes an interesting point when she reminds us that not only are patients apart of a network, but

patients themselves are networks—imbued with their own areas of expertise, their own ideas, and their own insight into their health. In this case, the patient's network enabled him to come to the correct diagnosis more quickly than the doctor's, which speaks to the need to take seriously the rhetorical agency of patients. Even in cases where a patient lacks the medical knowledge necessary to diagnose himself, more can be gained by invoking the patient's networked knowledge into diagnostic deliberation than excluding them.

An example of a series of doctors failing to pay heed to their patient's perspective can be found in "The Doctor Go Round," where the case begins with a doctor accusing his patient of not following his instructions prior to getting a medical test. He told her that the results were crazy. She'd pulled a muscle months before, and had gone to her primary care doctor with a swollen ankle/foot and painful muscle strain. In the ensuing weeks, she was tested for high blood pressure, a blood clot, obstructed blood flow, stomach abnormalities, leukemia, and a range of other diseases by multiple specialists: her internist, an endocrinologist, a gastroenterologist, and a hematologist. Finally, the patient begins to read a recent set of test results when she notices that she has an abnormal amount of cortisol. She quickly calls her doctor and tells him she thinks her problems can be attributed to Cushing's disease. Sanders notes that, rather than the doctor having to persuade the patient of her correct diagnosis, "The patient laid out her argument. With Cushing's, the body produces too much cortisol, one of the fight-or-flight hormones. This could explain her high blood pressure. She had other symptoms of Cushing's too" (n.p.). Still, the doctor remains unconvinced that the patient has successfully diagnosed herself simply by doing some research on her elevated cortisol levels and what it might mean. As a patient with no medical background, she has little credibility with her doctor as a contributor to the diagnostic process. The doctor decides to test her for Cushing's anyway, due to a lack of other ideas, and

when the test results are strange, he accuses of her of not properly following his instructions. When she insists that she has, he suggests another test. The results are conclusive: "She was right, the doctor conceded; she really did have Cushing's. She didn't have the classic features, perhaps because she hadn't had the disease long enough for the rest of the symptoms to manifest themselves" (n.p.). In this case, the patient's diagnosis is delayed because the doctor fails to trust his patient's analysis and consider her guess as to what's wrong. Instead, he works against the patient, in an almost adversarial way, to determine the cause of her illness.

While patient-networks can play an integral role in their own diagnostic processes, when they're unable to participate due to their failing health, their family members can step in and take their place, and they must therefore be added to our growing assemblage of actants involved in diagnostic rhetorical encounters. In "A Heart Loses Its Way," a 59-year-old woman who had a heart attack a month before is rushed to the hospital because of high blood pressure. Her legs are like Jell-O when she tries to stand, so her husband and several nurses must wheel her into the hospital. The patient's husband, alarmed by his wife's recent and sudden decline in health "felt overwhelmed and angered by his inability to help his wife of 36 years" (n.p.). He suddenly decided that he could help by going to his wife's doctor's appointment that afternoon, since his wife felt too ill to go. As he reviews recent events with his wife's internist, he advocates for something to be done and tells her, "We can't go on this way" (n.p.). The patient's husband and his adamancy inspire the internist to revisit the patient's chart as she listens to his reminders that none of her recent blood pressure readings have been in the normal range. She begins to rethink her approach:

> "I think maybe we are focusing on the wrong thing," Mayer said,
> pronouncing each word slowly and carefully as she thought through the
> problem. At each visit the patient had an abnormal blood pressure — usually

too high, but not always. And at each visit Mayer had adjusted the

medications. She hadn't really stepped back to look at the big picture. Until

now. It was clear that this wasn't a case of blood pressure that wasn't being

controlled; it was a case of blood pressure that couldn't be controlled, and

that was a very different kind of problem. (n.p.)

Mayer, the patient's doctor, shifts her thinking and wonders if the patient has a tumor secreting high levels of adrenaline, and after a test reveals that this is the case, the tumor is removed. The patient automatically experiences amelioration of all of her symptoms, much to her husband's relief. Sanders resolves the story, writing, "In medical school, I was often told that if you listen, the patient will tell you what she has. It turns out that sometimes the patient's husband will, too" (n.p.). Although the patient has no medical expertise, his expertise about his wife's failing health and insight into her condition leads him to successfully advocate for the doctor to revisit her case. His reminder to the doctor of her wildly varying blood pressure readings ultimately leads the doctor to the culprit. Thus, family members play a significant role within the diagnostic network because they advocate for a revisiting of the illness-assemblage, always pushing for doctors to look again and this time find the answer that will heal their loved one.

Perhaps the most striking example of a patient's family member intervening in the diagnostic network can be found in "What Caused this 15-Year-Old's Debilitating Headaches?" In this case, a boy suddenly develops a horrible headache that leads him to stay in his bed for days on end—not even getting up to eat dinner. After multiple visits to his internist and other doctors, the patient's mother gets tired of being told that he simply has migraines. When the symptoms fail to improve after multiple visits, the mother becomes increasingly scared because her previously healthy and active son will no longer even eat.

Frustrated by the repeated inattention to her son's rapidly declining health, she decides to lie to the doctors in order to convince them to take his condition seriously—and order a CT scan. Sanders explains, "In the E.R., the doctors asked the same questions: Any fever? Any nausea or vomiting? [In the past, she had honestly answered, 'No.'] But this time she had different answers . . . It didn't feel right lying to the doctors, but the mother thought that symptoms that fit their expectations would get action faster than her own motherly observations" (n.p.). Once the doctors finally order a CT scan, the problem is revealed: the boy has a disease that causes connections between arteries and veins to be disrupted, resulting in infection. In this case, the patient's mother had to lie to the doctors, and tell them an expected narrative, to convince them to perform a scan and find out what was wrong with her son. "Perhaps," Sanders notes, "her son would have gotten a CT scan without her 'fabrication' (as she calls it), but she didn't want to take that chance" (n.p.). This speaks to the rhetorical interactions that can occur when doctors fail to take actants within their network seriously. By refusing to listen to the patient's mother, the child's doctors failed to fully assess the range of possibilities for what was causing his illness. Fortunately, the mother was able to modify her rhetorical behaviors in order to save her son's life.

As these examples illustrate, patients and their families serve an important function within the diagnostic network. When doctors feel that they've done enough, patients and their families can remind them when they haven't. When doctors are satisfied with no answers, the patient and their families will provoke them to keep searching. When doctors are stumped as to the proper diagnosis, the patient/their families can make suggestions, even locating the accurate diagnosis in some cases. More importantly, though, these cases demonstrate the fact that patients are not isolated actants within diagnostic situations any more than doctors are, as they bring their own expertise and collectives with them. Doctors

must be constantly aware of the value their patients and their families bring to bear on their diagnostic assemblage, and they must treat patients/their families as capable rhetors who might collaborate in solving the case. Just as Latour assigns scientists and moralists different roles within the collective, as they work to solve the same problems using their different skills, doctors and patients might work together to reassemble illness assemblages by combining their own expertise.

Nonhumans and the Role of Chance

While doctors and patients are commonly included in literature about medical rhetorics and rhetorical diagnoses, the theorists previously mentioned fail to assign a role to nonhumans and chance. Although Gawande and Sanders insist that uncertainty haunts all medical interactions—from surgery, to diagnosis, to performing an autopsy—no theorists have discussed the integral role that unexpected and nonhuman actants play in diagnostic assemblages. However, as these surprising actants intervene in many of the "Diagnosis" cases to help doctors and patients determine what's wrong, they warrant analysis as to their unique rhetorical contributions to the collective.

In "Unresponsive," for instance, a patient is brought to the hospital in a coma after a night of partying. Because the man who brought her to the hospital refuses to tell doctors the full story, since he fears being prosecuted, the doctors have an especially hard time piecing together the cause of her sudden illness. They run a series of tests, looking for proof of a drug overdose, but the tests reveal that she has not had alcohol, marijuana, or amphetamines. The only clue doctors find is her low sodium. Desperate to figure out what is wrong with his sister, her brother wonders: "What about her cellphone? [He] rummaged through the bag of his sister's belongings and pulled out the phone. She had made a bunch of phone calls to her

friends — no surprises there. Then Cole started clicking through the instant messages. He saw several references to "Molly" — who was Molly? Google quickly provided the answer; it was another name for Ecstasy" (n.p.). Her brother spends the afternoon researching the link between ecstasy use and his sister's condition. He ultimately finds that ecstasy can cause extreme hyponatremia in young women. The doctors are able to treat the patient for her low sodium, and she's finally healed because her brother chose to invoke a pair of unlikely actants —a phone and Google—into the diagnostic assemblage.

A similar case can be seen in "Fear of Falling," where an elderly woman has lost use of her legs almost entirely. She says that she now "walks like a drunk," falls frequently, and has come to require a wheelchair due to her loss of sensation in both legs. The doctor tests her for cancer, a spinal cord injury, a tumor, and even West Nile Virus, but all of the tests reveal that she has none of these problems. A blood test reveals that she has too much Zinc and too little copper in her system, and the doctor begins to seek out the cause of this dangerous imbalance. As the doctor examines the patient and asks her about her Zinc exposure: "On the bedside table, Ahmed noticed a half-empty tube of denture adhesive. He picked it up. Didn't some of these adhesives contain zinc?" (n.p.). The doctor found that the woman was using five or six tubes of the adhesive a week since her dentures were ill fitting, even though when directions are followed, a tube should last for a month. Once the patient learned of the reason for her lack of mobility, she immediately switched to a less toxic denture adhesive, since she could not afford a better fitting pair of dentures. The observational skills of the doctor, in this case, enable him to find the nonhuman culprit behind the patient's illness. Or, put another way, the nonhuman demands to be heard by the physician, who has the ability to discern the relationship between the excessive zinc, the deficient copper, and the tube of denture adhesive. By recognizing the role the patient's dentures/denture adhesive is playing in

her illness, he's able to effectively treat her, although he cannot reverse the nerve damage done to her legs.

In some cases, too, the doctor finds an unexpected issue while attempting to treat a different condition. In one case, in particular, it is not the patient's or doctor's ability to assemble the illness' actants but the direct assertion of a nonhuman object that ultimately solves the case. In "The Tell-Tale Green Heart," a surgeon notices that his patient's heart is green during a routine bypass surgery. Although he's initially unconcerned by the strange hue, he biopsies a piece of the heart's tissue out of curiosity, because he's never seen such a hue in his career spanning 25 years. The strange color is ultimately determined to be a form of amyloidosis, a disease that causes excessive protein fibers to form in areas such as the heart, arms, and tongue. Most interestingly, the green heart—and the chance biopsy out of curiosity—reveals the underlying cause of the patient's other symptoms, such as his carpal tunnel (caused by protein deposits in his wrists) and his slurred speech (caused by tightly packed protein fibers in his tongue). Sanders writes:

> Often a patient will seek medical attention for one or more unexplained symptoms, and a diagnosis will be achieved when those symptoms are linked to a single disease. In this case, the patient and his doctors didn't think there were mysterious symptoms. Almost every ailment had been explained. He had an infectious diarrhea; he had carpal tunnel syndrome; he had coronary artery disease. It was only an incidental finding during surgery that led to the diagnosis that explained everything. (n.p.)

This narrative remains important because it illustrates how the interruption of a nonhuman actant—rather than the analysis of a doctor or patient—can ultimately reveal the diagnosis. Nonhumans are not merely useful when a doctor recognizes them; they can appear

unintentionally but forcefully at surprising moments to assert their significance and their role in the illness' network. A view, then, that diagnostic networks only involve human rhetors does so to its own detriment, as the interruptions of nonhumans can sometimes save a patient's life when listened to.

In some cases, the doctor and patient must extend the patient's network to their environment. In "Rough Patches," a four year old boy presents with a painful rash that looks "as angry-looking as a slap" on his mouth, nose, and penis. His eyes were also red, and he would cry through painful episodes with the rash, although they would recede after a few days only to return again. Two doctors who saw the patient diagnosed his rash as poison oak, but the boy's mother remained unconvinced—the only plants he ever had contact with were in his grandmother's garden, and she had no poison oak. Besides, the rash did not look like the classic blistered presentation of poison oak, and the rash was not itchy. The doctor begins to wonder if the boy has been exposed to a poisonous plant at his new nursery or in his grandmother's garden, but he's not sure. As he drove home later that day, Sanders describes, "He spotted a small gardening store he passed every day. Maybe he should get a consult, he thought, as he turned into the parking lot. Maybe he was missing something. In medicine, what you don't know really can hurt you" (n.p.). He turned out to be right. A man working in the greenhouse was able to immediately diagnose the patient's condition once the doctor listed off some of the vegetables growing in the boy's grandmother's garden. "That's easy," he tells the doctor, before explaining that "[p]umpkin vines more typically cause this kind of rash. It seemed as if the boy was allergic" (n.p.). Thankfully, the cure for the boy was simple: avoiding contact with the pumpkin vines would result in the retreat of his rash. As this narrative illustrates, sometimes doctors and patients aren't the only actants poised to listen to the contributions of nonhumans; in some cases, laypeople or those with differing expertise

may be better equipped to consider the roles that unrecognized actants are playing in the illness' network. This speaks to the need to recognize not only the expertise of those directly involved in the illness—such as the doctor and other healthcare providers—but to consider the ways in which experts in other areas might be better able to listen locate the actant destroying the assemblage. Furthermore, as previously mentioned, this narrative emphasizes the importance of environment as an actant within diagnostic assemblages. The patient-network brings to the doctor her entire history and her environmental circumstances, so she and her doctor must be able to consider the ways in which these factors might intersect with and act within the illness network.

Beyond the role that nonhumans play in diagnostic networks, several "Diagnosis" narratives highlight the role of abstract concepts like randomness and chance. For example, in "Full-Body Failure," a doctor receives a last minute message on a Friday afternoon about a patient who is "sick as hell" and in desperate need of attention. The doctor was already late for his weekly racquetball game but was intrigued by "what promised to be a tough case," so he decided to see the patient (n.p.). This chance decision, made arbitrarily, would ultimately save a young woman's life. When the doctor went to visit the patient, she lay in her hospital bed with highlighter yellow skin, her abdomen distended, and her body feverish. Test results trickled in with almost every one revealing an abnormality—she was anemic despite transfusions, her blood wasn't clotting, and her white blood cell count was high. Sanders explains, "These are the most difficult cases — patients who have so many things going wrong that it's nearly impossible for a doctor to process them all at the same time" (n.p.). By the time Dr. Walerstein was invited to join the case, the patient was near death. According to Sanders, "Having examined the patient and her chart, Walerstein took a moment to step back and look for some kind of pattern buried in the chaotic assemblage of numbers and

tests. Everyone else started with the bloody diarrhea. Maybe that was the wrong way to think about it" (n.p.). Walerstein instead focuses on the patient's liver failure and the destruction of her red blood cells. Considering these two symptoms in concert caused Walerstein to remember a "pearl of wisdom"—or a phrase used to memorize common symptom clusters for diseases. Explains Sanders, "Liver failure and this unusual kind of anemia were caused by an inherited condition known as Wilson's disease" (n.p.). As a result, the patient needed a liver transplant immediately, and she eventually made a full recovery. Sanders concludes this column by reflecting on the occasionally random nature of medical events; "But what would have happened," she ponders, "if Walerstein had been out of town that day or hadn't come back? Would this condition have been diagnosed? Would the patient have survived? Neither doctors nor patients like to consider how much of medicine depends on chance" (n.p.). Neither, it would seem, do medical rhetorics scholars always like to consider the role that chance plays in diagnostic networks and rhetorical interactions surrounding illness. Chance, in this case, governed the doctor's decision to take the case, his grouping of symptoms that hadn't been considered together, his memory of the pearl of wisdom, the availability of tests to determine what was wrong, and a new liver for the patient. Thus, beyond informing an actant within a network, chance inundates the assemblage and those who trace its movements. "Contingency and coincidence," Sanders declares, "can be as important in the moments between life and death as knowledge and skill. No doctor knows everything. Hippocrates's well-known aphorism expresses this ancient truth: '. . . It is not enough for the physician to do what is necessary . . . the circumstances must be favorable'" (n.p.).

In a final case, unfortunately, chance shines less favorably on a patient and his deteriorating condition. In "The Strep Throat that Wasn't," a 17-year-old boy is admitted to the ICU because he's unable to breathe despite his oxygen mask, which provides him with

five times more oxygen than the air we breathe. He's also suffering from a 105 degree fever, a sore throat, and horrible chills. A few days earlier, according to his chart, the boy had woken up feeling ill. "He saw his family doctor the next day," Sanders clarifies, "who diagnosed a strep throat and started the boy on a five-day course of azithromycin — an antibiotic widely used in part because it is convenient, needing to be taken only once each day. No strep test was done — probably, Garrett figured, because the diagnosis seemed obvious" (n.p.). Test after test yields no promising information, and a blood culture was not yet available. Finally, after days of fighting to simply keep the patient alive, a chance encounter reveals the problem. The blood culture results had finally come in, and the doctor noticed a resident looking at the boy's chart. "'What's that?' he recalls asking. The blood cultures finally grew strange bacteria, the resident responded, but it was probably just contaminant. What was the bacteria? Garrett persisted. Something called Fusobacterium necrophorum. The identification of the bacteria told Garrett all he needed to know. The boy had Lemierre's disease" (n.p.). The doctor immediately changed the patient's antibiotics, hoping that the proper medication could finally eradicate the patient's illness. Unfortunately, the patient died three weeks later in ICU with his family at his side.

Of course, this narrative underscores the randomness with which rhetoric and medicine intersect, albeit in a much more negative light than in the previous example. Acknowledging chance as an actant within each diagnostic network means recognizing that each diagnosis, each illness, has rhetorical and other contingencies beyond our grasp. There can be no ultimate control of diagnostic encounters, just as no rhetorician can fully control a rhetorical situation, no matter how hard she may try. However, more positively, this narrative also stresses the importance of adjusting one's network based on tragic assemblages and their dissolution. When the boy's mother informed their primary care doctor, who had mistakenly

diagnosed the boy with strep without performing a test, he openly wept for his fatal error. But he also readjusted his diagnostic network to be more effective in the future. He told Sanders that he refuses to miss this diagnosis again and "[h]e has changed his practice: now everyone with suspected strep will have a throat culture to check for both strep and Lemierre's. 'Maybe that's overkill, and I'll probably end up treating too many of my patients with antibiotics,' he added thoughtfully. 'But I don't ever want to lose a patient like this again'" (n.p.). As this doctor learned the hard way, while we may never be able to control our rhetorical or diagnostic networks, we may respond to troubled networks and intervene to enhance our practices, better serve the needs of others, and even save lives.

Networked Attachments

In *Reassembling the Social*, Latour maintains, "it is possible to trace more sturdy relations and discover more revealing patterns by finding a way to register the links between unstable and shiftable frames of reference rather than by trying to keep one frame stable" (24). In this chapter, I have attempted to disrupt the seemingly stable frame of rhetorical diagnosis to see how defining it through the lens of ANT might better account for the uncertainty that haunts medical events and relationships. My analysis of the "Diagnosis" column narratives complicates notions that medical rhetorics can be equated to persuasion, interpretation, or identification. Such frameworks presume relatively stable actants who share common language or knowledge, which is far from the case in many medical contexts. Furthermore, such rhetorical relationships generally exclude nonhumans and chance from analysis because of their humanist bent. The rhetorical relationships featured in the "Diagnosis" columns are far from a one-to-one relationship of shared discourse; instead, they are dispersed and disrupted networks, messy and chaotic, and brimming with

miscommunications and random interruptions. Perhaps most important, though, such rhetorical interactions hinge on acting despite limitations, or as Gawande puts it: "we are expected to act with swiftness and consistency, even when the task requires marshaling hundreds of people—from laboratory technicians to the nurses on each change of shift to the engineers who keep the oxygen supply system working—for the care of a single person" (*Better* 4). As Gawande emphasizes, ethical action in medicine calls for an understanding of the networked attachments one must maintain to ensure a patient's health. But what happens when the network breaks down, resulting in the misdiagnosis of a patient? I will explore this question, and the responsibilities of actants to their assemblage, more fully in Chapter 3.

CHAPTER 3:

QUARANTINE AND NETWORKED MISTAKES

As for the leper who has the infection, his clothes shall be torn, and the hair of his head shall be uncovered, and he shall cover his mustache and cry, 'Unclean! Unclean!' He shall remain unclean all the days during which he has the infection; he is unclean. He shall live alone; his dwelling shall be outside the camp. - Leviticus 13:46

Simply put, germs travel. - Howard Markel

On October 30, 2014, something unremarkable happened. Kaci Hickox and her partner, Ted Wilbur, left their home in Kent, Maine for a bike ride through their favorite three mile trail. What *was* remarkable about this event was that Hickox and Wilbur were chased out of their home and down the trail by reporters, who followed them on foot. The reporters screamed questions after Hickox while police officers looked on outside of her home. The bike ride was broadcast by major news networks, and figures including Maine Governor Paul LePage and Rush Limbaugh spoke out against her actions. *The Washington Post* called her "defiant" (Berman and Dennis n.p.) and *NBC News* referred to her relationship with government officials, who opposed the bike ride, as a "standoff"("Kaci Hickox, Nurse in Ebola Quarantine Standoff" n.p.)."It's a beautiful day for a bike ride," Hickox said as she embarked in the midst of this scene.

Hickox's unremarkable actions resulted in such an uproar because she had recently returned from treating Ebola patients in Sierra Leone, an area in Africa hit particularly hard by the epidemic. According to the Centers for Disease Control and Prevention, Sierra Leone had 8706 cases of Ebola in 2014 with 3956 deaths, with the outbreak ending in March 2016 ("2014 Ebola Outbreak in West Africa" n.p.). Comparatively, the CDC explains that the US had 4 total cases of Ebola in 2014, and one of these patients died ("Cases of Ebola Diagnosed in the United States" n.p.). Hickox returned to the United States on Friday,

October 24, landing in Newark Liberty International Airport. When a customs official learned that she had returned from West Africa, she was immediately subjected to seven hours of questioning and an unreliable forehead scanner test, which showed that she had a mild fever—potentially attributable to her long days of travel. According to Anemona Hartocollis and Emma G. Fitzsimmons, Hickox was "left alone for long stretches and given only a granola bar when she said she was hungry" (n.p.) Even though she tested negative for Ebola on Saturday, Hickox was quarantined in "[Chris] Christie's Ebola detention center" in an isolated tent outside of a Newark hospital until Monday, October 27 (Jacobs, Goldstein, and Siemaszko n.p.). Hickox openly challenged the involuntary quarantine, which opposed medical advice from the CDC and scientific research about Ebola and its transmission. She was quarantined because of fears that she'd transmit Ebola to others even though Ebola can only be spread through the exchange of bodily fluids. Also, as Hickox pointed out, only symptomatic people have Ebola, which means her asymptomatic state made it safe for her to resume her normal activities. Although ultimately Christie released her on October 27th, the frenzied fear surrounding the potential public health threat she posed continued to haunt her through the bike riding incident the next week and throughout the following year, as she ultimately sued Christie for violating her civil rights.

Since the long history of quarantine shows that it has tended to scapegoat vulnerable individuals, particularly immigrants and poor people, Hickox's quarantine and its subsequent media coverage is unique because she represents a Western, white, female, healthy face of Ebola. Hickox became the face of Ebola in the United States even while 28,637 cases and 11,315 Ebola deaths occurred worldwide, the majority of which occurred in the West African countries of Guinea, Sierra Leone, and Liberia ("Ebola in Africa: The End of a Tragedy?" n.p.). So obsessive was the media coverage of Hickox that it distracted from the

single Ebola death that occurred on U.S. soil. Thomas Eric Duncan, a Liberian, visited the U.S. for the first time in late September 2014 to visit family. He took himself to the hospital soon after arriving in the U.S. complaining of dizziness, abdominal pain, and a high fever, but although he told doctors he'd recently been in West Africa, they sent him home with antibiotics for sinusitis. Four days later, he returned to the hospital, and this time he was diagnosed with Ebola. Less than two weeks later, he died in the Dallas hospital.

Duncan's family later sued the hospital, Texas Presbyterian, claiming that they had acted negligently in caring for him — particularly because of his race. For example, a family friend pointed out to *The Washington Post*: "If you went to the hospital right now, and your temperature was 103 degrees, no doctor would send you home" (Justin Wm. Moyer n.p.). Others questioned not only the mistaken choice to not treat Duncan immediately, but the treatment measures employed once he was diagnosed. Thomas Geisbert, a professor of microbiology and immunology at the University of Texas at Galveston, said of the choice to use an experimental drug on Duncan, "It kind of came out of left field. I think the jury is still out on why this would have any activity against Ebola" (Moyer n.p.). Perhaps Moyer puts it best when he explains, "Unlike some other Ebola patients provided state-of-the-art experimental treatments and swept to advanced medical facilities like the National Institutes of Health (NIH), Duncan was poor. He had no insurance. And he was black" (n.p.).

Comparing Hickox's and Duncan's narratives as they were picked up by the mainstream media results in some suggestive parallels. Neither Hickox nor Duncan were believed when they made claims about their health, and in both cases they suffered as a result. Lawsuits were conducted on behalf of Hickox and Duncan because of civil rights violations. And both cases, of course, began with a misdiagnosis. Although Hickox was publicly misdiagnosed primarily by Christie and LePage, both of whom have no background

in medicine, and Duncan's doctors missed what should have been a fairly obvious diagnosis, both individuals were the victims of a breakdown in their diagnostic networks.

Although many narratives catalog successful diagnoses—both in medical literature and popular shows like *House*, few texts consider what goes wrong when misdiagnoses happen. In "Diagnosis: A Biocultural Critique of Certainty," Lennard Davis identifies three key obstacles to examining misdiagnoses: "the aura of faith" surrounding diagnosis, the erasure of an uncertain process post-diagnosis, and the conflicting goals of politics and ethics (82). First, Davis claims that diagnosis has been endowed with a level of religious certainty since at least the nineteenth century:

> Gnosis, as knowledge, implies the certainty of religious knowledge, and its adjective, gnostic, is opposed to the doubtful—that is to say, full of doubt— knowledge of the agnostic. The heyday of the use of gnosis and of diagnosis in the English language was the second half of the nineteenth century, coinciding with the rise of evangelical Christianity, as well as the professionalization of medicine. Without making too much of this point, could we not see the physician as displacing the divine as the source for certain knowledge? Diagnosis in this scenario would be the medical equivalent of the theological certainty offered by a knowing—in this case a knowing of the body if not the soul. (85)

Here, Davis argues that doctors, like priests, are unquestioningly endowed with the authority to classify humans into categories of well and sick, determine their illness, and identify the course of treatment. The confluence of specialized medical knowledge and seemingly infallible medical testing options have certainly reiterated the aura of faith that Davis identifies in the twenty first century. Such an aura of faith, for Davis, renders it difficult to

question medical authority and discuss medical failures, since to do so is to commit an almost blasphemous offense.

Furthermore, Davis argues that the erasure of the uncertainty and mistakes that haunt the diagnostic process once the correct diagnosis has been determined prevents us from learning from medical error and acknowledging medicine's fallibility. He explains, "Diagnosis is always synchronic. It always takes place in a clinical present moment of certainty. It has to willfully suppress the diachronicity of its own coming into being, because such history might reveal contingency, chance, convention, and so on" (90). Beyond the inability to grapple with physician imperfection, then, the aura of faith surrounding diagnosis results in a trained incapacity to recognize the uncertain process that leads to every medical breakthrough. When this process is discarded, information of immense value and alternative theories are lost. Medical narratives celebrate discovery, success, and correctness and skillfully conceal failure, past theories, and alternative ways of seeing. "Thus, the current diagnostic criteria are always the last step," Davis notes, "the hopeful, utopian moment, the final correction of a history of error. In this sense, the diagnostic process is amnesiac and is constitutionally incapable of being uncertain about its certainty" (90). Davis' conjecture highlights not only medicine's unwillingness to reexamine the uncertainty that haunts the diagnostic process, but its inability to do so due to the way the diagnostic process is traditionally conceived.

Finally, Davis locates the source of willful diagnostic certainty in its situatedness between both politics and ethics. He quotes Zizek as saying, "the ethical is thus the (back)ground of undecidability while the political is the domain of decision(s)" (Zizek 316, Davis 93). Davis continues, "We can say then that diagnosis hesitates between the undecidability of *nomos* and *dike*, between custom and justice . . . Hospitality requires an

undecidability, but diagnosis in its political sense requires decision. Like all sovereign decisions, it requires the certainty that comes from the amnesis of past" (93). The ethical and political projects, as defined by Davis, are at odds because hospitality postpones decisions in order to remain open to newcomers while politics requires decisiveness and action, a closure. Thus, "Diagnosis will require a repression of that coming into being in favor of the moment of judgment" (91-2). For Davis, then, medicine's relationship to both politics and ethics demands that physicians maintain an impossible tension between decisiveness—they must act quickly to save the patient and because of financial and time constraints—and ethics— what is the best course of action for this particular patient? The need to act, then, obscures ethical questions about negative outcomes because the doctor must deliberate and decide in the moment, often without all necessary information available.

Although Davis remains most interested in the way this certainty affects the doctor-patient relationship, I wonder how such an aura of certainty contributes to public misdiagnoses such as Hickox's. While I explored the interpersonal dimensions of doctor and patient diagnostic communication in Chapter 2, I want to turn my attention here to what happens when networks of actants misdiagnose. How can we account for networked failure in relation to diagnoses, and how can network theory help us to reintegrate misdiagnoses into their own situational networks? Davis gives us a clue: "We might then say that something in the diagnostic process might in fact provide a curative modality. If that were the case, what would that curative modality look like? As we said, the diagnosis would have to be attained in a condition of mutuality, one that took into account the history of not only the patient and the practitioner but also the profession itself" (94). The history of the profession of medicine, while vast, also offers us a clue as to the broken link in diagnostic networks such as Hickox's. Davis argues that "To diagnose is to attempt to emphasize

difference," and indeed the history of medicine involves categorizations based on difference: sick and well, different classifications of sickness, and the establishment of boundaries between them (88). Perhaps the tradition of quarantine serves as the best example of this boundary generation and maintenance as a way of separating those seen as a threat to the healthy citizenry. Quarantine establishes a separation because a group of people is waiting for a diagnosis that will send them into isolation, if they are sick, or back into their everyday lives, if they are well. Quarantine, then, generates tremendous fear because it generally arises in situations where people are fearful of contracting an infectious disease, and those in quarantine themselves often do not yet know whether they are sick. At the heart of Hickox's struggle, in fact, is a fight against the stigmatization and separation quarantine demands. Thus, in what follows, I will cover a brief history of quarantine as it has functioned to perpetuate diagnostic difference and separation. I will then discuss the ways in which Latour's Actor-Network Theory opens up an alternative way to negotiate with actants within a diagnostic network without excluding those deemed potentially dangerous. Finally, I will reread the Hickox misdiagnosis network through this framework of excluding actants and a Latourian concept of morality.

A Brief History of Quarantine

Upon returning to the U.S. and being forced into involuntary quarantine, Hickox contacted a friend who worked at *The Dallas Morning News*. The newspaper subsequently covered her quarantine and even invited her to pen an account about the experience. An early piece by Naheed Rajwani quotes Hickox as saying, "I am scared about how health care workers will be treated at airports when they declare that they have been fighting Ebola in West Africa . . . I am scared that, like me, they will arrive and see a frenzy of disorganization,

fear and, most frightening, quarantine" (n.p.). Indeed, as Hickox points out, quarantine has been historically linked to disorganization and fear. Quarantine takes its name from the 40 day isolation period required by fourteenth century Venetian port officials during the plague outbreak (Tom Koch 655). According to Eleanor Klibanoff in "Awful Moments in Quarantine History, "If a ship was suspected of harboring plague, it had to wait 40 days before any passengers or goods could come ashore. Venice built a hospital/quarantine center on an island off its coast, where sailors from plague-infested ships were sent either to get better, or, more likely, to die" (n.p.). Quarantine was heavily associated with both national and interpersonal barriers and was based on the belief that "plague was somehow transported from place to place by travelers and their goods" (Koch 655). Thus, over time, "The idea of quarantine expanded to include, at one scale, the isolation of communities within a region or nation and, at a still greater scale, the isolation of infected persons and their families in their homes or in designated sites distancing them from the general population" (Koch 655). Quarantine, then, involved the exclusion of Others—both at the national and interpersonal levels.

Donna Barbisch, Kristi L. Koenig, and Fuh-Yuan Shih are careful to distinguish quarantine's unique meaning from that of isolation or internment. They explain, "'Isolation' is for patients who are ill. Quarantine refers to the 'separation of symptomatic infected individuals from those who are not infected.' Thus, quarantine is for those with no signs or symptoms who have possibly been exposed to a contagious disease *and have the potential to transmit the disease to others*" (547). Quarantine occupies a peculiar space, then, within public health deliberation because it covers potential rather than proven cases of illness. The person in quarantine may become sick, but she has not yet, and she thus occupies a liminal space on the sick-well continuum. This liminality, of course, opens up a lot of room for individual

interpretation and even abuse. In "Quarantine," Kathryn Staiano-Ross argues that "[Disease] is always an event. It is polysemic, multilayered, historically full, and dynamic, not static. It is constructed over time and encumbered with interpretants according to the needs and preconceptions of those who argue they search only for truth" (84). Staiano-Ross finds in historical examples of quarantine the reinforcement of "prejudices both long standing and of recent origin. Disease proves useful as a justification for behaviors that might in other circumstances neither be legal nor appropriate" (84). The lack of regulation for quarantine procedures, and the uncertainty haunting those quarantined individuals who may or may not be infected, can therefore serve as a justification for racially and ethnically motivated exclusions and violence.

Quarantine's historical links to racism and scapegoating has been well documented, but a few suggestive examples may help to elucidate quarantine's link to separation and exclusion. In *When Germs Travel*, Howard Markel describes one such example:

> On December 12, 1899, health officials in Honolulu announced that a twenty-two year old bookkeeper named You Chong had died of bubonic plague. Within hours after the discovery of his death, U.S. military police cordoned off the fourteen-square-block area where more than 10,000 Chinese and Japanese immigrants lived. A few weeks later, on January 20, 1900, Henry Cooper, the president of the Honolulu Board of Health, ordered a controlled burning of some of the buildings in this district to rid it of plague. As bad luck had it, a gust of wind quickly changed the fire's status to 'uncontrolled,' and the blaze spread throughout Honolulu's Chinatown, lasting a full seventeen days, laying ruin to over 4,000 homes across some 38 acres, and leaving 4,500 people homeless. Nevertheless, bubonic plague

continued to appear episodically in Honolulu through early March 1900.

(57-8)

This example highlights the particular insecurities of turn-of-the-century Honolulu (and San Fransisco, for that matter) that Chinese and Japanese immigrants were carrying diseases into the United States. As cities expanded and disease spread, poor public health was blamed on immigrants rather than their deplorable living conditions and ineffective waste management, particularly in densely populated cities. Thus, immigrants were cordoned off from the rest of the population in order to supposedly protect the rest of the city, although the immigrants were often merely victims of disease due to their close proximity to other actants: rats, other vermin, and their poverty, which excluded them from access to doctors.

Quarantine procedures resulted in more than cordoning off immigrant neighborhoods—it also resulted in physical violence and loss of financial opportunity. In a similar suspected bubonic plague outbreak in San Francisco in February and March 1900, "Personal property [of Chinatown's residents] was confiscated and burned, Chinese-owned businesses were closed without sufficient explanation, and people were thrown out of their homes so that tenements could be disinfected. Those Chinese residents whom policemen deemed uncooperative were beaten on their heads and bodies with billy clubs" (66). Some were prevented from going to work while many were told that their businesses had to be shut down; Chinatown stores owned by white people remained open, however, resulting in a quarantine barrier that zig-zagged through the town. Of course, such a method highlights the lack of understanding for how disease was actually spread—it was suspected that white Americans could not carry disease even if they lived in the same quarters as the immigrants suspected to be contagious.

Furthermore, such discriminatory quarantine procedures also surfaced in early twentieth century treatment of tuberculosis. For example, based on stereotypes that poor people posed the greatest public health threat, "privately practicing physicians who treated the well-to-do were generally not required to report their tuberculosis patients to the public authorities while doctors working at free clinics, dispensaries, and other institutions that catered to the poor were" (Markel 34). This meant that "Many poor or immigrant patients either avoided the doctor altogether or sought out quacks who at least promised confidentiality" (34). Markel notes that despite findings that native-born Americans were more likely to have tuberculosis than immigrants, assumptions that vulnerable populations were to blame for tuberculosis inspired attempts to ban particular immigrant populations from entering the U.S. (35). Immigration restrictionists argued that "Diseased newcomers . . . not only threatened the public health in the present because of their propensity toward acute illness and poverty; they also threatened the future of American society as they passed on their defective genes in multiplicity" (36). As Ladelle McWhorter might remind us, this is yet another instance of "scientific racism" in U.S. history, wherein minorities, the poor, and other "degenerates" were thought to "pos[e] a serious threat to the continued purity of highly evolved Nordic germ plasm" (140). Although the restrictionists were never successful in banning supposedly diseased immigrants, their rhetoric clearly intersects with the eugenics movement and structural racism that continues to haunt U.S. immigrants even now.

A final example speaks to the sexist history of quarantine procedures: that of the venereal disease outbreak in the U.S. in 1917. According to Klibanoff, concerns circulated at the time about "the number of young men ineligible for the draft because of sexually transmitted diseases like syphilis and gonorrhea" (n.p.). When officials also noticed "an

uptick in 'camp girls,' prostitutes and other women hanging around U.S. training grounds and military recruitment centers," they decided to quarantine women who might potentially have STDs to prevent them from infecting men in the military (n.p.). Klibanoff elaborates:

> A federal order allowed for the incarceration of prostitutes and camp girls until they were deemed STD-free via mandatory testing. Harvard University medical historian Allan Brandt estimates at least 30,000 women were picked up in the raids. 'There's no evidence that this impacted the rates of transmission,' he says. 'But there was this notion that these women constituted a serious threat to our success in the war.' He notes that while the women were being rounded up and held in prison, often long after they'd tested negative, the Army was issuing condoms to soldiers shipping off to France. (n.p.)

Quarantine in this case performs not only an exclusionary function—as prostitutes are separated from society in the name of the public good—but a punitive one, as well. The prostitutes were held responsible for not only the infection of men eligible for the draft but potentially for undermining war efforts. Of course, the double standard found in the military's message that the prostitutes were unpatriotic and dangerous while the men were mere victims of their siren calls can be seen in the simultaneous encouragement for the soldiers to take condoms with them to France. The men were granted treatment and access to prevention methods while the women were held in prison.

Overall, as this brief sketch of several suggestive historic examples highlights, quarantine serves to exclude those who might be diagnosed from those who are presumed healthy. The uncertainty of potential diagnosis provokes such fear that those most vulnerable are often disproportionately affected, most often the working class, minorities, immigrants,

and women. Quarantine draws lines between those who may become ill and those who are temporarily healthy, but it also draws lines between citizen and foreigner, wealthy and poor, male and female, and white and non-white. Thus, Staiano-Ross has gone so far as to claim, "Who is to be isolated from the balance of society, for what period of time, and under what conditions, may depend more on the individual's social, economic, and political status and categorization as 'other' than upon his/her actual threat to the public's health" (83). If, to return to Davis' conjecture, there might be something with curative potential within diagnosis, perhaps we might locate it by considering how exclusions, enacted in the name of the public good, function within quarantine networks. Rather than isolated situations, these quarantines are complex events unfolding through a multiplicity of actants, both human and nonhuman.

Quarantine and Networks

Latour's concept of morality in many ways echoes Davis's concept of ethics, as contrasted with politics. Latour redefines morality as "*uncertainty* about the proper relations between means and ends"—that is, refusing to treat any entity "whale, river, climate, earthworm, tree, calf, cow, pig, brood" as "'simply a means' but…'always also an end'" (*Politics of Nature* 156; emphasis original). This revision of morality emerges from Latour's thesis that each actant is a vital contributor to the Earth's network, and asserting with certainty that any actant is simply a means to an end will have negative consequences upon the whole network. Latour suggestively notes that we must extend Kant's declaration that we should no longer treat human beings as means to ends to nonhumans as well (155). For Latour, each actant is both a means and an end; for example, a tree contributes to the network of which it is apart by supplying oxygen and other resources, but it is also an end in

itself, as a fully grown tree has realized its evolutionary goal of development. This new

conception of morality is situated within Latour's revision of the collective into four major

professions: scientists, politicians, economists, and moralists, that will share the common goal

of "decidi[ing] about the common world in which they live" (130). Latour tasks the scientists

with detecting new phenomena for the collective, the politicians with the generation of

"voices that stammer, that protest, that express opinions," and the economists with "giv[ing]

a common language to the heterogeneous set of entities" within the network (145, 51).

Rather than a morality that holds unswervingly to a few key foundational values, refusing to

accept the closure that politics demands, Latour's morality interacts with the other

professions in a more constructive way. Latour explains:

> Scientists, politicians, and economists, equally obsessed, though for different
>
> reasons, by the closing of the collective, are thus always in error in the eyes of
>
> the moralists who are going to equip the entities that have been set aside with
>
> the right to appeal that they can use when, in order to fulfill the requirement
>
> of closure, they are driven out of the collective in the name of their
>
> (provisional) insignificance. (156)

Whereas Latour acknowledges that closure is necessary for collective action, his concept of

closure is much less fatal than is Davis'—the closure is tenuous, subject to change, and open

to reintegrating excluded actants. The moralists, then, are those who must constantly ask

who has been excluded and who must be "reintegrated, at some later point, in the form of

friends, included parties, and potential allies" (157). Rather than a passive acceptance of new

actants, they must actively seek them out and facilitate their incorporation.

Moralists are furthermore tasked with the responsibility to prevent a network from

becoming too insulated from external networks. Moralists, Latour writes, "add to the

collective continual access to its own exterior by obliging the others to recognize that the collective is always a dangerous artifice" (157). Lest those within the network come to take its construction as natural or inevitable, the moralists will be there to remind them of its constructed and revisionist design. In addition to preventing complacency on the part of the network, moralists must also actively pursue new attachments and encourage them to approach the network. Moralists "*go looking for* [those who have been excluded] outside the collective, in order to facilitate their reentry and accelerate their insertion" (157). In this way, moralists serve almost as intermediaries that connect new actants to the network and bring them into the collective project of creating a common world.

In contrast to the relative decisiveness which scientists, politicians, and economists must employ, Latour further tasks the moralists with imbuing the network with a sense of constant anxiety. The moralists view the closure of the collective as impossible (their motto is "we can never call it quits"), but Latour again sees this clash with the other professions as generative rather than contradictory (158). "Far from opposing the politicians, as the old distribution of roles would have it, the moralist's requirement of starting over again is going to enter, on the contrary, *into consonance* with the work of the politicians, to keep on mending the fragile envelope that allows them to say 'us' without being unfaithful to their constituents. To every 'we want' or politics, the moralist will ad, 'Yes, but what do *they* want?'" (158). Furthermore, the moralist will "add . . . a constant anxiety over the rejected facts, the eliminated hypotheses, the neglected research projects—in short, everything that might make it possible to seize the opportunity to bring new entities into the collective" (158). The moralists therefore function as a kind of revolving door within the collective; while they do not completely prevent closure, they constantly renegotiate it by swinging the door back open and bringing in an excluded party when needed. Thus,

moralists are tasked with the vital work of renegotiating the constituents of collectives, reforming networks, and incorporating new actants into the network's larger shared project.

Perhaps Latour best sums up the way the moralists contribute to the collective when he writes, "With them, the collective is always trembling because it has left outside all that it needed to take into account to define itself as a common world" (158). To return to the quarantine process, perhaps it is the exclusion of moralist actants within diagnostic collectives that results in the exclusion of important, structural actants from consideration in public health scenarios. For example, in the bubonic plague outbreak situations described previously, poor living conditions in immigrant neighborhoods were excluded from the network and therefore from consideration. Thus, rather than addressing the problem of living conditions as it intersected with disease, the network chose to violate the rights of Chinese and Japanese immigrants by excluding them—literally and metaphorically. Public health concerns cannot be addressed adequately by exclusion, however, particularly now when air travel connects people with differing health care systems from around the world and public transportation brings people of all walks of life into close contact on a daily basis. The spread of Ebola and the frenzied quarantine of aid workers, in particular, highlights an anxiety on the part of Western countries that they can no longer remain blissfully ignorant of healthcare systems in underdeveloped countries, as lack of access to adequate care in Africa can result in an epidemic in New York City in less than 24 hours. The exclusionary move of quarantining actants rather than working alongside them to compose a healthier world, while commonly practiced throughout history, ultimately makes it more difficult to promote health and prevent the spread of disease.

In what follows, I will offer a rereading of Hickox's network that explores the ways in which networked exclusions occurred. I will argue that by excluding Hickox from the public

health network through quarantine, Christie and LePage sought to shore up a Western healthcare network that was self-sustaining and protected from outside influence. Beyond identifying how Hickox's Ebola quarantine represents the most recent attempt to exclude non-Western perspectives and bodies and nonhuman actants from Western networks, I will serve as a moralist in Latour's sense by arguing that we must reincorporate several actants back into the collective if we are to confront future Ebola outbreaks more effectively. In particular, I will consider the exclusion of nonhumans (particularly deforestation and destroyed habitats in Africa), African perspectives about and experiences of Ebola, and conservative political projects as they contributed to Hickox's quarantine and the breakdown of the network. I will finally describe the ways in which a moralist project, as proposed by Latour, might ameliorate future public health scares and offer us more effective ways to combat pandemics than quarantine.

Deforestation and Animal Habitats: The Silent Actants

Studies of Ebola's origins in humans almost always begin in West Africa, particularly in Guinea. Whereas the area was once covered in biodiverse, rich forests, meaning that natural boundaries were maintained between wild animals and humans, civil war in Western Africa between rebel groups in Liberia and Sierra Leone led refugees to flee to these forests and build settlements. Sonia Shah, author of *Pandemic,* explains of the deforestation: "The refugees cut down trees to plant crops, build huts, and turn into charcoal [ibid]. Rebel groups started logging the forest, too, selling timber to finance their battles. By the end of 1990s, the transformation of the forest could be seen from space . . . Of the region's original forests, only fifteen percent remained" (24-5). This mass deforestation, particularly given the relatively short period of time within which it occurred, naturally led to adverse effects on the

environment and wildlife. The tenuous borders between human and animal suddenly became much more permeable. While Shah mentions that many animals likely disappeared as a result of the deforestation, many remained, but now in much closer proximity to humans.

The story might have ended here, with war and deforestation converging to create a dire situation for people in affected areas. However, this already fraught network was soon met with another actant that transformed a humanitarian crisis network into a network of disease. This actant was an animal uniquely capable of carrying and transmitting disease to humans: bats. Bats survived the deforestation, and because they fly and have hollow bones (which means they "don't produce immune cells in their bone marrow like the rest of us mammals do") they were primed to spread the microbes that flourish within their bodies (25). Shah describes the new relationships between bat and animals, writing, "As the Guinean forest was chopped down, new kinds of collisions between bats and people likely occurred. Bats were hunted for meat, exposing hunters to microbe-laden bat tissue when the animals were slaughtered. Bats fed on fruit trees near human settlements, exposing local people to their saliva and excreta" (25). Thus, the deforestation which led bats and humans into closer contact put humans at a greater risk for contacting an infectious diseases carried by the bats. As Shah ultimately reveals, "At some point—nobody knows just when—a microbe of bats, the filovirus Ebola, started to spill over and infect people. In humans, Ebola causes hemorrhagic fever and can kill 90 percent of those it infects" (25). The disease began to further spread when the civil war ended in 2003 and refugees who had been living in isolated quarters rejoined communities where the disease was more challenging to contain. Just as the combined actants of civil war, people fleeing to the forests for safety, and deforestation had contributed to cross-species contamination with Ebola, it now enabled the virus to spread like wildfire through denser populations. Whereas the remoteness of locations

where Ebola occurred had previously prevented the disease from reaching epidemic proportions, its spread to larger villages and cities meant that it would now travel more rapidly and infect more people. Furthermore, as David Quammen points out in *Ebola: The Natural and Human History of a Deadly Virus*, "chimps and gorillas, like humans, are highly susceptible to Ebola" (8). This meant that those who managed to avoid contact with bats were nonetheless striken with Ebola if they consumed contaminated chimp or gorilla meat; this very method of transmission led to an outbreak in the Gabon village Mayibout 2 in 1996, killing over thirty people (Quammen 11-12). These nonhumans—destroyed habitats along with bats and gorillas—helped incite the epidemic that has now resurfaced twenty-six times in Africa alone ("Outbreaks Chronology: Ebola Virus Disease" n.p.).

With the conditions being ripe for the spread of an extremely deadly disease, why was mainstream media coverage so scarce, at first? According to Shah, the very conditions that led to the deforestation prevented others from intervening or learning about the budding epidemic until it was too late. She explains, "[N]obody noticed. The ongoing conflict had severed supply routes and communication networks, leaving the refugees hiding in the jungle bereft of outside help. Even the most stalwart aid organizations such as Médecins Sans Frontières had been forced to withdraw. The isolation coupled with the violence compelled the United Nations to call the West African refugees' plight 'the worst humanitarian crisis in the world'" (Shah 26). Beyond the human death toll of the disease (more than ten thousand died by 2015), the epidemic killed one-third of the world's gorilla population, and the "thousands of people infected with Ebola quickly overwhelmed the fragile economies and health-care infrastructures of the three most affected countries" (Shah 27). However, little of this was discussed in the mainstream media, which instead only gained interest in Ebola and its many adverse effects once it threatened to spread to the U.S.

In fact, a Google search reveals that the earliest available reports in the Western media about deforestation in Africa and its relationship to Ebola began to surface in 2014—at the same time that Hickox and others were returning to the U.S. after caring for West African patients.

I want to suggest that the nonhuman actants demand to be heard in the story of the Ebola pandemic, and that they must be reincorporated into the network if we are to combat Ebola outbreaks in the future. While of course the human cost of Ebola is an important focus for prevention efforts, these efforts will ultimately fail if work is not also done to address deforestation and its effects. The belief that we could exclude animals and forests from our human networks and maintain a healthy world have been proven false already by climate change research, but further research must be done to uncover the ways in which this exclusion leads to spillover (the technical term for when diseases in animals spread to humans). After all, Ebola is only one of many diseases caused by spillover; others include (to name just a few): rabies, West Nile Virus, bird flu, smallpox, and SARS.

While of course Ebola is a current and prominent example of a disease network that requires the inclusion of nonhuman actants, discoveries about the ways in which deforestation contributes to pandemics may have a larger effect on public health, more generally. In a 2009 report, "The Spread of New Diseases: The Climate Connection," Shah argues that we must not only identify the connections between non-humans, the environment, and medicine, but we must foster interdisciplinary collaboration to confront the effects of their intermingling. She writes, "These developments [in understanding climate change and its effects on disease] have given rise to a growing consensus among many wildlife biologists and public health experts who advocate a new approach to conservation and public health called 'conservation medicine,' which promotes interdisciplinary collaborations to

expose the links between ecosystems, the health of wildlife, and humans that lead to the emergence of new pathogens" (n.p.). Furthermore, as JA Ginsburg puts it succinctly in her article for *The Guardian*, "The bottom line is that there is no public health without environmental health" (n.p.). While developed nations must be more willing to admit underdeveloped nations into their healthcare networks, just as pressingly, medical networks must acknowledge the extent to which environmental actants play a role in shaping their projects.

Ginsburg also cautions against viewing environmental factors as solely to blame for recent outbreaks of pandemics such as Ebola and SARS. She writes, "Deforestation didn't cause this Ebola epidemic, but did make it much more likely. The region's legacy of war and poverty, its beleaguered health care systems, and a series of bureaucratic fumbles fanned a small and isolated outbreak into a full-blown epidemic fire, which has already killed more people than all previous 25 known Ebola outbreaks put together" (n.p.). Ginsburg's reminder to consider deforestation as a key actant—not the sole actant—within Ebola's network warns of the dangers of considering deforestation outside of the economic, medical, and political conditions that permitted its dire consequences.

In Chapter 2, Sanders' "Diagnosis" column narratives highlighted the need for a more dynamic, networked approach to diagnosis. Rather than isolating a single actant as wholly responsible for the network's success, the view of an interwoven string of actants working together and drawing on their own forms of expertise offers a more realistic picture of how diagnosis actually happens. As this example illustrates, such an approach also provides a helpful framework for thinking about misdiagnoses. Just as a single actant cannot be given full credit for a successful diagnosis, no single actant can ever be wholly to blame for a network's failure. Ebola's development in humans and transformation into an epidemic can

be attributed to a convergence of factors—among them deforestation, civil war, and increased contact between bats, gorillas, and humans. However, by excluding these nonhuman actants from the public's view by overly emphasizing Hickox's quarantine, the history of Ebola's development—and the problems that intersect with its spread—were also erased from public view. Networked problems demand networked responses on the part of those who would intervene, and failing to acknowledge these excluded actants makes it more difficult to address the questions they raise within the Ebola assemblage.

African Aid Workers: The Abandoned Actants

Beyond the nonhuman actants that must be reincorporated into public health networks if they are to more effectively prevent Ebola outbreaks in the future, the perspectives of Africans effected by Ebola must be heard and added to the networks. Beginning with the Ebola outbreak of 2014, *The Guardian* created a column on their website called "Ebola: Life on the Frontline." The summative statement for the series reads: "People living in countries affected by the Ebola outbreak share their experiences" (n.p.). Meant to combat the relative dearth of Ebola news written by those actually living in Ebola-striken Western Africa, the columns present the lived reality of African healthcare workers and journalists who were experiencing death, sickness, fear of contracting the disease, and economic hardship on a daily basis. In particular, a columnist named Isaac Bayoh contributed a series of updates on the state of affairs in Sierra Leone and West Africa. As a description of his role in fighting the Ebola outbreak, *The Guardian* explains, "Bayoh volunteers as an Ebola quarantine and awareness worker. He is part of a team that isolates the houses of those who have the disease, educates the family and neighbours, and monitors the patient's progress. Here, in his own words sent via WhatsApp, he shares his experiences about

how people and communities are affected" ("Life on the Ebola Frontline" n.p.). Bayoh's direct contact with the disease and its victims left him in an ideal position to describe the way Africans were responding to the Ebola epidemic to the best of their ability.

A prominent theme in his narratives are the lack of resources with which to combat the Ebola outbreak in Africa. In the first post in his series, he highlights the disconnect between awareness of the disease and the ability to effectively fight it. He writes, "'The Ebola virus is real, the Ebola virus kills, the Ebola virus is contagious.' These words are being said everywhere, on the radio, on the internet, even little children know the dangers of the virus, yet people are dying everyday, people are being infected everyday . . . Many who have contracted the virus and died, it is not because they didn't report it earlier or run away but because they lacked the intensive care they needed" ("Life on the Ebola Frontline: 'Survivors are Left Alone'" n.p.). In addition to the lack of access to care, Bayoh stresses that vital resources such as ambulances to carry the infected to a hospital are scarce. He recalls:

> A 16-year-old girl, Adama, died of Ebola symptoms at her home at the weekend, two weeks after the death of both of her parents. An ambulance was called multiple times through the helpline 117 and it took days before they finally arrived. There are so many people waiting for an ambulance, the fight against Ebola is going from bad to worse. The burial team is said to be overwhelmed and overworked. Dead bodies [have] been left on the street by relatives in fear of being identified as the victim's relatives. ("Life on the Ebola Frontline: 'Fear is Overpowering'" n.p.)

Without access to basic emergency medical care, the fear in West Africa remains palpable, according to Bayoh, who acknowledges that changes are being made and the government is now collecting dead bodies "24 hours upon call" (n.p.). In a later column, towards the end of

the outbreak, Bayoh considers that Ebola has revealed the problems with Africa's health care systems, and that such problems must still be addressed if Africa is to more successfully prevent or handle future outbreaks. He argues:

> Ebola exposed our health systems for what they are. It showed the trust that was lacking between people and services, it showed how our health facilities were often merely buildings rather than places providing care. It showed broken relationships. During the Ebola outbreak, many of these centres were closed, leaving people without medical help. Most of them are now operating again, although many still lack proper equipment or improved resources, and the absence of trust persists. Those with options prefer private hospitals. There have been some changes and improvements after Ebola, but the question will always remain: how ready is our health care system to fight another outbreak like this? Many things that need to be done are yet to be implemented. ("Ebola in Sierra Leone" n.p.)

Bayoh insists here that measures must be taken to develop facilities and resources in Western Africa that can serve as preventive measures for local epidemics—such work is just as important as supporting emergency response efforts. Rather than ignoring West African health systems when Western health is no longer at risk, we might work together to equip at-risk countries to more effectively prevent and combat such outbreaks in the future.

Beyond the healthcare system flaws that the Ebola outbreak brought to the surface, Bayoh stresses the economic and financial hardships that continue to haunt West Africa. For survivors of the disease, overcoming Ebola is only the first step towards regaining their lives—they must also confront the possibility that they will not be able to return to work because of the disease's stigma. In an interview with an ambulance driver named Momodu, who

contracted Ebola while transporting patients to the hospital, Bayoh explains, "Momodu is lucky to have got his job back after he fully recovered, but many have been stigmatized and left unemployed" ("Life on the Ebola Frontline: 'I Thought of Nothing Else but My Own Death'" n.p.). Even for those who manage to avoid contracting the disease, Bayoh explains that "many jobs have shut down [and] prices of food commodities have doubled three times" (n.p.). In a particularly poignant column, Bayoh reflects on the community's sadness about not being able to participate in regular Easter traditions of going to the beach and giving presents to his children. Although he tells his children to be happy even though "I couldn't buy many things as I did last time," he feels sorrow that Easter has been ruined for the community's children ("The Ebola Virus Took a Knife to Our Easter Celebrations" n.p.). During the time that should be celebratory, he reflects on the economic turmoil still facing West African communities. He writes, "Our lives are on hold and our livelihoods destroyed. Jobs remain difficult to find, as most organisations are still closed and we've had to adjust to the available work being related to Ebola" (n.p.). As an example of the career changes many have had to make to make ends meet, he reveals that "When Ebola came, Mr Kamara had to switch profession from teacher to grave digger" (n.p.). Just as Bayoh emphasizes the ongoing need to build better health care infrastructure in Africa, he also insists that economic hardship in Africa is not going away even if the epidemic has died down. He explains, "Yet our economy has gone from bad to worse. People say this because Ebola put our nation on hold. Even with all the money we received from donors it seems the poor are getting poorer and the rich, richer. Life was hard before Ebola and is still so after it" (n.p.).

Among the lingering effects of the Ebola outbreak is the stigmatization that continues to haunt survivors. In another column for *The Guardian's* "Ebola: Life on the Frontline" series, Huw Poraj-Wilczynski speaks to a nurse, Fatmata Sesay, who was among

the first responders to the Ebola crisis. She contracted the disease when a colleague whom she was caring for vomited on her shoulder; she subsequently infected her daughter, Tata, although both mother and daughter survived. Poraj-Wilczynski explains of Sesay's experience, "[T]he problems of the Ebola outbreak are not limited to the virus itself. Working in the Ebola treatment centre, even before she caught the disease, was a lonely experience…People stopped coming round to see her" ("Ebola in Sierra Leone: 'Remind People not to Forget'" n.p.). Because of the lack of understanding about Ebola in Western Africa, Ebola health care providers faced particular stigmatization. Sesay remembers: "It was very difficult for us nurses at the time…People in Kenema said we nurses were the ones who were killing the patients. They thought the president had given us money to reduce the population. They said Ebola was not real" (n.p.). Sesay and other nurses were met with suspicion despite the fact that they were fighting a disease they did not understand with inadequate resources for doing so; she mentions in particular that the protective garments they wore were thin and allowed liquids to seep through (n.p.). Stigmatization continues to haunt Ebola survivors as well. In Bayoh's account of Momodu, the ambulance driver who contracted Ebola, he describes the challenges of reintegrating into his community after he was pronounced Ebola-free. He explains, "My integration back into the community was a very difficult one. People were asked not to sit by me, others refused to come close. My money was rejected in the market. My neighbors were afraid of me, they said I still had the virus and until three months [had passed] no one should come close…After about two months, my community finally embraces me. But it was a terrible experience" ("Life on the Ebola Frontline: 'I Thought of Nothing Else but My Own Death'" n.p.). For survivors who have witnessed comrades dying beside them on a daily basis while in treatment centers for Ebola, such continued stigmatization perpetuates psychological trauma that will take a lifetime to recover from.

A final theme of "Life on the Ebola Frontline: 'I Thought of Nothing Else but My Own Death'" speaks to the continued work that must be done to foster more trust between Western aid workers and African community members. In a column entitled "Ebola Shuts Schools in Sierra Leone but Teachers Use Skills to Stop Disease," social worker John Momodu Kargo reports on the ways in which teachers repurposed themselves into public health educators after schools were shut down during the outbreak. He recalls the plan for teachers to educate their communities: "After the schools closed, the teachers we had trained were calling out to be put to work in preventing the spread of the virus. I soon realized that these teachers could be very useful in helping their communities by educating their own people in the attitudes and behaviour they needed to adopt to remain safe from infection" (n.p.). 145 teachers were ultimately trained to take Ebola prevention messages (most simply put: "Don't touch the sick. Don't touch the dead. Wash your hands with soap frequently") to 200 people per teacher and track Ebola outbreaks within their communities (n.p.). Such messages are vital in communities where Ebola is believed to be unreal, "a tool for the government to gain influence," or associated with "devils or evil spirits" rather than "a disease like malaria" (n.p.). Rather than sending Western healthcare workers to educate already suspicious and vulnerable communities, Kargo's method involved educating West Africans who might have more influence over their communities. He rationalizes:

> As they are highly respected and influential in their communities, teachers are ideally placed to change people's mindsets about Ebola. When they work among their own people, our teachers are seen as 'children of the village' so the community will trust them. Rural villages can be suspicious of people coming to talk to them. Their own son or daughter finds it easier to carry the messages that we need to disseminate. (n.p.)

Future efforts to educate rural communities about Ebola prevention measures might make use of this mix of Western and local to better serve communities and more effectively convince them to avoid Ebola infection.

Overall, this collection of narratives reveals many ways in which we must continue to reincorporate African perspectives into our Ebola network. In particular, we must collaborate with African governments and community leaders to address healthcare system needs, economic and financial needs, psychological trauma for survivors, and education efforts. The narratives also demand that Westerners acknowledge the extent to which Ebola still effects West Africans, even if we have the privilege and distance with which to move on. While Western aid workers can go home after an outbreak of disease, West Africans are left behind to pick up the pieces. Ebola cannot only be a network we address in times of emergency; it must be an ongoing fight, and our commitment to those affected must last longer than a few months. In addition to our ethical obligation to care for those in other parts of the world, the Ebola outbreak reveals the extent to which all healthcare system nodes are intricately connected. Ongoing disturbance in Western African nodes can have dire consequences on the rest of the network if another outbreak occurs.

The perspectives of African aid workers provide another important lesson for those who wish to intervene in public health crises: diagnostic networks cannot simply abandon their efforts when one set of actants (the Western, white ones) are no longer affected. As these narratives demonstrate, stigmatization against those affected by Ebola in Africa remains fierce, the economy is still broken, and picking up the pieces is a daily challenge. We need a long view of diagnosis that never feels complacent in its approach to disease; as the Ebola epidemic reminds us, we are all intricately interconnected through travel, and we are therefore always at risk for developing a disease. Furthermore, just as deforestation allowed

for increased human and animal contact, and therefore spillover, the ongoing destruction of habitats around the world might lead to increased risk for contracting new diseases. Diagnostic networks must do more than simply label a disease once it has surfaced. They can do perhaps more good by learning from past outbreaks, rebuilding communities where diseases have had especially devastating effects, and working with local leaders to institute preventive measures and training procedures. Hopefully such international systems can prevent epidemics from occurring or at least keep them from spiraling out of control in the future.

Conservative Politicians: The Isolationist Actants

The final actants that must be reincorporated into the network has never actually been excluded per se—only quietly overlooked. While the Ebola crisis raged on in Africa and fears circulated in the U.S. and other Western countries, one group benefitted from the paranoia and their time in the limelight: politicians. In a sarcastic editorial for *The Huffington Post*, editor Brian Rooney claims, "The Ebola virus is the best thing to happen to American politicians in years. Ebola has done what neither war, climate change, nor economic meltdown have accomplished. It has united our politicians in action because Ebola is bad" ("Ebola is Good" n.p.). Rooney offers a scathing critique of politicians who use the Ebola crisis to fear monger and take a heavy-handed approach—seemingly to demonstrate their effective leadership abilities. Rooney quips, "Alarm is good. Voters unite around politicians who tell you to be alarmed" (n.p.). While they perpetuated paranoia about contracting Ebola and fought media wars with Hickox and other Ebola nurses returning from Africa, they were also simultaneously engaging in actions that actually prevented the resolution of the Ebola crisis. In what follows, I explore several key ways in which politicians,

particularly conservative politicians, used Ebola to further their own political agendas in ways that were counterproductive.

First, Bobby Jindal, the Republican Governor of Louisiana, was publicly criticized when he banned medical workers who had returned from countries affected by Ebola from attending a medical conference meant to generate response strategies. According to Jess Bidgood and Kate Zernike, he "issued a stern warning . . . to medical experts coming to an international conference on tropical diseases that they should stay away if they had been in Ebola-affected countries in the past 21 days, and that those who defied would be confined to their hotel rooms" (n.p.). Rather than encouraging the collaboration of experts with the most knowledge of Ebola's treatment and prevention, Jindal instead prevented the very efforts that might have led to a faster resolution of the epidemic. According to Rooney, who again takes a more humorous approach, "Jindal, who likes to think of himself as having presidential mettle, is so tough on Ebola, he'll quarantine even the scientists thinking about Ebola. That's the kind of action we've come to expect from our politicians" (n.p.). Jindal's efforts effectively prevented networked problem solving among experts; which, according Dr. Alan J. Magill, the president of the American Society of Tropical Medicine and Hygiene, "harm[ed] crucial sessions where scientists, doctors and administrators who had been in the region were going to teach others" (Bidgood and Zernike n.p.). Such efforts, unfortunately, are also in keeping with conservative skepticism about the expertise of scientists, medical professionals, and others who advocate for the health and wellbeing of vulnerable populations.

Others were critical of the ways in which both liberal and conservative governors enforced harsh quarantine procedures in order to secure a solid foundation for future political maneuvering. Bidgood and Zernike point out that these procedures "went beyond what the federal Centers for Disease Control and Prevention and many medical experts have

said are necessary to prevent the spread of the disease" and that, conveniently, "Some of the toughest policies have been imposed by governors in tight races—such as Connecticut, where a Democratic incumbent was fighting a tough challenge, and Georgia and Florida, where Republicans were" (n.p.). Amongst governors and state politicians, fears circulated about the potential backlash that a local Ebola outbreak could foster. In Hickox's public statement against Christie, who detained her even though she never had Ebola or its symptoms, she directly identifies his particular motivation for quarantining her in an unheated outdoor tent with no access to a shower. She writes, "My liberty, my interests and consequently my civil rights were ignored because some ambitious governors saw an opportunity to use an age-old political tactic: fear" (Laura Wagner n.p.). Christie, who conveniently quarantined Hickox near midterm elections and later ran for president in 2016, responded to reports of the lawsuit by saying, "I've been sued lots of times before. Get in line" (n.p.). Hickox went beyond the lawsuit, though, penning an op-ed for *The Guardian* called "Stop Calling Me the Ebola Nurse." In it, Hickox reiterates to readers that she has never had Ebola and demands, "*I never had Ebola*, so please stop calling me 'the Ebola Nurse'—now!" (n.p.). She again highlights the ways in which she was quarantined because Christie and LePage (the governor of Maine, where Hickox lives), hoped to advance their careers by disregarding science and medicine and violating her civil rights. She writes:

> They bet that, by multiplying the existing fear and misinformation about Ebola—a disease most Americans know little about—they could ultimately manipulate everyone and proclaim themselves the protectors of the people by 'protecting' the public from a disease that hasn't killed a single American. Politicians who tell lies such as 'she is obviously ill' [Christie's comment about Hickox when it was proven that she did not have Ebola] and mistreat citizens

by telling them to 'sit down and shut up' [Christie's comment to an angry attendee at a Hurricane Sandy meeting] will hopefully never make it to the White House. (n.p.)

While Christie's White House bid was ultimately unsuccessful, Hickox correctly predicts Christie's motives for publicly lying about her health (he falsely claimed she had a fever and that she was ill even after she'd been pronounced healthy) and keeping her quarantined against her will.

Perhaps more painful for Hickox were the personal debates about her humanitarian intentions, which were launched against her when she defied quarantine orders. Unintentionally, Hickox became the center of a partisan tug-of-war over the way public health crises should be handled and the intersections of public health and individual rights. Hickox was particularly attacked by conservative politicians, or "loathed" by them, as a headline from the Washington Post put it. Rush Limbaugh suggested that her problem with the quarantine was not its lack of scientific basis, but rather the lack of attention she received while in quarantine, hidden away from the public eye. Of course, one wonders how he Limbaugh can see her isolation—and the subsequent media frenzy—as detracting attention. Still, he asks: "Is this not a little bit sanctimonious? I mean, here you volunteer and you let everybody know, by the way … 'I am a good person. I have volunteered to go to Africa, and I am helping Ebola patients. Look at me. See me? I am a good person.' You come back, 'I have just returned from Africa helping Ebola patients, and you are not going to quarantine me so that I can't be noticed'" ("Kaci Hickox, Rebel Ebola Nurse" n.p.). On the other hand, in another Washington Post piece, "Ebola Nurse Kaci Hickox: 'Flaming' Liberals Love Her. 'Bully' Conservatives Hate Her," Justin Wm. Moyer explains that although "Kaci Hickox may not have intended to become the center of a political debate . . . she is one now" (n.p.).

Hickox, who became "a stand-in for the entire labor movement" for standing up to "bully governors," was particularly beloved by liberals for standing up to Christie. Writes Moyer, "She . . . struck a blow for all the teachers, nurses, public employees, minimum-wagers and workers of all kinds that Christie has bullied, belittled and silenced over the years" (n.p.). Although Christie did not personally attack Hickox, he used her to "[take] up an unusual rallying cry for a member of the party of Reagan: the need for big government to contain a crisis" (n.p.). Thus, rather than drawing on Hickox's knowledge and firsthand experience with Ebola, political figures either turned her into the liberal advocate she never asked to be or demonized her efforts to stand up for health care workers who might be discouraged by the new quarantine policies and to fight a deadly disease in a country without proper resources by calling her petulant and self-serving.

The actions of Jindal and Christie, among others, had more extensive consequences than the violation of Hickox's civil and personal rights—they also prevented aid workers from volunteering to serve African communities at the heart of the outbreak. In "Ebola and Quarantine," Drazen et. al. argue that involuntary 21-day quarantine for Ebola aid workers returning from African countries is not scientifically based and is akin to "driving a carpet tack with a sledgehammer: it gets the job done but overall is more destructive than beneficial" (2029). While they understand the goal of protecting the public's health from an oftentimes deadly disease, they point out the contradiction of quarantining healthy Western aid workers while failing to stop the epidemic at its source by encouraging aid workers to volunteer in affected areas and honoring them when they return. They explain:

> Hundreds of years of experience show that to stop an epidemic of this type requires controlling it at its source. Médecins Sans Frontières, the World Health Organization, the U.S. Agency for International Development

(USAID), and many other organizations say we need tens of thousands of

additional volunteers to control the epidemic. These responsible, skilled

health care workers who are risking their lives to help others are also helping

by stemming the epidemic at its source. If we add barriers making it harder

for volunteers to return to their communities, we are hurting ourselves.

(2029)

In particular, aid workers returning from Ebola-striken areas could fear that in addition to

their own potential quarantines, their family members and friends could be quarantined if

they chose to see them. Doctors Without Borders was especially vocal in challenging the

policies of governors who reacted with panic rather than reasoned and scientifically-based

policies. In a press release on the Doctors Without Borders website, Sophie Delaunay,

executive director of Médecins Sans Frontières in the United States explains, "There are other

ways to adequately address both public anxiety and health imperatives, and the response to

Ebola must not be guided primarily by panic in countries not overly affected by the

epidemic. Any regulation not based on scientific medical grounds, which would isolate

healthy aid workers, will very likely serve as a disincentive to others to combat the epidemic

at its source, in West Africa" ("Ebola: Quarantine Can Undermine Efforts" n.p.). For aid

workers already anxious about the risks to their physical and psychological health of serving

in countries where they will have to watch children and adults alike die everyday from the

disease, the further risk of quarantine might be too much to bear. The press release explains,

"International MSF staff members commit to burdensome four-to-six week assignments in

the Ebola-affected countries. The risk of being quarantined for 21 days upon completion of

their work has already prompted some people to reduce their length of time in the field.

Others will be less inclined to volunteer in the first place" (n.p.). Thus, the politician's strict

quarantine enforcement did more than prevent conversations about prevention measures, serve their own political agendas, and violate Hickox's rights (among many others). It also prevented aid workers from volunteering to educate and treat patients in Africa or to reduce the amount of time they spent there serving affected communities.

The Ebola outbreak and the enforcement of heavy-handed quarantine procedures by U.S. governors should foster a critique of the ways in which politicians use public health scares to serve their own interests. Responses to epidemics cannot be determined by politicians who are more concerned with their favorability ratings than with scientific principles governing disease transmission and containment. Furthermore, politicians not only took control of the Ebola network in the U.S. in totalitarian ways, they attempted to exclude scientific and medical actants who countered their actions. For the ostensible cause of defending their constituents from possible illness, they failed to heed the advice of medical experts who deemed their quarantine procedures both unnecessary and dangerous. Gregg Gonsalves and Peter Staley sum up the disconnect between scientific arguments against quarantine and political action:

> The argument against these [quarantine] policies is based on the lack of
> scientific grounds for the quarantine criteria, the likelihood that unnecessary
> restrictions on those returning from the region will dissuade health care
> workers from volunteering to help fight the epidemic, the illicit and
> erroneous public health message sent by these quarantines that asymptomatic
> persons are a danger to their communities, and the inconsistency in applying
> the policies to health care workers who've had contact with Ebola in Africa
> but not those who've seen patients in U.S. facilities. ("Panic, Paranoia, and
> Public Health" 2348)

The involvement of politicians as actants within public health and diagnostic networks raises another important question: if we must, as I've argued, harness the energy of diagnostic networks to do more than address immediate threats, what role should politicians play in legislating disease? Here, Latour might remind us of the importance of never turning a network into a hierarchy; politicians must act while acknowledging the limitations of their knowledge and power and defer to other expert actants, such as scientists, aid workers, and even the patients themselves. By failing to defer to the expertise of scientists and physicians, politicians such as Christie and LePage risked stigmatizing Ebola to the point that aid workers would avoid volunteering to help stop the epidemic. Their actions could have also resulted in people hiding Ebola symptoms to avoid the media spectacle. Advocating for the common good cannot be a business of isolated decision making but rather networked and pooled expertise, a project I'll address more fully in Chapter 5.

Perhaps most frustrating of all is a point that Gonsalves and Staley miss but Shah picks up—the entire pandemic could have been prevented by more effective international cooperation amongst politicians and health care systems. Writes Shah:

> The Ebola virus broke out in a remote forest village in Guinea in early 2014. It would have been easy to contain using only the simplest, cheapest measures had it been squelched early on at its source. Instead the virus, which had previously infected no more than a few hundred people at a time, in a single year spread into five neighboring countries, infected more than twenty-six thousand people, and would cost billions to contain. Well-understood diseases that can be easily contained with drugs and vaccines escaped control even in the wealthy countries best situated to stanch them. (8-9)

As this example (and countless others, according to Shah), illustrate, a networked view of disease and diagnosis must be mobilized to stress international collaboration, the enrollment of nonhuman factors, and "reaching across the aisle" between different political parties and specialist and non-specialist audiences.

"Ebola is Good"

While "Ebola is Good" was obviously a sarcastic commentary on the ways in which politicians (ab)use epidemics and public health crises for their own gain, epidemics like Ebola offer us important opportunities to recalibrate public health networks. In particular, due to developments in air travel and human population concentrations in cities, bodies of U.S. citizens are more interconnected than ever with the rest of the world. This increased exposure to others must be reflected in our networked relationships; rather than excluding actants who we fear will contaminate us, we must find ways to work with such actants to promote global infectious disease prevention, research, and education. Rather than responding with fear mongering, we must respond with initiatives that are both scientifically-based and beneficial for all of the network's actants. As Jane Bennett argues in "Thing-Power," networked relationships change our ethical obligations, as we can no longer care only for the humans that we perceive as immediately affecting us. Recognizing that healthcare systems are comprised of global network of actants demands that we maintain responsibility for actants across the globe and expand our sense of whose health matters. She writes:

> The ethical aim becomes to distribute value more generously, to bodies as
> such. Such a newfound attentiveness to matter and its powers will not solve
> the problem of human exploitation and oppression, but it can inspire a
> greater sense of the extent to which all bodies are kin in the sense of being

inextricably enmeshed in a dense network of relations. And in a knotted

world of vibrant matter, to harm one section of the web may very well be to

harm oneself…A vital materialism does not reject self-interest as a motivation

for ethical behavior, though it does seek to cultivate a broader definition of

self and of interest. (48)

For Bennett, then, the so-called Ebola nurse quarantine illustrates the need for a greater sense

of responsibility, or, as Latour might claim, we need more moralists to seek out and enlist

actants into our public health networks.

Furthermore, we also cannot allow politicians to create their own networks to the

exclusion of public health specialists and experts. At the heart of the Ebola quarantine

struggle, wherein Kaci Hickox was only the first of several nurses to be quarantined after

returning from treating patients in West Africa, is a problem of expertise. While Latour

encourages us to always extend the number of actants who can participate in our networks

and to continually ask who has been prematurely excluded, the question remains of how we

might determine expertise in a network of flattened ontologies. For example, during an Ebola

outbreak that encompasses many actants—from nonhumans, to African Ebola patients, to

international aid workers, to scientists and medical experts, to politicians—how do we find

ways for expertise to be collaboratively shared rather than contested? If we cannot respond to

the demands of each actant all at once, how will we decide who to listen and respond to first?

This issue is of particular importance during an era when president-elect Donald Trump and

his administration express open disdain for academic and scientific expertise. For example,

Trump recently appointed former Texas Governor Rick Perry as the Secretary of Energy, a

post previously held by a nuclear physicist. He has also appointed a vocal climate change

denier, Myron Ebell, to lead the Environmental Protection Agency transition. Future

collaborations within diagnostic networks will demand shared work between politicians and expert healthcare and science specialists, and given Trump's recent nods to non-specialist and anti-science leaders, the future looks grim for medical and scientific research. Just as Christie and others chose to disregard the expertise of scientists and healthcare providers, future politicians might similarly let partisan interests cloud their judgement as they face future health crises. Global trends that show that pandemic outbreaks have historically occurred once every fifty years, and according to Sonia Shah, "90 percent of epidemiologists said that a pandemic that will sicken 1 billion, kill up to 165 million, and trigger a global recession that could cost up to $3 trillion would occur sometime in the next two generations" (Shah 8, Brilliant n.p.). And, she argues, the cause of the next pandemic may be the very disorganization and lack of networked care that the Ebola quarantine situation illustrates. She writes, "Partly, this sense of an impending pandemic derives from the increasing number of candidate pathogens with the biological capacity to cause one. But it's also a reflection of the shortcomings in our public-health infrastructure, modes of international cooperation, and ability to maintain social cohesion in the face of contagion. The way modern societies have handled outbreaks of new issues so far does not bode well" (8). Thus, the ANT frame might reach beyond the interpersonal dimension of diagnostic networks as they function in a hospital room and into the messy international arena of epidemic identification, treatment, and prevention.

Although Kaci Hickox has largely resumed her normal life after relocating to Oregon, she continues to pursue a lawsuit against Christie. Hickox, who is represented by the American Civil Liberties Union, was told last fall that while "Christie and state health officials are immune from federal civil rights charges," she can "proceed with parts of her lawsuit alleging false imprisonment and invasion of privacy" ("Judge Tosses Civil Rights

Claims" n.p.). Despite the ongoing legal battles, Hickox's public misdiagnosis has given her a platform for holding other actants accountable, and she serves as an excellent example of intervening within a network that simultaneously undermines public health policy, science, and civil liberties. And, perhaps most impressively, her experiences of being isolated as an actant within a complex and multi-faceted network has enabled her to generate a new network: one that might confront partisan approaches to public health policy and lead to the revision of the U.S. Ebola network.

CHAPTER 4:

DIAGNOSTIC (UN)CERTAINTY AND DELIBERATIVE RHETORICS

Doctors are men who prescribe medicines of which they know little, to cure diseases of which they know less, in human beings of whom they know nothing. - Voltaire

I carry tattooed upon my heart a list of names of women who did not survive, and there is always a space left for one more, my own. - Audre Lorde

On August 1, 2009, artist Megan Hildebrandt discovered a lump on her throat. It throbbed with pain when she drank beer. And it wouldn't go away. Hildebrandt, an MFA student attending the University of South Florida at the time, didn't have health insurance, which made it difficult to get in to see a doctor. She explains, "Finally, by the end of August —I could no longer ignore it. I went in to the University ER . . . There I was given a CT scan and told I was too young to have cancer, and that I was more likely to be HIV positive. (wtf) I was given 7 days of antibiotics and told to get tested for HIV" (Hildebrandt). Hildebrandt waited two weeks, giving the antibiotic time to work and the lump to go away. But when it got worse instead, she decided to get checked again, this time pursuing a diagnosis at the student health center at USF. She recalls that "the lump was huge by this point—the antibiotics had not worked on CANCER" (Hildebrandt). Still perplexed, the student health center referred Hildebrandt to Moffitt Cancer Center, "where I was quickly given blood tests, another CT scan, and finally, biopsy surgery. It was late September by the time I was actually diagnosed with Hodgkin's Lymphoma, Stage 2A" (Hildebrandt). Hildebrandt, who had been made to wait two months for a diagnosis, "began chemo immediately [with] ABVD infusions every two weeks until the beginning of April. Then I was declared cancer-free" (Hildebrandt). However, her doctor advised that she should get regular CT scans in order to ensure that the cancer hadn't returned. Hildebrandt was worried

Figure 4.1. Megan Hildebrandt. *Counting Radiation I*, ink on
paper, 96 x 54 in, 2012. Courtesy of the artist.

about the levels of radiation she was being exposed to during her regular CT scans, but she
trusted her doctors.

Approximately two years after beginning treatment, Hildebrandt's doctor told her, "I
think we should stop giving you so many CT scans" ("Culture Vultures"). He admitted that
her continued exposure to radiation, via the CT scans, put her at an elevated risk for cancer
recurrence. New research had revealed the link between radiation exposure and cancer, which
had resulted in stricter guidelines regarding how many CT scans patients should receive.

When she asked how much radiation she'd been exposed to for each CT scan, he told her, "For each CT scan of your head and neck we've given you, you've been exposed to one lifetime of radiation" ("Culture Vultures"). He then asked her, "How many have we given you?" She replied, "You're my doctor, don't you know?" She finally told him she had had sixteen CT scans over two years. He said, "Okay, that means you're about thirteen hundred years old in radiation years" — a revelation that was particularly hard for her to process, she notes, as she was still a young college student at the time ("Culture Vultures"). Upon returning to her studio, Hildebrandt began to wonder, "How am I going to deal with this number? It's huge" ("Culture Vultures"). She started to break 1300 down into months, weeks, minutes, and seconds worth of exposure in an attempt to process the quantity of radiation she had endured.

Overwhelmed by the giant number, she began to represent it visually through a landscape drawing of crosshatches, broken down in increments of five sets of tally marks. The pieces in Hildebrandt's
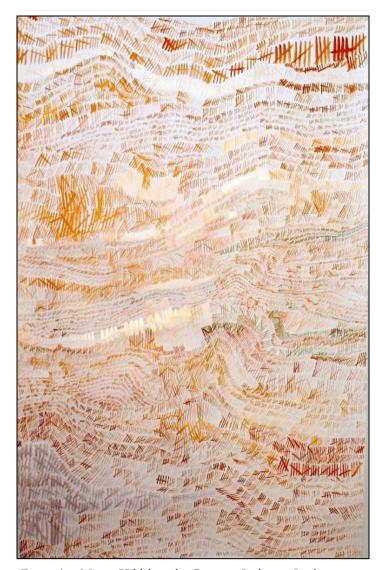

Figure 4.2. Megan Hildebrandt. *Counting Radiation II*, ink on paper, 96 x 54 in, 2012. Courtesy of the artist.

Counting Radiation series, which are about eight feet tall, loom over viewers, viscerally

communicating the intensity and weight of the number 1300. "The bigness and scale was so important," Hildebrandt reflects, "[It was important] that it was bigger than my body" (Hildebrandt). The repetitive marks became a source of comfort for Hildebrandt, who says she achieved a state of flow while creating the pieces because she didn't have to think about anything but moving her body while she tallied.

Now, almost 8 years after her diagnosis, Hildebrandt feels perhaps more anxiety about her risk for disease than she did while she was going through treatment. "The liminal space post-treatment is harder," she muses, adding that going through treatment allowed her to focus her energies on getting better rather than dwelling with daily uncertainty. "Cancer is chronic," she tells me, "I think of it as 'carrying the diagnosis' with me [because it's always with you, even when they tell you you're a survivor]" (Hildebrandt). Given her 50 percent chance of cancer recurrence, and coupled with the extra radiation exposure she endured to monitor her cancer treatment's efficacy, she feels the heaviness of the tally marks perhaps more now than she did when she created the pieces.

Hildebrandt's emphasis on the challenge of living with uncertainty

Figure 4.3. Megan Hildebrandt. *Counting Radiation III*, ink and graphite on paper, 96 x 54 in, 2012. Courtesy of the artist.

post-diagnosis, and the dread that accompanies risk for or recurrence of disease, offers an important addition to the way the illness narrative genre, broadly speaking, conceives of diagnosis. While the diversity of the illness narrative genre renders any description of "norms" challenging, a common approach to diagnosis in much of the illness narrative literature involves a shocking reveal—one that the person has never known she should fear. For example, in Marisa Acocella Marchetto's *Cancer Vixen,* she depicts Cancer as a villain with skeletal hands and a Grim Reaper costume knocking on her door on a random May day. She reveals the diagnosis via a knock knock joke, picturing herself peering through the peep hole to meet her new guest: "Who's there?" she asks. Cancer responds, "Cancer." She responds, "Cancer Who?" And Cancer tells her, "Cancer your wedding! Cancer your career! Cancer your life!" (64). This sudden interruption presents diagnosis as an unexpected shock —not a new chapter in an ongoing saga of disease and anxiety or a confirmation of her worst fears. Prior to her diagnosis, we do not see Marchetto staying up all night, worrying about cancer, pacing waiting room hallways, and furiously googling symptoms. Instead, she meets the love of her life and gets engaged, which postures cancer as an unwelcome intrusion within an otherwise pleasant narrative. For Marchetto, these uncertain experiences come later, once Cancer has knocked on her door.

Marchetto's narrative, while striking in its playful irreverence, is not unique in its shocking reveal of a diagnosis. Other contemporary examples include *Breaking Bad* lead character Walter White's sudden lung cancer diagnosis in the pilot episode, award-winning film *Still Alice*'s Alice Howland's sudden diagnosis of familial Alzheimer's disease, and the *The Diving Bell and the Butterfly*'s author Jean-Dominique Bauby, who communicated the text of the book by blinking after a sudden and massive stroke rendered him paralyzed save for his left eye. However, the narrative convention of sudden diagnosis fails to account for other

relationships to disease: What about those at risk for disease who are fearful before they ever exhibit symptoms? What about those who are not surprised to see Cancer (or another villain) lurking towards their door but are rather relieved that it has finally arrived? The surprise diagnosis convention can emphasize the shock of discovery to the point of masking the experiences of those for whom diagnosis is not a surprise.

Two shifts within medicine have generated a space for the kind of living-with-risk narrative shared by Hildebrandt. First, enhanced treatment and vaccination for diseases like cancer mean that more people are surviving initial bouts with disease, which means that more people are also at risk for recurrence. This is particularly true for cancer, as treatment and predictive testing have become more effective in recent years. According to their "Annual Report to the Nation on the Status of Cancer, 1975-2012," A. Blythe Ryerson et. al show that cancer death rates have decreased "by 1.5% per year from 2003 to 2012" for both sexes and all types of cancer (1312). They also found that "Overall, cancer incidence and mortality declined among men; and, although cancer incidence was stable among women, mortality declined" (1312). Thus, more and more people are living with the daily uncertainty that Hildebrandt describes and anticipating future diagnoses. Furthermore, medicine's ability to detect genetic mutations through predictive or presymptomatic testing has generated a population of people who can know in advance whether they will develop a genetic disease. In May 2013, Angelina Jolie raised awareness about precisely this issue when she published an op-ed entitled "My Medical Choice" in *The New York Times*. In the piece, Jolie wrote, "[T]he truth is I carry a 'faulty' gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer" (n.p.). According to Jolie, "My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer, although the risk is different in the case of each woman" (n.p.). In response to this news, Jolie opted for

preventive surgery: "Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventive double mastectomy" (n.p.). Although she admits that genetic testing for the BRCA1 and BRCA2 genes are financially challenging for most—the cost is "more than $3,000 in the United States"—she insists that "It has got to be a priority to ensure that more women can access gene testing and lifesaving preventive treatment, whatever their means and background, wherever they live" (n.p.). She ends with an exhortation for women to undergo testing so they can know whether they are at risk for disease:

> I choose not to keep my story private because there are many women who do not know that they might be living under the shadow of cancer. It is my hope that they, too, will be able to get gene tested, and that if they have a high risk they, too, will know that they have strong options. Life comes with many challenges. The ones that should not scare us are the ones we can take on and take control of. (n.p.).

For Jolie, interestingly, being informed and having options are linked to taking control of genetic risk —as if testing itself can release a person from the anxiety potential disease brings. Her exhortation was nonetheless effective, as a study by Sunita Desai and Anupam B. Jena found that "Daily BRCA test rates increased immediately and sharply after publication of the editorial" ("Do Celebrity Endorsements Matter?" 2). They identify a change in "BRCA testing rates of 52%," although they also note that Jolie's editorial was less effective at reaching the subgroups most at risk for the BRCA gene (3). Overall, though, Jolie helped to popularize a relatively unknown diagnostic phenomenon, and her endorsement of it encouraged others to explore their options and risk.

Despite these shifts towards diagnostic risks pertaining to recurrence and genetics, the illness narrative genre has been slow to generate alternative approaches to diagnosis. While my goal is not to criticize the way writers choose to present their experiences of illness, I am struck by the relative dearth of narratives that focus on someone who is at risk for a disease and must learn to dwell with her uncertainty. Such experiences are perhaps more challenging to represent as they are anticipatory of a potential, future diagnosis—they are more abstract, for example, than the experience of Marchetto being visited by an unwelcome house guest or the shock of seeing Jolie's column in the *New York Times*. This is not to say that illness narratives do not involve uncertainty—uncertainty abounds regarding such important questions as: How will I pay for treatment? Will my friends and family continue to support and love me? How will I change as a result of my changed body / abilities? What kinds of treatment will I undergo? Will I live? But sustained uncertainty about whether one will become sick and when is relatively rare in illness narratives, where the very title of the genre tends to give away the plot to some extent. In narrative terms, we might say that such questions anticipate a future narrative event that may never come.

Despite their relative rarity, when such narratives do exist they tend to take one of two forms: (1) a person is at risk for a disease due to genetic factors, as in the case of Jolie, or (2) a person is at risk for a recurrence of their disease, as in Hildebrandt's case. For patients who fear recurrence, the diagnosis is just a node on a network of illness that may also include the experience of a migraine triggering fears that cancer has returned and the terror of returning for a yearly check-up. And for those at risk for a genetic disease, the story involves fearful symptom checking and anxiety that an ordinary experience—such as tripping while walking down the street—signals the development of a looming inherited disease. Susan Sontag's immortal words, with which she opens *Illness as Metaphor and AIDS and Its*

Metaphors, perhaps come closest to presenting the uncertainty of fluctuating within the liminal space between health and illness:

> Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (3)

Sontag, herself as breast cancer survivor by the time she wrote her most famous text, highlights the oscillation that illness engenders, and the constant fear of shifting (back) into the "night side of life." She views such a shift as inevitable, a part of life, although tellingly she also allows for a shift back into the kingdom of the well. Although this opening to her text is a bit tongue-in-cheek, as it masterfully captures the very metaphorical treatment of illness that she finds so unethical, Sontag was primed to narrativize such an experience, as she had lived through three decades of uncertainty about cancer recurrence. According to Abigail Zuger, she first survived her "breast cancer metastatic to the lymph nodes," in 1975, which she considered unlikely ("A Fight For Life" n.p.). Still, Zuger explains:

> She survived the draconian treatment and the years spent expecting her unlikely remission to end, only to develop unrelated uterine cancer in the late 1990s. Again she survived, and again she developed a new cancer: this time myelodysplastic syndrome, a virtually untreatable variant of leukemia, probably related to the treatment for the first two. She died in 2004. (n.p.)

But rather than describe "what it is really like to emigrate to the kingdom of the ill and live there" in *Illness as Metaphor and AIDS and Its Metaphors*, Sontag chooses instead to challenge "the punitive or sentimental fantasies concocted about that situation" (4). Rather than

discussing her own experiences with dual citizenship and anxiety about sudden deportation to the other place, she focuses on the metaphors used to describe illness, emphasizing the way such metaphors have disempowered or unfairly heroized patients over time. Thus, Sontag's classic treatise—while brilliant—perpetuates the silence about diagnostic dread and uncertainty that haunts the illness narrative genre.

Perhaps one reason for the lack of narratives about potential, future diagnoses and bodies at risk can be attributed to Western medicine's concern with—some might say obsession with—certainty. For example, shows like *House* generate faith that no matter how challenging a case, doctors will eventually figure out the problem and be able to treat it. Such expectations have led to a new genre of memoirs by physicians and residents-in-training who refute such god-like portraits of clinicians and present instead the challenging, uncertain circumstances they face while on the job. Chapter 2 disputed the idea that medicine is an exact science, and physicians such as surgeon Atul Gawande and internist Lisa Sanders are quick to point out the extent to which healthcare professionals are often making informed guesses in high pressure situations—hardly the portrait of medical perfection and certainty that dominates in Western culture. Siddhartha Mukherjee, a physician famous for his books *The Emperor of All Maladies* (2010) and more recently *The Gene: An Intimate History* (2016), agrees with Gawande's and Sanders' assessments, writing of his time in residency:

> I had never expected medicine to be such a lawless, uncertain world. I
> wondered if the compulsive naming of parts, diseases, and chemical reactions
> —frenulum, otitis, glycolysis—was a mechanism invented by doctors to
> defend themselves against a largely unknowable sphere of knowledge. The
> profusion of facts obscured a deeper and more significant problem: the
> reconciliation between knowledge (certain, fixed, perfect, concrete) and

clinical wisdom (uncertain, fluid, imperfect, abstract). (*The Laws of Medicine:*

Field Notes from an Uncertain Science 6)

Despite Western perceptions of medicine as a perfect science, and efforts by physicians to make their work seem more exact (through classification methods, for example, as Mukherjee suggests), the daily reality of practicing medicine offers an alternative, messier picture. Mukherjee furthermore claims that, far from being a medical anomaly, uncertainty is at the heart of what physicians do every day—in fact, he bookends his TedTalk (later printed as a book) with reminders of medicine's fallibility. In the introductory section, he quotes a surgeon he observed during his residency who left him with important advice for his medical career: "It's easy to make perfect decisions with perfect information. Medicine asks you to make perfect decisions with imperfect information" (4). In the conclusion, Mukherjee affirms his former mentor's words, now speaking from his prestigious position as a renowned physician and writer:

> The discipline of medicine concerns the manipulation of knowledge under
>
> uncertainty. Abstract away the smell of rubbing alcohol and bleach; forget the
>
> adjustable beds and ward signs and the gleaming granite of hospital lobbies;
>
> erase, for a moment, the many corporeal indignities of a man in a blue cotton
>
> gown in a room or the doctor trying to heal him—and you have a discipline
>
> that is still trying to reconcile pure knowledge with real knowledge. The
>
> 'youngest science' is also the most human science. (70)

Mukherjee adds his voice, then, to the chorus of physicians stressing that what they do is not an exact science and calling for recognition of the limitations of physician ability and knowledge, despite their years of schooling and experience. As Mukherjee reiterates, doctors

are constantly negotiating the pure knowledge they've gained in school with the real knowledge of treating real human bodies.

Lennard J. Davis also reminds us that perhaps nowhere is this fixation on certainty more prevalent than in diagnostic encounters. As described in Chapter 2, the very definition of the word "dia-gnosis"—to know with certainty—highlights the discomfiting parallels between medicine and religion; we expect doctors to be able to at least identify what is wrong with us even if they cannot cure us, just as we might expect a priest to be able to identify our sin and (we hope) pardon it. The word also refers to a process of *distinguishing* a disease from a list of other possibilities and arriving at a *conclusion* based on *evaluation*. Such terminology itself points to a scientific orientation for diagnosis, perhaps to again reify medical authority and make the practice of medicine seem less tied to chance, randomness, or guessing. However, such expectations for diagnosticians to always know "what's wrong" condition us to have perhaps unrealistic expectations for what doctors can reasonably do. Furthermore, such expectations can lead to further frustration for individuals facing questions diagnosis cannot answer: Will I live a long life? Will I develop cancer? MS? Will I develop a genetic disease? What lifestyle factors put me at risk for contracting a disease in the future? Finally, and perhaps most importantly, such assumptions about the invincibility of doctors' diagnostic knowledge and abilities presume that knowing one's diagnosis is always a good in itself. The anxiety we feel before Dr. House solves the case (generally in the last five minutes of the show) indicates an unwillingness to live without a diagnosis—a discomfort with uncertainty that potentially has more to do with a desire to know than a desire to be diagnosed.

Furthermore, I want to highlight an aspect of diagnosis that Davis leaves out of his study: the extent to which diagnosis invokes a decision or judgement on the part of a doctor.

For example, the Cambridge Dictionary defines diagnosis as "the *making of a judgment* about the exact character of a disease or other problem" and Merriam-Webster defines it as "the *decision reached* by diagnosis" ("Definition of 'Diagnosis' in the Cambridge English Dictionary"; "Diagnosis"). These definitions suggest that diagnosis hinges on the doctor's decision, an idea I called into question in Chapter 2. However, they also reveal that diagnoses rely not only on relations between networked actants but on their generation of deliberative contexts. In Chapter 2, I argued that diagnoses are rhetorical assemblages, and I suggested that the assemblages' aim was to answer questions of conjecture, definition, and quality (or, the first three levels of stasis). In this chapter, I shift my analysis to consider how diagnostic assemblages relate to the fourth level of stasis, policy. Once an illness has been defined, or if it cannot be defined, questions remain regarding how to proceed and which course of action to decide upon. While previous chapters have explored the makeup of diagnostic networks, I want to now turn our attention to how a decision is made based on their coming together. And whereas previous chapter have emphasized more "traditional" cases where patients experience surprise diagnoses, I want to shift my focus towards the way decision-making happens for patients at risk for diseases. How might they engage in decision-making processes with their healthcare providers in order to ensure their continued (physical, emotional) health? And how might doctors shift their decision-making processes to best account for these rapidly expanding populations?

In what follows, I will suggest an alternative approach to diagnoses in potentia that better accounts for the reality of uncertainty not just in practice for doctors, such as Mukherjee, Davis, and others, but in patients' lives. First, I will draw on two key examples to further explore the focus on certainty in Western presentations of diagnosis. My analysis will focus on two enigmatic communities who have much to teach us about the drive to

certainty: bug-chasers, a subgroup of gay men who pursue HIV positive partners, and those at risk for genetic disease who choose not to be tested. In considering the way both groups confront uncertainty and risk, I will seek to first consider the way (un)certainty influences the decisions that both subgroups make regarding their health. I will then argue that we need an approach to deliberative rhetorics within medical contexts that is as complex as the patients doctors treat. I locate such an approach in Arabella Lyon's feminist and non-Western framework for deliberation in *Deliberative Acts: Democracy, Rhetoric, and Rights*. Although Lyon cultivated her framework specifically for human rights deliberations, I will address the benefits of applying such a model to medical and diagnostic contexts.

Bug Chasing and the Desire for Certainty

In "The Existence of a Bug Chasing Subculture," David A. Moskowitz and Michael E. Roloff define bug chasers as "physiologically healthy, HIV-negative gay men [who] . . . actively see[k] seroconversion by engaging in unprotected sex with HIV-positive partners" (347).[3] The phenomena was not well-known by the mainstream media until a 2002 article in *Rolling Stone,* "Bug Chasers: The Men Who Long to be HIV+," shocked readers by providing insight into the bug chasing subculture. Gregory A. Freeman estimated, at the time, that about 25 percent of HIV+ of newly infected gay men "[fell] into" the bug chasing category (about 10,000 men per year) (n.p.). He furthermore explains that the internet has helped foster a community bent on contracting the disease, since most bug chasers turn to anonymous communities to share their deadly interests and find potential partners (n.p.). In an interview with a bug chaser named Carlos, Freeman learns that HIV is now viewed by

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[3] Thanks to Tamika Carey for bringing this phenomena to my attention as it relates to my project.

some bug chasers as a "minor annoyance" rather than a devastating death sentence — "It's like living with diabetes. You take a few pills and get on with your life" (n.p.). However, Carlos also acknowledges that "I know what the risks are, and I know that putting myself in this situation is like putting a gun to my head" (n.p.). Nonetheless, for Carlos, contracting HIV is a kind of dream because it constitutes the most subversive and radical thing he can do as a gay man (one, it's worth noting, who volunteers at a crisis center for gay men and educates others about safe sex). Freeman offers a contrasting account from a man named Doug Hitzel, a former bug chaser who "successfully" contracted HIV. Hitzel regrets his decision to contract HIV and becomes angry when he hears people irreverently discussing "bug chasing" now that he has to live with the daily reality of the disease. "Whenever I have to deal with things like medication, days when I'm really down," he tells Freeman, "I have to look myself in the mirror and say, 'You did this. Are you happy now?' That's the one line that goes through my head: 'Are you happy now?'" He says it with a snarl, full of anger" (n.p.). In contrast to Carlos, who brags about his uncertain HIV status and the number of positive partners he has each week, Hitzel takes a more reflective approach. According to Freeman, "Looking back on it, Hitzel says he was committing suicide by chasing HIV, killing himself slowly because he didn't have the nerve to do it quickly. Hitzel is ashamed and embarrassed that he actually sought HIV, but he's willing to tell his story because he hopes to dissuade others who are on the same path" (n.p.). Thus, Freeman's account exposes two approaches to understanding bug chasing—one informed by an infatuation with gaining entrance into a community through subversive sexual acts and the other a form of slow suicide due to the end of a relationship.

So unsettling was this story for readers that articles quickly proliferated attempting to prove whether bug chasing was a real subculture or a mere "urban legend or an inductive

fallacy" (Moskowitz and Roloff 355; Grov and Parsons 493). Moskowitz and Roloff proved the existence of this subculture and distinguished it from the barebacking subculture (specifically as it applies to gay men who practice unsafe sex), noting that while bug chasers actively pursue serodiscordant partners or indicate ambivalence regarding the partner's status, none of the barebackers in their study sought a serodiscordant partner (352). They did indicate, however, that while discourse surrounding bug chasing holds that "Bug chasers are purportedly in search of 'the bug,'" "only 8.7% reported a preference for a certifiably positive partner and the majority (60.6%) of bug chasers reported the HIV status 'doesn't matter'" (352). Thus, for more than half of the people Moskowitz and Roloff studied, bug chasing seemed to be less about active pursuit of HIV and more about the excitement of risking infection and/or a resignation to the likelihood of being infected resulting in indifference.

Because of the counterintuitive premise of bug chasing—why would someone *want* to contract HIV on purpose?—many writers have attempted to explain the practice. Deann K. Gauthier and Craig J. Forsyth suggest four major explanations for bug chasing, based on their analysis of bug chasing literature and internet resources: "fear and relief," "risk taking as eroticism," "loneliness and group solidarity," and political actions" (93-5). Each of these explanations is highly suggestive, particularly the idea that a gay man who has been routinely stigmatized might chase the bug because he desperately wants to find acceptance and compassion. The question of how Western culture treats gay men with HIV in comparison to how we treat healthy gay men warrants much more analysis than this current research can pursue. However, I want to focus particularly on a motivation that correlates with a drive to diagnostic certainty: the desire to contract HIV in order to know one's status definitively. Freeman explains, "For some, the chase is a pragmatic move. They see HIV infection as

inevitable because of their unsafe sex or needle sharing, so they decide to take control of the situation and infect themselves. It's empowering. They're no longer victims waiting to be infected; rather they are in charge of their own fates" (n.p.). Freeman highlights the significance for a gay man, who may know or sense that he has a high probability of contracting HIV, choosing to be in control of his fate by choosing when—and by whom—he will be infected. Indeed, some bug chasers even speak about contracting the bug in language that mirrors pregnancy, although being "impregnated" with HIV fosters death rather than a new life. Furthermore, to return to Gauthier's and Forsyth's four explanations for bug chasing, those who pursue HIV out of "fear and relief" typically feel that "fear of infection inhibited their behavior in the past to such an extent that their perceived quality of life had diminished to unacceptably low levels" (93). In response, "These individuals wish for the 'relief' of knowing that they are infected. For them, infection is often viewed as 'the great inevitable,' and thus they wish to merely quicken the inevitable so that they can get on with the business of living out their lives in a more uninhibited fashion, however short that life may be" (93). Again, given the new sense among some gay men that HIV is a "manageable infection," contracting HIV may seem necessary in order to achieve "increased quality of life" (93). For example, in a 1999 article in *POZ* by Michael Scarce, a 33-year-old gay man named Pete said, "I was so afraid of becoming positive for such a long time, and once it happened, I felt relief" ("A Ride on the Wild Side" n.p.). Rather than feeling that HIV has ended their life, bug chasers may instead experience a feeling of invincibility: what more can happen to them once they have contracted HIV? What will they have to fear after infection? While of course there are many more things to fear—including side effects from treatment, the development of AIDS, and contraction of illnesses that will further compromise the immune system—for some, contracting HIV can offer respite from the endless questions and

"what ifs" of practicing unsafe sex. Thus, in contrast to public health efforts to encourage safe sex and diminish the spread of HIV, the bug chasing subculture seeks relief from their uncertainty by pursuing the virus.

Bug chasing highlights two key needs on the part of chasers—first, a desperate need for certainty in the face of risk and disease and second, a sense of agency in an otherwise chaotic and dangerous practice. Bug chasers in the aforementioned texts almost unanimously express a desire to catch HIV so they will no longer have to live with the terror and anxiety of not knowing if—or more likely when—they will contract it. Instead of waiting for the virus to strike when they least expect it, bug chasers pursue it so they will no longer be held back by fear. As Carlos puts it to Freeman: "It's about freedom . . . What else can happen to us after this? You can [do whatever you want as much as you want], and nothing worse can happen to you. Nothing bad can happen after you get HIV" (n.p.). Although Hitzel would disagree, pointing out that several days on the HIV medication that makes him constantly vomit would make most realize how devastating the lived reality of HIV is, Carlos highlights the extent to which bug chasers see themselves as untouchable post-infection. In narrative terms, bug chasers see an HIV diagnosis as an inevitable future event in their lives and organize their actions around (and in fact cause) the ending they forsee. Once they have achieved the life event they planned for, they feel a greater sense of narrative freedom because they can now pursue other narratives not bound up in illness. Hitzel, it's important to note, labels this a false hope.

Furthermore, others posit that bug chasing gives them a sense of agency in what would otherwise be a highly uncertain process of risking HIV infection. Even the verb "chase" suggests an approach to disease that can be controlled rather than passively feared. To again cast the impulse in narrative terms, for gay men who feel as if they cannot control the

inevitable conclusion of their story, bug chasing can be a tragic assertion of agency. If they contract HIV because of unsafe sex practices as a gay man, they might be seen as another victim of the disease in a community already ravaged by it. They may fear that their identity will be subsumed in their illness, and their individuality will get erased in a sea of statistics. If they transgress against the traditional narrative of HIV positive gay men by intentionally contracting it, then they will (potentially) be seen as martyrs rather than victims of a disease. They will also assert their individuality (bug chasing appears to be a relatively rare occurrence) and uniqueness. While they ultimately comply with a seemingly inevitable (to them) conclusion of their narrative—developing HIV and then AIDS—they recast their role within the story as an active tragic hero rather than a passive casualty.[4]

The bug chasing phenomenon offers a profound indictment of the way illness narratives treat diagnosis as an anchor. Such narratives set up an expectation that illness is inevitable, and the anxiety such an expectation engenders might be particularly unbearable for groups already especially vulnerable to contracting contagious diseases due to their lifestyle practices or genetic traits. The feeling that illness is inevitable but never quite realized might lead some to prefer contracting the disease rather than living in its constantly looming shadow. A narrative emphasis on the inevitability of disease can also create a dangerous impulse to find agency even in committing a form of suicide—signaling a feeling of powerlessness to control the narrative's outcome but a measure of agency to control one's response to (or acceptance of) it. Overall, bug chasing highlights the limitations of viewing

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[4] It's also worth noting that bug chasers may be complying with the demands of those who would like to see LGBTQ+ individuals disappear from society. Perhaps bug chasers seek to identify with homophobic aggressors by contracting HIV—thereby placing themselves beyond the reach of their vilification. Some bug chasers may believe that contracting HIV will make them more sympathetic to those who would otherwise hate them, allowing them to elicit their pity rather than their disgust.

diagnosis as the only narrative option for vulnerable populations; bug chasers don't seem to acknowledge other alternative futures as viable for themselves, and they therefore resign themselves to their ostensible fate. Additionally, bug chasers might feel that there is more they can do if they have been diagnosed than they can do as they wait around for a potential diagnosis. In a way, diagnosis empowers patients to take action, whereas waiting for a diagnosis leaves most frozen in uncertainty. Thus, one diagnostic problem that rhetoricians might be particularly well-suited to address includes collaborating with potential patients or those at-risk for developing diseases to forsee and plan for alternative futures that can be pursued with as much agency as bug chasing. Such an approach, about which more later, would need to both suggest an alternative to inevitable diagnosis and help potential patients to find ways of envisioning a future diagnosis as not necessarily destructive of their narrative.

Genetic Testing and Choosing Not to Know

While some bug chasers pursue HIV positive partners in order to gain certainty about their health status, another community offers us an alternative portrait of the way at-risk populations grapple with diagnostic uncertainty. In *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*, Alice Wexler combines a memoir about her mother's diagnosis with and death from Huntington's disease with the story of how her father and sister, Milton and Nancy Wexler, successfully led efforts to identify the genetic mutation responsible for the disease. Huntington's disease (HD) is an inherited disease caused by dying brain cells and resulting in dementia and an inability to move. A person with Huntington's will typically start to exhibit symptoms in her mid to late thirties, and at first she may have trouble walking steadily and concentrating. She will develop, at some point, shaking and restless limbs that resemble Parkinson's disease symptoms, and she will slowly lose the ability to walk,

speak, and even swallow. The disease is incurable and tragic, a disease that robs sufferers of *both* their physical and mental capacities early on in life. So cruel is the disease that, according to Samuel Frank in "Treatment of Huntington's Disease," "25% of patients attempt suicide, which is a cause of death in 8–9% of patients" (154). Before the detection of the gene that causes HD, anxiety about contracting the fatal disease was typically coupled with guilt when a person who had not known their risk had children who were also suddenly at risk. A person whose parent has HD has a fifty percent chance of inheriting the disease, a terrifying statistic when the child will have to watch her parent die a slow and painful death while wondering whether she, too, or perhaps one of her siblings, will endure a similar fate. Such was the case for Wexler, who watched her mother slowly lose her vibrant personality, her will to live (she attempted suicide several years before she died), her ability to move, her ability to do her favorite things (smoke and write letters), and finally her mental capacities that had once been so sharp. As she did so, she worried extensively that either she or her sister would also inherit the disease, and both sisters struggled to decide whether or not they should have children when they were not sure if they had inherited the HD gene. Her memoir, thus, differs from other illness narratives because "it is really less about an illness than about the possibility of illness, less about the medical dilemma of living with disease than about the existential dilemma of living at risk" (xxii). Thus, in contrast to Jolie's assumption that women should want to know their genetic risk, Wexler presents an alternative picture—one that is ultimately more comfortable with uncertainty.[5]

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[5] Of course, there are important differences between bug chasing subculture and at-risk populations who choose not to undergo genetic testing. Significantly, one can voluntarily expose oneself to HIV, whereas HD is an inherited disease for which there is no treatment or cure. In considering these two sets of potential patients alongside each other, I hope to highlight productive tensions and parallels within their experiences that might help us envision an alternative approach to communication in uncertain medical contexts.

The Wexler family's involvement in the identification of the HD gene began in 1968 when Milton Wexler started the Hereditary Disease Foundation (HDF), which is dedicated to conducting research and raising awareness for hereditary diseases, especially HD. According to Douglas Martin, Wexler "formed the [HDF] to gather young scientists from different disciplines and institutions for freewheeling talks about Huntington's as well as to sponsor research" (n.p.). The creativity his foundation inspired, and Wexler's ability to draw on his background in psychoanalysis, was both inspiring and controversial to the scientists he enlisted: "His strategy was one he developed for group therapy among creative people: no-holds-barred discussion toward a common purpose in a nonthreatening climate" (n.p.). Wexler always maintained that his activism was the result of his wife's diagnosis with HD, her brothers' and fathers' deaths from the disease, and the risk that one of his daughters would develop the disease. Calling his activism "terribly selfish," he admits that he was "scared to death one of my daughters would get it, too" (n.p.). One of the daughters, in fact, developed her father's passion for studying the disease. Although Nancy Wexler "was pursuing a PhD in clinical psychology at the time of her mother's diagnosis," according to Kristin Darwin, she soon shifted her focus to genetics and "devoted her life to the study of HD" (1). Darwin summarizes Wexler's own contributions thusly: "In 1979, Wexler and her colleagues began a research project in Venezuela to search for the HD gene. They surmised that finding the gene was the most direct route to the development of treatments, even cures! They developed a pedigree of over 18,000 individuals and collected more than 4,000 blood samples from the largest extended family with HD ever to have been discovered. Their data led to the identification of the gene responsible for HD" (1). Nancy's team published their findings in a paper, "A Polymorphic DNA Marker Genetically Linked to Huntington's Disease," which was published in the November 1983 issue of *Nature*. Subsequent news

coverage in *The New York Times*, *The Wall Street Journal*, *Time Magazine*, and other major presses praised Nancy as a heroine, and "[e]veryone lauded the astonishingly rapid localization of the Huntington's gene to the short arm of chromosome 4 as the first significant breakthrough in the entire history of Huntington's disease" (Wexler 219). Nancy, then, extended the research efforts her father had initiated and ultimately solved the HD mystery that had haunted their family—and thousands more— for decades. However, her team's discovery, while exhilarating, instigated a painful dilemma for her family to consider.

The discovery of the genetic mutation responsible for HD meant that Nancy and her sister would now be able to receive reliable test results regarding their risk for contracting the disease. Although Nancy had once been thrilled at the idea of predictive testing for HD, particularly as it might enable would-be parents to decide whether or not to have children, the newfound ability to determine whether *she* possessed the genetic mutation responsible for HD gave her pause. Alice Wexler quotes "a widow and mother of several individuals who had died of Huntington's" who she spoke with at the time as wondering, "Do you really want to know that in 10 to 15 years, you too will be stricken by the disease, or would you rather live in uncertainty?" (221). Such was the dilemma now facing the Wexlers, who had pioneered research for the predictive testing they now resisted. Milton Wexler was particularly opposed to his daughters undergoing the test, which led to a nasty blowup in a conversation with his daughters as they held a family meeting to consider whether or not to move forward with it. For a time, the father and daughters did not communicate as a result of their conflicting feelings about the test. As he explained in a 1986 interview with Diane Sawyer, which was later transcribed in Alice Wexler's memoir: "What I have now is joyousness. If I knew they [Nancy and I] were free of the disease, I'd feel ecstasy. It's not that great a gain. But there's an immense difference between joy and discovering one of them carried the gene. It's not worth

the gamble" (233). Nancy, for her part, also acknowledged her sudden shift in perspective—from a scientific to a more disconcerting personal uncertainty. "I've always believed in knowledge for its own sake. And it is ironic that after working for precisely that, I'm now finding it much more complex than I ever thought it would be" (233). Diane followed up by asking, "Did you think you'd take the test when the linkage was discovered?" And Nancy replied, "Absolutely. Yes. I never doubted it. And now I'm not sure" (234). Alice and Nancy finally resolved not to undergo testing, choosing instead to live with uncertainty. "The decision not to take the test—at least for the moment," writes Alice, "meant learning once again to live at risk, with no thoughts now of a final release, no fantasies of freedom from the possibility of HD" (234). Thus, in exchange for an ending to their uncertain narrative of living at risk for HD, the Wexler sisters chose instead to live without closure.

The Wexler sisters were not alone in their decision. After the discovery of the HD gene in 1983, testing programs were opened in the U.S., Canada, England, and in other European countries. However, "relatively few people actually completed the test, despite the enthusiasm for a predictive test in the days before the marker was discovered and the euphoria of the discovery in 1983" (235). By 1990, only 1,400 people worldwide had been tested for the gene, in spite of mounting pressure from the media and medical experts, who advised that those at risk should get tested (235). Wexler mentions that doctors and counselors often "portray[ed] those who took the test as somehow stronger, braver, more optimistic, more 'normal' than those of us who chose not to know. But isn't it also possible that those who opt not to know are more able to live with uncertainty and ambiguity?" (235). When Alice Wexler questioned those who did take the test about their decision, many said they needed to "escape the oppressive uncertainty" of living at risk so they could resume their lives—even if a positive test result indicated that their lifespan would

be shortened (236). As one man who chose to be tested explained to her, "You think about it constantly . . . I wanted to set my mind at rest one way or another" (236). Wexler sums up her discussions with those she interviewed: "The issue of control loomed large. Knowledge one way or the other appeared to give a measure of control, or at least of choice, over how one lived one's life: at the very least, knowledge of one's future in relation to Huntington's seemed to increase the terrain on which one could knowledgeably make decisions" (236). However, many found that their uncertainty was only amplified post-testing, as they now lived in constant fear of the onset of symptoms or learned that they were not at risk but their siblings were. Acting because of their uncertainty, the Wexler sisters decided not to have children in order to avoid putting any future offspring at risk for HD.

Wexler's 1995 "Afterword" to her memoir and scientific-historical treatise revisits the imperative to undergo genetic testing because of some elusive benefits dangled in front of potential patients by doctors or the media. "[T]he number of people actually going through with testing has remained relatively low," she writes, "under 20% of adult people at risk," with more women electing to undergo testing than men (268). Speaking out against the "potential benefits" of testing, Wexler cites research that proves that those who undergo testing actually have a harder time planning for the future—particularly when they have considerable economic constraints that diminish their ability to secure financial decisions (271). She furthermore highlights that "these assertions of 'psychological benefits' enter a social and political world in which pressures for presymptomatic testing are growing while insurance coverage shrinks" (272). Such contradictions within the research surrounding predictive testing and its dubious benefits seem particularly significant given reports that "as many as a third of all medical geneticists (who are primarily physicians) believe, in general, that people should be informed of their genetic status even if they do not want to

know" (272-3). In response to the potential for physician coercion and a lack of cure for HD, Wexler ends her text by calling for "new metaphors to talk about a deeply existential choice" (275). Choosing not to be tested must be recognized as a viable and even courageous act, an assertion of how one wants to live, just as choosing to know one's genetic risk for HD must be understood as a complex choice that can never fully satisfy one's desire to know.

Wexler's account of the pain certainty engenders, its elusive qualities, and its contested benefits offers an important critique of Western medicine's assumption that we should want to know what our futures hold. The Wexler sisters—and the other 80 percent of people who chose not to undergo testing at the time of Alice's writing—assert the importance of living without a diagnosis and accepting a state of being that embraces uncertainty. It's important to note that this perspective seems particularly popular in terms of HD because it is incurable, so predictive testing could not result in a changed outcome or preventive measures. Unlike the bug chasers, who choose to contract HIV to open up their life story's possibilities once they have eliminated diagnostic uncertainty, people like the Wexlers, who choose not to know what their diagnostic futures hold, feel that their life stories might be more bearable if they don't know the ending. Similarly, while bug chasers seek agency by intentionally contracting the disease, those who choose not to undergo predictive testing assert their agency by resisting a medical model of disease that values certainty over quality of life, knowledge over happiness. In some ways, bug chasers' assertion of agency—the will to know regardless of the consequences—is more in keeping with such a model than the decision to not learn one's genetic disposition for disease. However, Wexler's account raises a significant question that rhetoricians are perhaps uniquely qualified to answer: instead of insisting that people undergo genetic testing, and vilifying those who choose not to, why can't we instead generate an alternative framework for dwelling with

uncertainty—not until more information is discovered, but because we want to live without knowledge that might do more harm than good?

An Alternative Approach to Deliberative Practice

In describing the importance of HD as an instigator of renewed debate surrounding what it means to live at risk, Wexler writes, "Huntington's disease may serve as a space where many discourses collide and therefore help make visible the hidden stakes in this contest for human survival and identity in which all of us are at risk" (xxv). Indeed, both bug chasing and choosing not to undergo predictive testing remind us of some such hidden stakes: namely, the human costs of technological advancements that claim to offer greater insight into our bodies and medical futures than ever before. With the possibility of learning more about our risk for disease comes new questions about whether we would actually like to know. Furthermore, physicians' ability to detect diseases but not necessarily cure them can leave many at-risk populations feeling hopeless, as they know they are at risk for diseases that cannot be fully managed by the doctors who diagnose them. While predictive tests and treatment methods are of course crucial medical developments, they cannot assuage the anxieties that surround the possibility of illness and a future life story tinged with pain, disability, or disease. Even when doctors can generally answer questions of probability and causation, they cannot as simply answer questions about when we will be affected or how we can live with the knowledge of future disease. The accounts by bug chasers and the Wexler family highlight the importance of alternative frameworks for engaging with patients at risk for diseases so that they can learn to live with uncertainty and so that uncertainty can be recognized as an integral part of deliberation.

The purposes of my analysis thus far have been twofold: first, I want to highlight that diagnosis is only part of the story. While previous chapters have emphasized the diagnostic encounter as a networked exchange, I want to contextualize this analysis by considering how potential or future diagnoses get framed within narratives. Some bug chasers pursue a particular narrative ending—and diagnosis—because they would rather know their status than live with uncertainty. On the other hand, the Wexlers remind us that some would rather live their lives without a diagnosis—even if one is available. As these two groups challenge assumptions that diagnostic certainty is always a good thing and call on us to reexamine diagnostic practices surrounding certainty, I want to consider what rhetoric might offer to those who seek to better equip patients to dwell with the uncertainty that diagnosis entails. How might physicians work with patients to reframe living at risk in ways that both parties can better navigate? Additionally, how might their collaboration shift patients away from a view of doctors as gods and towards a model that values deliberative assemblages wherein doctors merely play a role and contribute one type of expertise?

In *Deliberative Acts: Democracy, Rhetoric, and Rights*, Lyon offers a framework for reimagining deliberative rhetorics in ways that account for difference and uncertainty. She begins by distinguishing her framework from the Aristotelian model of persuasion and the Burkean model of identification. For Lyon, there are three key problems with Aristotle's persuasion-focused deliberation model, in particular. First, as she writes, "persuasion [via Aristotle] presumes a powerful speaker (even a demigod) and a docile audience, not a relationship between equal interlocutors" (33). Aristotle's failure to account for a diverse public and disparate set of citizens means that they are a collective not intended to actually challenge or engage with a speaker's ideas. As Lyon puts it, "Aristotle's audience may make judgments, but they do not make counterarguments"—thus, their decisions are always

already constrained by the one in power (33). Second, Aristotle's model of persuasion is "driven to hopeful, future outcomes, which may not be the true purpose of the persuasion" (33). Lyon conceives of Aristotle's rhetoric as "a calculation of the means to an end" that has endowed us with a deliberative rhetorics tradition that "is outcome-based" rather than relationship and process based (36-7). Such an approach overly emphasizes the success or failure of the persuasive act to the neglect of other moments in the deliberative process. Finally, Aristotle's deliberative rhetorics "presumes a common core of interests, knowledges, and spaces" (33). By failing to account for the reality of diverse perspectives, Aristotle again doubts that his audience will engage in challenging agonistic inquiry, a duty he reserves for the speaker.

Beyond her rejection of Aristotle's outcome-driven model, Lyon also levies critiques at Burke's identification model, which she calls a sort of "magical thinking" that emphasizes "my [the speaker's] feeling about your similarity" (59). As she explains, "Our identification is all my pretense, cloaking co-optation and narcissism as it ignores differences" (59). One key issue with Burke's model, for Lyon, is that it emphasizes the individual over the collective in deliberative contexts. Identification also "distorts the difficulty of difference" while it emphasizes the speaker's ability to find and mobilize perceived similarities to move an audience towards their preferred outcome (59). While Lyon acknowledges the usefulness of identification in some contexts, "it is a deeply troubled term in deliberative situations" because "in privileging sameness and bonding, identification is imbued with power's innate normativity, and too often, as a[n] abstraction, it depoliticizes the most political and contingent acts of deliberation—the many becoming action" (60). Although it does add an emphasis on human relationship to its model, by failing to adequately account for the challenges of deliberative engagement, identification, too, falls short of the mark. Ultimately,

for Lyon, both Aristotle's and Burke's models fail to account for deliberation across specialization, culture, and difference.

Her generation of an alternative framework for deliberative rhetorics has two key components: an emphasis on non-Western (and particularly Chinese) approaches to deliberation and an adoption of Hannah Arendt's concept of "inter-est" as a new mobilizing principle. First, Lyon looks to classical Chinese deliberators and finds that they "eschew persuasion and argumentation as dangerous and inappropriate to human relationships" (38). Rather than persuasion or argumentation, classical Chinese texts reveal that remonstration is the preferred means of deliberating about future action. As she explains, "The communicative act is an opening of the undecided and uncontrolled future to consideration by interlocutors" rather than an act of co-optation by an agentive speaker (39). Lyon pays particular attention to the root meaning of persuade and remonstrate, highlighting the conceptual differences between the two words. In contrast to persuade, "*Monstrare* . . . emphasizes the act of showing or demonstrating," which involves an audience who must be engaged in the demonstration and interpretation of such an act (39-41). Lyon's breakdown of the differences between persuasion and remonstration are worth quoting at length as they distinguish a teleological from a relational model for deliberation:

> 'Remonstrate' is a process verb, lacking a *telos*. 'Persuade' is a terminus verb. If I say, 'I persuaded him that . . .,' there has been an end. The act of persuasion rarely occurs in the present tense, as an ongoing process . . . Almost always, when one speaks of persuading, there has been a change in him, and the act of persuading is ended. In fact, if we think of this in temporal terms, the future and the past are the realms of persuasion: 'I will persuade you' or 'I persuaded you.' This is all less true of 'remonstrate,' which even lacks the

grammatical object, a person to be moved. If I say, 'I will remonstrate that . . . ,' it is less clear that there has been an end, or what would constitute an end, or who would judge an end. The remonstration simply stops . . . In remonstrating, one can run out of time, energy, or materials, but otherwise one can continue the performance, always in the present. In persuading, one has a temporal progression, a narrative from a strategic beginning to an end marked by a change in the audience . . . The persuader may do most of the action, but the end is in changing an audience. With remonstration, the effect is less clear and unnecessary for judging the speech act: the remonstrator will do all the identified action. The end is when the demonstration finishes, rather than when an audience changes, jointly decides, or enacts an event. Although an audience is implied in remonstration, there is no defined manipulation. The remonstrator simply shows something. Those who observe the performance are free to interpret it, heed it, repeat it, ignore it, or refute it. (40)

Remonstration shifts us away from a Western value of action and certainty and towards a messier project of ongoing conversation about a particular issue. By calling on a classical Chinese framework, Lyon shifts deliberation away from an outcome-based process and towards rhetorical moves that "keep a community engaged in ongoing communication" (42). If Western deliberative rhetorics fears a lack of outcome, Chinese remonstration might be said to fear silence—an end to the perpetual conversation. In sum, Lyon writes: "In privileging the continuance of relationship over an outcome-based model of persuasion and the movement of interlocutors to consensus, a remonstrative model of deliberation considers the possibility of proceeding without end, proceeding to exhaustion or engagement, without

emphasizing the closure of a singular, future position" (43). Thus, remonstration remains bound in the present struggle rather than looking ahead to future decisions, and it emphasizes ongoing communication rather than decisive closure.

To supplement the concept of remonstration and build on its relational qualities, Lyon incorporates Arendt's framework of inter-est. For Arendt, inter-est refers to: "the overlapping concerns that initiate citizens' unique relations and separations" and the process of binding diverse people together within a common struggle (56). "From its start," Lyon writes, "the question of inter-est considers 'what we should do *together*'" (56; emphasis original). Rather than emphasizing an end to deliberation as the ultimate aim of discourse, Arendt instead focuses on the moment of recognition, the coming together of deliberators to work towards a common goal. Lyon reads Arendt as arguing that:

> inter-est designates the shared actions and words that make collaboration possible, the finding of what is common or cosmopolitan, and the matters that make remonstration effective or that allow deliberation to begin . . . inter-est arises and asks, 'What binds you to others?' More than something of interest or concern, inter-est implies the multiple ties among people which prompt recognition and the complex openness of shared action. (56-7)

Arendt's alternative rhetorical frame for deliberation acknowledges the impossibility of humans determining the ends of their discourse and moves deliberative rhetorics away from an outcome driven approach out of necessity. Lyon explains that for Arendt, "Agents cannot know the end of their actions, a scary predicament for human affairs . . . deliberation cannot be imagined in ends, for there are not ends to human acts" (58-9). What Arendt and Lyon are after is prior to identification or deliberation as it involves the discovery of "what binds us together," since deliberation must hinge on "the significance of other people to fashioning

who I am and who you are: that is, who we are in apposition, for who we are in apposition forms what we can do together" (57). Far from success hinging on "individual views negotiated," successful deliberation would be "an enactment of inter-est in an in-between, a shared agency arising in the present moment of engagement" (57). Thus a communal positioning, rather than pushing an agenda in pursuit of a future action, would govern the process of deliberation.

Taken together, remonstration and inter-est shift deliberation away from an individualistic, outcome-driven model of persuasion or identification and towards a communal, relationship-focused process of ongoing dialogue. While Lyon does not deny the eventual outcome of such deliberative work, the outcome is not inevitable within her model, as other possibilities can emerge and outcomes can shift and change over time. Remonstration is always subject to revision, and the decisions made through its process are constantly in flux. She also resists making the outcome the sole moment of importance within the exchange, focusing instead on the fusing of perspectives and interchange of ideas that makes deliberation possible at all. In what follows, I will briefly trace some ways in which Lyon's model might enhance diagnostic deliberation practices for patients at risk.

Deliberative Rhetoric and Diagnosis

What, one might wonder, does all of this talk of remonstration and inter-est mean for diagnostic deliberation practices? Lyon's approach to deliberation fits nicely with problems of power and difference that haunt interactions between patients and their assemblages (doctors, nurses, insurance companies, family members and friends, medications, etc.). Approaches to diagnostic deliberation that attempt to mask issues of power cannot adequately account for the way doctors (to recall Chapter 2) or politicians (to

recall Chapter 3) might co-opt networks for their own purposes rather than negotiating with the rest of the network for the good of the patient. Lyon's framework also gels nicely with diagnostic deliberations such as the ones described by bug chasers and the Wexlers because there isn't yet a problem to respond to; therefore, the network can focus on reshaping relationships and building trust amongst actants in order to prepare for a potential future crisis. Lyon's approach to deliberation may be less useful in climate change networks, for example, where perpetual action and decision-making can be enriched—but not altogether replaced—by the kind of ethical work she wants to encourage. However, her shifted emphasis to relationship building provokes some ideas for how pre-diagnostic deliberation might happen differently for patients at risk.

What bug chasers and the Wexlers are implicitly calling for is an alternative way of approaching uncertainty in diagnostic contexts—the same thing, in fact, that doctors are calling for in many cases. While previous chapters focused on ANT have stressed the importance of networked responses to the problems both doctors and (potential) patients identify, I want to make a few suggestions myself given Lyon's alternative approach. First, Lyon's model reminds us that Western medical deliberation must shift away from its overemphasis on outcome-based measures, which are not always the best way to respond to individual health crises. Particularly when the crises are hypothetical or potential, diagnostic actants might learn to take a step back and engage in dialogue about the patient's risk. As Gawande and Sanders might remind us, while doctors are trained to act quickly and decisively in highly uncertain situations, they are generally less adept at listening and advising patients on how they might cope with their risk for disease. Such patients may not always require a decision as much as compassionate care or conversation about their health. For example, Rita Charon's narrative therapy practice provides an important model of holistic

care that does not distinguish between emotional, physical, and diagnostic support. She even maintains that patient care is enhanced over the long term because of her ability to acknowledge a patient's uncertainty and ongoing health concerns as important aspects of providing care (67). What Charon's practice values is not the outcome of a particular visit, per se, but the ongoing wellbeing of the patient; this approach necessarily involves taking a long view of a person's diachronic narrative of health. The physician, rather than intervening in a momentary emergency or solving an aberrant mystery, engages with the patient's network on a regular basis, thereby focusing less on an immediate outcome and more on long-term care.

Lyon also shifts towards a deliberative practice that emphasizes relationship over expertise. Lyon's conception of relationship differs from Burkean identification by fusing an acceptance of difference with an openness to change. It also, significantly, reserves the power to decide with the audience or listener (in contrast to Western theories of persuasion where the rhetor persuades others to act as she wishes). Rhetorical engagements within medicine hinge on expertise—while the doctor may possess specialized knowledge unavailable to the patient, the patient knows her body's history. But as I have argued in previous chapters, pitting expertise against expertise results in adversarial relationships between stakeholders who should be working together and combining their areas of expertise to confront the problem at hand. Doctors might enhance expertise negotiations by learning when to make recommendations based on their expertise and when to defer to patients' wishes. Such an approach seems particularly apt in cases of genetic testing, where doctors may possess knowledge about a patient's risk that the patient does not want to know. If patients are aware of the doctor's recommendation and choose not to learn test results that indicate their risk for an incurable disease, can an acceptance of the patient's decision be considered an act of

care? And what of patients who know that an undesirable result would be more than they can reasonably handle? Relationships within diagnostic networks built on trust become crucial in such conversations, as patients will be more likely to take the advice of a doctor who has taken the time to listen to their feelings about their risk, make their emotional and psychological care a priority, and provide them with the answers they need. On the other hand, doctors who know that patients have important reasons for not taking their advice— and that such advice has been thoughtfully considered—might be less likely to pressure them to pursue unwanted procedures or testing.

Lyon suggests, though, that relationships are not enough—we must also ask challenging questions about what we have in common. She shifts deliberative practice away from an emphasis on the outcome and towards a closer examination of pre-deliberative negotiation. Rather than focusing on the moment of decisive action, she postulates that a more important event occurs when the many calibrate their needs and perspectives, thereby deciding to engage in deliberation together. Such a delicate practice involves finding common ground, which Lyon would again be careful to distinguish from the sort of identification project Burke pursues. Finding common ground cannot simply be about encouraging another person to share our point of view; it must involves asking challenging questions about what we have in common that might best enable us to work together. What mutual needs or concerns do we share, and how might these commonalities help us to act together? How might our differences enrich our deliberation and sharpen our problem-solving abilities? To apply such questions to diagnostic deliberation would necessarily involve dialogue between doctors and patients about their common ground: uncertainty. Both doctors and patients must learn to act in the face of uncertainty, and this can serve as an important starting point for conversations about mutual concerns and shared values.

Furthermore, because both doctors and patients live with the knowledge that they are temporarily able-bodied, vulnerability might also function as common ground where doctors and patients can negotiate what it means to live at risk or in diagnostic limbo. In both cases, rather than viewing uncertainty as a necessary evil of medicine, an embarrassment to be concealed through classification systems and emblems like white coats, doctors might harness uncertainty as a way of relating to patients for whom they do not always have answers.

Perhaps the most important shift that must occur if diagnostic deliberation is to become more encompassing of those who live at risk will be a relinquishing of the idea that diagnosis is medicine's *telos*. While successful diagnosis is a crucial aspect of healthcare, we would do well to reexamine what a fixation on the identification of disease can mean to patients for whom diagnoses are unavailable or unbearable. When diagnosis is medicine's *telos*, those without a diagnosis may feel hopeless and outside of medicine's reach. The Wexlers and bug chasers described previously demand that we focus on other values within medicine that will broaden the scope of what it means to provide care. Diagnosis is a means to an end—providing effective and ethical care—rather than a good in itself. Rather than celebrating diagnosis for certainty's sake, diagnostic stakeholders should strive to understand the particularities of patients who choose or are forced to live without an understanding of their body's status. This will likely entail medical training that emphasizes flexibility in responding to potential or future diagnoses. When doctors presume that patients will want to know if they carry a mutated gene, for instance, they falsely assume that this situation requires the same response as an instance where a patient has just presented with symptoms for a serious disease. However, diagnosis cannot always be the rhetorical response within medicine, and we need new ways to articulate other aspects of care that can occur instead, such as counseling and instruction. Doctors must also do more than test patients for HIV

and other STDs; when they fail to engage at-risk gay men, for example, in conversations about prevention measures and alternative futures free from disease, they may unknowingly be reiterating expectations that living at-risk means that contracting disease is inevitable. In both cases, diagnoses should open up dialogue and serve as starting points in a person's ongoing narrative of care rather than the penultimate moment in medicine.

An Exemplary Lesson

Before I conclude this chapter, I want to briefly return to Sanders' *Diagnosis* column to discuss a case that illustrates the dangers of viewing diagnosis as medicine's *telos*. As the narrative demonstrates, when the identification of disease becomes medicine's focus, rather than providing long-term care based on the patient's wishes, the stakes are quite high: patients' lives may even be at risk. This is certainly the case in "Why Was This 3-Year-Old So Irritable, and What Was Wrong With Her Eye?," wherein a mother notices that her child has suddenly started to misbehave and develop red lesions around her eyes. She asks her husband's sister Amber Bard, a third-year medical student who is in town to visit her niece, to look into the source of the problem. Her sister-in-law, though nervous due to her lack of experience, uses VisualDx to check the symptoms. The program is "one of a dozen or so programs known as decision-support software, designed to help doctors make a diagnosis," and Bard chooses this particular program because of its focus on skin-related problems (n.p.). She sorts through several possibilities, including sties and pink eye, paying special attention to the images as she tries to discover her niece's condition. Finally, though the images of herpes keratitis do not resemble her niece's red lesions, the potential for the disease to result in blindness leads her to gently suggest to her sister-in-law that her daughter might have herpes (n.p.). The mother admits that she had had a cold sore weeks earlier, and that a

bedtime kiss near her daughter's eye might have resulted in an infection. Bard consults with her colleagues at work, asking them about the potential for herpes to be transmitted during a kiss—they all find it highly unlikely (n.p.). Further, when her sister-in-law takes the child to the doctor, "[She] listened carefully as the mother described the girl's eye and her recent behavior. She asked if they could be linked. Unlikely, the doctor told her. Then she examined the child. The eye itself looked fine, the doctor said, and her vision wasn't affected . . . There was no need for any testing or treatment at this point, she said" (n.p.). This should have been good news: her daughter's eye would be fine, and they wouldn't even need to test her to see what was wrong. The symptoms would resolve on their own. But the mother refused to be reassured by the doctor's lack of concern, reluctantly asking about the possibility of herpes. Sanders explains, "That also seemed unlikely, the doctor replied. The mother asked if she could test the girl anyway. Bard had been so insistent that the child be tested that the mother was determined to push for it if she had to. But the doctor readily agreed to the test and quickly swabbed the center of each sore to send for a culture" (n.p.). Thus, with Bard resisting the advice of her colleagues and the mother rejecting the doctor's consolation, both women waited to hear the results of the test.

Despite the doctor's reassurances, the little girl tested positive for herpes infection around her eye, meaning that early intervention would likely save her vision. Although future recurrences that would require treatment were likely, her eyes were saved because of the persistence of her aunt and mother. While the doctor and colleagues in the story are wrong, they are by no means villains, as part of doing their job effectively entails using probability to determine the most likely causes of diseases. They have been indoctrinated within a healthcare system that values finding an answer—and moving on quickly when a patient's symptoms seem negligible. After all, there are always more patients in line who may be facing

much more life-threatening conditions. However, the narrative highlights the limitations of this probabilistic and outcome-based method of deliberation. In this case, as in many others, Bard is actually better able to anticipate an unlikely cause of her niece's condition because of her lack of immersion in the deliberative process of medicine; her lack of expertise makes her better able to see other possibilities beyond the few diagnoses (such as sties and pink eye) that might be more likely. In addition to her unique perspective as someone with access to diagnostic aids, but without enough experience to dismiss her niece's condition, her affection for her niece leads her to feel that even an unlikely disease should be treated as a serious threat given its potential to cause blindness. The mother's persistence in this story, also motivated by her affection for the child, similarly demonstrates the significance of not only looking beyond the purview of traditional deliberative criteria—diagnostic stakeholders must also advocate for patients when the network fails to do so. Thus, in this case, non-experts offered vital contributions to the deliberation, and in doing so, they not only solved the case, they saved the patient.

Such an approach exemplifies Lyon's approach to deliberation because it highlights the need for a process that can escape the confines of the outcome-driven, probabilistic approach to diagnosis. In this case, as in many others, the diagnosis is only possible when an outsider's perspective identifies an unlikely, but serious, potential problem that must be considered. Sanders' narratives commonly focus on the role an inexperienced healthcare provider, such as a medical student or intern, plays in identifying a diagnosis or crucial detail that a more seasoned doctor misses. They have not yet been fully trained in how to see, and they are therefore better able to consider uncommon diagnoses, pay attention to gut feelings, and notice unusual details. This offers a powerful validation of Lyon's claim that identification erases the importance of conflict as a vital component of problem-solving;

when everyone learns to see the same things in the same way, alternative solutions and approaches will be overlooked. The liminal space Bard occupies as a novice medical student also exemplifies the importance of this difference within diagnostic contexts—rather than identifying with her colleagues and ignoring her own hunches to fit her perspective to theirs, she insists that the potential risks of an untreated herpes infection are too serious to ignore. As Lyon indicates, this productive tension actually enhances the network's efficacy and benefits the patient.

One unresolved problem with the narrative involves the proper use of technology as an actant within diagnostic deliberation. Interestingly, even the software Bard uses seems to disprove her theory that herpes is to blame, as the images don't resemble her niece's condition. Her shame at even broaching the subject with her sister-in-law almost prevents her from bringing it up at all. On the other hand, she might never have learned about the potential diagnosis—and its significant risks—if not for the diagnostic program. Research indicates that other problems, such as an unwillingness to use such programs, have presented additional challenges in terms of inviting technologies and non-human actants into deliberative processes. An unwillingness to adopt such programs cannot be attributed to any inadequacy on the technology's part: in addition to its helpfulness in this case, "a study published in 2011, and conducted at U.C.L.A-Harbor Medical Center and University of Rochester Strong Memorial Hospital, showed that physicians using VisualDx were four times more likely to suggest the correct diagnosis for patients admitted to the hospital for serious infections that those who didn't use it. Without VisualDx, admitting physicians made diagnostic errors 28 percent of the time" (n.p.). According to Sanders, "Despite such evidence of the effectiveness of diagnostic-support software, studies show that doctors rarely use" (n.p.). Such data makes one wonder whether the little girl would have been properly

diagnosed at all if Bard had been a more seasoned physician, one who doubted the usefulness of such a program in comparison to her hands-on experience. In this case, an acknowledgment of uncertainty, and a willingness to look beyond oneself to multiple actants with their own forms of expertise, ultimately resulted in the best possible care for the patient. No actant offered the correct answer, and yet the deliberative process yielded a favorable result because Bard insisted that the child be tested anyway. In this case, Bard decided to test the technological actant's contribution, but the situation could have easily turned out quite differently had she relied on her own expertise—or that of her medical network. While Lyon's model offers an important alternative to outcome-based, identification models of diagnostic deliberation, future research should seek to articulate better methods for diagnostic networks to respond to technological contributions. I will further explore such a problem in Chapter 5, where I consider the problem of expertise in diagnostic contexts.

On the Threshold

House episodes almost always end with a diagnosis. Within the last few minutes of each episode, Dr. House victoriously identifies the disease, and the patient goes home still puzzling over the strange man who cured them. But diagnosis can only be the end of the story for the doctor who solves the case. If the cameras continued to roll once the patient left Dr. House's care, a new story would emerge, one in with the diagnosis was merely the beginning of a series of treatments, a life lived in illness' shadow, a slow decline towards death, or of a future haunted by uncertainty. Diagnosis irrevocably alters a person's life story, but it never ends there. What doctors and patients and other actants must learn to do is reconcile their alternative feelings about diagnosis' role in their ongoing narratives. Doctors must learn to see diagnosis not just as a medical victory but as a new beginning for patients

—and generally not a positive one. They must guide patients through the new chapter in their stories, connecting them with resources and support systems that can supplement their care. They must demonstrate an openness to hearing how the diagnosis they revealed will affect the patient's life, and they must answer questions about how the patient can cope. And, perhaps most of all, they must empathize with the patient whose life has been changed by the news they delivered.

Furthermore, doctors must adopt strategies for advising and empathizing with patients who choose not to learn their risk for disease or for whom diagnoses are not available. Doctors must understand that diagnoses cannot be taken back once they have been revealed, and they must respect the wishes of people like the Wexler sisters, who make informed decisions not to learn their status. Such a choice represents not only a decision to preserve one's emotional wellbeing, it can also encompass an insistence on protecting one's narrative and regulating the way it unfolds over time. While we cannot always control what happens to our bodies, patients should have some say in whether they actually want to learn of their risk for disease in situations where the news may cause more pain than good.[6] Such negotiations must govern conversations for those whose lifestyle choices may put them at risk for diseases, too. Although patients may conceal bug chasing activities from doctors, doctors might respond to the phenomenon by warning patients of the dangers of bug chasing, educating them about prevention measures (such as medications like PrEP), and monitoring patients who may be at risk for engaging in such intentional acts. While more research must be done so that healthcare providers might more successfully intervene and perhaps stop

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[6] I want to be careful here to distinguish my advocacy for patients to be able to choose whether or not they want to learn about their genetic risk—and have their decision honored by healthcare providers—from advocating for doctors to withhold information from patients. Patients should be primed for such decisions by doctors, who can discuss risks and benefits with them based on their unique circumstances.

would-be bug chasers from pursuing a deadly disease, demystifying diagnosis and making it more concrete might aid prevention efforts. And finally, to more adequately care for patients like Hildebrandt, doctors must emphasize their ongoing relationship with patients post-diagnosis and foster dialogue to support those in remission as they negotiate fears about recurrence and cope with ongoing effects of disease. This will involve an attunement to what matters to patients, anticipation of their needs, and an openness to extend care beyond the crucial diagnostic moment and into the more crucial questions regarding what to do next.

In the end, diagnosis looks less like the neatly packaged *House* endings and more like the popular *Choose Your Own Adventure* stories. While of course doctors and patients cannot always control what happens in their narratives (much as they'd like to), they must deliberate together to respond or act decisively in response to plot twists. And, in other cases, they must develop relationships that will prepare them to act in the face of challenging, potential future decisions. What this chapter has hopefully illuminated is that response need not always hinge on decisive action, and that deliberation is comprised not just of such moments but of moments of collective thought and engagement. I would like to close this chapter, then, with one such pensive moment.

Sam Taylor Johnson's *Self Portrait in a Single Breasted Suit with Hare*[7] shows Johnson soon after her recovery from cancer. Because it was her second incidence of cancer, Johnson decided to have a mastectomy (hence the "single breasted" word play). In the photo, Johnson stands before a door, indicating her position on the threshold of illness. She holds a hare in her hand which represents a return to lust and humor now that she is in remission. Her black and white suit indicates her readiness to return to her regular life, but her tennis shoes

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[7] I am indebted to Diane Price-Herndl for sharing this photo and her insights about it with me.

indicate her lingering sense that she will always be running from something—perhaps from her illness. She stands on a checkered floor that resembles a chess board, poised uncertainly with one foot on the ground and one hovering in the air. And yet, despite all of the liminal, uncertain elements in the room, Johnson's face is determined as she presses down on the button that will snap the photo. She asserts her existence in the face of uncertainty about her illness, choosing to act anyway.

CHAPTER 5:

NETWORKED ETHOI:

DIAGNOSTIC ASSEMBLAGES AND PROBLEMS OF EXPERTISE

Beware of diagnoses that would reduce your generative powers . . . Break out of the circles; don't remain within psychoanalytic closure. Take a look around, then cut through! - Hélène Cixous

Trauma bleeds. Out of wounds and across boundaries. - Leslie Jamison

While previous chapters have argued that a networked approach to diagnosis is not only generative but necessary, questions of how best to respond to multiple ethoi remain unanswered. While I will trace a more complex definition of ethos later in the chapter, I will begin by focusing on traditional conceptions of ethos as an appeal to authority and/or expertise. In "The Presumptions of Expertise: The Role of Ethos in Risk Analysis," Carolyn R. Miller argues that this approach to ethos represents "a narrowing" of its original (Aristotelian) meaning, which emphasizes expertise ("the first of Aristotle's three constituents"), while neglecting "moral qualities (*arete*) and goodwill (*eunoia*)" (194). Furthermore, for Miller, such a definition actually distorts the first constituent by shifting it from "Aristotelian *phronesis*, a knowledge focused on prudent action in the social world, to *episteme*, a knowledge that is close to what we call expertise" (194). While Miller's critiques of the easy conflation of ethos with expertise productively complicate contemporary definitions of the ancient term, I focus on this traditional definition/distortion in the first part of this chapter because it saturates healthcare contexts. The extent to which ethos as expertise dominates in medical networks can be perhaps most easily identified via the "Trust me, I'm a doctor" cliché. As my subsequent analysis will demonstrate, feminist ecological approaches to ethos reincorporate a focus on deliberation, ethics, and care, thereby recalibrating Aristotle's three constituents for ethos and mobilizing them for advocacy and social justice projects.

Negotiations of ethos in healthcare settings remain a pressing problem both within my project and the broader field of medical rhetorics. Many writers—from concerned healthcare providers such as Lisa Sanders, to narrative medicine scholars like Rita Charon, to feminist therapists such as Laura S. Brown, to sociology scholars like Becky W. Thompson—have highlighted the inequitable power dynamics that emerge between doctors and patients in diagnostic interactions. Within a networked framework, though, wherein patients and doctors are parts of complex diagnostic networks and no single actant's ethos can be privileged within diagnostic interactions, a related but slightly different question arises: how can doctors, patients, and other actants negotiate the competing ethoi that emerge? Within diagnostic settings, ethoi proliferate; doctors possess specialized knowledge about administering and interpreting tests, nurses have specialized knowledge about patient care, patients have specialized knowledge about their bodies, and family members have specialized knowledge about the patient's history. Even objects reveal information about the patient's habits, secrets, and experiences—we might recall, for example, the cell phone from Chapter 2 that uncovered an unconscious patient's drug use. At the community or national level, politicians purportedly possess specialized knowledge about confronting crises and protecting citizens, while health experts and national organizations possess specialized knowledge about public health matters. However, as the networked approach to diagnosis in Chapter 2, public misdiagnosis in Chapter 3, and inadequate networked deliberation practices of Chapter 4 indicate, more analysis regarding the management of these multiple forms of expertise is warranted. Thus, in what follows, I will address methods for negotiating the multiple forms of ethoi that networked actants generate.

In *The Body Multiple: Ontology in Medical Practice*, Annmarie Mol wonders what happens when a patient and doctor rely on different forms of expertise that prevent them

from understanding the patient's condition. Mol's central thesis is that if bodies are multiple, then so are diseases, and she argues that their enactments within different settings result in not various presentations of the same disease but multiple presentations of multiple diseases. Her study of atherosclerosis in Hospital Z leads her to consider the atheroscleroses that emerge in various spaces: patient rooms, surgeries, and autopsies. An emphasis on multiplicity, though, ultimately leads Mol to the same impasse that networked diagnosis reaches: if ethoi can be collaborative, then they can also be competitive. She explains:

> A week later I spend another day with the same technician. A patient, let's call him Mr. Somers, lies on the examination table. Again cuffs are inflated and allowed to slowly deflate. Again the stethoscope is used to listen to the sound of turbulence in the arm arteries and the Doppler apparatus is used to listen to the velocity of the ankle flow. The technician writes down her numbers. She makes her calculations. There's the ankle/arm index. It's within the normal range. 'I can find nothing wrong. Nothing at all,' the technician says to the patient in a tone that's meant to reassure him. But it doesn't. 'That's very strange,' Mr. Somers replies, 'for I feel something. It hurts a lot when I walk.' The technician shrugs: 'Well, there's nothing wrong.' Mr. Somers insists: 'Oh, but that's strange. Are you sure? I admit, they're only my feelings, but then they are *my* feelings.' His tone is one of disbelief. Disappointment. The technician, in what is clearly meant to be her closing remark, sounds impatient. 'Well, you'd better discuss that with your doctor, then, what all you feel.'" (62)

In this case, the actant Mr. Somers possesses knowledge of his embodied experience and the pain he's experiencing, while the Doppler apparatus and stethoscope possess their own forms

of ethos—they are tools wielded to determine ankle and arm blood flow, respectively. The technician finds herself within the role of negotiator, as she must determine whether Mr. Somers' or the Doppler/stethoscope actants are to be granted greater authority to determine the patient's condition.

Mol responds to this problem by suggesting three possible ways in which competing ethoi can be made to cohere: through creating a hierarchy, "adding up," and calibrating ethoi. First, perhaps most obviously, actants tend to generate hierarchies amongst disparate forms of expertise, labeling some more objective or credible than others. She clarifies, "In order to achieve . . . coherence, a hierarchy between diverting measurements may be established. This is often done. In cases where two facts contradict each other, one may be accorded more weight than the other" (63). In Mr. Somers' case, for example, "a hierarchy with the lab on top" would enable the vascular surgeon to say, "No, Mr. Somers. I'm really sorry, there's nothing I can do for you. I don't doubt that you have a lot of pain, but I'm only good at unplugging vessels, and your vessels are in no need of unplugging" (63). Thus, by siding with the lab results and indicating the limits of his expertise, the doctor will shift the patient back to his general care practitioner (63). Without discounting the patient's embodied ethos, the doctor nonetheless grants the test results greater epistemic weight. Although Mr. Somers will likely receive other tests to try to locate the cause of his pain, the Doppler and stethoscope actants are granted the ultimate authority to reject a particular diagnosis.

While creating a hierarchy is a common method for resolving disputes amongst networked actants, other scenarios might find similar sets of actants in conflict—even seemingly infallible lab results. How, Mol wonders, might the expertise of competing actants at the same level of the hierarchy be negotiated? As a second approach to the addition method, Mol writes, "When different tests give different outcomes, it is not obligatory to

abandon one. It is also possible to understand the objects of two different techniques as indeed being different objects" (66). Rather than discarding test results that fail to align, Mol suggests the addition method, which can occur when "surgeons do not ask 'what is the matter?' but rather 'what to do?' Because when the vascular surgeons of hospital Z try to decide 'what to do,' they are not only interested in complaints and the results of pressure management. They draw in a lot more elements" (69). Shifting away from a diagnostic question—what is wrong?—to deliberative practice—what to do?—encompasses a shift in thinking away from classification and towards assemblage. When responding to the patient's atheroscleroses as a composite, "the patient can now be diagnosed as having two 'atheroscleroses,'" each requiring their own interventions (68). Rather than cancelling each other out, competing lab results can be added together to enable doctors to offer more complex and effective care based on the patient's unique presentations of disease. When tests are not assumed to have a "common object," "it takes tests as suggestions for action: one bad test outcome may be a reason to treat; two or three bad test outcomes give more reason to treat" (84). Thus, rather than discarding test results that fail to align, diagnostic networks may draw on the contributions of each actant and his/her/its expertise as they deliberate.

Finally, perhaps Mol's most rhetorical method for resolving diagnostic ethoi disputes is the calibration of test outcomes. She explains, "If test outcomes were listened to as if they were each speaking for themselves alone, they might get confined within different paradigms. The question whether different tests say the same thing or rather something different would not be answerable—indeed it could hardly be asked" (84). Tests that measure different objects, then, can be calibrated to see what they mutually indicate about a patient's health. For example, doctors and researchers might "tinker" with PSV ratios (which measure stenosis, or the narrowing of arteries) and lumen loss (which measures changes in the artery

width following a stent procedure) to find correlations: "It turned out that a PSV ratio of 2.5 proved a good cutoff point for differentiating between lesions of more and less than 50 percent lumen loss" (77). Thus, "the objects of angiography and duplex are coordinated into a single common one: the severity of some patients' stenosis" (77). By translating test results and correlating findings to determine what they might indicate together, ethoi might be calibrated by finding a relationship between actant contributions. Significantly, such a process must involve the presentation of a third actant who can mediate between the two or more disputants; for Mol, these often take the form of correlation studies. She discusses the role correlation studies play at length, since they serve as the means for translating test results into common measures:

> The possibility to negotiate between clinical notes, pressure measurement numbers, duplex graphs, and angiographic images only arises thanks to the correlation studies that actively make the comparable with one another. The threat of incommensurability is countered in practice by establishing common measures. Correlation studies allow for the possibility (never friction free) of *translations*. (84-5)

Mol's concept of calibration nicely aligns with Latour's ANT method of tracing actants, although she more fully explicates how actants within medical or diagnostic networks might negotiate their findings. Her emphasis on intermediaries who might correlate and translate test findings, seeking relationships between measures and mutual reinforcements, is particularly apt for an ANT approach to understanding diagnostic network negotiation.

Despite the usefulness of Mol's model of adding up and calibrating varying forms of expertise within diagnostic contexts, S. Scott Graham levies two major critiques at Mol in his book, *The Politics of Pain Medicine*. First, Graham cites Mol's failure to look at networked

interactions beyond the purview of the hospital to see how ethos gets negotiated as a major oversight. He writes, "Despite Mol's compelling analysis, the practices that stage disease ontologies do not exist in a vacuum. They are controlled, influenced, and regulated by broader calibrating practices that exceed the local site of clinical doings" (110). He argues that by neglecting the institutional actants that shape and restrict networked negotiations, Mol misses several major players in her analysis—such as the insurance industry, third-party payers, and the DEA. After all, he reiterates, "clinical practice is accommodated to the economic structures of the health-insurance industry," thus highlighting the ways in which such institutions plays in shaping networked interactions on the micro-level. In addition to his emphasis on actants Mol misses, he stresses the importance of considering context as an active contributor to hospital negotiations. For example, in discussing methods for treating patients with opioid addiction, he explains that "the climate of opiophobia is so pervasive that addressing the practical-translative stasis cannot happen within the clinic" (112). Thus, not only does Mol's analysis offer an incomplete picture of how diagnostic negotiations happen surrounding ethos (as they are both verified and controlled by institutions such as the FDA, the pharmaceutical industry, and medical boards), but her selection of a site within a hospital limits the interactions and presentations of atheroscleroses networks that she can witness.

Relatedly, Graham's second major critique of Mol is that she fails to consider the meta-level of networked calibration. In some ways, Mol doesn't go far enough in considering *how* not only diagnostic practices but ontologies get calibrated:

> Here we see calibration is a sort of meta-activity. In fact, it's so meta that in Mol's study it only gets a quick mention as something that happens in correlation studies. The details of these studies are beyond the scope of Mol's

analysis. As a rhetorician, it is precisely spaces like these studies that interest

me. The work of calibration is predicated on the metapractical discourse of

correlation. How do different diagnostic ontologies get calibrated? How are

the different forms of diagnostic practice realigned, reinterpreted,

rearticulated so that they may 'speak' to each other, so that translation may

occur? (87-8)

Graham finds, then, Mol's theory of calibration to be crucial, although her treatment of the

actual work of calibration is lacking. The shift, he explains, is from an emphasis on

"Ontological calibration" or "the 'what'" to a question of "how?" networks calibrate their

forms of expertise (88). As he notes, rhetoricians are particularly qualified to take up such

questions as they pertain to medical and diagnostic networks.

In response to Graham's suggestions that Mol better contend with the meta-level of

calibration, and that she attune herself to the contexts within which networked negotiation

occur, this chapter will apply Mol's approach to networked calibration while shifting towards

an emphasis on context and institutional levels of analysis. While Mol does not explicitly

refer to ethos, her analysis of the various ways in which expertise gets negotiated within

medical networks offer some generative starting points for reframing ethos. Thus, drawing on

Mol, this chapter will argue that a more dynamic approach to diagnosis must entail a more

complex conception of ethos. I will first review several challenges regarding ethos within

diagnostic networks which were raised, but not fully addressed, in previous chapters. I will

pay particular attention to doctor, patient, and other stakeholder perspectives. In addition to

considering how multiple ethoi might be juggled within diagnostic contexts, I want to

highlight the ways in which actants must also navigate their own multiple ethoi within such

interactions. Finally, in an attempt to fuse Mol's theories of networked ethos "adding up" and

calibration with Graham's cautions against dismissing global level concerns, I will suggest an alternative framework that ties together an ANT and feminist framework for networked ethoi. Drawing on feminist ecological approaches to ethoi, I will suggest that diagnostic networks adopt a model of ethoi that is multiple, dispersed, and fluid within diagnostic settings.

Ethos Generation in Networks

A networked conception of diagnostic ethoi raises important questions about how to navigate differences of expertise and decide whom to trust in crucial moments. While Mol's analysis remains clinical and detached in considering ethos negotiation, real life scenarios can be much more fraught. In a crisis scenario, with a patient's life on the line and time in short supply, should a mother's hunch, a doctor's training, or a test result be heeded? In Chapter 2, I explored alternative frameworks for diagnostic rhetorics apart from approaches that hinge on persuasion, interpretation, and identification. In analyzing Dr. Sanders' "Diagnosis" column, complex relationships between doctors and patients emerged that challenged traditional conceptions of the doctor as the ultimate authority and the patient as the passive text to be read. For example, in several cases, patients actually solved their own diagnostic mysteries or lied to the doctor in order to be taken seriously. However, other relationships also emerged between not only doctors and patients but family members, healthcare providers, technologies, tests, and other community members. Furthermore, diagnostic success in these narratives often resulted from collaborations between stakeholders. These collaborations involved, for example, a brother checking his unconscious sister's cell phone for clues ("Unresponsive"). In other cases, doctors collaborated with colleagues with different specializations or even with residents and interns to determine the cause of the patient's

condition. Thus, drawing on Latour's theory of Actor-Network Theory, I recast diagnoses as assemblages of human and non-human actants that sometimes work together and, at other times, work at cross-purposes. While such an approach allows for more dynamic doctor-patient relationships, it also extends the number of actants who must be considered when making a diagnosis. The narratives Sanders shares also highlight the need for a sufficiently intricate approach to diagnostic ethos.

Sanders' narratives vividly demonstrate the multiple types of ethoi that emerge in diagnostic networks. For example, in "What Caused this 15-Year-Old's Debilitating Headaches?" Sanders tells the story of a mother who advocates for her son's treatment by lying to the doctors. Although they tell her repeatedly that her son simply has migraines, a gut feeling tells her that something more serious is to blame. When she lies to the doctors and tells them that her son has a fever, they immediately order the CT scan she wanted and find the cause of her son's sudden illness. The mother's experience with her son's normal reactions to illness and her gut feeling enable her to push for a diagnosis that otherwise might have been missed. While the mother's attachment to her son informed her tenacity and ingenuity within the diagnostic network, in other cases, actants do not even need to know the patient to effectively intervene. In "Losing Consciousness," for instance, a gastroenterologist encounters a patient who cannot stop bleeding rectally. Recognizing the woman's risk of bleeding to death due to her blood's inability to clot, the doctor contacts a hematologist friend to ask for his input. He determines the patient's condition immediately, attributing it to a reaction to combined histamine and anti-depression medications. This narrative stresses the significance of cross-specialty collaboration, as no doctor can possibly recall all diseases and pearls of wisdom for each area of medicine at all times. In fact, Sanders reiterates the diagnostic vitality of "a phone and a friend" throughout her "Diagnosis"

narratives ("Losing Consciousness"). In other cases, expertise from an entirely different discipline—such as botany—can prove more useful than any medical specialty. In "Rough Patches," when a little boy breaks out with a mysterious rash that his doctors are unable to identify, a chance decision by his doctor to stop by the local greenhouse ends up revealing the cause of his patient's condition. When the doctor recites some of the plants growing in the boy's grandmother's garden, a greenhouse employee is able to attribute the rash to a pumpkin vine allergy. As all of these examples indicate, expertise within diagnostic settings can be as diverse as the myriad illnesses patients experience. While doctors are primarily tasked with treating disease, Sanders' narratives suggest that actual diagnoses can often be performed by other actants whose expertise resides in personal experience, a different medical specialization, or a different field of study altogether.

Beyond the multiple *kinds* of ethoi that diagnostic networks reveal, it is important to note that such ethoi also tend to emerge through collaboration rather than individual actions. In a sense, McIntyre's thesis in *Relational Agency, Networked Technology, and the Social Media Aftermath of the Boston Marathon Bombing* that agency is relational and dispersed applies to the view of ethoi that Sanders' narratives present. In particular, McIntyre's argument that agency is a shared power to act co-created through networked relationships is suggestive for an ANT approach to diagnostic ethoi. Such a definition fits especially well for collaborative ethoi that emerge when doctors deliberate together on diagnostic mysteries; when doctors collaborate to diagnose a patient—perhaps one doctor responding to a gut feeling, another recalling a pearl of wisdom, and another noticing an odd test result—their ethoi are communally actualized. In McIntyre's assessment, the Boston Marathon bombing mobilized a network of actants, including Twitter, hashtags, and Bostonians, to interact with the media, police, and victims, in order to help those affected by the bombing. She writes:

[F]ollowing the bombings, as many runners and other tourists were barred by law enforcement from retrieving their belongs and returning to their hotels, numerous Twitter users began to tweet offers for food and shelter using the aforementioned hashtag [#BostonHelp]. These acts of kindness are intentionally agentive acts enabled by a network of technologies (spaces like Twitter as well as the internet itself and the hardware necessary to connect), material goods (the food and shelter they offer), and the human kindness that underlies the offers. (17)

Thus, McIntyre finds that agency is *enabled* by the network, and that it emerges through interaction rather than in isolation. Similarly, I want to suggest that ethos can be seen as emerging in contexts of difference, disagreement, and negotiation, since Sanders' narratives highlight the inefficacy of a solitary expert solving problems in everyday diagnostic contexts.

For example, to return to her instructive set of narratives a final time, Sanders' October entry, "Why Was this Woman Suffering from Terrible, Unrelenting Pain" illustrates this interactional approach to ethos generation. In this narrative, a generally healthy 43-year old woman suddenly begins to experience debilitating abdominal pain that makes it impossible for her to eat or sleep. Although she works as a lawyer, she is rendered unable to work due to the pain, which keeps her in bed most days. All tests for the usual suspects, such as Crohn's disease or another gastrointestinal blockage, came back negative. According to Sanders, the one problem physicians did identify was gastroparesis, which occurs when food moves too slowly through the GI tract. It's a particularly challenging condition, Sanders explains, because: "It's a difficult problem to treat. Eating smaller, more frequent meals and taking medicine to stop the nausea caused by the backlog of undigested food can help. If it doesn't, patients are put on a liquid diet or given medicine to make the stomach work faster.

Some patients must receive their nutrients through a tube into the small intestines" (n.p.). Still, "The couple resigned themselves to the situation," apparently figuring that this unfortunate and painful situation would be their new normal (n.p.). Before the couple could fully accept their fate, however, a sudden phone call from an unexpected source brought some hope. Sanders recalls, "[O]ne afternoon, the patient got a call. It was Lois Abrams, a friend of her mother's whom she had known since childhood. Abrams explained that she had a friend who had a niece who had something that sounded like what the patient was experiencing" (n.p.). When the patient followed up with Abrams' friend's niece, she discovered that their symptoms were identical, and that a surgery to remove the compressed celiac artery and associated nerves had cured her entirely. The woman consults with the niece's surgeon, who proposes a simple test to see if she, too, suffers from MALS. "A specialist would inject a numbing medicine into her celiac ganglion," the doctor explained, "If it relieved the pain for a few weeks, there was an excellent chance that surgery would solve the problem. After the injection, she felt no pain for six weeks and regained most of her lost weight" (n.p.). Surgery followed, and the woman experienced a full recovery of her pain-free existence, thanks to the collaborative efforts of the networked actants.

This example highlights the ways in which networked actants mobilize the expertise of other actants. For example, the niece's personal experience with MALS led her to be a compelling source for the patient, who turned to an expert surgeon, who suggested a test to determine her condition (n.p.). Each source's ethos was only mobilized when another actant called it to action. Furthermore, each actant's ethos is actually constituted through its interactions with other actants, since the surgeon's expertise is reliant on the niece's recommendation, which leads the patient to seek him out. The test, too, only demonstrates its ethos when the doctor suggests its usage as a way to determine the patient's condition and

predict the likelihood of surgical success. As this narrative indicates, it is not enough to simply recognize ethos as a collaborative endeavor; instead, a framework for ethos generation must take into account its constitution through interaction and communal decision-making. Ethos, then, might be more productively conceived of as hinging on relational deliberation, meaning that we need an alternative framework for understanding how to intervene within such situations to better grasp the way diagnostic ethos gets created. In some ways, this approach to ethos exceeds Mol's conception of ethos by moving towards a more complex and meta-level approach to ethos constitution. A better approach to ethos generation, about which more later, will need to account for the extent to which ethos cannot always be isolated within a single actant but must be traced within interactions amongst actants.

Ethos, Networks, and Negotiation

Beyond the relational qualities of generating networked diagnostic ethoi, I want to also consider how such ethoi get *negotiated* in healthcare settings. Chapter 2's emphasis on expanding conceptions of diagnostic rhetorics beyond the doctor and patient and towards contributions of other stakeholders (such as family members and non-humans) culminated in Chapter 3's consideration of how ANT might better explain what happens when networked mistakes happen. In describing the public misdiagnosis of the so-called "Ebola nurse," Kaci Hickox, I drew attention to the roles played by unlikely actants whose actions had been masked by the public panic over Ebola. In particular, I analyzed the role played by deforestation in Africa, which placed animals capable of incubating and transmitting Ebola in closer contact with at-risk human populations. I then emphasized the contributions of African aid workers, who were the first responders to the crisis. Often working without the same precautions and resources of Western aid workers, who arrived later, this population

suffered both physically—many of them contracting Ebola themselves, emotionally—many faced stigmatization and even accusations that they were working for the government to infect Africans with the disease, and financially—since Ebola devastated African economies in a way that Western outsiders failed to grasp. Furthermore, these African aid workers often served as intermediaries between local populations and Western aid workers, who were mistrusted by such groups. Finally, I explored the contributions of conservative politicians, such as Governors Chris Christie and Paul LePage, who took unnecessary measures to quarantine Ebola aid workers against their will. In so doing, they hoped to demonstrate their effectiveness in responding to public health crises—although their actions defied the expert testimony of public health officials and healthcare providers.

Like Chapter 2, Chapter 3 opened up important questions about ethos, as the actants who ultimately misdiagnosed Hickox were politicians—not medical experts. In many ways, Chapter 3 tells a cautionary tale about what happens when networks ineffectively negotiate ethoi, discarding one form of expert testimony in favor of another rather than adding them up. For example, public health officials and politicians might have coordinated their efforts based on their differing forms of expertise, one on matters of health, and the other on matters of governing. They might have worked together to ensure that aid efforts were continually encouraged and supported while simultaneously protecting Western audiences from contracting the deadly disease. However, in the Trump era, part of the emerging conservative ethos involves a defiance of expert testimony in favor of fear mongering; this strategy is effective at generating citizen support, in some cases, but less effective at controlling contagious disease. In addition to violating Hickox's rights, by enforcing her quarantine and then requiring that she remain under house arrest (she refused), the

networked mistake resulted in unfounded public terror about Ebola transmission in the United States and a reduction of aid workers willing to serve in Africa.

Beyond the major problems of networked ethoi within the Hickox/Ebola narratives, the emphasis on the relationship between African and Western aid workers reflects a disconnect between local and global ethoi. Local aid workers, often from the villages affected by Ebola, possessed an ethos amongst their people based on their understanding of the culture and their familiarity with local customs. Rather than dismissing beliefs that Ebola was a government project designed to kill African people, they persuaded local citizens that the Western disease management techniques were designed to protect them. They also worked with villagers to reform cultural traditions of washing corpses of deceased victims, encouraging them to stop engaging in this tradition until the outbreak ended to prevent the continued spread of Ebola via contaminated water sources. Such efforts were so successful that Western aid workers set up training workshops for African aid workers where they taught them how to teach their fellow villagers about Ebola prevention and treatment. While this negotiation of ethoi worked well, African aid workers were subsequently abandoned by Western aid workers when the immediate threat of Ebola dwindled. As the narratives by Isaac Bayoh in *The Guardian's* "Ebola: Life on the Frontlines" series highlight, African aid workers and citizens have been left to pick up the pieces of the economic, interpersonal, and infrastructural devastation left in the wake of the Ebola epidemic. As he describes the post-Ebola rebuilding process, Bayoh points to the lack of resources and healthcare infrastructure, wondering "how ready is our health care system to fight another outbreak like this? Many things that need to be done are yet to be implemented" ("Ebola in Sierra Leone" n.p.). Thus, while aid workers from Africa and other countries, such as the United States, were able to calibrate their ethoi in the moment to respond to a crisis, ongoing coordination between

their groups failed. The insights of Bayoh and other aid workers he interviews reiterate the need for continuing calibration amongst public health networks to contain disease outbreak risks, research diseases and treatment methods, and educate the public about prevention measures.

A final ethos problem invoked by Chapter 3 involved the coordination between not just public health officials in varying countries, but environmental and animal experts. Ebola's status as a zoonotic disease (meaning it is transmitted to humans by animals) indicates the importance of incorporating scientific experts from a range of disciplines into conversations about outbreaks. Furthermore, the effects of deforestation on animal disease—and human risk—incorporates a range of ecological activists and researchers into the growing network of disease. In fact, this issue is the focus of David Quammen's *New York Times* bestseller *Spillover: Animal Infections and the Next Human Pandemic*. In his opening chapter, he argues that "The subject of animal disease and the subject of human disease are . . . strands of one braided cord" (13). Each chapter that follows traces these strands, in the Latourian sense, and he unpacks the interrelationships of nature, animals, microbes, viruses, diseases, and humans. In such contexts, the diagnosis of a disease involves both animal and human diagnoses, and such a central part of human medical encounters becomes a mere starting point. He writes of finally diagnosing the mysterious Hendra virus, which randomly killed horses and then humans that had had contact with infected horses, "Identifying the new virus was only one step in solving the immediate mystery of Hendra, let alone understanding the disease in a wider context. Step two would involve tracking that virus to its hiding place. Where did it exist when it wasn't killing horses and people? Step three would entail asking a further cluster of questions: How did the virus emerge from its secret refuge, and why here, and why now?" (19). These questions—of identification, tracking, timing, and spreadability

—encompass a range of actants who must contribute their expertise. For example, the Hendra case involved horses, bats, horse owners, veterinarians, botanists (who could study the trees where bats had gathered—and under which the first infected horse had nestled), bat carers, medical experts, microbiologists, journalists, and a host of other stakeholders. Each actant possessed his or her own expertise that had to be collaboratively considered in order to successfully answer any of the questions Quammen poses.

In many ways, the shift from Chapter 2 to Chapter 3 can be understood as a shift from the interpersonal to the institutional level of network tracing. While Chapter 2 emphasized the interplay of local actants and their expertise—such as a doctor, patient, family members, and specialists with relationships to primary doctors—Chapter 3 takes a meta approach to such interactional ethoi. Rather than isolated doctor-patient networks, Quammen's analysis—and Chapter 3's—takes a different approach to understanding problems within diagnostic networks, focusing instead on institutions such as ecology, the Australian horse racing industry, veterinary precautions for treating sick animals, and the environmental effects of colonial efforts to introduce horses into Australian habitats in the late 1700s. While the meta-level networks are more complex and frightening—in the sense that they indicate a future pandemic that will wipe out millions of people, just as influenza and AIDS have done—they also offer greater possibilities for actant intervention. A key tenet of Quammen's analysis, in fact, is that humans are actually bringing pandemics and epidemics upon themselves by destroying habitats and the environment. He writes:

> Make no mistake, they are connected, these disease outbreaks [AIDS,
> influenza, Ebola, Nipah, West Nile, Sars, avian flu, Hendra, etc.] coming one
> after another. And they are not simply *happening* to us; they represent the
> unintended results of things we are *doing*. They reflect two forms of crisis on

our planet. The first crisis is ecological, the second is medical. As the two

intersect, their joint consequences appear as a pattern of weird and terrible

new diseases, emerging from unexpected sources and raising deep concern,

deep foreboding, among the scientists who study them. How do diseases leap

from nonhuman animals into people, and why do they seem to be leaping

more frequently in recent years? To put the matter in its starkest form:

Human-caused ecological pressures and disruptions are bringing animal

pathogens ever more into contact with human populations, while human

technology and behavior are spreading those pathogens even more widely and

quickly. (39-40)

While reducing ecological destruction and the carbon footprint cannot entirely eradicate

infectious and zoonotic diseases, Quammen provides a possibility that reforming ecological

practices—at the individual and global level—might at least help lessen the severity of such

diseases or enhance containment efforts. In this way, Quammen highlights the vitality of not

only coordinating different forms of expertise but of calibrating our expertise to respond to

the challenges that face our world.

   This approach to ethos exceeds the boundaries Mol inadvertently imposes on ethos

by limiting her study to ethos negotiation in hospital settings. While saving a patient's life is

the ultimate measure of successful network negotiation for Mol, for Quammen and Bayoh,

successful negotiation hinges on higher stake projects: protecting entire countries from public

health outbreaks and ensuring that steps are taken to create healthcare infrastructure that can

adequately respond when outbreaks do occur. While saving an individual patient's life is

obviously an important and worthy goal, the scope of Mol's project fails to account for larger

scale projects that must be undertaken by more complex networks. Thus, in addition to

accounting for the ways in which ethos is generated via actant interaction, an alternative

approach to networked ethos must address how expertise gets negotiated within public

health networks.

When Ethos Goes Unrecognized

Whereas Chapters 2 and 3 emphasized networked relationships, Chapter 4 focused

on the role one often-neglected actant plays in diagnostic deliberations: uncertainty. I began

by arguing that diagnostic deliberations tend to overly value outcome-based, probabilistic

approaches over open-ended and ongoing ones. This habitus of Western deliberative rhetorics

has influenced healthcare providers to stress the significance of acting quickly in response to

imperfect or even conflicting information. However, this model's appreciation for acting

decisively in the moment fails to adequately serve populations of potential patients, such as

bug chasers and those at risk for genetic disease, whose risk for disease requires a different

rhetorical approach. Lyon's approach to deliberative rhetorics presents an alternative picture

of deliberation as an ongoing conversation where actants seek to understand rather than

persuade one another. She furthermore emphasizes the moment when actants come together

to make decisions as a situation wherein differences can be calibrated, to borrow Mol's term,

rather than erased. Rather than a model of persuasion or identification, Lyon's approach to

deliberation mobilizes Arendt's concept of inter-est to stress the significance of locating a

common struggle that can enable multiple actants to correlate their actions. I finally posited

that diagnosis can no longer be medicine's sole *telos*, and that diagnostic deliberation

networks might start to locate their common ground in the uncertainty that all actants

within diagnostic settings face.

Beyond Chapter 4's focus, though, uncertainty raises additional questions about negotiating ethoi in diagnostic contexts. In fact, a key challenge facing medical authority—or ethos—is its susceptibility to change. In *Exploring Medical Anthropology*, Donald Joralemon argues that "The social and cultural authority of a healer is supporter by anything that appears to his/her clients to be a cure, but when the results are ambiguous or negative, the healer's authority can suffer" (70). Thus, a healer's guesswork is not only significant for her patient but also for the population which she serves, which may lose faith in both her and the healing practice she represents if she fails. Joralemon continues, "[W]hen a new disease appears, for which existing therapies are ineffective, the cultural authority of healers may be challenged. If other healers, representing a different medical system, have greater success, there may also arise a contest over social authority" (70). As an example of such a contest— and shift in healthcare paradigms—Joralemon points to the Amerindian shamans who attempted to protect their communities from disease from Spanish invaders in the 1500s. He explains, "European explorers and colonists brought with them an array of epidemic agents to which indigenous populations had not previously been exposed, including smallpox, measles, mumps, yellow fever, and bubonic plague . . . Shamans and other indigenous healers were impotent in the face of these devastating new diseases and they quickly lost credibility in their communities" (70). Far from simply eliminating community faith in the healer's abilities, such a shift away from indigenous healing "represented a significant loss of social and cultural authority, one which undermined existing religious beliefs with a corresponding decay in the entire social fabric" (70). Thus, one problem with expertise is its capacity to evolve—one can be an expert of disease, for example, until suddenly a new disease comes along about which the would-be expert knows nothing. Expertise is both circumstantial and

evolving, then, as few things worthy of expert knowledge and understanding remain the same for long.

Another problem with medical expertise, and perhaps a more troubling one, involves uncertainty about whether an actual expert will be regarded as such by an audience due to his or her race, gender, ethnicity, or appearance. In *Black Man in a White Coat: A Doctor's Reflections on Race and Medicine*, Dr. Damon Tweedy explores the ways in which his race has affected his medical school, training, and professional experiences. He first recalls his excitement as a new student at Duke University's Medical School, although he explains that a professor's confusion about why he was in the classroom—and his question about whether he was there to fix the lights—deflated his spirits. Later, as a medical student and then M.D., patients often made assumptions about his athletic abilities, assuming that he was a basketball player due to his race and height. "At least once a day during my rotations," Tweedy clarifies, "my race would come up in an interaction with patients. The racial conversation was usually implied rather than explicit, as one person after another, usually white, took one look at me and inquired about my basketball skills" (113). While some asked where he played ball, others spoke of his career opportunities: "You're wasting your time in school. You should be playing in the NBA" and "A tall black like you with long arms and legs should be on a basketball court and nowhere else" (113). Beyond making Tweedy feel uncomfortable, this commentary on his assumed athletic prowess caused him to wonder whether these assumptions actually caused patients to doubt his medical proficiency. He reflects, "[A]long with some people's certainty that I could dribble and shoot came, at least to my thinking, an assumption that I was a dumb jock . . . Would they doubt my ability to be a competent doctor? If so, would that hinder my career?" (114). Tweedy not only had to endure racist remarks in addition to the already strenuous work of keeping his patients alive,

then, he was also made to doubt his own authority due to the assumptions underlying such remarks. Added to the normal anxieties about whether one can master a new and challenging craft, Tweedy was made to wonder whether his race would make patients doubt his ethos altogether. While this unsolicited commentary and subsequent self-doubt are troubling generally, I want to particularly focus on Tweedy's encounters with Chester and Robert, two patients Tweedy worked with as a medical intern.

Before Tweedy even entered Chester's room, he had made racist assumptions about the kind of care he could offer. Chester had asked his nurse why so many black people were in the hospital, and he had informed her: "I don't want no [black] doctor" (106).[8] Tweedy recalls that the experience was a surprise—an unexpected and unwelcome interruption into his daily tasks. "I was struggling with this adjustment [from medical student to first responder] along with the rest of my colleagues, my mind focused on the objective analysis of lab results, EKGs, and chest X-rays—medical tasks that had nothing to do with race. But Chester's words had unceremoniously shoved me out of 2003, and back into a world that felt more like 1963" (106). Suddenly singled out, Tweedy is offered the opportunity to not treat the patient; however, he decides to do it anyway, coupling the pressure of saving the patient's life with the stress of knowing that the patient will hate him because of his race. As they entered Chester's room, the doctor in charge, Audrey, introduced herself, Tweedy, and another doctor two years out of college. Chester replied, "Where's my real doctor?"— evidently unsatisfied that one of his doctors was a woman and one was black (109). Tweedy remembers that the conversation progressed thusly: "'We are your doctors,' Audrey fired back. 'And I'm the one in charge.' Chester looked past her, his eyes settling on me for an instant, his face a nasty scowl, before they rested on Gabe. 'I only wanna deal with

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[8] Chester uses a racial slur here, which I have omitted.

you'" (109). Gabe, though the least qualified of the three doctors, was a white male, and therefore infinitely more capable in Chester's eyes. When Audrey reiterated that she was in charge, and he could either work with her or wait hours for a new doctor, he finally complied and allowed them to continue their examination. However, as Tweedy notes, it took one and a half weeks before Chester even acknowledged his existence enough to respond to a question, despite his dire physical condition (120).

Audrey and Tweedy also faced challenges with Chester's family members, who were no less hostile to the ones responsible for their father's care. As the two doctors met his daughter and grandson for the first time, the daughter was wearing a Confederate flag t-shirt and the son had a "shirt pocket [that] flaunted a smaller Confederate flag" (119). "With manners similar to her father," Tweedy describes, "Molly derisively asked: 'Who's in charge here?'" (119). Chester's daughter Molly challenged Audrey's authority when she described what was wrong with her father, although she finally relented after Audrey confidently replied to every question (119). Tweedy finds himself in a challenging position where he must again decide whether he will continue to treat the patient (and deal with his and his family's racist attitudes) or assign him to a new team of doctors. Tweedy decides to continue caring for Chester, but he later questions his own motives for doing so. When Chester ultimately dies, he is confronted by conflicted emotions about the experience and his response. "I was proud of the way I'd handled Chester's case," he writes, "but I was also left with a twinge of guilt. Though I was certain I had worked as hard as I could, motivated in part to show Chester and his family that I was a competent doctor, I knew that my clinical diligence had as much to do with wanting to impress Audrey and my other supervisors" (128). Even after Chester is dead, then, his prejudices and the hateful attitude

with which he encountered his non-white, non-male doctors leaves Tweedy unnerved and uncertain of his own efficacy as a doctor.

Beyond the challenges Tweedy faces from Chester and his family members, he recalls a similar experience where a patient initially refused his care—but this patient was black. As Tweedy entered the room, Robert demanded of him, "Does anyone in your family have sickle-cell?" (123). When Tweedy said no, Robert asked what he knew of the disease. With his expertise so brazenly challenged, Tweedy froze and was initially unable to say anything about the disease. "Man," Robert responded with a sneer (123). When Tweedy asked the man what he meant, he replied, "C'mon man, we both know what the deal is. I'm sure you did good in school and everything, but they're passin' you off on me. And they think I won't care because I'm supposed to be some dumb [black man][9]. Go tell your boss I don't want no black doctor" (123). Tweedy describes his painful emotional response, writing, "Dazed, I retreated a half-step. I felt my heart thump and blood pulse through my ears. In the clearest of terms, Robert was saying that black doctors were incompetent, and that I was the latest example" (123). This experience was more painful for Tweedy than Chester's dismissal of his medical expertise, "given what it said about how we felt about ourselves as a race" (125). Thus, internalized racism provokes the same distrust of a black doctor's authority—and disgust at being passed off on an ostensibly under-qualified doctor—causing Tweedy to further doubt his own expertise.

Tweedy ultimately gains the trust and affection of both Chester and Robert. Although Chester dies, and Robert lives, he teaches both men an important lesson about judging ethos based on physical appearance. However, the additional pressure and stress he faces due to the racist beliefs of both black and white patients, and the responsibility he feels

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[9] Robert, too, uses a racial slur, which I have omitted.

to prove himself as a capable medical professional in spite of his patient's blatant racism, speak to a huge political problem facing medical ethos. Just because one has been deemed an expert by Duke University, a medical board, or a prominent hospital does not mean that a doctor will be granted the same authority by patients, who bring their own fears, biases, and prejudices to such interactions. Uncertainty about how best to respond to diagnostic problems—and risks for developing diseases in the future—intersects with uncertainty about how one's authority will be perceived and/or challenged by others. Further, these experiences cause Tweedy to initially doubt himself and feel an unfair pressure to prove himself, not just as a doctor but as a black doctor.

Tweedy's narratives speak to the importance of understanding ethoi as contextual and culturally generated. In particular, patients may bring prejudices that label minorities or women as inferior, and therefore less qualified to do their job. Even the institutions that verify credentials and those responsible for preparing and vetting future experts may promote such racist ideologies, whether intentionally or not. We may recall, for example, the professor who initially made Tweedy feel like an outsider, like a lesser authority or an undeserving member of the medical profession. As Tweedy notes, although his race may have granted him access to the medical field (he claims that he would not have been accepted to Duke if he were not black), it failed to also provide him with the attendant ethos usually reserved for medical experts. A final requirement for an alternative framework for ethos generation and negotiation, then, must account for sociocultural factors that determine who will naturally be treated as experts, and who will have to work doubly hard to have their ethos recognized.

Feminist Ecological Ethos

As the previous recaps and analyses have argued, ethos haunts this project in that it haunts medicine and diagnosis. This is particularly true of a networked approach to diagnosis, as enlisting more actants into consideration will bring with it attendant conflicts regarding whose ethos matters most and why. Although previous chapters have emphasized ANT via Latour, I want to shift now towards a feminist ecological approach to ANT to consider how their conceptions of ethos might resolve, and productively complicate, the problems with ethos that this project uncovers.

The field of rhetoric has a complex relationship with ethos that can be traced back to at least the writings of Homer. According to Charles Chamberlain, "In most writers of the fifth century B.C. and later, *ēthos* can usually be understood and translated as 'character.' In earlier writers however 'character' is often an impossible or at best a misleading translation, not surprisingly, since the word originally designates 'the places where animals are usually found' [or 'animals' haunts']" (97). Such a definition responds to the Aristotelian tradition of defining *ēthos* as "moral character" or "the trustworthy character of a speaker as artistically created in a speech" (Kennedy 148). Aristotle, for his part, frames ethos as a necessary component of deliberation: "But since rhetoric is concerned with making a judgment . . . it is necessary not only to look to the argument, that it may be demonstrative and persuasive but also [for the speaker] to construct a view of himself as a certain kind of person and to prepare the judge" (112). For Aristotle, *ēthos* is a useful rhetorical tool that seeks to ingratiate the audience to the speaker in order to win their approval for a suggested course of action. This can be achieved by demonstrating good will or generating common ground, as Aristotle notes: "[I]t makes much difference in regard to persuasion . . . that the speaker seem to be a certain kind of person and that his hearers suppose him to be disposed toward them in a

certain way" (112). Thus, Kennedy argues that although *ēthos* has come to mean "the projection of the speaker's character," Aristotle initially intended for the term to denote "the speaker's success in conveying to the audience a perception that he or she can be trusted" (x). Aristotle's approach to *ēthos* via generating trust and goodwill significantly places an emphasis on the relationship between speaker and audience, thereby setting the stage for critiques of the ways in which this relationship might be corrupted or exclusionary. In particular, Aristotle's account of *ēthos* fails to account for marginalized populations whose forms of expertise have been dismissed and whose efforts involve seeking to change conversations rather than attain goodwill from audiences.

In contrast to the Aristotelian tradition, Chamberlain traces the ongoing development of *ēthos'* meaning through alternative historical texts, beginning with Homer's pluralistic use of *ēthea* ("the places where animals are found") and location-based *ētheios* ("one who is found in a certain place") (97). For Homer, the various forms of *ēthos* encompass "an arena or range in which the animal naturally belongs" (97). Such a belonging is innate or at least ingrained within the animals, since they experience distress when humans try to rehabituate them in a new environment. Writes Chamberlain, "the humans hope to change the horse's habits by using hunger to make it regard the manger at home. But the power of habituation (*eiōthōs*) is too strong to be overcome. Homer emphasizes the horse's joy . . . in order to show the power of habituation. The horse longs to be in his *ēthea*, feels pain at being locked away at the manger and joy upon breaking free" (98). This understanding of ethos points to a logic that defies logic, something that Chamberlain will pick back up later on in his piece (102). But before he does so, Chamberlain shifts to an analysis of Hesiod's and Theognis's poetry, where "*ēthos* is applied more widely and is used regularly in the singular," attributed to humans rather than animals, and "used in a derogatory sense" (98). *Ēthos*

becomes, in their poetry, a title that indicates deceitfulness or false friendship rather than good character (99). Despite the suggestions that *ēthos* is innate or somehow deeply embedded in human and animal consciousness, Chamberlain credits Pindar with the question of whether *ēthos* "can be affected at all . . . Can one 'change' one's *ēthos*?" (100). His tentative answer is yes, based on passages by Hesiod, Herodotus, and Sophocles, which suggest that women, barbarians, slaves, and children can evolve to possess more desirable (to Western white men) *ēthea* (100). He explains that their passages "suggest that the *ēthos* is susceptible to change, but only through a process of long association best done in childhood" (100). While Chamberlain fails to acknowledge it, the process might also be seen as a form of coercion, whereby those in power seek to change or "reform" the *ēthea* of those deemed inferior.

A final significant moment for *ēthos* can be located in the "political use of the word," or its' associations with "the peculiar characteristics which citizens of a *polis* acquire as part of their civic heritage" (101). Thus, *ēthos* can refer not only to an individual's place of belonging but of a *polis*'. As Chamberlain explains, this collective "*ēthē* forms a kind of moral ambience which is peculiar to a certain *polis* and whose most important influence is upon the children of that place," an idea that Aristotle in particular mobilized (102). Chamberlain finally sums up his review of ancient conceptions of *ēthos,* explaining:

> Like the pasturage which the horse calls its own, there exists a part of our
> being which is untouched by higher reasons of love or friendship or duty, and
> may come to light in a crisis . . . It is an apparently irrational or
> unaccountable entity which nevertheless follows a rational principle or
> principles of its own. To put it more suggestively, the *ēthos* has its own *logos*
> which is in a sense beyond the reach of *logos*. (102)

Chamberlain just stops short of identifying *ēthos* with *phusis*, thereby establishing it as a contradictory or contrasting concept to *nomos,* or the laws and customs that would try to habituate *ēthos*.

I begin by explaining this approach to *ēthos* at length because it powerfully introduces major themes of feminist ecological conceptions of the storied and multi-faceted term(s). In the "Introduction" to *Rethinking Ethos: A Feminist Ecological Approach to Rhetoric*, Kathleen J. Ryan, Nancy Meyers, and Rebecca Jones are careful to distinguish ēthos from ethos, noting that "The etymology of ethos, according to the Greek-English Lexicon compiled by Henry George Liddell and Robert Scott, is simply 'custom' and 'habit,' while the denotations of ēthos and its plural, ēthē, entail social, ethical, and located dimensions" (6). As such, ēthē becomes a compelling starting point for a feminist approach to understanding the development of authority or character that is social, respondent to power dynamics, and situated within particular contexts. In the "Preface" to the same collection, the editors conceive of their purpose for the book thusly: "We are compelled . . . to ask how else have, do, and might women compose their ethos? By focusing on ethos, we highlight a complex issue: the cultural, historical, and social positions that restrain and invigorate women's rhetorical prospects as agentive rhetors" (vii). The writers anticipate a shift away from "male orators in positions of power" and toward multi-faceted, disruptive ethos generation, and that women offer particularly powerful examples of how best to enact these shifts due to their long history of marginalization (4-5). They furthermore argue that "By naming women's ethos practices as feminist ecological ethoi, we shift away from an Aristotelian framework toward a conceptualization of women's ethos that accounts in new ways for interrelationality, materiality, and agency" (viii). Feminist ecological ethoi, located "at the confluence of ecological thinking and feminist rhetorical thinking" seeks to challenge and "shift the

dominant discourse" rather than cultivate a socially acceptable ethos (2). Ryan et. al argue

that "Common, normalizing ethoi (i.e. Mormon woman, mother, angel of the house, whore,

bitch) ascribed to women do not lend themselves readily to public speaking. As such, new

ethoi must be created and defined to push against these socially determined ethoi" (2).

Indeed, feminist interventions against normalizing ethoi include work by radical feminists

such as Andrea Dworkin, who "cultivate[s] a productive, confrontational ethos by rejecting

social convention in her rhetoric, embodiment, and relationships" (Palmer-Mehta 66).

Rather than seeking to appease her audience and generate feelings of good-will, she instead

"commanded the floor with force, scarcely pausing to justify her presence. Rather than

adapting to the audience or making conciliatory gestures, she called on them to adapt to her

way of thinking" (66). In this way, Dworkin exemplifies the value of habit-disruption by

"engaging in a strategic reversal . . . mov[ing] the burden of cultivating an appropriate ethos

onto her audience," rather than seeking to prove her own (67). Thus, feminist ecological

ethos can be disruptive and responsive to power structures that oppress and exclude some

from civic participation. Rather than seeking to generate goodwill between a rhetor and

audience, ethos might be mobilized to confront an audience and productively shift the

relationships among actants.

Another key tenet of a feminist ecological approach to ethos is its multiplicity,

fluidity, and emphasis on nonlinear relations. "Feminist ecological ethoi," Ryan et. al write,

"open up new ways of envisioning ethos to acknowledge the multiple, nonlinear relations

operating among rhetorics, audiences, things, and contexts (i.e. ideological, metaphorical,

geographical). This theorizing recognizes all elements of any rhetorical situation as shifting

and morphing in response to others, generating a variety and plurality of ethos, or ethoi" (3).

This approach recognizes the ways in which context influences ethoi, which must shift in

response to new audiences and purposes for speaking. Similarly, it acknowledges the extent to which any individual or *polis* might possess multiple ethoi: as a doctor, scholar, researcher, and writer, and mother, for example, a woman might have a variety of ethoi that inform her identity and expertise. This awareness of the multiplicity of ethoi is a result of the marginalization of women, for Ryan et. al, who note that "marginalized rhetors have a keen sense of the burdens of ethos negotiation" and the tools through which they might "alter ecosystems" (3). As an example, we might recall Tweedy's reflections on the way race affected his medical practice; as a black male doctor, he was expected to be able to seamlessly switch from his expertise as a doctor to expertise on sports, particularly basketball, to an understanding of issues affecting minorities—both social and health-related. Thus, taking a multiple or fluid approach to *ethos* should not encompass an uncritical embrace of what can oftentimes become a burden for marginalized populations to "prove themselves" as experts due to their status as non-white, non-male, non-hetero, and non-Western rhetors.

Finally, a major shift that Ryan et. al instigate within conceptions of ethos involves a move away from location and towards relationship. Crediting Craig R. Smith with the idea that "ethos dwells not just at specific locations but also in the speaker and audience relationship," Ryan et. al are careful to note that their conception of relationships includes both human and nonhuman actants (7; Smith 15-6). They begin to identify the necessity of the "ecological" component of their definition by noting the responsibility we bear to not only other humans—particularly marginalized populations—but to the earth, environment, and nonhumans, such as animals. "Ecological thinking," they clarify:

> is about a way of living in the world oriented toward cohabitation; it
> acknowledges the dynamic construction of relationships within and across
> location and between people as constituting knowledge and values. Ethos is

neither solitary nor fixed. Rather, ethos is negotiated and renegotiated,

embodied and communal, co-constructed and thoroughly implicated in

shifting power dynamics. (11)

Ethos, too, is not a self-serving endeavor that seeks to cultivate one's own authority; instead,

in Ryan et al.'s hands, it becomes a way to "encourage the flourishing of all people" and take

responsibility for the work we do (11). In this sense, the authors draw on Lorraine Code's

Ecological Thinking: The Politics of Epistemic Location, where she conceives of habitat and

ethos within a feminist framework of responsibility. She posits that "the transformative

potential of ecological thinking can be realized by participants engaged in producing a viable

habit and ethos, prepared to take on the burdens and blessings of place, identity, materiality,

and history, and to work within the locational possibilities and limitations, found and made,

of human cognitive-corporeal lives" (5).[10] The responsibility, for Code, resides with any

rhetor who seeks to affect the ecology of which he or she is apart. "He/she," she elaborates,

"is self-critically cognizant of being part of and specifically located with in a social-political

world that constrains and enables human practices, where knowing and acting always

generate consequences" (5). Because of the "worldly implications" of ethos cultivation and

renegotiation, then, feminist ecological ethoi emphasizes relationship to stress responsibility

between actants who must negotiate (Ryan et al. 11).

Feminist Ecological Ethos and Diagnostic Networks

In their "Introduction," Ryan et al. stress the strength women have historically

demonstrated their expert cultivations of ecological ethoi, but they also argue that "any

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[10] See also Donna Haraway's "Situated Knowledges" for another important feminist
approach to responsibility and ecological thinking.

marginalized rhetor can employ ecological ethoi" (4). While not all actants within the medical and diagnostic networks that have been covered in this chapter are marginalized, I want to briefly explore the value of such a model for diagnostic ethoi construction and negotiation before I conclude this chapter.

First, feminist ecological ethos offers an alternative approach to ethos generation that can be relational and fluid. As previously mentioned, we should be wary of efforts to embrace fluidity to the neglect of interrogating ways in which it can be used to disempower some who will be expected to exceed expectations due to their race, gender, sexuality, ability, or ethnicity. However, the strength of such an approach is its recognition of the constantly shifting parameters of expertise and the challenges of ever attaining enough authority to make declarations about human bodies, which are ever-changing and ultimately unknowable. The value of fluid ethos within diagnostic contexts might be its insistence that ethos must evolve just as networks do, and that actants can pool expertise to generate solutions, rather than relying on individual knowledge. While we might all appreciate a world where doctors became certified with perfect knowledge of all medical conditions, a more realistic approach to ethos generation would recognize the limitations of expertise and the vitality of relational approaches to diagnosis.

Furthermore, just as Mol fails to account for the meta-level of networked deliberation beyond hospital contexts, she also fails to suggest a method for challenging the status quo. Feminist ecological ethos, on the other hand, acknowledges the significance of and offers suggestions for generating ethoi that challenge and reshape networks. Rather than simply accepting the network's project and working within its confines, actants must be capable of working to change the conversation altogether by cultivating ethoi that reframe relationships amongst actants. This approach offers possibilities for responding to diagnostic networks that

fail to account for the sociocultural conditions that shape them, and it also shifts creative power to the rhetors, who might cultivate forms of ethoi that will be most effective rather than limiting their ethos construction to the pursuit of goodwill.

Finally, and perhaps most importantly, feminist ecological ethoi challenge me to speak to the meta-level of my own project. While my primary focus for this project was broadening the scope of diagnostic networks in hospital settings, feminist ecological ethoi projects highlight the significance of paying attention to the broader scale problems facing healthcare networks now and in the future. We must learn to recognize the contributions of ecological and non-human actants—not only because to do so is ethical and humane, but because it might help us actually preserve and enhance human life. Our ethical obligation to protect the environment and care for animals intersects with our responsibility to create a world that is inhabitable for all humans—particularly those who are rendered most vulnerable by the effects of climate change and other global atrocities, such as deforestation and the over harvesting of seafood. These problems will have real effects on human lives and human health in the decades to come, and they require networked intervention to the same degree—if not more—that a patient requires a diagnosis.

Conclusion

Part of the reason why I chose to focus on ethos in this, the final chapter of my dissertation on diagnostic networks, is because of its significance to decision making. Diagnosis hinges on decisions made not by medical experts alone, but by actants who are thrust together by chance, disease, and constraints of time, location, and finances. Since ethos is a mobilizing force that generates action on the part of actants, then, its alternative framing seems a significant way to close this project, which has attempted to shift the ways in

which diagnostic communication and deliberation gets framed rhetorically. More specifically, reconsidering ethos is an important final step towards resituating diagnosis because it deals with the realm of the possible, opening up pathways for intervention and responsibility. According to Smith, "*ethos* informs decision making, thus moving a people to their potentiality" (4). Additionally, "The teleological dimensions of *ethos* lead the speaker toward a higher potential, one capable of advancing a cause, uplifting an audience, and guiding a society aright, one that can improve the mutual dwelling place" (15-6). Thus, ethos generation and negotiation offers what perhaps few other concepts within this project can: a chance to make a difference.

Diagnostic communication is bound up in specialized language and isolated in settings far removed from the average American—unless, of course, they are being diagnosed themselves or are witnessing the diagnosis of a friend or family member. However, there are two major ways in which we might intervene to positively affect diagnostic networks. First, in "The Empathy Exams," Leslie Jamison invites readers to enter the strange world of medical acting. Jamison works hourly as a pretend patient, testing medical students on their knowledge, diagnostic accuracy, and—most interestingly—their ability to empathize. Although she primarily describes her job as getting paid to "play sick," she also highlights the rhetorical elements of the scripted interactions:

> You get a script and a paper gown. You get $13.50 an hour. Our scripts are ten to twelve pages long. They outline what's wrong with us—not just what hurts but how to express it. They tell us how much to give away, and when. We are supposed to unfurl the answers according to specific protocol. The scripts dig deep into our fictive lives: the ages of our children and the diseases of our parents, the names of our husbands' real estate and graphic design

firms, the amount of weight we've lost in the past year, the amount of alcohol

we drink each week. (1)

Jamison and her fellow actors are supposed to evaluate medical students based on their

identification of "crucial pieces of information" within the patient's narrative (2). For

example, the "STD Grandma" character is supposed to "hid[e] behind her shame like a veil"

for having "cheated on her husband of forty years [with] a case of gonorrhea to show for

it" (3). Jamison explains wryly, "If [the student] asks the right questions, [STD Grandma

will] have a simulated crying breakdown halfway through the encounter" (3). In less

emotionally intense interactions, the student might get points for uncovering previous drug

abuse, medication allergies, or past trauma—such as the death of a close friend or relative. By

piecing together the clues and deciphering the actor's unspoken symptoms, students are to

determine the correct diagnosis. In this way, the first part of the exam ask students to do, in a

contrived setting, what they will do in the future as they work with patients: collaboratively

construct narratives about which the patient herself may not be totally conscious.

While the end goal of the first part of the exam is for students to correctly identify

and diagnose the presenting problem, Jamison labels the second half of the checklist "the

empathy exams." Jamison reveals that "Checklist item 31 is generally acknowledged as the

most important category: 'Voiced empathy for my situation/problem'" (3). Some students

fail this test by aggressively attempting to "wrestl[e] [Jamison] into eye contact" even though

her script tells her to avoid it (4). One student fails by forgetting the pretense of the situation

and asking in-depth follow-up questions about her fake hometown "beyond the purview of

the script" (4). Others technically fulfill the test's requirements by adopting a mechanical

method for expressing empathy: "*that must be really hard* [to have a dying baby], *that must be*

really hard [to be afraid you'll have another seizure in the middle of the grocery store], *that*

must be really hard [to carry in your uterus the bacterial evidence of cheating on your husband]" (4-5). Jamison finds, through her tests, that empathy cannot be reduced to an item on a checklist; it involves attunement to the other person and her unique needs. But perhaps more importantly, empathy is interactional—"we're holding the fiction between us like a jump rope," Jamison writes—and intentional (23). Jamison explains, "Empathy isn't just something that happens to us—a meteor shower of synapses firing across the brain—it's also a choice we make: to pay attention, to extend ourselves" (23). Rather than viewing empathy as a kind of innate impulse that medical students must learn to reveal to patients, Jamison instead argues that empathy is a choice they must make, an intentional positioning of themselves as open and responsive to the patient's needs.

Ultimately, Jamison argues that empathy is not only interactional; it involves, too, an acceptance of one's limitations within the interaction. "[E]mpathy isn't just measured by checklist item 31," she writes:

> Empathy isn't just remembering to say *that must be really hard*—it's figuring out how to bring difficulty into the light so it can be seen at all. Empathy isn't just listening, it's asking the questions whose answers need to be listened to. Empathy requires inquiry as much as imagination. Empathy requires knowing you know nothing. Empathy means acknowledging a horizon of context that extended perpetually beyond what you can see: an old woman's gonorrhea is connected to her guilt is connected to her marriage is connected to her children is connected to the days when she was a child. All this is connected to her domestically stifled mother, in turn, and to her parents' unbroken marriage . . . Empathy means realizing trauma has no discrete edges. Trauma bleeds. Out of wounds and across boundaries. (5)

In some ways, Jamison's ultimate conception of empathy transforms the two checklists into contradictory tests: one measuring the medical students' expertise and the other measuring their willingness to be uncertain. Jamison speaks to the challenging role physicians play as they must not only demonstrate their competence but also their humanity through their willingness to accept what they do not know. Part of this process involves, as Jamison points out, recognizing that patients are never singular just as illness itself is never singular.

Jamison's presentation of the multiple, sometimes conflicting identities doctors must cultivate speaks to the multiple ways in which we might intervene within networks: cultivating empathy for the people who require care. While this might seem like an obscure invitation to care for others, I want to suggest that caring for others is never a trite endeavor. As Jamison reminds us, it is always intentional, always slightly uncomfortable, and it demands of us a willingness to listen to what another person might need or want. Caring for others in diagnostic network contexts could involve, for example, advocating for the vulnerable populations who might be affected by efforts to cut access to affordable healthcare, such as those with preexisting conditions who might have been denied insurance coverage if the American Healthcare Act had passed. This might involve listening to a friend who has been diagnosed with a disease or who has just learned that she is at risk for a disease. This might mean working compassionately with students who are affected by disease, who live with daily uncertainty, and reforming course policies to serve such students. It might even mean educating oneself about how to respond empathetically when a person needs support due to a recent diagnosis—beyond saying "*that must be really hard*." Empathy is hard, but it is nonetheless a responsibility that emerges through diagnostic networks; if we are all connected via networks of health and disease, then we all bear a responsibility to care for each other and participate within such networks as global citizens but also human beings.

Furthermore, a second major way in which we might intervene within healthcare networks involves larger scale change—one that moves beyond the realm of the interpersonal. In order to illustrate the scope of our responsibility as global citizens, who each have a small but important role in shaping public health networks, I want to quote Quammen's list of the ways in which humans bring pandemics upon themselves at length, as it speaks to both the complexity and necessity of our intervention and response. He positions citizens as the secondary respondents to disease crises—just after expert public health official and scientists—and therefore charges them with the responsibility to be informed and active. He elaborates:

> The experts have alerted us to these factors [that cause disease] and it's easy enough to make a list. We have increased our population to the level of 7 billion and beyond. We are well on our way toward 9 billion before our growth trend is likely to flatten. We live at high densities in many cities. We have penetrated, and we continue to penetrate, the last great forests and other wild ecosystems on the planet, disrupting the physical structures and the ecological communities of such places. We cut our way through the Congo. We cut our way through the Amazon. We cut our way through Borneo. We cut our way through Madagascar. We cut our way through New Guinea and northeastern Australia. We shake the trees, figuratively and literally, and things fall out. We kill and butcher and eat many of the wild animals found there. We settle in those places, creating villages, work camps, towns, extractive industries, new cities. We bring in our domesticated animals, replacing the wild herbivores with livestock. We multiply our livestock as we've multiplied ourselves, operating huge factory-scale operations involving

thousands of cattle, pigs, chickens, ducks, sheep, and goats, not to mention hundreds of bamboo rats and palm civets, all confined en masse within pens and corrals, under conditions that allow these domestics and semidomestics to acquire infectious pathogens from external sources (such as bats roosting over the pig pens), to share those infections with one another, and to provide abundant opportunities for the pathogens to evolve new forms, some of which are capable of infecting a human as well as a cow or a duck. We treat many of those stock animals with prophylactic doses of antibiotics and other drugs, intended not to cure them but to foster their weight gain and maintain their health just sufficiently for profitable sale and slaughter, and in doing that we encourage the evolution of resistant bacteria. We export and import livestock across great distances and at high speeds. We export and import other live animals, especially primates, for medical research. We export and import wild animals as exotic pets. We export and import animal skins, contraband bushmeat, and plants, some of which carry secret microbial passengers. We travel, moving between cities and continents even more quickly than our transported livestock. We stay in hotels where strangers sneeze and vomit. We eat in restaurants where the cook may have butchered a porcupine before working on our scallops. We visit monkey temples in Asia, live markets in India, picturesque villages in South America, dusty archeological sites in New Mexico, dairy towns in the Netherlands, bat caves in East Africa, racetracks in Australia—breathing the air, feeding the animals, touching things, shaking hands with friendly locals—and then we jump on our planes and fly home. We get bitten by mosquitos and ticks. We alter the

global climate with our carbon emissions, which may in turn alter the

latitudinal ranges within which those mosquitos and ticks live. We provide an

irresistible opportunity for enterprising microbes by the ubiquity and

abundance of our human bodies. (515-6).

As Quammen's intersectional analysis of the problems caused by human actants within global health networks illustrates, suggestions for responding within such networks will require complex, collaborative, and multi-layered efforts. In some ways, the problems Quammen presents might seem insurmountable because of the sheer volume of actants involved. However, Quammen's analysis also demonstrates the significance of a networked approach, since within both ANT and ecological models for understanding global health networks, relations between actants always stand open to revision and intervention. Thus, in my closing remarks, I want to make several suggestions for how concerned actants might begin to take action and reshape public health networks while we still can.

The first steps for reshaping public health networks via public policy and environmental ethics entails shifting towards a networked, relational view of such practices, as problems facing the environment also affect animal habitats, human health, and the availability of crucial resources. In some ways, this first recommendation speaks to the limitations of ANT-based approaches to networked problems, as the larger social conversation about global health concerns tends to isolate each problem and cultivate individual responses. Future research should seek methods for mobilizing ANT for public audiences and facilitating collaborative problem-solving not just within higher education but within the public at large. Sonia Shah reiterates the importance of a global, relational view of health as she stresses the importance of ensuring that all countries and hotspots for disease are adequately prepared to monitor and respond to outbreaks. In particular, she finds the idea

that past prevention methods will work for future diseases dubious at best. "Fixing the

present surveillance system is no small task," she writes, "it will require easy and affordable

health care for people everywhere. A network of clinics, staffed with health-care workers

trained to recognize and report new pathogens, could do the trick" (212). Shah posits that

disease networks are global constructions, and that we ignore this to our own detriment.

Rather than simply concerning ourselves with affordable healthcare, treatment, and

medication in the United States, Shah reminds us that we have to look beyond our own

borders to foster effective healthcare and disease surveillance systems globally in order to

prevent disease outbreaks and respond effectively to them. Howard Markel echoes Shah's

observations, arguing that "the human race is simply too interconnected to rely on walls or

borders as public health safeguards" anymore (208). Diseases slip through barriers—from

person to person, animal to person, skin to cells, and country to country. They travel

unchecked through security checkpoints at airports all over the globe. And the diseases

spread, sometimes invisibly and always randomly. Thus, global health infrastructure must

reflect the complexity of these diseases, which slip into bodies and countries and leave

devastating statistics in their wake.

Furthermore, we must educate ourselves about the global and individual practices

that currently threaten to perpetuate violence against the environment and thereby

undermine the health of vulnerable populations worldwide. This aspect of intervening in

global health networks might involve enlisting more concerned actants who are unaware of

threats to global health or environmental destruction—thereby educating them about the

problems that exist. However, a more important approach seems to be educating everyone

about the ways in which they can combat such consequences within their own networks. For

example, making the personal choice to only consume antibiotic and hormone free meat can

help undermine an industry that pumps medications into animals that humans consume, often with very little thought (if any) about the consequences of this process. While I am not advocating for this decision as a complete solution, I do want to commend the thought behind it; only by seeking to understand the local *and* global impact of our actions can we make ethical choices.

This emphasis on educating ourselves and others about global risks for disease, and human causes of pandemics and disease outbreaks, means that we must continue to grapple with a challenge that has faced public health officials since at least 1892: we tend to forget about public health infrastructure so long as Western countries remain relatively untouched by contagious disease. Howard Markel clarifies, "[W]e continue to grapple with the essential paradox of public health . . . when the system is working effectively [at least for those in the West], it is a silent venture and there are relatively few outbreaks of disease. These very successes lead most of us down a complacent path of false confidence, apathy, and assumptions that the endless dance is over" (210). Markel insists that while "'Public health is purchasable,'" in that we can fund healthcare and vaccinations for the world's vulnerable and poor populations rather than paying for weapons to fight them and walls to isolate them, "it is an investment that works best when purchased in advance rather than paid out as each crisis arises" (213). Failing to adequately communicate the relational and networked nature of diseases can mean that we only respond—and demand response on the part of our government through the allocation of resources—once a crisis is already underway. Markel also highlights the importance of individual contributions to collective problems when he personalizes the response that everyday citizens might take: "Sachs and his colleagues have estimated that if every person living in a high-income nation today denied him-or herself the luxury of one movie ticket and a bag of popcorn each year, the control of infectious killers

such as AIDS, malaria, and tuberculosis could be easily funded at the levels recommended by the United Nations" (213). By recasting networked relations as a series of informed choices, we might encourage the thoughtful consumption and allocation of resources at the local level, which might ultimately inspire national and global policy reform. One of the key arguments of this project, then, is that failing to see that disease networks always encompass global actants will have deadly consequences.

Finally, we must interrogate actants within public health networks, hold them accountable, and protest their efforts when they fail to support vulnerable populations. We must advocate for the reshaping of networks when they fail to adequately meet our healthcare needs. In this sense, recent protests at town halls held by conservative politicians over the attempted Obamacare repeal highlight the power of concerned actants holding those in power accountable. Ultimately, the Obamacare repeal was unsuccessful at least in part due to fears, on the part of conservative politicians, that they would not be re-elected if they failed to heed the concerns of those they represent. However, the success of protestor efforts in relation to dangerous healthcare legislation has failed to translate into successful response to Trump's proposed EPA budget cuts. In "I Ran George W. Bush's EPA—and Trump's Cuts to the Agency Would Endanger Lives," Christine Todd Whitman claims that Trump's proposed 31 percent decrease in EPA funding—it "would stand to lose approximately one-third of its total budget"—will have serious and permanent effects on public health (n.p.). For example, Whitman cites Trump's halving of the Clean Air Act's budget as a particularly dangerous decision, since "A 2013 Massachusetts Institute of Technology study reported that roughly 19,000 more people die prematurely from automobile pollution each year than die in car accidents" (n.p.). The budget will also "reduce funding for the Great Lakes Restoration Initiative, or GLRI, by more than 90 percent" even though "The Great Lakes are the largest

surface freshwater source in the word . . . provid[ing] drinking water to approximately 40 million people in the United States and Canada" (n.p.). Thus government regulations of both air and water pollution will be significantly diminished, likely resulting in heightened health complications and even death in the short term. Long term effects, of course, will include further depletion of the ozone layer and the contamination of precious freshwater resources. However, these structural risks that will affect human health (not to mention the environment and animals) fail to generate the same kind of outrage and responsiveness as proposals to nix Obamacare precautions that provide coverage for the poor and protect Americans at risk for disease.

Within this landscape—of an inescapable future haunted by a pandemic that will kill millions of people worldwide—the good news is that public health networks are already mobilized. We must support and add to the ongoing efforts of such organizations at the national and local level. We need to contribute our own resources of time, money, and energy to collective efforts to ensure effective worldwide healthcare, and we need to pressure our elected officials to do the same. We must, ultimately, learn to do what doctors do: move beyond the diagnosis of a problem and towards deliberation about what to do next.

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