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ENABLING PAIN, ENABLING INSIGHT: OPENING UP POSSIBILITIES
FOR CHRONIC PAIN IN DISABILITY RHETORIC
AND RHETORIC AND COMPOSITION

Hilary Selznick

151 Pages

In the dissertation “Enabling Pain, Enabling Insight: Opening up Possibilities for Chronic Pain in Disability Rhetoric and Rhetoric and Composition,” Hilary Selznick argues that pain is rhetorical, accessible, and communicable to those without the lived experience of chronic pain. Additionally, she argues for the necessity of considering chronic pain as a disability and not merely as a symptom of a disability. In order to make these arguments possible, Selznick crafts a political-relational-rhetorical methodology that challenges restrictive models of disability and theoretical and commonplace assumptions that pain is resistant to language. Specifically, Selznick’s methodology, which combines disability scholar and activist Alison Kafer’s political-relational model of disability with research in disability and feminist rhetorics, makes visible the socio-political, cultural, economic, and material realities of living with chronic pain and the generative power of rhetoric to transform commonplace understandings of disability. In so doing, this dissertation reveals disability as positive difference. In this way, Selznick’s dissertation not only disrupts and intervenes in problematic rhetorics of chronic pain, but also introduces alternative and productive rhetorics of pain that account for pain as a necessary and privileged position. By doing this work, this dissertation provides a presence for chronic pain and persons with chronic pain in disability rhetoric, rhetoric and composition, disability studies, feminist

rhetorics, and medical rhetorics, while also forging critical alliances between these diverse yet intersecting fields.

KEYWORDS: Chronic Pain, Composition, Disability, Pain, Rhetoric, Technical
Communication

ENABLING PAIN, ENABLING INSIGHT: OPENING UP POSSIBILITIES
FOR CHRONIC PAIN IN DISABILITY RHETORIC
AND RHETORIC AND COMPOSITION

HILARY SELZNICK

A Dissertation Submitted in Partial
Fulfillment of the Requirements
for the Degree of

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H. S.

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PROLOGUE

“Do you think it’s true, that pain destroys language?” asked the self-identified patient advocate in the second row. She was poised and assured. She looked about my age. When I didn’t answer right away (I was sure I was looking at her blankly, although my mind was running a 50-yard dash trying to pull up a reference), she continued, “That’s what trauma theorists say, Elaine Scarry. . . .” After swallowing back a “who?” and my initial response of “that’s ridiculous,” I thought back to a class I took on trauma and the Holocaust and remembered something about how during traumatic events, survivors don’t actually experience what happens, that it is not until they tell their story to another, that it is witnessed, that it becomes lived.

It was my second time presenting at an academic conference and my first time doing so at the Conference of the Society for Disability Studies (SDS), so I had not yet learned from my advisor to say, “I need to take some time and think about that, thank you,” nod, and then write down the question in my notebook. Instead I found myself replying, what I thought at the time was, at best, naïve: “I don’t know. But I think we should at least try.”

And yet, not knowing the answer to that question became a pivotal moment, a moment that inspired this dissertation, a moment that brought me back to my own experiences with chronic pain (not that I actually ever leave them), but this time to seek a different answer. I think of the many times over the years that I tried to explain to my husband and wondered if he was “getting” the twisted ache in my belly, the spasms that split across my abdomen, the reason why I dropped to the floor with my arms around my belly. I would repeat over and over again how it felt, using as many descriptive words as possible, just in case he didn’t “get it,” because if he did, couldn’t he make it go away? And I think back to those days, months, a year with my mother and father—back in their house, back in the little room upstairs, instead of being away at graduate

school, looking up at their faces, knowing that they would never really understand as I tried to sleep with my legs up against the wall (to take the pressure off my back), and instead only saw their youngest daughter in tears and in pain and felt the helplessness of it all.

And I remember being in the sixth rheumatologist's office, he telling me that there are no trigger points on the feet and gesturing to a map—the outline of a woman's body—indicating the 18 fibromyalgia trigger points, even though I was having trouble walking and the bottom of my feet were sore and raw and numb. The same doctor who a year later wouldn't give me a handicap placard (but had no problem giving my husband one for the same condition) because technically I could walk the 200 feet to my destination from my car. But then I think about the place where I met my husband, the Mayo Clinic's Pain Center, and how maybe we wouldn't be celebrating our 10th wedding anniversary if we didn't, in some way, share each other's pain.

After the Q&A, I followed other SDS conference attendees to the Indian restaurant a few blocks away from the hotel. I was grateful to be invited, so I didn't ask them to slow down, wait, or help me carry my bag (made heavy with the computer inside). Instead I remained silent and found myself lagging behind the rest of the group while I worried about how much the Indian food would hurt my stomach. Then I took notice of the wheelchairs and canes, the long boot that lengthened one foot to meet the other, and I knew that this time I was not alone, and that in this group I was the one who looked “abnormal.”

At the restaurant, we made quite a commotion, seven unapologetic women needing what others might call special accommodations, what we called our equal right to occupy public space. When the shuffling was over, the woman beside me told me she was at my talk and that a friend of hers at the conference was doing similar work (the two of us, I later realized, were the

only presenters at the four-day conference addressing pain and disability). She gave me her contact information, and then, as I moved my fork around pretending to eat my saffron rice, I told her how hard it was to keep and make friends with chronic pain.

“That’s because you need crip friends,” came a voice from the middle of the table. I turned around to see the speaker gazing in my direction, realizing she was blind. “Yes, that’s right,” the woman I had been talking to called back and then added: “Hey, we can be your crip friends.” I immediately heard myself say, “Yes, please.”

I was reminded of a presentation earlier in the conference in which Simi Linton discussed her memoir, *My Bodily Politic*, and her upcoming film “An Invitation to Dance,” which was followed by a Q&A. She spoke about the giving up of one life for another, such an interesting way, I thought, of describing the transition from abled to disabled. One was not more valuable or whole than the other, she had said in response to a question. She then spoke about her activism in the DS movement and how claiming a disability made her a part of what she described as a loving and supportive community. As I gazed around that table, at the strangers I just met a half a mile ago, I wondered: Perhaps I had just been let in.

CHAPTER I

CHRONIC PAIN, DISABILITY, AND RHETORIC

Pain is not only an inevitable component of human existence but also thoroughly entangled with our experiences of love, joy, humor, and intimacy.

—Susannah Mintz, *Hurt and Pain*

The central argument of this dissertation is that pain is rhetorical. As such, pain is accessible, communicable, and representable to those without the lived experience of chronic pain. However, before continuing, let me be careful to note that by making this claim I am not attempting to suggest that pain is easily understandable or that it can ever be fully realized by another (as is true of all human experience). Instead I am offering a beginning, a space to listen to pain, a possibility for engagement with pain that moves beyond suffering and tragedy and unknowability. This beginning is made possible only by exploring and opening up opportunities to witness and access alternative rhetorics of chronic pain that move beyond linear, print-based, sole-authored, alphabetic text. In order to do this work, this dissertation will first challenge theoretical and commonplace assumptions that pain is resistant to language¹ and lacks rhetoricity,² while also disrupting other such problematic rhetorics of chronic pain. Next, this dissertation will intervene in these problematic discourses by offering up a productive and

¹ Scholarship on pain, in particular Elaine Scarry's 1985 landmark work *The Body in Pain: The Unmaking and Making of the World*, argues that pain destroys language and is uncommunicable.

² The term rhetoricity coined by Lewiecki-Wilson ("Rethinking Rhetoric") and Prendergast ("On the Rhetorics of Mental Disability") refers to those who are perceived by dominant society as having rhetorical agency. Lewiecki-Wilson and Prendergast counter the commonplace belief that persons with mental illness lack rhetoricity because they are presumed "not to be competent, nor understandable, nor valuable nor whole" (Prendergast 26) and cannot communicate. Prendergast further explains that "to lack rhetoricity is to lack all basic freedom and rights, including the freedom to express ourselves and the right to be listened to" (26-27). Similarly, I use the term rhetoricity in relation to persons with chronic pain to refer to how this population has been oppressed and silenced by the assumption that pain is an uncommunicable personal tragedy.

generative alternative rhetoric of chronic pain that honors the lived experiences of persons with chronic pain. In addition, this alternative rhetoric of chronic pain will account for pain as a necessary and privileged position that opens up experiences for interdependence, access, and identification, which are key principles of disability studies and feminist rhetorical methodologies guiding this dissertation.³

Before continuing, I wish to identify the two definitions of rhetoric that I will use throughout this dissertation to differentiate between problematic rhetorics of chronic pain and the generative alternative rhetoric of chronic pain I will be presenting. The former (problematic rhetorics of chronic pain) defines rhetoric as the persuasive use of language, wherein language induces audiences to accept certain versions of reality, which can thus be interpreted, contested and revised, while the latter (alternative rhetoric of chronic pain) defines rhetoric as the study of how embodiment produces knowledge, identity, and ways of being-in-the-world.⁴ Making this distinction is fundamental to the arguments of this dissertation. Of course, these two definitions also inform each other since how we live in the world is influenced by language about the world. In addition, I wish to make clear that for the intents and purposes of this dissertation, the pain I refer to throughout this project is physical pain and not mental pain. I realize that by making this distinction I am in danger of endorsing the mind/body Cartesian split that in most instances I believe is an artificial construction and detrimental to theories of embodiment in the very fields I claim an investment in. However, there are several reasons, including the lack of scholarship on physical pain in relation to mental pain in disability studies, the limited scope of this dissertation,

³ For further discussion of the methodology used in this dissertation please see chapter 2: “Theorizing a Political-Relational-Rhetorical Methodology.”

⁴ I wish to express my thanks to Dr. Julie Jung who assisted me in crafting these definitions of rhetoric.

and the tendency for medical professionals to dismiss chronic physical pain as all “in one’s head,” that makes this distinction necessary, even if, at times, fraught.

The exigency of this project emerges from the relative absence of chronic pain and persons with chronic pain in rhetoric and composition, medical rhetorics, disability studies, feminist rhetorics, and in particular disability rhetoric,⁵ despite the growing national and worldwide population of this marginalized and stigmatized group. Chronic pain differs from acute pain. Unlike acute pain, which is temporary, chronic pain lasts for more than three months and has no discernible cause. Also unlike acute pain, such as pain resulting from touching a hot stove, dental pain, or broken bones, chronic pain does not indicate that the body is in danger and in need of immediate medical attention. Common chronic pain conditions and syndromes include chronic fatigue syndrome, fibromyalgia, interstitial cystitis, complex regional pain syndrome, neuropathy, rheumatoid arthritis, and migraines. The absence of discussion of these syndromes from scholarship and activism reveals that chronic pain as a disability (and not merely a *symptom* of a disability) has yet to be considered in disability studies, by disability activists, the medical profession, and government agencies such as the Social Security Administration. The failure to account for chronic pain as a disability results in further alienation of persons with chronic pain, the potential loss of benefits and resources that can come with a recognized disability status, and the perpetuation of problematic rhetoric that casts the chronic pain figure as suspect, lazy, difficult to manage, and drug-seeking. Furthermore, as long as silence surrounds pain it will be

⁵ Disability rhetoric is a subfield of rhetoric and composition. Disability rhetoric scholars (see, for example, Brueggemann; Dolmage; Dunn; Kerschbaum; Lewiecki-Wilson; Price; Vidali) adopt or integrate disability studies research, perspectives, and theory into their rhetoric scholarship. They argue that naming, cultural practices, institutions (both educational and medical), media representations of persons with disabilities, and hegemonic ableism contribute to the rhetorical construction of disability.

denied a voice and millions of persons with chronic pain will remain undiagnosed and undertreated.

Even more troubling are recent statistics from the International Study of Pain that show that the risk of suicide for persons with chronic pain is roughly twice as high than for other people and that 17% of those in chronic pain who are not actively suicidal often wish they were dead (Foreman, *A Nation*). These statistics, I argue throughout this dissertation, are in large part a product of problematic rhetorics of chronic pain. Suicide is not the only deadly consequence of misunderstanding, silencing, and fearing pain. Disability studies scholar Tobin Siebers also warns in his essay “In the Name of Pain” that as long as pain is silenced, people will continue to fear it and conclude that a “painful life is a wrongful life” (186). The ramifications of such fear, Siebers argues, have resulted and can continue to result in the termination of those lives deemed by others as a “life not worth living” (184). He points to the euthanasia of Terri Schiavo and the forced mutilation and sterilization of Ashley X⁶ as the terrible and frightening consequences that come from the rhetorical assumption that pain is synonymous with suffering and that those in pain do not have a life of value. Siebers is one of few disability studies scholars who takes up pain in his scholarship and by doing so demonstrates its necessity. However, without the support and understanding of more disability activists, disability scholars, and disability rhetoric scholars, persons with chronic pain will continue to be problematically defined solely by the media, the medical community, and framed by pharmaceutical advertisements. Hence, this

⁶ Ashley X was born with cerebral palsy. In 2006, her parents legally induced a medical state of permanent pre-pubescence in their daughter at the age of six by surgically removing her breast buds and uterus and by placing her on high doses of estrogen to stunt her growth. Her appendix was also removed. Later these procedures became known as the Ashley Treatment. Despite the controversy and the overturning of the ruling years later, her parents defended their actions in the name of reducing their daughter’s pain (Siebers 85).

dissertation argues that chronic pain should be theorized as a disability. As such, it is the ethical responsibility of disability rhetoric and the larger disability studies community to account for persons with chronic pain by making visible the oppressive discourses and distorted representations of the chronic pain figure in medical and public contexts.

Problematic Rhetorics of Chronic Pain

Sitting in a restaurant was agony if the table was too high, which forced my arms and shoulders up. So was sitting in the movies, looking up to see the screen. Shifting from sitting or kneeling on the bed to lying down was excruciating—there is simply no way to do it with a bad neck. So, new, shocking, and incomprehensible was all this that I felt utterly alone, convinced that no one had ever felt like this before. But, of course, I was not alone. America, as I soon discovered, was then—and is still—in the midst of a chronic pain epidemic.

—Judy Foreman, *A Nation in Pain*

The fact that fifty million Americans suffer from chronic pain does not comfort me. Rather, it confounds me. “This is not normal,” I keep thinking. A thought invariably followed by doubt, “Is this normal?”

—Eula Biss, “The Pain Scale”

Pain is tragic. Pain is suffering. Pain is subjective and deeply personal. A painful life is not thought of as a human life. Pain is inexpressible. The words for pain—hurt, throbbing, aching, burning—are inadequate in the face of the feeling. Pain is un-American, not part of the pull yourselves up by your bootstraps mentality. Pain is temporary. Pain is something that happens to “others” (usually “exotic” foreigners) over “there” (usually in “third-world” countries). Pain is

always unpleasant. To be in pain is to be against God. A painful life is easily terminated. These are just a few of the commonplace beliefs regarding pain.

And yet despite these commonplaces, many of us know little of the realities of lives in pain or that chronic pain has reached “epidemic” proportions. Here are the figures: According to a 2011 report by the Institute of Medicine, 100 million Americans live in chronic pain (Foreman, *A Nation*). Of those 100 million, 60 million are partially or totally disabled (Morris). Yet, these numbers are low estimates because they do not account for adolescents, children, and infants who also experience chronic pain. Also, the actual number of persons with chronic pain is said to be difficult to determine because pain is underreported. The stigma brought on by cultural, religious, and social interpretations of the meaning of pain is most likely the reason pain is underreported (see Morris; Goldberg). Still, even with a low estimate, the American Academy of Pain Medicine reports that pain affects more Americans than cancer, diabetes, and heart disease combined (Mintz) and yet only about one percent of the \$30.8 billion [2012] budget for the National Institutes of Health [NIH] is devoted primarily to pain research (Foreman, *A Nation*). Likewise, the fact that medical schools require doctors to have, on average, less than 31-to-41 hours of pain education (veterinary students receive more than twice that much) (Foreman, *A Nation*) is evidence of the lack of seriousness with which pain is regarded by the medical profession.

It is also important to note that chronic pain is not just an American problem. The most recent worldwide figure puts the chronic pain population at 1.5 billion (Borsook). The British Pain Society estimates that nearly 10 million citizens of the United Kingdom suffer from chronic pain and The Canadian Pain Society offers a similar figure. In addition, the International Association for the Study of Pain [IASP] claims that chronic pain is the number one reason for

patients to seek medical attention and that pain relief has become a multi-billion-dollar industry (Mintz). The cause of such high numbers of persons with chronic pain is in part due to, but not limited to, longer life-spans, improper surgical post-op treatment, medical professionals' insufficient knowledge of treatments for chronic pain, health professionals' lack of empathy for persons with chronic pain, and federal research underfunding of chronic pain conditions.

With such staggering statistics, it is difficult to comprehend why the problem of chronic pain has not received more attention from medical professionals, disability advocates, and the fields of disability studies and disability rhetoric. The fact that chronic pain is what leading pain scholars refer to as “bad” or “ugly” pain is indicative of its disfavor among scholars, advocates, and physicians (see especially Cervero; Dahl and Lundgren; Schleifer). Unlike acute pain, or “good” pain, which is described as temporary, productive, and, at times, life-saving (since it functions as the body's alarm system to indicate harm), chronic pain is often described as meaningless since it is believed to send messages of danger that are not real. Pain researchers explain that “chronic pain is not protective; its intensity bears no relation to the amount of tissue damage and may in fact, arise without any damage at all. It is like a broken alarm that rings continuously, signally only its own brokenness” (Thernstorm 44). As witnessed in this brief excerpt, the rhetoric surrounding chronic pain is disheartening and might in fact cause persons with chronic pain and their loved ones additional suffering.

Also, most unfortunate is that the rhetoric surrounding the uselessness and suspicious nature of chronic pain is placed on pain patients. Such problematic rhetoric (that those with chronic pain are somehow responsible for their pain) is prevalent not only in the medical profession but also in sociopolitical, legal, economic, and public media contexts, which results in stigma and isolation felt by those living with chronic pain (specific cases of problematic rhetorics

of chronic pain will be discussed in chapters 3 and 4). This rhetoric of blame echoes past and present religious beliefs that pain is a punishment for those who have sinned.⁷ Blame and suspicion of the chronic pain patient are also heightened by the fact that since most chronic pain conditions are invisible (they fail biotechnology by not appearing in most imaging testing such as X-rays, MRIs and Cat Scans) they are easily contested and so are the patients claiming to experience pain. Chronic pain patients often report feeling stigmatized and ostracized by the very healthcare professionals they seek treatment from.

Ethnographer Jean E. Jackson, working on a study involving chronic pain patients at the Commonwealth Pain Center, posits that the stigma is a consequence of the fact that chronic pain conditions confound biomedicine because pain does not correspond to known physical pathology and challenges mind-body dualism (332). I would also add that persons with chronic pain cause uneasiness in others (not just healthcare workers) because they cannot be adequately defined as either “sick” or “healthy,” but exist somewhere in an in-between state. In addition, most people understand pain as a symptom that accompanies an illness, but for those with chronic pain the pain becomes its own disease. The fact that women disproportionately to men seek medical care for chronic pain also discredits chronic pain conditions such as fibromyalgia, migraines, chronic fatigue syndrome, gastrointestinal disorders, and complex regional pain syndrome, which are frequently dismissed as the “hysterical” imaginings of emotional females.⁸ Another reason for the poor reputation of the chronic pain patient is that we require a lot of physicians’ time since

⁷ Disability rhetoric scholars James C. Wilson and Cynthia Lewiecki-Wilson locate the origins of the rhetoric of blame in the Christian Rhetorical Tradition that demonizes the disabled. They write, “The religious concept of affliction, casting disability as corporeal testimony of sin and punishment, was an embodied rhetoric persuading Christians of the power of God and the doctrine of the church” (“Disability, Rhetoric, and the Body” 15).

⁸ Most chronic pain conditions are gendered female. Amy Vidali explains in further detail the medical industry’s phenomenon of the “hysterical female” in her essay “Hysterical Again.”

our conditions are not easily treatable. Ultimately, taking all of the above into consideration, it is no wonder that the chronic pain patient is dismissed by the medical profession, the media, and even, at times, family members and friends as lazy, deceitful, and drug-seeking.

Perhaps the conflation between the drug addict and persons with chronic pain is one of the most damaging and distorted problematic rhetorics of pain covered in this dissertation. This is because many persons with chronic pain believe the rhetoric from the medical profession and fear that they will become addicts and therefore do not seek opioid pain medication; those that do have difficulty gaining access to them. Not surprisingly, then, pain researchers estimate that one third of chronic pain patients who need opioids do not receive them (see especially Foreman, *A Nation*). Medical writer and chronic pain “survivor” Judy Foreman notes that The Institute of Medicine refers to this conflation as an *opioid conundrum*: “People with chronic pain (often older people with no history of substance abuse) can’t get the opioids they need and could probably use responsibly while street abusers, often young people, get them all too easily” (127). For instance, in order to receive opioid medication for the treatment of chronic pain, many patients are forced to sign “pain contracts” (further information on pain contracts can be found in chapter 3). These pain contracts blame persons with chronic pain for their inability to control their pain while relinquishing doctors’ responsibility if the patient becomes addicted to the prescribed medication. In addition, the pain contract regulates persons with chronic pain by restricting them to access only one provider for pain medication prescriptions. Furthermore, each refill requires a doctor’s appointment, which is costly for those with insurance and impossible to acquire for those without insurance, thereby cementing the subjugation of persons with chronic pain and, in particular, those of low socioeconomic status.

The problematic rhetorics of chronic pain discussed above are just some of the exigent reasons why it is necessary for chronic pain syndromes to be considered disabilities and worthy of study and advocacy by rhetoricians, disability studies scholars, and the disability rights movement. However, before closing this section, I wish to touch upon two more exigent reasons why chronic pain syndromes need to be acknowledged as disabilities. Without being recognized as disabled by the disability rights movement and the disability community, persons with chronic pain have extreme difficulty being awarded Social Security Disability Benefits and employment protection under the Americans with Disabilities Act (ADA). As legal disability scholar Elizabeth Emmons points out, court decisions often reflect societal beliefs and popular opinions. Perhaps that explains why most chronic pain syndromes do not appear on the Social Security Administration's (SSA) List of Impairments, which assists in determining disability benefits. Likewise, despite the broadened definition of disability brought forth by the 2005 Americans with Disabilities Amendments Act (ADAA), persons with chronic pain syndromes rarely receive employment protection and reasonable accommodations because of the distorted representation of the chronic pain figure and their reputation as financial burdens.⁹ Furthermore, since chronic pain has not been considered a disability by disability advocates or scholars, not much thought, if any, has been given to the kinds of "reasonable" accommodations the ADA might be able to provide persons with chronic pain so they can maintain or gain employment. Without accommodation suggestions and requests, it is difficult for judges to conceive of the ways in

⁹ Being considered a financial burden to society is not a new experience for the disabled. However, still surprising is the amount of space that national pain organizations spend on detailing the costliness of chronic pain to the workforce rather than providing information on chronic pain conditions and advocacy for the very persons they are supposed to represent.

which the ADA can protect equal employment opportunities and job security for persons with chronic pain.

Alternative Rhetorics of Chronic Pain

Theorizing alternative rhetorics of chronic pain is a feminist project, a disability studies project, a rhetoric and composition project, and most definitely a disability rhetoric project. What these fields have in common is their commitment to working for social justice by challenging the inequities found in normalized language practices and by recovering subjugated, marginalized, and oppressed populations who have been silenced and deemed by dominant society as both failed rhetors and failed human beings. The work of this dissertation, then, is to combine these fields and their projects in order to provide a presence for persons with chronic pain in their scholarship and practices as well as in their social justice work inside and outside of academia. Perhaps then we can carve out a path to providing symbolic, material, and structural changes in the way that chronic pain and persons with chronic pain are represented, understood, and treated by society-at-large. However, this path cannot be carved out without first addressing the overwhelming scholarship and public opinion that declares that because pain is deeply personal and subjective, communication with those outside of the experience of pain is impossible¹⁰. To accept this belief as truth, I argue, is to close the door to the possibility that pain is rhetorically generative, provides insight into the human condition, and has value for persons in pain, the disability community, and *all* bodies.

¹⁰ Most scholarship on pain historically comes from the field of trauma theory. Leading trauma theorists such as Elaine Scarry, Cathy Caruth, and Dori Laub contend that the experience of pain is not representable to others, and even to oneself, because the trauma of pain shatters the human subject and fractures language.

Before continuing further, I want to put to rest any suspicion that what I am suggesting by advocating that chronic pain be viewed as a valuable experience is that pain is a gift or a blessing. Acknowledging that a life in pain can also be full of joy and love and community does not negate the material reality that pain can at times be terrible, feel unbearable, and cause loneliness and fear. But if that is all we know about pain, the terrible part, as medical, pharmaceutical, legal, and even public rhetoric suggests, then those with chronic pain will believe that their lives hold no meaning or value. For this reason alone, the need for alternative rhetorics of chronic pain is undeniable.

Alternative rhetorics of chronic pain, then, would need to respond to disability rhetoric scholar Jay Dolmage's call for a new "futuristic" disability studies that "will not be about the eradication of disability, but about new social structures and relationships, made possible by new rhetorics" (2). Such new productive and generative rhetorics of chronic pain have the potential to add to the future of rhetoric and composition and disability studies by laying the foundations for a more expansive definition of disability that welcomes persons with chronic pain. In addition, by claiming a disability identity, persons with chronic pain will benefit from the support that comes from being a part of a shared community.

Chapter Overview

Chapter 2, "Theorizing a Political-Relational-Rhetorical Methodology: Providing a Presence for Persons with Chronic Pain in Scholarship and Practice," provides an overview of the theoretical frameworks that inform this dissertation and describes my political-relational-rhetorical methodology. This methodology puts disability scholar Alison Kafer's political-relational model of disability, which accounts for both the material realities of living with a disability and the socio-political construction of disability, into conversation with disability

rhetoric and feminist rhetorical theory. In doing so, it becomes possible to account for persons with chronic pain in the fields of disability studies, disability rhetoric, and feminist rhetorics by allowing for the theorization of chronic pain as a disability, establishing the communicability of pain, and, most importantly, making it possible to imagine the future of disability differently by honoring and valuing the lives of persons with chronic pain.

In Chapter 3, “Toward a Re-Imagining of Chronic Pain: Disabling Rhetorics of Suffering and Surveillance,” I analyze, critique, and intervene in problematic rhetorics of chronic pain that dehumanize and threaten the lives of persons with chronic pain. Specifically, this chapter investigates and intercedes in the proliferation of two of the most insidious problematic rhetorics of chronic pain: rhetorics of suffering and rhetorics of surveillance. The former (rhetorics of suffering) equates living with chronic pain as a “nightmare” and a “curse” and, in so doing, insists that a life in pain holds no value, while the latter (rhetorics of surveillance) regulates, punishes, and criminalizes persons with chronic pain for not being able to control their pain. In order to narrow my range of analysis, I analyze and critique one problematic text for each type of problematic rhetoric: medical journalist Melanie Thornstrom’s *The Pain Chronicles: Cures, Myths, Mysteries, Diaries, Brain Scans, Healing and the Science of Suffering* to illustrate rhetorics of suffering and the “pain contract” as an example of rhetorics of surveillance. Following these analyses, I argue that without intervention from disability studies scholars and disability rhetoricians, persons with chronic pain will continue to be defined solely by dangerous and oppressive medical and public discourses and as a result will be further marginalized and stigmatized.

In the fourth chapter, “‘Relaxed, but not lazy’: Rhetorics of Rehabilitation and the Making of the Chronic Pain Patient,” I build on the previous chapter’s investigation of problematic

rhetorics of pain by analyzing the rhetorics of normalcy and rehabilitation in a particular site of medical discourse—the Mayo Clinic’s Comprehensive Pain Rehabilitation Center (PRC) patient manual. By doing so, I reveal how biomedicine uses the rehabilitation approach to disability and the “myth of control” (Wendell) to silence and regulate persons with chronic pain whose “deviant” bodies threaten the health of the nation-state.¹¹ In addition, as a former patient of the PRC, I engage with my lived experience to show how the program’s practices reinforce and perpetuate the manual’s problematic rhetorics. I pay particular attention to the manual’s section on “Forbidden Pain Behaviors,” which disciplines patients with the threat of expulsion from the center who speak about and use the word *pain*. The value of this particular chapter is that it considers the ways medical discourse, as evidenced through the Mayo Clinic’s Comprehensive Pain Rehabilitation Center patient manual, purposefully denies a language of pain by making such expression unspeakable.

In Chapter 5, “Changing the Status Quo: Listening to Alternative Rhetorics of Chronic Pain,” I turn away from those in dominant positions of power and their use of problematic rhetorics of chronic pain and listen instead to those who live with chronic pain and have different stories to tell. These stories offer alternative rhetorics of chronic pain that disrupt stigmatizing representations of chronic pain and persons with chronic pain and instead provide more genuine and honest interpretations of chronic pain. As a result, these rhetorics reveal how pain is a valuable, insightful, and a necessary part of the human condition. Next, I explain how alternative rhetorics of chronic pain challenge normative language practices and allow for greater access to

¹¹ To argue that persons with disabilities are seen as a problem for a modern nation-state that relies on homogenized standard bodies in order to survive, I will be using Michel Foucault’s term biopower—a political-judicial-institutional state—that relies on the control of the normalization of bodies. In addition, I will be forwarding disability studies scholar Lennard Davis’s own use of this term in *Bending Over Backwards*.

and multiple ways of knowing chronic pain and its effects on those living with chronic pain conditions. To best show how alternative rhetorics of chronic pain do this work, this chapter analyzes PainExhibit.org, an online chronic pain art exhibit that functions as an alternative and generative rhetoric of chronic pain.

Chapter 6, “Collective Affinities: Normalcy, Intersectionality, and Multimodality in Disability-Themed Writing Courses,” is devoted to analyzing my article “Investigating Students’ Reception and Production of Normalizing Discourses in a Disability-Themed Advanced Composition Course,” published three years ago in *Disability Studies Quarterly*, and reflects on the class that informed that article through the lens of this dissertation’s political-relational-rhetorical methodology. The aim of this reflection is to gain insight into my evolving pedagogy and to consider ways of improving a future iteration of this course based on the new knowledge I have gained through the researching and writing of this dissertation. Some of the issues I reflect on in relation to “Investigating” and my “Discourses of Normalcy” class are: subjectivity, normalization, intersectionality, “white disability studies,” and multimodality.

Lastly, in the “Epilogue” of this dissertation I return to the question posed in the “Prologue” concerning the communicability of chronic pain and reveal how my own lived experience with chronic pain enables me to conclude that pain generates rather than destroys language. In addition, the “Epilogue” recognizes the limitations of my dissertation and points to further inquiries into the relationship between pain, rhetoric, and disability. These inquiries also suggest areas of scholarship that still need to be pursued by scholars in the fields of rhetoric and composition, disability studies, medical rhetorics, and feminist rhetorics in order to continue to provide a presence for persons with chronic pain and account for chronic pain in our research and practice.

CHAPTER II

THEORIZING A POLITICAL-RELATIONAL-RHETORICAL METHODOLOGY: PROVIDING A PRESENCE FOR PERSONS WITH CHRONIC PAIN IN SCHOLARSHIP AND PRACTICE

In order to support the arguments of this dissertation—that pain is rhetorical and needs to be theorized as a disability in disability studies, disability rhetoric, and feminist rhetorics—I will first outline the theoretical frameworks that inform this project and describe the hybrid-methodology I will be using to provide a presence for chronic pain and persons with chronic pain in the above-mentioned fields. In so doing, I will also enact a core principle of disability studies, disability rhetoric, and feminist rhetorics—to make transparent the theories that inform my work—with the aim of being an ethical and responsible scholar.

Disability Studies

Although growing steadily, the interdisciplinary field of disability studies is relatively new to the academy. Disability studies first appeared in academia, specifically in the social sciences, as an outgrowth of the 1960s political movement of disability rights activists and organizations across the world. Both disability studies scholars and activists critique the commonplace belief that disability is an individual tragedy needing to be overcome. In contrast with Western medicine's prevailing medical model of disability that locates disability as an individual, biological "defect" to be "fixed" or "cured," disability studies have long adopted a social model of disability, also known as the British model of disability, coined by sociologist and disability scholar Michael Oliver. Oliver and fellow British disability sociologists Len Barton and Colin Barnes use the social model of disability to show that "disability" is a sociopolitical, historical, and economic category and a form of social oppression that further

stigmatizes an already marginalized population (Barnes; Barnes et al.; Barton; Barton and Oliver; Oliver; Thomas). The social model of disability has been taken up and forwarded many times over by disability scholars and activists since its advent and now is a key element of disability studies theory. As such, it makes possible important critiques of ableism, the construction of normalcy, disabling and discriminatory attitudes and practices, inaccessible buildings, and other social barriers in education, housing, employment, transportation, political rights, and healthcare.

Primarily written by scholars with lived experiences of disability, scholarship in the field crosses the disciplines of history (Longmore; Schweik); social sciences (Barnes et al.; Goffman; Oliver); cultural studies (Mitchell and Snyder; Shakespeare; Siebers); English language and literature (Davis; McRuer; Stoddard-Holmes); feminist and queer studies (Garland-Thomson; Kafer; Lindgren); philosophy (Wendell); health and medicine (Barton; Segal); life-writing (Couser; Jureic; Kleege; Mairs); and rhetoric and composition (Brueggemann; Dolmage; Dunn; Jung; Kerschbaum; Price; Vidali; Yergeau; Wilson and Lewiecki-Wilson). Although disability studies is an interdisciplinary field, as evidenced by the above, scholars in disability studies are joined together by their core beliefs.

One crucial belief held by scholars and activists in disability studies is that disability is a positive identity that forges a thriving, supportive, inclusive community with power and agency for social change. As a community, disability studies scholars and activists are also united in their aims to: [1] expose the two-thousand-year history of the exclusion of persons with disabilities from civic and public life, with particular focus on eugenics, genetic testing, institutionalization, and the limitations of Americans with Disabilities Act (ADA) legislation; [2] reclaim the body from the colonization of biomedicine; [3] reassign meaning to the terminology

used to oppress persons with disabilities (see especially Linton); [4] rewrite commonplace narratives that represent persons with disabilities as tragic, pitiful figures who need to be rescued (see especially Couser); and more. I share these core beliefs, which direct and inform the phenomena I choose to analyze, challenge, and contest in this dissertation: problematic rhetorics of chronic pain. Unfortunately, scholarship on chronic pain in the field of disability studies is lacking, due in part to the limitations of the social model of disability, which I describe in more detail below.

Despite the commonality of beliefs between disability studies scholars across the disciplines, there exist some tensions in the field, particularly in regards to the social model of disability. While some scholars and activists maintain strict allegiance to the social model of disability, including Michael Oliver and many of the British sociologists, other scholars find the social model limiting because it fails to acknowledge pain, which disability scholar Tobin Siebers claims is often the cruelest reality of living with a disability:

Many people with disabilities realize that pain is an enemy. It hovers over innumerable daily actions, whether the disability is painful in itself or only the occasion for pain because of the difficulty in navigating one's environment. The great challenge every day is to manage the body's pain, to get out of bed in the morning, to overcome the well of pain that rises in the evening, to meet a hundred daily obstacles that are not merely inconveniences but occasions for physical suffering. (*Disability* 72)

Just from this brief quote it is clear why pain and disability are rarely discussed together in the field of disability studies. Even those scholars who, like Siebers, call for a reimagining of the social model of disability that “would raise awareness of disabling environments on people's lived experience of the body” (25) agree that during the early days of the disability studies

movement it made strategic sense to distinguish pain from other disabilities for timely political and social justice aims. For example, in order to argue that disability was a societal creation and not a tragic medical condition worthy of pity and rehabilitation, it was necessary to divorce pain and impairment from disability, causing what would become a disability/impairment binary in the field. More recently, and despite some scholars' still strict adherence to the social model of disability, critiques of the social model's disability/impairment binary (see especially Crow; Kafer; Shakespeare; Siebers; Wendell) have gained momentum in the last fifteen years. However, the fact that a new model of disability has failed to take hold is evidence of the power and endurance of the social model. The rigidity of the social model, I argue, is a primary reason why chronic pain and persons with chronic pain are not fully accepted into disability studies and the disability community.

Disability, feminist, and philosophy scholar Susan Wendell's critique of the social model of disability perhaps speaks best to this dissertation's claims that persons with chronic pain are still stigmatized within disability studies and that chronic pain needs to be theorized as a disability. Writing from her lived experiences with myalgic encephalomyelitis/chronic fatigue immune dysfunction syndrome (ME/CFS), Wendell further delineates the social model's impairment/disability binary as a division between those disabilities considered "healthy" and those considered "unhealthy." She explains that the "unhealthy" or "bad" disabled are usually associated with persons who are sick, in chronic pain, diseased, chronically ill, and in need of medical treatment (i.e., ME/CFDS, MS, fibromyalgia, endometriosis, HIV, AIDS, lupus, Lyme's disease), whereas the "healthy" or "good" disabled are associated with persons who have stable

conditions (i.e., blindness, deafness, paraplegia) and are not in need of medical treatment.¹²

Wendell explains that the disability rights movement is reluctant to accept persons with “unhealthy” disabilities into their community because they contradict the movement’s aim to de-medicalize disability. Wendell disagrees and adds that all persons with disabilities, even those considered “healthy,” have recurrent health problems.

What is also exigent about Wendell’s work to this dissertation is that she considers what is at stake when persons with chronic pain and illness are convinced that they are not deserving of a disabled identity. Without the option to claim disability, persons with chronic pain feel greater shame and responsibility for not being able to control their pain and are unable to receive the material, social, and emotional support that can come from claiming a disability identity. They are most likely, she writes, to try to “pass” as able-bodied or lose their employment. Furthermore, they feel further isolation for having illegitimized illnesses and, as a result, lack friends and familial support. Wendell believes that by dismantling the disability/impairment divide, *all* persons with disabilities would have the freedom to discuss the material effects of living with a disability. For example, she imagines that many persons with disabilities in the disability rights movement have pain and fatigue, which they keep secret in order to be considered “good” activists. Although Wendell is not a rhetoric scholar, it is important to note that all of the above discussion aligns with the work of this dissertation to not only critique problematic rhetorics of chronic pain, but to also show the dangerous effects of such rhetorics on those who live with chronic pain.

¹² Wendell’s discussion of the “healthy” and “unhealthy” disabled is reminiscent of the medical profession’s description of chronic pain as “bad” or “dirty pain” as explained in chapter 1 of this dissertation.

Although this would be a good place to move on to the section on disability rhetoric, I want to first give space to another key concept of disability studies theory: access. To begin, I want to stress the fact that the concept of access from a disability studies perspective differs greatly from how it is perceived by an ableist society. Outside of disability studies and the disability experience, the term *access* has become a buzz word used by legislatures, institutions (both medical and educational), politicians, the marketplace, and social media, promising inclusion and participation of “disadvantaged groups” and other marginalized communities into mainstream society. As a result, *access* becomes a term that has been co-opted by bureaucratic institutions to include some bodies over others while masking discrimination as “natural” exclusion and further stigmatizing persons with disabilities through surveillance and regulation. In such a way, access is defined and determined not by those who need it but by those who already have it. As a consequence, access in an ableist society becomes a privilege rather than a human right. This conceptualization of access contrasts greatly from how access is defined in disability studies and by disability advocates.

Access, as understood by the disability studies community, is more than just a question of inclusion and accommodation, but rather, as Tanya Titchosky describes, “a complex form of perception that organizes socio-political relations between people in social space” and “an insight into how disability is perceived by the able-bodied” (9). Most, if not all, disability studies scholars share Titchosky’s conception of access. Aimi Hamraie, whose work is situated in architecture and disability, adds: “The very presence of stairs *argues* for a particular understanding of citizenship—one defined by the ability to climb steps—that results in an implicit and potent exclusion of people with mobility or sensory disabilities from the symbolic and physical aspects of space.” In *Crip Theory*, Robert McRuer writes, “[A]n accessible society,

according to the best, critically disabled perspectives, is not simply one with ramps and Braille signs on ‘public’ buildings, but one in which our ways of relating to, and depending on, each other have been reconfigured” (1). Hence, these three disability scholars and activists make it clear that access is more than just a bureaucratic false promise of inclusion. Instead they reveal that access is a concept that *does* work.

Doing access from a disability studies perspective means creating spaces where human difference is not only valued but encouraged. It means questioning assumptions about normalcy and abled-bodiedness and challenging unquestionable truths such as “you can’t accommodate everybody” and “it’s always been this way.” Most importantly, access is a concept that enables and constrains what we think we know about disability and it opens up the possibility of knowing disability differently—as already belonging to the fabric of social life. The importance of understanding these conflicting conceptions of access is vital to the arguments of this dissertation. For example, it makes it possible to explain how persons with chronic pain are simultaneously promised and denied access in fundamental ways, particularly in relation to healthcare and other human rights.¹³

Disability Rhetoric

As noted in chapter 1, my work is situated primarily in the field of disability rhetoric. As mentioned in that chapter, disability rhetoric scholars integrate disability studies research and theory into their scholarship and practice. Because they share the core beliefs of disability studies discussed above, disability rhetoric scholars also function as a voice for marginalized persons and groups who are stigmatized and oppressed by hegemonic discourses. Disability rhetoricians

¹³ For further discussion of access as it relates to persons with chronic pain, please see chapter 3, “Toward a Re-Imagining of Chronic Pain” and chapter 4, “Relaxed, but not lazy”.

argue that acts of naming, institutions (both educational and medical), media representations of persons with disabilities, and hegemonic ableism contribute to the oppressive rhetorical construction of disability (see especially Brueggemann; Dolmage; Wilson and Lewiecki-Wilson). Since language practices are a primary domain of rhetoric, scholarship in disability rhetoric concentrates on the way bodies are constructed through language and how labels are used to marginalize persons with disabilities, particularly by scientific discourses that claim to be “natural” and “objective” (Lewiecki-Wilson and Dolmage). Consequently, disability rhetoricians aim to reframe disability as positive difference rather than “deviance,” showing that bodily difference can have rhetorical value.

Other inquiries in disability rhetoric focus on recovery work (see especially Dolmage); issues of access in higher education (especially in the composition classroom) (Dolmage; Dunn; Kerschbaum; Price; Jung; Vidali) and the rhetorical construction of particular disabilities such as deafness (Brueggemann, *Lend Me*); neuroatypical conditions such as autism and Asperger’s syndrome (see especially Yergeau); muscular sclerosis (Krummel; Mairs); learning disabilities (Dunn); functional gastrointestinal disorders (Vidali, “Hysterical Again,” “Out of Control”); and mental illness (Lewiecki-Wilson; Prendergast; Price). However, missing from this list is chronic pain. Possible reasons for this absence, as mentioned earlier in this chapter and in chapter one, include the limitations of the social model of disability, skepticism over chronic pain as a legitimate disability, and problematic representations of the chronic pain patient.

Another possible reason for the lack of scholarship on chronic pain is the construction of normalcy. Analyzing and critiquing rhetorics of normalcy is fundamental to the work of disability rhetoric. Indeed, disability rhetoric scholar Jay Dolmage refers to the norm as the rhetorical center of disability (*Disability* 21). Most discussions on rhetorics of normalcy in

disability rhetoric begin with disability studies scholar Lennard J. Davis's work on the construction of normalcy. First theorized in *Enforcing Normalcy*, Davis explains that the concept of the norm is a fiction, or rather an ideology, constructed by the most powerful to dominate and oppress the most vulnerable. Davis traces the roots of the construction of normalcy to the concept of the bell curve, invented by 19th-century Western European statisticians, that was used to construct the "average man" and to separate the desirables from the undesirables, the normal from the abnormal, and the abled from the disabled. Still prevalent today, the bell curve locates those who fall beneath the curve as deviants. Thus, persons with disabilities, since the advent of the bell curve, have been and are continued to be viewed as deviants. Davis adds that "under the rubric of normality, there is an imperative for people to conform, to fit in, to strive to be normal, to huddle under the main part of the curve" (*Bending* 105).

What is most interesting about Davis's last statement is that it shows how the concept of normalcy does rhetorical work on persons with disabilities. It hints at both the external and internal pressures that persons with disabilities have to pass as able-bodied and conform to a normalizing society. The ability to pass as able-bodied in a society in which the norm operates, no matter how difficult, can externally save some persons with disabilities from further stigmatization, marginalization, oppression, and economic hardships. But perhaps even more significant is the ways in which the concept of the norm can work internally on persons with disabilities to feel shame and blame for not being "normal" and for their inability to control their disabilities. This discussion is vital to understanding the ways in which the concept of the norm

is used by the medical establishment and normates¹⁴ to discipline and punish persons with chronic pain.

Disability rhetoric scholars attribute the process of normalization and the policing of norming to the rise of medicine and science. This rise, explains Cynthia Lewiecki-Wilson and Jay Dolmage in “Refiguring Rhetorica,” “further schematized and multiplied categories of bodily deviance and deformity” (29), resulting in the medical model of disability, which casts disability as a personal deficit needing to be cured. In so doing, they explain:

The modern medical paradigm has done more than categorize and control people with disabilities: It has enforced sterilization, institutionalization, and eradication—a history of oppression that disability scholars are now recovering and studying. (29)

In conclusion, they argue, “how we see others and ourselves is shaped by the medical-scientific paradigm, which is in turn shaped by disability and normativity” and “that it is only against an othered body that the normal body is allowed to perpetuate this deceit” (31).

The importance of the above logic, that in order for the normalizing process to be enforced there needs to be both a normal and another dichotomy, is crucial to recognizing how persons with chronic pain are able to be disciplined and punished for not managing to control or hide their pain through passing. For, as long as there is the belief that normalcy is attainable, persons with chronic pain will be expected to reach such a state through rehabilitation. As a

¹⁴ The term normate was coined by feminist disability scholar Rosemarie Garland-Thomson and is defined as “the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them” (8).

result, chronic pain patients are frequently sent to pain clinics where the main goal is not treatment for pain but rather a return to normalcy through passing (for further discussion see chapter 4, “Relaxed, but not lazy”). Given all of this context, it is an ethical imperative for disability rhetoric scholars to critique and intervene in such problematic rhetorics of chronic pain by redressing the hegemony of the norm. By doing so, the field of disability rhetoric can begin to provide a presence for persons with chronic pain in their scholarship and practice.

Feminist Rhetorical Studies

Feminist rhetorical studies emerged as a discipline within the field of rhetoric and composition in the eighties and early nineties amongst much resistance and criticism. Prior to that time, the dominant, Western-centric history of rhetoric focused on works by ancient philosophers such as Aristotle, Cicero, and Quintilian and then named this one history “the rhetorical tradition.” Women were missing from this version of rhetorical history. Since they deviated from the norm—male embodiment—they were cast off from civic and public life and were dismissed as unfit rhetors¹⁵. Likewise, women professors in America were pushed to the margins, ignored, silenced, or viewed as what feminist rhetorician Gesa Kirsch describes as “museum pieces, curious objects to be noted but not central actors in shaping academic institutions.” (5). Considering this history, it is not surprising that much of the early work in feminist rhetorical studies centers on reframing Western rhetorical history and reclaiming women rhetors from the margins of that history (see especially Glenn; Jaratt; Logan; Lunsford; Powell; Royster).

¹⁵ Cynthia Lewiecki-Wilson and Jay Dolmage explain that “rhetorical fitness came to be described to just a narrow range of (white, male, able) bodies” and that those outside this range were deemed unfit rhetors (“Refiguring” 27).

Yet, feminist rhetorical studies refused to remain stagnant. Although recovering women rhetors and reclaiming rhetorical history continues to be important work in the field, feminist rhetorical studies is also invested in expanding rhetorical sites of inquiry by including globalization, transnational rhetorics (Dingo; Hesford; Hesford and Schell), technological environments (see for example, Blair and Takayoshi; Haas; Hawisher and Selfe), and rhetorics of science (see for example, Condit; Jack; Jung, “Systems”; Wells) in their scholarship and practices. In addition, feminist rhetorical scholarship expands the reach of the field of rhetoric and composition by challenging what counts as rhetoric and questioning the dominance of traditional, linear, white-male-oriented, alphabetic texts as elitist and normalizing (Dolmage; Haas; Hawisher; Royster; Selfe; Shipka). Furthermore, feminist rhetorics widens the scope of rhetoric and composition studies by participating in interdisciplinary scholarship through gendered analyses of a variety of social, medical, and political texts and discourses (see, for example, Emmons; Segal; Vidali, “Out of Control”). Guiding all of these inquiries are the following core commitments of feminist rhetorical research methods and methodologies: accounting for one’s own subjectivity, destabilizing gendered norms, acknowledging one’s own embodiment, practicing self-reflexivity, utilizing strategic contemplation¹⁶, and engaging in ethical and responsible action.

I share the above core commitments, which are fundamental to the work of this dissertation. For instance, like scholars in disability studies, feminist rhetoricians challenge assumed norms, such as assumptions about who counts as a rhetor and is therefore worthy of historical study (see especially Logan; Powell; Royster, “Disciplinary”; Royster, *Traces*).

¹⁶ Coined by Jacqueline Jones Royster and Gesa E. Kirsch, strategic contemplation refers to the research method of “deliberately taking the time, space, and resources to think about, through, and around our work as an important meditative dimension of scholarly practice” (21).

Similarly, by challenging the assumed norm in disability studies about what counts as a disability, my work seeks to recover the experiences of persons with chronic pain as viable and worthwhile subjects of inquiry. In addition, feminist rhetoricians challenge the norms associated with what counts as rhetoric by moving beyond male-dominated discourses and texts to include such genres as letters, diaries, and poetry, as well as calling attention to the importance of material practices with rhetorical functions that are not text-based, such as needlework samplers (Goggin), wampum belts (Haas), and quilts (Derksen). Likewise, my dissertation challenges normative rhetorical practices by investigating alternative rhetorics of chronic pain and analyzing an online chronic pain art exhibit to allow for greater opportunities of access to pain for those without the lived experience of pain.

Another core commitment of feminist rhetorical studies that relates to this dissertation is attending to gender inequality in social, medical, and legal texts and discourses. As discussed briefly in chapter 1, rhetorics of chronic pain are gendered, and women are disproportionately diagnosed with chronic pain syndromes than are men while receiving inferior medical care (for further details, see chapter 3). Perhaps the most crucial commitment of feminist rhetorical research to the project of this dissertation is the field's emphasis on accounting for one's own subjectivity in research practices (see especially Bizzell; Royster and Kirsch; Schell and Rawson). Unlike conventional academic research, Patricia Bizzell explains, feminist rhetoricians challenge the norms of objectivity and detachment by "bringing the person of the research, her body, and emotions, and dare one say, her soul into the work" (qtd. in Schell and Rawson 4). As a feminist rhetor and researcher, I understand that my own experiences with chronic pain shape this dissertation's inquiries and arguments and direct the texts and discourses I choose to study.

A Political-Relational-Rhetorical Methodology

In refusing to acknowledge pain, fatigue or depression, our collective affinity to conceive of, and achieve, a world which does not disable is diminished.

—Liz Crow, “Including All of Our Lives”

Over time, I argue, pain—and whether subjective pain is real pain—came to represent not just a clinical and scientific problem, but a legal puzzle, a heated cultural concern, an enduring partisan issue.

—Keith Wailoo, *Pain: A Political History*

In this section, I develop the political-relational-rhetorical methodology I will use to guide this dissertation. This methodological approach encompasses the core commitments of disability studies, disability rhetoric, and feminist rhetorics and, as an effect, allows for the theorization of pain as a disability, establishes the communicability of pain, and, most importantly, makes it possible to imagine the future of disability differently by honoring and valuing the lives of persons with chronic pain and their contributions to the fields chronicled above. A political-relational-rhetorical methodology achieves the above aims by combining feminist disability scholar and activist Alison Kafer’s political-relational model of disability with disability rhetoric and feminist rhetorical theory. As such, this hybrid methodology makes it possible to conduct the research of this dissertation while also attending to my scholarly and political commitments. For the remainder of this chapter, I will make apparent how Kafer’s new model of disability resonates with my disability-feminist commitments and, in turn, how these commitments extend Kafer’s model of disability. As a result, it will become clearer how a political-relational-rhetorical methodology best serves the arguments of this dissertation.

In *Feminist, Queer, Crip*, Kafer presents an alternative to both the problematic individual/medical model of disability and the limited social model of disability discussed earlier in this chapter. Kafer characterizes her political-relational model of disability as a “friendly departure” from the social model of disability. Although she recognizes that the social model rightly exposes the social barriers that often lead to disability, she argues that the social model’s sharp division between disability and impairment fails to recognize that both are social, and that “simply trying to determine what constitutes impairment makes clear that impairment doesn’t exist apart from social meanings and understandings” (7). In contrast to the belief shared by the majority of disability scholars and activists, she resists the argument that impairment is purely physical, explaining instead that impairment shifts across time and place and is dependent on economic and geographic contexts. Kafer also points out that the impairment/disability binary fails to recognize the often disabling effects of the body. For instance, she writes, “social and structural changes will do little to make one’s joints stop aching or to alleviate back pain. Nor will changes in architecture and attitude heal diabetes or cancer or fatigue” (7). Kafer’s scholarship aligns with disability rhetoricians’ critique that the social model of disability fails to represent the experiences of persons with chronic pain and therefore makes it difficult for this population to find a presence in the disability community and in the field of disability rhetoric. However, by collapsing the impairment/disability divide, Kafer’s political-relational model forges a path to imagine disability differently as an expansive and unfixed category that includes persons with chronic pain and chronic illness and makes it possible to theorize pain as a disability. This is just one example of how Kafer’s model of disability serves the disability-feminist rhetoric commitments of this dissertation.

Also, noteworthy to this dissertation is Kafer's argument that the social model of disability marginalizes persons with pain, illness, and fatigue for simultaneously desiring medical intervention and wanting to identify as disabled. A strict social model, Kafer explains, "casts cure out of our imagined futures; cure becomes the future no self-respecting disability activist and scholar wants." As an effect, Kafer writes, "disability rights activists and disability scholars deny their own feelings of pain and depression for fear of being rejected from the disability community" (8). What is most important about this statement is that it makes visible how *all* persons with disabilities, not just those with chronic pain, are negatively affected by the failure to account for chronic pain in disability studies and in the disability community. Kafer's discussion of the pressure to resist a cure is also reminiscent of Susan Wendell's description of the "good" activist earlier in this chapter. However, what is unique about Kafer's scholarship is that in addition to critiquing the social model of disability for its limitations, she also addresses those limitations by theorizing a new model of disability that attends to the social model's shortcomings as well as its omissions. In so doing, she accounts for the reasons why persons with chronic pain are not represented in disability studies and by activists, while also creating an opening for their presence. The fact that Kafer's model addresses *and* critiques the social model of disability aligns with a core disability-feminist belief that engaging in ethical and responsible action can lead to social change.

Now it is time to take a closer look at the core tenets of Kafer's political-relational model of disability and how they relate to the project of this dissertation. One of these core tenets is that disability is *relational*, meaning it is "experienced in and through relationships" and "does not occur in isolation" (8). Such an understanding speaks to the emotional pain that persons with chronic pain often experience when their pain is suspect and misunderstood, especially by loved

ones. The relational part of Kafer's model also supports this dissertation's claim that how persons with chronic pain understand and experience their pain is impacted by their relationships with their doctors and the medical profession (for further discussion on these relationships please see chapter 3, "Toward a Re-Imagining of Chronic Pain" and chapter 4, "'Relaxed, but not lazy'"). Also, Kafer's use of the term *relational* represents family and friends of the disabled who are also affected by the discrimination and marginalization that accompany disability. This is an important and radical feature of Kafer's model, and it reinforces my argument that chronic pain is not an individual problem to be "overcome" by strength and willpower, as is true of all disabilities, but a societal problem that needs to be addressed by disrupting the socio-political, cultural, and economic barriers that keep persons with chronic pain disabled.

Another core tenet of Kafer's political-relational model is that disability is not a "natural" condition that can simply be fixed by medical intervention or rehabilitation. According to Kafer, the assumption that disability is a medical defect rooted in an individual body denies that disability is *political*, and, as such, is a product of the power relations and assumptions that are embedded in the discourses and practices that are used to stigmatize and marginalize the disabled. It is important to note here that this core tenet of Kafer's model also aligns with the kinds of critiques made by scholars in disability and feminist rhetorics. The political framework of Kafer's disability model also makes visible the widespread depoliticalization of disability and its consequences for persons with disabilities. One of these consequences is that medical approaches to disability are viewed as being "completely objective and devoid of prejudice and cultural bias" (8). The implications of this consequence can be deadly, especially in terms of physician-assisted suicide and selective abortions of suspected disabled fetuses. This is especially salient for persons with chronic pain, since physicians who perform assisted suicides

and “right to die” advocates often use pain as a way to legitimize their practices (see especially Siebers, “In the Name”; Wailoo). Another unsettling consequence of the depoliticalization of disability is that discrimination and prejudice are viewed as acts of individual cruelty rather as products of structural inequity. Both of these examples demonstrate what is most troubling to Kafer: that divorcing politics from disability ignores the collective responsibility society has to affect the ways in which disability is understood and treated now and in the future. Kafer’s concern is also one that I share.

It has been far too easy to divorce politics from chronic pain. For example, chronic pain is depicted as an individual problem born from a weakness in character rather than a product of socio-political practices and policies. As a result, persons with chronic pain are often cast off by society as drug addicts in need of regulation and surveillance. This can most clearly be seen with the advent of “pain contracts,” which require persons with chronic pain in need of opioid medication to relinquish their prescribing doctor from fault if they become dependent on said medication. The pain contract also limits chronic pain patients’ choice in doctors, since the contract specifies that patients can only receive pain medications from the physician who first prescribed the medication. In addition, chronic pain patients are required to attend an office visit with their doctor *each* time their prescription needs to be refilled. Lastly, persons with chronic pain who need opioid medication must appear in person at the pharmacy with a written prescription and photographic identification in order to obtain their medication. All of these actions are especially hard for persons who are in daily, constant pain. In addition, these practices further stigmatize and marginalize persons with chronic pain, especially those with low social-economic status, and reduces the accessibility of pain medication for those who often need it the most and who are least likely to be opioid abusers (Foreman, *A Nation*). It is also important

to note here that pain contracts fail to mention the enormous amount of profit that the pharmaceutical industry gleans from pain medications and the increasing number of pain clinics that have recently arisen, not to treat pain, but rather to rehabilitate persons with chronic pain primarily through relinquishing their pain medication. Therefore, as long as politics are divorced from chronic pain, persons with chronic pain will continue to be blamed for their inability to manage their pain, and as a result the possibility of social change and a better future for this population is rendered impossible.

Another core tenet of Kafer's political-relational model of disability, which contrasts greatly to the social model, is that "non-disabled" and "disabled" are not discrete or self-evident categories, but continuously open for debate. Disability rhetoric scholars similarly problematize fixed categories of disability and expose the ways in which strategic naming is used by dominant groups to marginalize persons with disabilities. Kafer adds that a political-relational model of disability is more interested in asking questions rather than answering them and chooses instead "to explore the creation of such categories and the moments in which they fail to hold" (11). In doing so, Kafer further explains, it becomes evident that deciding who fits in the "rubric of disability" is too difficult to determine. In response, Kafer calls instead for a "collective affinity" in terms of disability, which has the potential to

encompass everyone from people with learning disabilities to those with chronic illness, from people with mobility impairments to those with HIV/AIDS, from people with sensory impairments to those with mental illness. People within each category can all be discussed in terms of disability politics, not because of any essential similarities amongst them, but because all have been labeled as disabled or sick and have faced discrimination as a result. (11)

I wish to pause here at this passage to emphasize that Kafer's hope of a collective affinity in terms of disability is one I will hold onto throughout this dissertation, knowing that it speaks best to the future I imagine: a future that honors and values the lives of persons with chronic pain and their contributions to the fields of disability studies, feminist rhetorical studies, disability rhetoric, and disability activism.

While Kafer's political-relational model of disability does important work, such as accounting for persons with chronic pain by dismantling the disability/impairment binary, establishing a relational and political framework of disability that illustrates how persons with chronic pain are further disabled and marginalized by the medical profession's policing policies and practices, and rendering it possible to imagine a desirable future for the disabled, it is not explicitly rhetorical. As such, my hybrid methodology extends Kafer's political-relational model of disability in important ways. First, it recognizes that disability is rhetorical, meaning it is a product of language practices and ableist discourses that construct disability as a tragic existence in need of rescue and cure. Next, it reveals the generative power of rhetoric to transform commonplace understandings of disability, and in so doing shows disability as positive difference. Lastly, it offers strategies for intervening in current problematic discourses and practices that stigmatize disability, therefore making it possible to implement the new, positive reframing of disability that Kafer's model seeks to produce.

Disability rhetoricians James C. Wilson and Cynthia Lewiecki-Wilson's scholarship "challenge[s] the names, the language, and the frameworks for understanding disability" and "revise[s] official histories of disability and develop[s] new ones" (*Embodied* 17). They also argue that transforming disability "will require transforming economic, social, ethical, and educational practices, reimagining social spaces, and rethinking ordinary habits" (18). This is

especially true, they contend, when challenging the “hegemony of scientific discourse.”

Although Wilson and Lewiecki-Wilson are not alone in expressing the need for a rhetorical framework of disability and a critical alliance between disability studies and disability rhetoric (see especially Dolmage, *Disability*) to transform disability, their scholarship aligns most closely with the goals of this dissertation’s political-relational-rhetorical methodology. For instance, their insistence on a rhetoric of political engagement to challenge the hegemony of scientific discourse speaks to the need for this dissertation to critique problematic rhetorics of chronic pain, such as pain is a medical and individual defect and a weakness of character. Also, Wilson and Lewiecki-Wilson’s emphasis on how language and naming reinforce problematic ideologies of disability points to the need to critique and interrupt discourses (especially those found in medical and legal texts) that normalize and dehumanize persons with chronic pain. However, none of these interventions are possible without a hybrid methodology that combines Kafer’s political-relational model of disability with disability rhetoric and feminist rhetorics.

In response, I offer up a political-relational-rhetorical methodology to communicate the socio-political, cultural, economic, and material realities of living with chronic pain. As such, it assists in creating a new future for disability: one that values disability as positive difference and allows for the representation in disability studies and the disability community of persons with chronic pain and all persons who experience the stigma and oppression of bodily norms. And yet, although my methodology calls for a more expansive definition of disability that includes the above populations, it does not attend to the concept of intersectionality, which investigates the ways in which identity categories (e.g., race, gender, sexuality, class, age) intersect to cause

multiple forms of oppression.¹⁷ Although considerations of intersectionality are instrumental in confronting social injustices and enacting positive social change, my political-relational-rhetorical methodology does not take up this work in the context of disability studies, since persons with chronic pain's claim to a disability identity is still contested. However, my methodology takes an important first step in attending to the ways in which chronic pain converges with other marginalized identities and the subsequent effects by arguing that chronic pain needs to be theorized as a disability. Thus, by theorizing chronic pain as a disability, it then becomes possible to engage in intersectional analyses that can lead to a richer understanding of the oppression of persons with chronic pain and how to better address the injustices they face.

¹⁷ However, I do discuss intersectionality in relation to my pedagogy in chapter 6, "Collective Affinities." Also, in the "Epilogue," I point out further inquiries into the relationship between chronic pain, rhetoric, disability, and intersectionality.

CHAPTER III

TOWARD A RE-IMAGINING OF CHRONIC PAIN: DISABLING

RHETORICS OF SUFFERING AND SURVEILLANCE

People in chronic pain are often simply difficult to be around. They are constantly distracted, self-centered, often angry, and can find ordinary interpersonal behaviors and gestures in those they interact with to be dismissive and hateful. Such behaviors can literally drive people away. Time and time again as I read heart-wrenching accounts of people suffering from chronic pain, I saw often unconscious gestures of anger and blame directed at those around them. For healthcare workers and other caretakers and companions, chronic pain requires deep patience and a constant sense that suffering is the basis of behavior and attitudes that necessitate that caring patience.

—Ronald Schleifer, *Pain and Suffering*

Acute pain is good for us. It is a protective component of our sensory repertoire, an alarm signal that warns of danger and keeps us out of harm. Yet if pain persists, if pain becomes chronic, if an injury fails to heal quickly, or if pain appears without an apparent cause, this protective sensation becomes a nightmare, a curse, something that we want to get rid of by any means possible. The feeling of pain doesn't change, it remains unpleasant and emotionally negative, but its significance to our lives undergoes a dramatic switch from good and protective to awful and nasty.

—Fernando Cervero, *Understanding Pain*

The above passages are representative of what my dissertation refers to as problematic rhetorics of chronic pain. It has become commonplace to associate chronic pain with a “nightmare,” a “curse,” and “a fate worse than death,” as it has become commonplace to depict

persons with chronic pain as “difficult,” “self-pitying,” and “burdensome.” Disability rhetoric scholars and activists may find these characterizations of chronic pain eerily familiar to disability tropes such as disability is “a tragedy in need of overcoming” and “a problem needing to be eradicated.” For this reason, and those discussed in previous chapters, it is necessary to theorize chronic pain as a disability and for disability studies scholars and disability rhetoricians to take up scholarship on chronic pain by critiquing and intervening in these and similarly oppressive problematic rhetorics of chronic pain. In this context, and in the remainder of this chapter’s discussion of problematic rhetorics of chronic pain, I define rhetoric as the pervasive use of language, wherein language induces audiences to accept certain versions of reality, which can thus be interpreted, contested, and revised (for further discussion of the two types of rhetoric used in this dissertation, please see chapter 1). Problematic rhetorics of chronic pain are widespread and indiscriminant, appearing in myriad forms of popular culture as well as in medical, scientific, legal artifacts, and academic texts.

In response, the work of this chapter is to examine two of the most insidious and damaging problematic rhetorics of chronic pain—rhetorics of suffering and rhetorics of surveillance—while also disrupting, and thereby interceding in, their proliferation. Engaging in this work also aligns with my political-relational-rhetorical methodology which points to the need for disability rhetoric scholars to expose how language reinforces problematic ideologies of disability by critiquing and interrupting discourses that normalize and dehumanize persons with chronic pain. To most effectively do this work, I will narrow my range of analysis and examine one problematic text for each type of problematic rhetoric that best illustrates the damage that these rhetorics have on persons living with chronic pain.

Rhetorics Of Suffering

A modern chronicler of hell might look to lives of chronic pain patient for inspiration.

—Melanie Thernstrom, “Pain, the Disease”

If our vernacular of pain remains locked in malevolence and affliction—pain invades, wounds, and tyrannizes—is it possible to think our way out of adversarial and frightened reactions to physical hurt?

—Susannah Mintz, *Hurt and Pain*

It is impossible to confront chronic pain without also enduring indescribable suffering, or at least that is what scholarship on pain insists upon. Much of this scholarship appears sporadically across the disciplines; however, the majority of the work on chronic pain is authored by psychology, medical, science, history, and trauma studies scholars (see especially Bourke; Cervero; Melzack and Wall; Scarry; Schleifer). In addition to perpetuating problematic rhetorics of chronic pain, the discourses used in these texts are also damaging since they promote the medical model of disability and the hegemony of scientific discourses that disability scholars Jay Dolmage and Cynthia Lewiecki-Wilson claim “objectifies the disabled and understands disability through the categories of abnormality, deviancy, and deficits to be cured” (31), thereby further stigmatizing persons with chronic pain and those with other forms of disabilities. Consequently, it is important for all disability scholars to analyze and critique these problematic texts.

Scholarship on chronic pain has also reached outside the walls of academia. Considering the growing awareness that chronic pain is a national health concern and the increased media coverage of prescription opioid abuse, practicing physicians have lent their expertise, and often their patients’ stories, to explore how chronic pain can lead to a lifetime of suffering (e.g.,

Fishman and Berger; Groopman; Kleinman). Likewise, medical and science writers (see especially Thernstrom), often with their own experiences of chronic pain, have turned the page to uncover the hidden ‘mysteries’ of chronic pain and to contemplate the ‘science of suffering.’

Although a number of these books are doing important work, such as making the problem of chronic pain more visible and bringing attention to how healthcare professionals are failing this population, they still participate in what I call problematic rhetorics of suffering. This type of rhetoric, which equates pain with suffering in much the same way that disability is equated with tragedy, insists that a life with pain is isolating, full of despair, and identity-destroying. This conclusion is more easily realized when chronic pain is considered an individual medical defect and a private and isolating experience rather than a product of political, relational, and rhetorical discourses and practices. Left unchecked, I argue, the culmination of a rhetoric of suffering is death. In this chapter, I begin by identifying key tropes of rhetorics of suffering found in one widely circulating problematic text: medical journalist Melanie Thernstrom’s *The Pain Chronicles: Cures, Myths, Mysteries, Diaries, Brain Scans, Healing and the Science of Suffering*. In addition, I explore the danger that this rhetoric can have on its readers, especially persons with chronic pain and their loved ones. I then analyze and critique the genre of the “pain contract” to demonstrate the dangers of a second widespread problematic rhetoric of pain: that of surveillance.

I have chosen Thernstrom’s critically acclaimed national bestseller as this section’s site of analysis not only because of its large audience, but also for its considerable use of rhetorics of suffering as a refrain for understanding the experience of chronic pain. As her subtitle suggests, Thernstrom’s is a quest narrative that takes her and her readers on a journey through time, medicine, and magic—stopping along the way to consider Babylonian gods and devils, ancient

Egyptian prescriptions, spells and enchantments, the great Fall, the discovery of tuberculosis and later anesthesia, and contemporary pain clinics—all with the hope of demystifying what she refers to as the “special suffering” of chronic pain. “To be in physical pain,” she explains is to find yourself in a different realm—a state of being unlike any other, a magic mountain as far removed from the familiar world as a dreamscape. Usually pain subsides; one wakes from it as from a nightmare, trying to forget it as quickly as possible. But what of pain that persists? The longer it endures, the more excruciating the exile becomes. *Will you ever go home?* you begin to wonder, home to your normal body, thoughts, life? (3).

This brief passage already reveals what I consider to be key tropes of rhetorics of suffering. One such key trope is to use metaphor to shroud chronic pain in mystery and darkness in order to convey its tendency to confound biomedicine and resist diagnosis. This then makes chronic pain seem more elusive and frightening, which, in turn, increases levels of pain and despair and forges a resistance to seeking medical care. Thernstrom’s magic mountain is one such metaphor.¹⁸ The fact that the magic mountain is in a “different realm” also speaks to another key trope of rhetorics of suffering: that chronic pain leads to isolation and to alienation from oneself and others. The question, “*will you ever go home, home to your normal body, thoughts, life?*” is also a common trope in chronic pain scholarship since it simultaneously Others persons with chronic pain as abnormal while also implying that chronic pain fractures the self and leaves in its wake a lesser, “sick” version. For Thernstrom, this sick version is not only a

¹⁸ Other metaphors Thernstrom uses for chronic pain are far less pleasant, such as: “the tormentor,” “the torturer,” “poison,” “a chamber of hell,” and “the devil.”

“shadow of one’s former self,” but a decaying mass of flesh and bone. Thernstrom best exemplifies this trope in her remarks following a visit to a pain clinic:

What the majority of doctors see in a chronic-pain patient is an overwhelming, off-putting ruin: a ruined body and a ruined life. It is the doctor’s job to rescue the crushed person within—to locate the original source of the pain—the leak, the structural instability—and begin to rebuild: physically, psychologically, socially. (131)

Thernstrom’s remarks are particularly threatening to persons with chronic pain and to the possibility of creating greater understanding of chronic pain not only because they are likely to cause greater hopelessness, but also because they reinforce the stigmatized belief that disability is a defect (or in this case “a structural instability”) located in an individual needing to be cured or eliminated.

Also, evident in the above passage is a key disability trope: that persons with chronic pain are “victims” and “sufferers” in need of rescue. One dangerous effect of this particular rhetoric is that persons with chronic pain can come to identify themselves as chronic pain sufferers and are more likely to interpret their pain as a tragedy beyond their control. As a consequence, persons with chronic pain are more likely to become passive and less willing to question medical decisions made on their behalf. In addition, persons with chronic pain come to be viewed by those without the experience of chronic pain as pitiful and helpless. This becomes especially true when chronic pain is not understood as political, relational, and rhetorical.

To be fair, Thernstrom counts herself amongst these “victims” and “sufferers.” Part of the journey of the *Pain Chronicles* is her own. Dispersed throughout the book are excerpts of Thernstrom’s pain diary in which she recounts her experience with chronic pain and her eventual diagnoses of spinal stenosis and cervical spondylosis, neither of which can be cured by surgery

or medical treatments. And yet, Thernstrom also spends much of her personal narrative disassociating herself from other persons with chronic pain. This is most noticeable during a physical therapy visit, in which she shares that she is afraid of turning into a “cripple”:

I shrank away from the other patients, afraid to be grouped with the tired, old, sick, disabled, and sad. Although there was a stray college athlete with a chipped bone, en route to health, most of the patients looked like inhabitants of the village of the damned. I didn't want to be a weak, pain patient. (54)

Earlier in her book, Thernstrom also distinguishes herself from other persons with chronic pain when she notes that she is not from a third-world country but a “woman in real silk pajamas lying on a king-sized Tempur-Pedic mattress under a white Shabby Chic comforter in a room with a decent view. *In Manhattan.*” (42). Although it would be easy to conclude from these passages that Thernstrom is classist and stigmatizes persons with disabilities, rather I believe that these are compelling examples of the very pervasiveness of rhetorics of suffering. Thernstrom unknowingly has become vulnerable to the very rhetorics of suffering that she puts forth in her book. As an effect, she fears pain even more and most likely causes herself more pain by discontinuing physical therapy. This is an example of another dangerous effect of rhetorics of suffering: that persons with chronic pain might resist treatments that could decrease their pain levels because of fear and feelings of hopelessness.

Nonetheless, I have no doubt that some of Thernstrom's readers will be relieved to find themselves in her story: in the long hours she waits in doctors' offices, her lover's lack of empathy, disbelieving friends and family members, the exhaustion of trying alternative treatments, and the confusion and fear of not knowing why her body is in so much pain. To be honest, there was a time in which I too would have experienced similar relief. Like many people

with chronic pain, it took me years to find a diagnosis. During that time, I tried every well-meaning suggestion for pain relief including more mainstream alternative therapies such as acupuncture, acupressure, special diets, and homeopathic remedies, and less mainstream suggestions such as drinking three scalding glasses of water first thing in the morning, sleeping on wooden slats with my feet up against a wall, going for colonics three times a week, and visiting a Shaman to find my spirit animal to return my body to health and wholeness. Finally, after seventeen doctors (I kept a list), and many “it’s all in your head” diagnoses, several visits to world re-known pain clinics, an unconventional surgery, physical therapy, and yoga, I improved significantly, even though my pain will never go away. While this was happening, I experienced the loss of friends, a job, and even the skepticism of my own loved ones. I tell this story not to ask for pity or to inspire determination, but rather to show how scared and vulnerable it is to be in chronic pain. Thernstrom does not exaggerate the desperation that can come with chronic pain, nor does she exaggerate the awful sensations of that pain, nor the loneliness that can also accompany living with chronic pain. For these reasons, years ago at my sickest, I would have been comforted by Thernstrom’s book, by the knowledge that I was not alone in my suffering. However, her book would never have made me psychologically or spiritually improved, nor would it have spurred me on to seek additional medical guidance. Rather, it would have left me stuck in my own misery.

Perhaps this is because, despite the positive temporal quality of *The Pain Chronicles* and rhetorics of suffering, they offer no path forward, no possibilities of imagining that persons with chronic pain can have a desirable future. In fact, the very opposite is occurring. As I mentioned in the beginning of this section, the culmination of a rhetoric of suffering is death. Pain research concludes that persons with chronic pain are twice more likely to commit suicide than other

people and even when persons with chronic pain do not contemplate actual suicide, seventeen percent have passive thoughts about death (*Foreman, A Nation* 161). I, by no means, am implying that Thernstrom and other medical journalists writing similar texts are suggesting that suicide is preferable to a life with chronic pain; rather, I argue their use of rhetorics of suffering adds to the discourse already surrounding chronic pain and other disabilities that posit a life in pain as a life not worth living. This rhetoric is particularly harmful considering disability scholar Rosemarie Garland-Thomson's point that the relief of pain and suffering is often linked to "legitimized-assisted suicide, mercy killings, and the withholding of nourishment" (779). In addition, rhetorics of suffering obscure the fact that much of the suffering that accompanies chronic pain is a result of social, political, relational, and economic factors.

The above arguments are exemplified in a recent and rare article on chronic pain and disability. In "Recovering a Cripistemology of Pain," disability scholar Alyson Patsavas recounts how popular discourses regarding the horrors of living with chronic pain and disability shaped her experience of pain and nearly resulted in a suicide attempt:

Last night at school I walked across the street to the parking garage and climbed six floors to the top. I walked to the edge and stood on the railing thinking about how I would rather not live than be in pain all my life. I don't know how long I stood there, but in the moment I fully rationalized dying. Death is full of happiness, exemption from this suffering. (21)

After many years of living with chronic pain and working in disability studies, Patsavas writes that she came to realize that dangerous totalizing messages, such as pain is a fate worse than death, "not only fail to account for the rich, varied, and complex lives that people with chronic pain lead," but also "often cause greater suffering" (23). Furthermore, she adds that such

discourses “frame pain as an isolating, devastating experience crystallized to prevent the exploration of alternative explanations for why chronic pain might be (or seem to be) unlivable” (23.) One of these explanations, I argue in the section below, is that persons with chronic pain are problematically linked to the rise in prescription opioid abuse and as such are often denied access to much-needed prescription pain medicine. Other explanations are problematic doctor-patient relationships, government under-funding of pain research, gender bias, and a lack of social support and resources for persons with chronic pain, none of which are adequately addressed in *The Pain Chronicles*.

Rhetorics Of Surveillance

A patient will present to a physician difficult-to-diagnose ailments such as severe back pain or muscular pain that are typically treated with a pain killer. After receiving the prescription, the patient will repeat the performance for three or four more physicians.

—On “doctor shopping,” qtd. in Wailoo, *Pain: A Political History*

I do feel, and my other pharmacist who’s with me today feels, like part of this crackdown is such a big stigma with pain medicines that your general practitioner is not as willing to write for pain patients who are legitimate.

—Alyson Roby, qtd in Yap, *Pharmacy Today*

Initially I wanted to begin this section with a detailed discussion of the opioid pain medication OxyContin and then blame that medication for what I refer to as problematic rhetorics of surveillance. Such rhetorics, I argue, are a form of what Foucault characterizes as biopower in which persons in dominant positions of power regulate, punish, and criminalize persons whose bodies do not conform to nation-states’ ideologies of normalcy, which, in this instance, are persons with chronic pain (Rabinow 258-59). Most pain scholarship points to

OxyContin, which, supposedly, when first advertised was resistant to addiction, as causing the global increase in prescription opioid abuse.¹⁹ However, instead of discussing how OxyContin led to the rise in prescription drug abuse and to the restriction of opioid medications, I want to take a step back and look at the culture of pain and disability in which OxyContin emerged. Such an investigation, I hope, will yield a much richer understanding of the causes and dangers of rhetorics of surveillance to persons with chronic pain. By moving in this direction, I wish to enact my political-relational-rhetorical methodology, which calls on disability rhetoric scholars to consider the larger power relations and practices that make possible problematic rhetorics of chronic pain. Only afterward will I engage in a rhetorical analysis of one specific problematic text, the pain contract, as an example of how rhetorics of surveillance further marginalize and stigmatize persons with chronic pain and lead to their under-treatment.²⁰

As the opening passages of this section reveal, and as discussed previously in this dissertation, persons with chronic pain are suspect: their legitimacy is always up for debate. This should come as no surprise. Fakery and illegitimacy have long been associated with the disabled. Disability historian Susan Schweik traces the suspicion of the disabled to the 1880s-1890s

¹⁹ In a *World of Hurt*, New York Times reporter Barry Meier recalls how Purdue Pharma claimed that because of its time-released mechanism, OxyContin would be less prone to abuse than fast-acting painkillers like Percocet because those drugs produce the type of quick jolt that addicts crave” (n.p.). This claim, explains Meier, reassured doctors who usually did not prescribe opioids to dispense it, leading to the “21st Century painkiller boom.” However, Meier notes, such a claim was misleading, since “drug addicts and curious teenagers had discovered that OxyContin’s entire narcotic payload could be released at once by simply crushing or chewing a tablet” (n.pag). Similarly to Meier, pain researcher Marcia Meldrum in her article “The Ongoing Opioid Prescription Epidemic” also recounts how “Purdue’s advertised OxyContin as non-addictive because the drug was released within the body over 12 hours,” even though “recreation users quickly learned to get high by crushing or dissolving the pills.” Meldrum also informs that the ready supply of OxyContin led to “an epidemic of drug overdose deaths, which increased 137% from 2000 and 2014” (1365).

²⁰ Thirty percent of persons with chronic pain are said to be undertreated for fears of regulatory scrutiny (*Foreman, A Nation* 138).

American Ugly Laws, which surveilled, regulated, and imprisoned “the imposter beggar” and “sham cripples” for simulating deformity in order to “steal” money from hard-working Americans (121-23). This same suspicion operates today in Social Security Disability screenings in which the disabled are called on to perform²¹ disability by undergoing periodic physical and psychiatric evaluations²² in order to maintain their benefits. Similarly, at Americans with Disabilities Act hearings, disabled employees are often called on to perform disability in order to prove that their employers neglected to grant them reasonable accommodations in order to carry out their job responsibilities.²³ Considering all of this, it is not surprising that persons with chronic pain are suspected of “doctor shopping”²⁴ for performing disability in a culture that demands performance. It is this culture, and not merely a drug, that fosters rhetorics of surveillance.

Instead of “doctor shopping,” most persons with chronic pain see more than one doctor because they do not receive adequate healthcare due to doctors’ lack of pain education, resistance to prescribing opioid medication, and suspicion of persons with chronic pain. As a result, many persons with chronic pain are passed along from doctor to doctor through the use of

²¹ To act in ways that make one’s disability noticeable.

²² Usually these evaluations are general and do not reflect a specific individual’s disability. For instance, a person receiving benefits for a mental disability might be asked to pick up and carry weighted objects even though they are not physically disabled; the reverse is also true.

²³ Disability performance is a complex issue often taken up in disability studies scholarship (see especially Brueggemann; Price; Siebers). Most recently in their edited collection *Disability and Passing*, Jeffrey A. Brune and Daniel L. Wilson discuss how persons with disabilities are often called on to draw attention to or exaggerate their disability to get some type of benefit or care and how such performances reveal “what is at stake when it comes to disability and nondisability identification” (1).

²⁴ In *Pain: A Political History*, Keith Wailoo describes what is referred to as “doctor shopping” as “the process by which patients fraudulently move from physicians to physicians to circumvent controls on the quantities of pain prescription drugs available to individual consumers” (170).

referrals. By the time that OxyContin gained Federal Drug and Food Administration (FDA) approval for the treatment of chronic pain in the early 1990s, chronic pain patients were already culturally and socio-politically constructed as “problem” patients. Often their pain was declared as “all in their head” and dismissed as “psychogenic, unreal, and imaginary” (Reddy) because it failed to appear on standard biomedical tests such as Cat-Scans and MRIs (see also Morris; Wendell). In addition to being thought of as “fakers,” chronic pain patients were also often described by healthcare professionals as “bothersome,” “angry” and “self-pitying” (Fishman; Schleifer; Walton).

The above characterizations of the chronic pain patient are particularly aimed at female patients: more women than men are diagnosed with the majority of chronic pain conditions such as fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, migraines, and neuropathic pain (see especially Foreman, *A Nation*). The fact that these conditions are more prevalent in females can also explain why chronic pain is not taken seriously and research for chronic pain conditions is underfunded. This is due to the fact that despite the advancements in medical care, women are often still regarded as “hysterical,” and “overly emotional” and are therefore easily dismissed as “frauds.”²⁵ The fact that female patients’ reports of pain are usually met with sedatives rather than pain medication is indicative of such gender discrimination. Research also indicates that other minorities, specifically Latinos and African Americans, are more likely than white males to have their pain dismissed (Wailoo 201). Health disparities in the treatment of chronic pain is also evidenced by Donald Barr’s work on how race/ethnicity effects pain

²⁵ Examples of this stigmatizing and discriminatory characterization of the female patient can be found in Judy Segal’s work on the rhetorical history of the migraine patient who is gendered feminine and described as “neurotic, hysteric, hypochondriac, and a fraud” (*Health* 45) and in Amy Vidali’s scholarship on the “gastrointestinal woman” who is “characterized as having unjustified anxiety and is to blame for her condition” (“Hysterical” 43).

treatment, which reveals that “there is a clear pattern of blacks receiving an opioid medication less often than whites, especially for the treatment of back pain and migraine headaches” (189). Economics, along with gender and race, also reveals similar troubling health disparities. For example, doctors treating patients in low-income neighborhoods are also less willing to prescribe pain medication for chronic pain patients, “fearing drug dependency and accusations of fostering addiction” (Wailoo 200) and pharmacies in low-income, predominately nonwhite neighborhoods have inadequate amounts of opioids in stock due to the fear of illicit use and theft (Primm et al.). Undertreatment of pain also occurs in emergency rooms in which women and other minorities have longer wait times and female patients are more likely to be asked psychosocial questions and less likely than male patients to have lab tests requested (Foreman, *A Nation* 69) and Hispanics are nearly twice as likely to receive no medication for pain during their treatment (Barr 188).

The general population’s characterization of persons with chronic pain “as people who sit around watching TV most of time” (Wailoo 179) also adds to the negative depiction and stigmatization of persons with chronic pain and ultimately to rhetorics of surveillance. In addition to being constructed as “lazy,” the media offers another problematic image of persons with chronic pain, that of the drug addict. This representation is fueled by heightened media coverage of “over-indulgent” celebrities such as Rush Limbaugh, Charlie Sheen, and Eminem who publicly announced their addictions to the prescription pain-killers Vicodin and OxyContin.

Given this culture of pain, it is no wonder that persons with chronic pain have been unjustly targeted as being in need of surveillance and punishment, despite the fact that less than one percent of persons with chronic pain become addicted to pain medication, and the majority of those that do have previous histories of substance abuse (see especially Foreman, *A Nation*;

Wailoo). In fact, pain research indicates that roughly seventy percent of opioids that end up on the street come from initially legitimate sources,²⁶ not from “doctor shopping²⁷” or “pill mills.”²⁸ I mention these statistics not because I feel the need to defend OxyContin and other opioid medications for the treatment of chronic pain or to suggest that opioids do not have dangerous and life-threatening side-effects; rather, my intention is to separate the problem of opioid abuse from the problem of chronic pain. It is only by understanding this distinction that it becomes clear how regulatory documents aimed at disciplining persons with chronic pain, such as “pain contracts,” fail to solve either problem, and, due to the increased surveillance of persons with chronic pain, actually lead to their undertreatment. This knowledge alone reveals why a disability rhetorical analysis of problematic rhetorics of chronic pain is valuable.

In brief, pain contracts/agreements are technical documents presented to a patient by a healthcare professional that detail the prescriber’s expectations of the patient and the conditions under which the physician will prescribe or terminate opioids. Although these contracts or agreements are supposedly helpful tools that inform chronic pain patients of the potential dangers of opioids including addiction and are meant to promote a trusting doctor-patient relationship, the opposite is often true. Instead, pain contracts/agreements use rhetorics of surveillance to punish persons with chronic pain for not being able to overcome their pain without pain medication by regulating and restricting their access to opioid therapy. Pain patient

²⁶ According to a government 2009 National Survey on Drug Use and Health, the majority of abusers got their pain relievers from a friend or relative for free (Foreman, *A Nation* 156).

²⁷ The same survey as above reported that only 2.0 percent of abusers got their pain relievers from more than one doctor (Foreman, *A Nation* 156).

²⁸ The term “pill mills” usually refers to “shady operations often advertised as pain clinics in which unscrupulous doctors hand out prescriptions for opioids” (Foreman 135).

advocacy groups and bioethics scholars not only question the efficacy of the contracts but also the unethical consequences of such documents. For example, in “Opioid Contracts,” Mark Collen points out that referring to these documents as contracts or agreements is misleading because doing so suggests that both parties, doctors and patients, negotiated the terms of the contract, reached amicable arrangements, and have a shared responsibility in carrying out the contract’s terms (841-42). Instead, Collen further explains, pain contracts detail guidelines and rules for a patient to follow in order to maintain their patient status with little or no mention of the prescribing physician’s responsibilities to the patient. Bioethicist Richard Payne adds that many of these contract rules, such as “you will be on time for your appointments” and “you will not call after business hours,” have little to do with communicating the risks of opioid medications and instead are intended to control patient behavior (6-7). These rules also could indicate that healthcare professionals already have discriminatory attitudes toward chronic pain patients even before a person with chronic pain walks into their offices. Other ethical concerns pointed out by bioethicists regarding pain contracts are that they are paternalistic, unjust, and impair physician-patient communication (see especially Payne et al.). Of course, bioethicists are not the first to point out how asymmetrical relations of power between doctors and patients, as well as the erosion of trust between them, can result in poor treatment outcomes (see especially Albrecht; Beisecker; Charon; Davis; Heifferon and Brown; Segal, Scott; Wyatt). This is especially true for persons with chronic pain.

In order to make the above criticisms regarding pain contracts more evident, I will now move away from a general analysis of pain contracts and turn to examine one specific pain contract, which I received at a recent visit to a pain clinic. This contract was presented to me during my second visit to the clinic, even though I was not taking, nor did I mention being

interested in taking, opioids for pain management. The contract is two double-spaced pages and titled: “Contract for Controlled Substance Therapy.” It was handed to me on a clipboard along with insurance forms and a patient questionnaire. Despite the fact that supporters of pain contracts, particularly the American Medical Association, maintain that one positive outcome of pain contracts is that they facilitate much needed dialogue between patient and physician regarding the risks of opioid therapy, not one of the three practitioners I saw at the clinic that day mentioned the contract. Consequently, I had the impression that instead of facilitating a dialogue between the doctors and myself regarding opioid therapy, the contract was merely a waiver form to protect the clinic’s fear of liability. Although studies indicate that there is little risk to doctors being persecuted for overprescribing pain medication (see especially Collen; Foreman, *A Nation*), many doctors still shy away from prescribing opioid medications because of this fear and because they are genuinely concerned with their patients becoming addicts. It seems then that physicians, along with their patients, are susceptible to rhetorics of surveillance that problematically conflate the drug addict with persons with chronic pain.

My pain contract was finally discussed after I informed the third practitioner that I would not be signing the contract based on ethical reasons and because, as they already knew, I was not receiving controlled substances from them or any other medical practitioner and I had no history of substance abuse. Nonetheless, I was implored to sign the contract “for my own good” and “just in case I decided to take pain medications in the future.” In response, I cancelled my next appointment and never returned.

Before continuing with this discussion, I want to pause here and acknowledge my own privilege in order to enact my methodology’s call for self-reflexivity. Unlike many people with chronic pain, I had the opportunity to leave the pain clinic to find another practitioner due to the

fact that I was not in desperate pain at the time of my visit. Consequently, I was less vulnerable and therefore less likely to be coerced into signing the contract. Also, I lived in a relatively large city with access to several pain clinics and pain specialists²⁹ and was able to save on transportation costs by driving my own vehicle. In addition, even though medical bills plagued me in the past, I had relatively good insurance at the time, which allowed me the freedom to see multiple doctors and choose my own practitioners. I feel that it is important to note this privilege and by doing so also point out that in addition to decreased access to opioid medication, one of the consequences of rhetorics of surveillance is unaffordable medical care. Pain contracts make this especially true since they require office visits for each prescription refill and the additional costs of “random” drug screenings in the form of urine and blood tests are often not covered by insurance.

In my pain contract, I was warned about such random drug screenings on the second page, under “Rules for Controlled Substance Therapy.” Other rules include: “I agree to a pill count”; “I will be responsible for my own medicine. I will not sell, trade, or share any controlled substances”; and “I will not get a refill or prescription for controlled substances from any other provider, urgent care, or emergency room.” These rules are examples of rhetorics of surveillance. They not only monitor persons with chronic pain, but they also infantilize and criminalize them. The last rule is particularly problematic considering that a patient may need a controlled substance for an emergency unrelated to their chronic pain diagnosis yet still be dismissed from their medical practice for not obeying the contract rules. The consequences of being dismissed from a medical practice in the middle of opioid therapy are far greater than just not being able to

²⁹ There are approximately only 4 board-certified pain specialists for every 100,000 patients (Collen 841).

continue treatment with the prescribing provider. For example, dismissal before being tapered off opioid medication can lead to experiencing withdrawal symptoms due to physical dependence. This is very likely, since the shortage of pain specialists and lengthy patient waiting lists result in a long wait for medication refills. In addition, if opioid treatment is terminated before tapering, pain levels suddenly increase. The emotional cost of being dismissed is also often great, since persons with chronic pain already feel ostracized and are blamed for their pain.

In addition to stigmatizing and criminalizing persons with chronic pain and controlling access to much-needed pain medications, one of the most harmful effects of pain contracts is that they mask the real systemic issues that are responsible for an increase in addiction to controlled substances and a problematic culture of pain. Such a culture punishes patients and doctors rather than scrutinizing the pharmaceutical industry, regulatory agencies such as the FDA and the Drug Enforcement Agency (DEA) for their part in the rise of opioid prescription abuse (Meier), and the National Institutes of Health's (NIH) gross underfunding of pain research. Pain contracts also increase the risk of underdiagnosing and misdiagnosing persons with chronic pain. For example, by concentrating on periodic drug screenings and enforcing the contract rules, persons with chronic pain are pigeonholed as drug addicts and less time is spent on determining the reasons for their constant pain.

OxyContin is still a problem. The fact that OxyContin in addition to Hydrocodone is responsible for three times as many deaths as heroin a year testifies to that truth (Wailoo 192). Taking this into consideration with the fact that other treatments might even benefit persons with chronic pain more than opioid medications, such as acupuncture, meditation, massage therapy, and yoga, it might seem curious that I spent the majority of this section critiquing pain contracts and not OxyContin as I originally planned. However, if I blame OxyContin for rhetorics of

surveillance and the undertreatment of chronic pain, I would fail to take responsibility for my work as a disability rhetorician, which is to locate and expose dangerous rhetorics that mark persons who have been marginalized and subjugated by those in dominant position of power as abnormal, other, and, even worse, disposable. It is my hope then that this work—my critiquing and intervening in the rhetorics that cause increased surveillance and harm to persons with chronic pain—will forge a path for more disability rhetoricians to intervene in similar injustices aimed at persons with chronic pain and other disabilities.

Before closing this section, I want to make clear that the above critiques of problematic rhetorics of chronic pain would not have been possible without putting chronic pain and disability into conversation and using a political-relational-rhetorical methodology to guide these inquiries. Both make it possible to engage with medicine, to consider its affordances and limitations to the project of disability studies, while also rejecting the medical model of disability. This is just one example of the benefits of theorizing chronic pain as a disability and the advantages of including chronic pain scholarship in the fields of disability studies and disability rhetoric.

Differently Imagined

Can we, in fact, broaden our conception of what pain means, alter the deeply entrenched notion of pain as a threat, not to tissue or bone (which of course it usually is) but to identity.

—Susannah Mintz, *Hurt and Pain*

I would like to close this chapter with an experiment in imagination. This experiment to imagine chronic pain differently is spurred on by disability scholars Susannah Mintz, Jay Dolmage, and Alison Kafer, each of whom asks us to imagine the future of disability differently,

one in which those with disabilities are valued and living with disability is considered a meaningful and joyful experience. I believe the same can be said for persons with chronic pain and living with chronic pain. In fact, I argue that persons with chronic pain are already living what Alison Patsavas refers to as “rich, varied, and complex lives” (23). However, these lives are undermined by rhetorics of suffering and rhetorics of surveillance. Therefore, in order to witness these lives and create possibilities for more of them, I imagine a future in which chronic pain is not enslaved by dark and menacing metaphors. A future that recognizes that pain is experienced in and through relationships and that these relationships thrive on interdependence and mutual respect. A future in which persons with chronic pain are valued for their insights and contributions rather than pitied and victimized and criminalized and ridiculed. I imagine a future in which medical schools require more pain education rather than focusing on managing “burdensome” and “difficult” pain patients. And I imagine a future in which pain is recognized as a necessary universal human experience, one that unites instead of ostracizes. However, in order for this all to happen, for this imaginary future to become real, disability rhetoric scholars and the larger disability community need to intervene and complicate problematic rhetorics of pain. And then we can start anew.

CHAPTER IV

‘RELAXED, BUT NOT LAZY’: RHETORICS OF REHABILITATION AND THE MAKING OF THE CHRONIC PAIN PATIENT

Down the hall, two doors to the left, in the group therapy room, a woman with quivering hands hides them beneath the table while the man beside her closes his eyes against the piercing fluorescents overhead, taking advantage of the moment the nurse turns around to write on the whiteboard. We must be on our best behaviors here when eyes are watching us, at the ready to spot weakness, pointing at our failed attempts at performing normal. Here is the best research hospital in the world. Here is where the untreatable come to be saved.

I didn't have a choice, not really. I suspect that is true for many of the patients who make the long journey to the Mayo Clinic as a last hope after trying everything else. It's not just the distance that makes the journey long; the waiting list for an appointment, even with a referral, sometimes extends beyond a year. Another option is to arrive at the clinic without an appointment and stay at one of the many nearby hotels, motels, or boarding houses while spending each day, sometimes for weeks, sitting in one of the dozens of lobbies waiting for a cancellation. However, this option is not accessible to many who cannot afford the expense of staying indefinitely in Rochester, Minnesota, without a promise of an appointment. Since I couldn't afford this choice and the severity of my pain made the thought of waiting a year for an appointment excruciating, I made a deal with the gastroenterology scheduling office to guarantee an earlier appointment. In only two months, I would be seen by the gastroenterology diagnostic team and receive the specialized physical therapy my referring doctor recommended, if I also agreed to spend three weeks living in Rochester in order to attend the Mayo Clinic's Comprehensive Pain Rehabilitation Center's (PRC) adult outpatient day program, which I knew

nothing of. That was before. Before I ever heard of chronic pain. Before my not-yet-diagnosed GI disorder was accused of being “all in my head.” Before being told that it was my weakness and lack of effort that kept me from “managing” my pain. Before becoming a student of rhetoric and disability studies and realizing that the Mayo Clinic’s Comprehensive Pain Rehabilitation Center used rehabilitation as just another process of normalization. Before I had the knowledge to save myself from the trauma that the PRC still inflicts upon me today.

This chapter does the work that I once could not. It exposes the way rhetorics of rehabilitation employ normalizing discourses and practices to discipline and silence persons with chronic pain whose “deviant” bodies threaten the health of the nation-state. These rhetorics reinforce a rehabilitation approach to disability, which focuses on removing the “lack” from the disabled so that they may return to their assumed, prior normal state and to the able-bodied workforce (Stiker 122-23). In critiquing these rhetorics of rehabilitation, I also hope to make visible the often subtle ways they legitimize behavior modification as a method of treatment rather than attending to patients’ actual medical needs. As such, this chapter contributes to my dissertation’s larger project by calling on disability scholars and disability rhetoricians to theorize chronic pain as a disability in order to intervene in the harm that results from rhetorics of rehabilitation. This work also attends to my political-relational-rhetorical methodology by making explicit the ways in which rhetorics of rehabilitation function relationally and as a governmental tool to discipline and control what Foucault refers to as “docile bodies,” or bodies that in a capitalist society are not deemed “productive” members of the labor force.

In order to most effectively address and redress the dangers of rhetorics of rehabilitation, this chapter will move from an overview of the rehabilitation approach to disability to analyzing, critiquing, and intervening in a particular site of rehabilitation discourse—the Mayo Clinic’s

Comprehensive Pain Rehabilitation Center (PRC) patient manual, paying specific attention to the section on “Pain Behaviors,” which disciplines patients who speak about and use the word *pain* with the threat of expulsion from the center. In so doing, I show how the PRC purposely denies a language of pain by making such pain unspeakable. In addition, as a former patient of the PRC, I will engage with my lived experience to show how the program’s practices reinforce and perpetuate the patient manual’s rhetorics of rehabilitation.

However, before continuing with this analysis, it is first necessary to provide an introduction to the rehabilitation approach to disability by looking at the cultural, political, and economic climate in which the approach emerged. Such an exploration reveals how rhetorics of rehabilitation, such as the “myth of control” and pain behaviors, developed as a way to enforce the rehabilitation approach to disability. It is only through this exploration that it becomes clear how rhetorics of rehabilitation are being used today to stigmatize and marginalize persons with chronic pain.

The Rehabilitation Approach to Disability

Early in the week, we watch a VHS tape of a middle-aged man with a hypothetical back problem performing ergonomically correct kitchen duties. Then we go to work. We lift and carry pretend foods from cupboards to the cabinets below: milk cartons and orange juice jugs filled with sand, peanut butter and jelly jars filled with pebbles, and empty metal soup cans. Being there reminds me of the house corner in the kindergarten room I used to teach in. I look around for a plastic sunny-side-up egg frying in a plastic pan, and I imagine children playing with recycled dolls with bruised faces and tangled hair. The goal, we are told, is to work in the kitchen without increasing our back pain. It doesn’t seem to matter that only Rhonda has a back problem. We are all treated the same, so if one of us has a back problem, we all have a back problem.

Disability scholars point to the First World War and the return of thousands of injured soldiers “crippled” by the devastating effects of modern warfare, the increase in work accidents, and the advent of social security as the beginning of the rehabilitation approach to disability (Healey; Kumar; Schweik; Shakespeare; Stiker). This approach fundamentally changed the ways in which disability was constructed, and, as an effect, how the disabled were and are treated in Western society. Prior to the First World War, at best, the disabled were treated as aberrations in need of a cure; when a cure was not possible, they were sequestered away from “normal” society and placed into asylums, prisons, almshouses, and custodial care; at worst, they were subject to elimination by eugenicists.

The present day goal of rehabilitation differs greatly from the above, although a close examination of the approach reveals that stigmatizing attitudes toward the disabled have changed little (see especially Kumar; Schweik; Shakespeare). Instead of excluding the disabled from society because they fail to be cured, the aim of rehabilitation is to eliminate disability through transformation by “restoring the patient’s former appearance or function usually by emphasizing ways of thinking and behaving which are consistent with ‘normality’” (403 qtd in Kumar) so that they may be returned to “or replaced into a habitat, a home, a habitus from which the subject has been dislodged” (Schweik 230). Such an aim only became possible with the advancements of technology brought by the war, particularly the replacement of body parts with prostheses. As an effect, all persons with physical disabilities, and not just the war-injured, became candidates for rehabilitation and as such were freed from the asylum, separated from the mentally disabled, and placed into rehabilitation centers, another form of institutionalization, where they were trained to return to work.

I want to pause here for a moment to speculate what this history reveals about the concept of rehabilitation and, by doing so, join its critics. For example, although rehabilitation seems to concern itself with medical interventions to approve the functioning of the disabled, such as the fitting of a prosthetic limb and subsequent physical therapy, disability studies scholars instead contend that rehabilitation is primarily a social concept enforced through normalizing discourses that demand overcoming and passing, sometimes even at the expense of more pain, greater discomfort, and loss of function (Hammel). Disability historian Susan Schweik adds that instead of being motivated by charitable benevolence and the spirit of inclusion, rehabilitation was fueled by the fear of more disabled beggars lining the streets with their unsightliness, thus emphasizing the financial and social burden of dependency, rather than on improving the lives of persons with disabilities. Schweik also informs that the rehabilitation approach to disability claims that disability is an attitude that can be changed, making disability seem “optional as well as reversible” (238). Ashwin Kumar explains that the rehabilitation approach reinforces the medical model of disability and “focuses on disability as an individual problem which requires individual change” (402). The rehabilitation approach to disability thus denies that disability is also a product of socio-political, relational, and economic forces.

What is most revealing about the rehabilitation approach is its insistence that disability is an attitude that can be changed through individual will. The aim of rehabilitation, then, is not to actually eliminate the medical and social problems that cause disability, but rather to give the appearance of normality through disciplinary power, which Foucault defines as the methods used by the nation-state to “control the operations of the body” (180). Kumar adds that this disciplinary power is not very different from the normalizing power used in the penitentiary

system designed to “reform” criminals and that in both contexts rehabilitation is assured of maintaining its power “to define, target, and marginalize” (402).

Given the above, perhaps it would not be a reach to say that rehabilitation centers are institutions of incarceration. In their edited collection, *Disability Incarcerated*, disability scholars Liat Ben-Moshe, Chris Chapman, and Allison C. Carey seem to make this argument as they claim the term “institutional archipelago” to account for the diverse sites of incarceration and segregation (such as group homes, sheltered workshops, and day programs) that “all trace back to undifferentiated confinement and its ongoing reform” (14). These diverse sites of institutionalization, the editors explain, “loosely share a structure of political relationality: under the right conditions imposed from the above, degenerated, disabled, criminalistic, or uncivilized peoples can be brought up to normative standards” (6). This belief, as is true of all rehabilitation approaches to disability, is enforced through rhetorics of rehabilitation.

The above quote also speaks to the necessity of building a coalition among scholar-activists who care about chronic pain, disability, and other forms of difference, since all share similar marginalization and discrimination in regards to rehabilitation. It is also important to note here, before moving on to an overview of the Mayo Clinic’s Comprehensive Pain Rehabilitation Center (PRC) and their use of rhetorics of rehabilitation, that despite its supposed improvement on other forms of treating the disabled, the goal of rehabilitation to eradicate disability is disturbingly similar to that of the eugenics movement. It is only the means that differ. These means are most aptly expressed by Henri-Jacques Stiker:

Rehabilitation marks the appearance of a culture that attempts to complete the act of identification, of making identical. This act will cause the disabled to disappear and with

them all that is lacking in order to assimilate them, drown them, dissolve them whole in the greater social order. (xii)

The Mayo Clinic's Comprehensive Pain Rehabilitation Center (PRC): An Overview

What strikes me the most about Kim is her vulnerability. She is so incredibly hopeful and scared at the same time. I know I feel that way, as do many of the others, but she shows her desperation so openly. At one point she asks me if the program is working. No one is in the lunchroom but me, Kim, and her family. She is asking only me, and I want to be truthful. It is quiet and my hesitation hangs in the stale air. I want to tell her no, that it isn't helping, that the program is letting me down, and that the only reason I am still here is because I have nowhere left to go. But I don't want to tell her that. Instead I tell myself that maybe the program will work for her, that I am sure her pain will get better, that she will be rehabilitated and her husband and children can have her back the way she used to be: healthy and normal.

The PRC is a unique chronic pain rehabilitation center. Although it treats common chronic pain conditions that are similar to those treated at other pain centers (e.g., fibromyalgia, chronic back pain, chronic fatigue syndrome, complex regional pain syndrome, migraines, and neuropathic pain), most of its patients have already tried numerous medical interventions and alternative treatments for chronic pain by the time they reach the PRC and consider the program their last chance for relief. This knowledge, which I will continue to use in this chapter to supplement, or rather interrupt the “expert” knowledge of the PRC’s medical discourse, is a product of my lived experience as a former PRC patient.

Unlike at other pain clinics, the majority of PRC patients come “from across the United States and the world” (“Comprehensive”), often leaving their homes, families, and workplaces to participate in the 7:30AM to 4:30PM, Monday through Friday, three-week adult day-patient

program with the promise of “returning to a healthier lifestyle” (“Comprehensive”). As such, the PRC operates similarly to earlier rehabilitation centers that separated patients from their life-worlds and “healthy” society until they were rehabilitated and returned to a “normal” state. Even though normalcy is a social construct and is therefore unattainable (see especially Davis; Linton), the PRC capitalizes on what Henri-Jacques Stiker refers to as the disabled’s desire to be “like everybody else” and their willingness to be “integrated into the norm” (143). It is for this reason, along with the hope and longing that the reputation of the Mayo Clinic inspires and subsequent family and friends’ expectations, that some patients, like myself, remain in the PRC despite its use of rhetorics of rehabilitation to intimidate and shame patients into compliance.

Perhaps an even greater reason for enduring the program’s rhetorics of rehabilitation is the financial hardship that many patients experience in order to attend the PRC and the emotional need for that hardship to be of value. For example, in order to participate in the program, prospective patients must have the means to pay for travel to Minnesota, three-weeks of lodging costs, and program fees not covered by insurance. For those without insurance a recent call to the Mayo Clinic’s Estimating Services indicates that the approximate cost of the program is \$32,000 to \$46,000. Although the cost of the program for those with Medicare is reduced to \$7,000 to \$9,000 dollars, patients with this type of insurance will not know until after the services are rendered how much is actually covered. Even those who have the privilege of affording greater coverage, such as Blue Cross/Blue Shield, still have to pay out of pocket expenses for uncovered fees. For instance, although I had Blue Cross PPO, the insurance company found occupational therapy unnecessary, and since it is not possible to opt out of any part of the program, I had to cover the \$2,000 cost of this service. As for lodging, this is also a considerable expense, especially since there are only a limited number of non-profit and charitable housing

opportunities, and most are restricted to persons with specific health care needs such as transplants and cancer treatments. Given all of this information, it is not surprising that PRC patients are invested in making the program work for them despite the PRC's use of disciplinary power to control patient-behaviors through rhetorics of rehabilitation. Examples of these rhetorics are found throughout the patient manual given to patients on the first day of the program.

The PRC's Patient Manual and Rhetorics of Rehabilitation

I spend the majority of my days over a long oval table, listening to the staff talk about how we shouldn't talk about pain. Instead there are scheduled topics to discuss during group therapy, such as: time management, assertiveness training, and sleep hygiene. Through these scheduled discussions, I learn that the ideal chronic pain patient should be assertive, but not aggressive; active, but not overly so; relaxed, but not lazy; time-managed, but not inflexible; and successful, without being overly ambitious.

PRC patients are instructed to have their patient manual with them at all times. Patients are also encouraged to read the manual as soon as possible and to complete the reading by midweek. The sheer volume of the information in the manual is overwhelming and seems to suggest that persons with chronic pain need more education on their own bodies and behaviors in order to be properly rehabilitated. The patient manual is a thick, three-ring binder and contains approximately two hundred pages of information on the PRC and its goals, including descriptions of the different types of therapies provided (occupational, physical, and group), examples of behavioral modification techniques, educational materials on chronic pain, self-help worksheets, and medical forms. The information is separated by twenty-seven tabs with headings

such as: Coping Techniques, Problem Solving, Anger, Chemical Dependency, Assertiveness, and Time Management.

The Mayo Clinic publishes the manual and holds the copyright. As an effect, the manual reads as if it has one author: the prestigious Mayo Clinic. As such, it is difficult to challenge the material presented in the manual because of the ethos and authority of its author. This authority is even more pronounced by the use of second-person narration. The pronoun “you” appears throughout the manual, which has the rhetorical effect of segregating the clinic’s patients from the program staff and thereby heightening the power differentiation between the two. This power differentiation is evident in the very beginning of the patient manual on the “Daily Schedule” page that states: “As part of the program’s rehabilitation focus, we expect you to attend every scheduled activity in spite of your level of pain.” This sentence is revealing not only because it makes evident the unequal power distribution between the staff and its patients, but also because it reveals that the PRC believes that persons with chronic pain need disciplining even before they begin the program. Also, the repeated use of the second person pronoun makes it clear that the program reinforces the rehabilitation approach to disability, which locates disability in the individual and as a consequence attributes reduction in pain to an individual patient’s willingness to be rehabilitated rather than according to the dictates of the PRC program and its staff.

The following passage in the “Personal Responsibility” section of the patient manual emphasizes this point:

The path to health includes being able to have your emotional needs met without remaining ill. The first step down this path may involve a change in perspective that will lead to accepting responsibility. (n.p.)

The patient manual's emphasis on individual will and personal responsibility also echoes Susan Schweik's earlier criticism of the rehabilitation approach to disability, which claims that disability is an attitudinal problem that is "optional as well as reversible" (238). The PRC's belief that chronic pain is a temporary state that depends on individual effort and on a change of attitude is a powerful rhetoric of rehabilitation found throughout the patient manual. This rhetoric, that persons with chronic pain are responsible for their own recovery, seems to stem from the PRC's belief that persons with chronic pain have chosen to remain in pain. Although the manual does affirm that chronic pain conditions are "real," it also suggests that persons with chronic pain are still somehow at fault for having these conditions. This is made clear by the manual's stigmatizing discourse about persons with chronic pain, which is reminiscent of the negative depictions of the chronic pain patient analyzed in previous chapters. For example, consider the following passage on "secondary gain" from the "Workplace Issues" section of the manual, which characterizes persons with chronic pain as exaggerators who use their pain as an excuse for not being "productive" members of the nation-state:

When a person is living with chronic pain, there may be occasions when symptoms can be used to avoid the unpleasantness of the workplace. This is called "secondary gain." However, secondary gains do not lead to rehabilitation; rather they often contribute to a pain problem While these secondary gains may seem like benefits, in the long run they become problem behaviors that can lead to deconditioning, anxiety, and prolonged preoccupation with your pain problem. Furthermore, avoiding the workplace makes it more and more difficult to fulfill workplace duties and responsibilities, which increases stress, which in turn slows down the rehabilitation process. (n.p.)

This passage is significant not only because it makes visible the stigmatizing and discriminatory attitude that the PRC has toward persons with chronic pain, but also because it serves as another example of how the program uses rhetorics of rehabilitation, such as disability is “optional and reversible,” to enforce the rehabilitation approach’s main objective: to return “docile” bodies to the labor force. In fact, the passage even accuses persons with chronic pain of deliberately choosing to leave the workforce instead of acknowledging that many workplaces are inaccessible to persons with chronic pain and other disabilities.

Also, in order to convince persons with chronic pain that they are responsible for their pain problems and are not justified in leaving the workforce, the manual informs patients that they do not have a disability, and they should not take advantage of benefits or compensation. This is made evident in the “Pain Problems and Disability: Common Misconceptions” section of the manual that states it is a “misconception” that “a person living with chronic pain or illness is disabled and is therefore entitled to compensation,” while claiming instead that “injury/illness does not mean that one’s ability to work stops. The goal is to rehabilitate and get back one’s ability to work. Compensation may help with the rehabilitation process, but it is not a ‘retirement payment’” (12). Even though I agree that returning to work, if possible, could be beneficial to PRC patients, I find the above discourse problematic and stigmatizing because it assumes that persons with chronic pain *want* to leave work and remain unemployed. Also, placing the responsibility on patients to reduce their pain and not on the program and outside forces ignores the political, relational, economic, and social factors that have made chronic pain an “epidemic” and a “burden.” In addition, maintaining the belief that patients can be rehabilitated through individual will falsely suggests that persons with chronic pain have the psychological ability to control their own bodies through the power of their minds. This belief is another powerful and

dangerous rhetoric of rehabilitation found throughout the PRC manual and enforced by the program's practices. I refer to this rhetoric of rehabilitation as the "myth of control."

In *The Rejected Body*, Susan Wendell introduces the "myth of control," which she describes as the commonplace belief that the mind controls the body and that persons with chronic pain and chronic illness consequently have control over their pain and poor health. The "myth of control," Wendell informs, is perpetuated by the medical community as an explanation for why persons with chronic pain and illness fail to be diagnosed and cured. As Wendell explains:

First, [the myth of control] contributes to the illusion that scientific medicine knows everything it needs to know to cure us (provided that we cooperate fully) because there is no physical problem for which it cannot provide a diagnosis. Second, it transfers responsibility for controlling their bodies to the minds of those patients who cannot be cured; the problem is not that the medicine cannot control their bodies, it is that their minds are working against them. (94)

Consequently, "the myth of control" "is useful in maintaining medical omnipotence." In addition, the thought that "'she could be cured if only she wanted to get better' is comforting to both healers and those who want to believe in their power" (Wendell 95). In this way, the PRC uses the myth of control to maintain its own ethos and power while simultaneously instructing patients that changing their minds can change their bodies. This rhetoric is most evident in the patient manual's explanation of the "Cycle of Control."

The "Cycle of Control" is a series of worksheets located in the "Chronic Pain" section of the manual and attempts to explain to PRC patients how managing their emotions can control their pain. The first "Cycle of Control" worksheet lists a series of questions that asks patients to

identify how their emotions keep them from “controlling” their pain. Following this worksheet are several pages of visual representations of the “Cycle of Control,” each with a circle in the middle of the page with the words “Pain in Control.” On the outside of the circle are clockwise arrows showing the direction of the cycle. Also, along the outside of the circle appear the following words and phrases: “Focus on the Pain,” “Sense of Loss of Control,” “Increased Anger,” “Withdrawal/Withhold,” “Sadness,” and “Decreased Self-Esteem.” These words and phrases serve as headings that are used to prompt patients into thinking how they might control their “Cycle of Pain” and to show patients how the failure to control their emotions leads to more pain and greater despair.

The first page of the cycle is already filled out with suggestions from the program written underneath each heading on what steps patients might take in order to improve coping and take control of their emotions, such as: “avoid pain behaviors, especially isolation,” “improve self-talk and communication skills,” and “use anger management strategies.” The second page is left blank, except for the headings, in order for patients to consider and write down the steps they will take to better manage their emotions in the future. Patients are then expected to share their results with the whole group and as a response the group leader praises those patients who “correctly” identify the steps they will need to take to control their emotions, while instructing those who failed to do so to try harder. At the end of group therapy, patients fill out the last worksheet of the cycle, which contains only a circle in the middle of the page with the word, “You in Control.”

Before continuing with this analysis, I want to take a moment to make clear that I realize that emotional health does have bearing on physical well-being. I also know that emotions can affect the experience of pain. And yet, I still find the PRC’s use of the “myth of control”

problematic and potentially dangerous. I find it problematic to promise patients that their pain can be controlled through a change in emotions considering that one of the symptoms of chronic pain is that it is sporadic and uncontrollable. I also find it problematic that the “Cycle of Pain” worksheets are built on the assumption that chronic pain is the result of uncontrollable emotions rather than a disease of the body. This assumption aligns with another version of the “myth of control,” which Wendell explains as

the belief that if you take proper care of your body, you will stay well and fit until you die. This has the ugly implication that if you are ill or disabled, you must have failed to take care of yourself. Another is that people ‘make themselves ill’ or disabled by mismanaging their lives, their psyches, or their spirits in some way. (103)

The PRC’s use of this version of the myth of control is evident in the “Cycle of Control” worksheets and is a powerful rhetoric of rehabilitation used throughout the patient manual.

Consider, for example, the PRC’s explanation of their “Approach,” which once again implies that persons with chronic pain have mismanaged their lives and their health and need to make behavioral and emotional changes to control their pain:

Managing chronic pain is a process rather than an act—a process in which you will make choices and changes that will affect your lifestyle. These changes will help you stop or decrease behaviors that cause problems in your life and help you focus on appropriate, wellness-oriented behaviors. (n.p.)

What is most dangerous about the passage above and the PRC’s overall use of the “myth of control” as a rhetoric of rehabilitation is that it hinges on the self-disgust and shame that many persons with chronic pain already experience through marginalization and stigmatization while amplifying that experience. Also, since controlling chronic pain is not possible, I argue that the

PRC's use of the "myth of control" is not intended to improve the pain of their patients, but rather to teach them to pass as able-bodied. This is done most effectively through the program's emphasis on pain behaviors, which I examine in the next section.

Forbidden Pain Behaviors

As soon as I see the list, I know I am in trouble. I am guilty of doing every item on the list, except limping. Crying is my greatest weakness; I spent most of the last three years crying, and I consider the action involuntarily. I also do most of my crying in bed, and I wonder if I'll be in twice the amount of trouble for doing two pain behaviors at once. And when I continue to think about it, I realize I sometimes do three or four pain behaviors at the same time. When I cry (2) in my bed (4), sometimes I also put my hand on my stomach when I have spasms, which I learn is a protective posture (5) and I'm sure I must be grimacing (3) as well. My only hope is that perhaps doing them out of order isn't as big of a deal.

Bad Back Bob is a big man, about 6'4 and bulky, and when he falls onto the wooden floor the second time around, his body makes a loud thud. We all turn away from Bob's embarrassment, from his cry of pain. Finally, Aaron helps Bad Back Bob up, Bob leans on him hard, his weight heavily spilling onto Aaron's shoulder. But when he stands up, he isn't given his cane back. "Limping and using protective posture," Aaron tells him, "are pain behaviors."

Even now, eleven years after my time at the PRC, when I put my hands on my belly to calm the pain that moves inside of it, I still feel guilt and shame at my attempts to soothe myself.

As soon as I notice that I am engaging in this "protective posture," I quickly drop my hands to my sides. Using "protective posture" was just one of the pain behaviors listed in the PRC manual, which are described as:

[A]ny action or response that lets others know or reminds you, that you are experiencing pain. Pain behaviors are used as a way to try to escape pain or to obtain care and support from others. Pain behaviors usually lose their usefulness with time, but some people continue to engage in these behaviors as habit. Often pain behaviors become a social problem and isolate you from friends and family. Your healthcare team can help you identify and address any pain behaviors you may have. (n.p.)

I can still hear the staff, whom we had come to call The Pain Police, telling me that I touched my belly because I wanted to draw attention to myself, to seek pity.

I was not the only one in my group who apparently used protective postures. A fellow patient was reprimanded during “individual time” for putting her legs up against a wall, a common resting pose in yoga, to take the pressure off her back. Another patient with migraines was instructed to remove her baseball cap in group therapy since it only served to bring attention to herself rather than shield her from the bright lights overhead. Even assistive devices, particularly canes and braces, were considered using protective posture and were taken away from patients when the staff deemed them unnecessary. Leaning against the wall for support was also forbidden. As an effect, we were always on high alert, feeling unsafe in a supposedly safe environment. Using pain behaviors was taken very seriously, and those who continued to use them disappeared. We only knew of their dismissal from the program when they went missing from morning meeting the next day. The staff never talked about their absence and their loss was heavy and quiet.

We guessed that patient dismissals were decided by the program’s psychiatrist, Dr. Matthews, who every Tuesday and Thursday of the program had us form a line outside of his office door to await judgment. We waited tensely, never knowing the order in which we would

be called and weary of being chastised for accidentally leaning against the hallway walls. Some of us held hands. When a name was called, each patient walked into the office alone and came to stand in front of Dr. Matthews and the program team seated in a small conference style room that reminded me of being in the courtroom of my Social Security Disability hearing. At this meeting, Dr. Matthews summarized the patient's progress or lack thereof based on her ability to taper off pain medication and reduce or eliminate pain behaviors. Afterward, each member of the program team had the opportunity to ask the patient specific questions and to comment on any problematic or redemptive qualities that she had exhibited. We did not talk as we waited, in part because the fear made us quiet, and in part because talking about pain was a pain behavior.

I share these stories not to seek attention or pity, as the PRC would contend, but rather to provide another example of the ways in which the PRC uses rhetorics of rehabilitation, in this case in the form of pain behaviors, to enforce the rehabilitation approach to disability that demands normalization as a necessary step toward inclusion. Since a cure for chronic pain is impossible and treatments for chronic pain such as occupational therapy and physical therapy are time-consuming and unpredictable, having patients eliminate pain behaviors, which I argue is a form of what the field of disability studies refers to as “passing” or “the way that people conceal social markers of impairment to avoid the stigma and pass as normal” (Brune and Wilson), is the only way for the PRC to ensure the illusion that their patients returned to normalcy.

The need for PRC patients to identify and eliminate pain behaviors is also emphasized repeatedly in the patient manual, starting with the “Pain Behavior” list and the “Daily Pain Record” forms. The “Daily Pain Record” forms are completed and turned in at check-in each morning of the program. The forms contain a checklist of what the program has identified as the most common types of pain behaviors—talking about pain; limping; crying; grimacing; moving

slowly; rubbing affected area; using protective posture (brace, cane, splint); lying down; withdrawing from people; and avoiding activity—and ask patients to identify how often they engage in these behaviors. These forms are then given to the program team and are used to evaluate patient improvement and compliance. Pain behaviors also appear in the “Goal Setting” section of the manual and are further described as “actions or words that communicate to people that you have chronic pain.” Apparently, then, the PRC believes that having chronic pain and appearing to have chronic pain need to be kept hidden. Patients are then instructed to choose reducing pain behaviors as one of their program goals.

Pain behaviors also appear in the “Difficult Day” and “Group Therapy” sections of the manual; patients are told to “avoid talking” about pain and symptoms. Talking about pain is also condemned in the “Relationships” section of the patient manual, which explains that “people communicate through actions as well as their words,” which apparently results in the loss of relationships and “sexual intimacy.” This rhetoric of rehabilitation, that talking about pain makes pain worse and destroys relationships, is the most damaging of the PRC’s forbidden pain behaviors because it denies a language of pain by making such pain unspeakable. Consequently, persons with chronic pain are further stigmatized, marginalized, and eliminated by being forced into silence. This forced silence is also indicative of how Western medicine fails to address pain effectively, and, as a result, is responsible for the commonplace belief that pain “destroys” language and is uncommunicable. It is also important to emphasize here that it is not chronic pain that fails language, but rather the medical establishment that disallows persons with chronic pain access to language.

I remember the rise and fall of voices. The after-hours when the program doors closed for the nights and the weekends. When we gathered in each other’s motels, hotels, and boarding homes

in far-away Rochester, Minnesota, to talk about how we could not talk about pain. And in that talking, we came to know each other's stories, where and when the pain began and who was there or not there to support us in the moments when we needed support the most. We talked about the hurting, the throbbing, the stabbing, the pins and needles, and then the pain of the waking up of joints and muscles and bones. I remember how the words kept coming and coming, and how in them we found another way to be in pain, another way to speak.

CHAPTER V

CHANGING THE STATUS QUO: LISTENING TO ALTERNATIVE

RHETORICS OF CHRONIC PAIN

I explore what it means to speak with cracked voices, to use words, language, and rhetoric, in cries and rants, teases and taunts, that refuse to accept the status quo.

—David L. Wallace, *Compelled to Write*

Much of what we know of chronic pain comes from those in dominant positions of power—medical experts, the pharmaceutical industry, popular media outlets, and legislative bodies. Despite critiquing and disrupting these institutions’ voices, I have still allowed them to dominate this dissertation, and all they have spoken of is the drug addict, isolation and despair, suicide, and illegitimacy and fakery. Thus, all they have given to us is what this dissertation has referred to as problematic rhetorics of chronic pain. In this chapter, I heed David L. Wallace’s above call and listen instead to the “cracked voices,” the “cries and rants,” and the “teases and taunts” of those who live with chronic pain and have different stories to tell (3).

These stories offer alternative rhetorics³⁰ of chronic pain that provide more genuine and honest interpretations of chronic pain that include both the often terrible material realities of

³⁰ The two major works that I will draw on for explanations of alternative rhetoric are David Wallace’s *Compelled to Write* and editors’ Laura Gray-Rosendale and Sibylle Gruber’s *Alternative Rhetorics*. Wallace uses the singular form “alternative rhetoric” in his book, while Gray-Rosendale and Gruber use the plural form “alternative rhetorics” when referring to a singular instance of a type of alternative rhetoric. For example, in their book they refer to one activist website as a site of alternative rhetorics and multiple activist websites as alternative rhetorics, while Wallace would refer to the former as an alternative rhetoric and the latter as alternative rhetorics. Gray-Rosendale and Gruber explain that they choose to use the plural form in order to “emphasize multiplicity and fragmentation within and between different rhetorics and different traditions” (5). Although I understand their reasoning, I also find it confusing. Therefore, unless I am referring to Gray-Rosendale and Gruber’s work, I will be using the singular form of alternative rhetoric for the purposes of this chapter. However, I will use the plural form when referring to multiple examples of alternative rhetorics of chronic pain.

living with chronic pain and the transformative power that a life in pain affords. In so doing, these rhetorics also speak to this dissertation's political-relational-rhetorical methodology, which calls for [1] troubling the hegemony of biomedicine and its medical model of disability that defines chronic pain as an individual defect unaffected by political, societal, economic, and relational factors; [2] disrupting stigmatizing representations of persons with chronic pain; [3] challenging the prevailing belief that chronic pain is uncommunicable and inaccessible to those without the lived experience of chronic pain; and [4] problematizing the supposed invisibility of chronic pain. To best show how alternative rhetorics of chronic pain do this work, this chapter analyzes a particular site of alternative rhetoric—PainExhibit.org—an online chronic pain art exhibit. However, before moving on with this analysis, I first wish to provide a brief theoretical overview of alternative rhetoric and its capacity to enact positive social change.

Alternative Rhetoric

Most discussions of alternative rhetoric occur amongst scholars in the field of rhetoric and composition studies who challenge the Greco-Roman classical rhetorical tradition that is authored largely by white, middle-to-upper-class men in prominent positions of power (see, for example, Dolmage; Glenn; Gray-Rosendale and Gruber; Powell et al.; Schroeder et al.; Wallace). Those engaged in alternative rhetoric—feminist rhetoricians, rhetoricians of color, disability rhetoricians—speak from a place of marginalization and stigmatization. They offer alternative histories of rhetoric and rhetorical thought by recovering and expanding the rhetorical canon. By doing this work, these scholars “give voice to those whose discursive acts went unrecognized by Western culture” and were instead “marginalized, ghettoized, neglected, or overlooked within our historical context as well as other historical contexts for particular cultural, social, and political reasons” (Gray-Rosendale and Gruber 2). Also, alternative rhetoric scholars have and

continue to pave new rhetorical landscapes by including rhetorics of race, gender, sexuality, disability, and identity formation in their research and teaching. In addition to redefining who counts as a “rhetor,” alternative rhetoric scholars also question what counts as “rhetoric” by challenging the hegemony of male-dominated, alphabetic, print-based, linear, so-called objective discourse (Bizzell; Dolmage; Haas; Powell, “Listening”; Schroeder, et al.; Shipka).

Alternative rhetoricians focus instead on material, visual, digital, and multimodal rhetorics as legitimate and rigorous intellectual rhetorical practices that increase opportunities for inclusivity and accessibility. For example, in “Listening to Ghosts,” Malea Powell speaks of the necessity of challenging dominant discourse (or Euro-colonialist discourse) with “other ways of knowing, other ways of being and becoming that frequently go unheard of and unsaid in scholarly work” (12). She advocates for alternative discourses that “tell a story that mixes worlds and ways, one that listens and speaks” (12), and then does so in her hybrid essay that defies linearity and weaves together storytelling, scholarly discourse, poetry, journal entries, and other remembrances. Maureen Daly Goggin similarly “pushes at the boundaries of what counts as rhetorical practice and who counts in its production” in her work on the rhetorical practice of needlepoint sampler-making (310). In “Wampum as Hypertext,” Angela M. Haas challenges hegemonic understandings of digital rhetoric, calls for revisions of how we understand digital rhetoric and digital literacy, and proposes “digital and visual rhetoric sovereignty” by recognizing that American Indians have composed and used wampum belts, which Haas describes as “a living rhetoric,” to “record hundreds of years of alliances within tribes, between tribes, and between the tribal governments and colonial government” (78). The work of alternative rhetoric scholars is also felt in the composition classroom through the integration of alternative discourses within traditional academic discourses. According to the editors of *ALT*

DIS, these new discourses “accomplish intellectual work while combining traditional academic discourse traits with traits from other discourse communities” and “invoke a counter-cultural image that bespeaks the political resistance to hegemonic discourse that these new forms express.” (Schroeder, Fox, and Bizzell ix).

Perhaps the greatest effect that alternative rhetoric has on the field of rhetoric and composition and the public sphere is its capacity to change the status quo. As David L. Wallace argues in *Compelled to Write*, alternative rhetoric helps “to sort out both the ways that some groups have been systematically marginalized by dominant discourse practices that pretend neutrality and the means those who have been so marginalized have used to challenge the discourses of power” (4). He also adds that the “lion’s share of the work of alternative rhetoric will, for the seeable future, revolve around exposing the inequities in our society, and the means by which traditional approaches to language and rhetoric support those inequities” (24) and, conversely, demonstrate how nontraditional approaches enact alternative ways of being and knowing. In this chapter, I intend to contribute to and honor the aforementioned commitments of alternative rhetoricians by showing how an oppressed group creates an online art exhibit that provides an alternative rhetoric of chronic pain. As an effect, PainExhibit.org enacts positive social change for persons with chronic pain, the field of rhetoric and composition, and the disability community by offering counter-narratives to problematic rhetorics of chronic pain that redefine what it means to live with chronic pain and other disabilities.

The most insidious rhetoric that PainExhibit.org seeks to challenge and redress is the theoretical and commonplace belief that pain is inexpressible and resistant to language. This rhetoric comes largely from the field of trauma studies (see especially Caruth; Felman; LaCapra; Laub; Scarry), which theorizes that the experience of pain is not representable to others, and

even to oneself, because the trauma of pain shatters the human subject and fractures language. Most known for this theory is Elaine Scarry, whose seminal work, *The Body in Pain*, argues that pain “evaporates from the mind because it is not available to sensory confirmation.” She also insists that pain “comes unshareably into our midst as at once which cannot be denied and that which cannot be confirmed” (4). However, despite the pervasiveness of Scarry’s work, it has not gone unchallenged. Scarry’s most persistent detractors are disability life-writing scholars. For example, in *Illness as Narrative* Ann Jurecic points to the abundance of literature about pain as testimony to argue that that pain is not resistant to language. She explains that what makes pain difficult to communicate is the challenge of making “readers receptive to stories of pain” and the “restrictive biomedical language for pain” (51). Martha Stoddard Holmes also questions Scarry’s conclusions about pain in her essay “Thinking Through Pain,” in which she speaks of her own encounters with pain as a “site not of language erosion but generation” (133). Holmes recounts how writing in her Moleskine notebook “anchored her to the waking world” as she endured six months of chemotherapy, characterizing it as a time in which she wrote the most in her adult life. In contrast, she describes how her experience of acute surgical pain, whose visit she slept through, was “muted by the sense of a clear trajectory to the day when pain would be gone and forgotten” (127). That language came more readily to her with chronic pain than with acute pain suggests that we reread Scarry’s work as a treatise about acute pain, rather than chronic pain. Holmes also urges her readers to “look at a wider range of relationships between pain and language” (133).

As if in response to Holmes’s call, Susannah Mintz takes up this work in *Hurt and Pain* by “capturing the fullness of pain’s iterations” and “broadening our study of pain as a matter of language ingenuity,” which she does in her investigation of pain across literary genres (5).

Mintz's work is also important to this dissertation not only because it argues that "pain can be uttered," but also because it tells us what is at stake when we believe that pain is unspeakable, such as "perpetuating the loneliness and fear that pain can inspire" and "reinforcing the idea that pain forestalls our forward motion; that it is an interruption or aberration of our regular life" (9). Instead she urges us into becoming writers and readers of pain expressed in alternative forms, allowing us to

witness pain in very different guises; as generative, for example, rather than overpowering; as the foundation of lyric and storytelling, the occasion for touch and intersubjective understanding, the very substance as our status as moral but no less resilient beings. (9)

PainExhibit.org, I argue, is one of these alternative forms. In the section below, I show how PainExhibit.org challenges the commonplace belief that pain is uncommunicable and inaccessible to those living outside the experience of chronic pain and instead offers multiple ways of knowing chronic pain and its effects on those living with chronic pain conditions. In addition, I also describe how the multimodality of PainExhibit.org complicates trauma theorists' argument that pain is resistant to language, given the understanding that language is not limited to linguistic forms of expression (see especially Haas; Kress; Powell et al; Shipka; Rice; Yancey).

PainExhibit.org—An Introduction

PainExhibit.org is an online visual arts exhibit that features art by persons living with chronic pain. The exhibit's mission, which can be found on the site's homepage, is to "educate healthcare professionals and the public about chronic pain through art" and "to give voice to the many who suffer in silence." Founded by Mark Collen, who— after "herniating his disk in his

lower back resulting in chronic nerve pain” struggled “to find quality pain management” and to communicate the severity of his pain to his physicians—“made art of his pain.” Collen concludes in the history section of the exhibit’s site that “art was far more effective at communicating pain than words, and resulted in the receiving of better quality healthcare.”

Upon realizing the power of art to communicate pain, Collen began PainExhibit.org by inviting artists “from around the globe” to “express some facet of their pain experience,” and then assembled a collection of their artwork online. Rhetorically, PainExhibit.org creates a community for stigmatized and marginalized persons with chronic pain and brings its artists’ struggles with chronic pain into the public sphere and collective consciousness. This community also extends to exhibit visitors with chronic pain who may find comfort and support in seeing their own similar private experiences with chronic pain reflected back to them. In addition, given that the exhibit is virtual, this community fosters inclusivity by making it possible for persons with chronic pain and other disabilities who are often ostracized by traditional art exhibit spaces to “attend” the exhibit. By creating this community, PainExhibit.org offers an alternative rhetoric of chronic pain—one of belonging—that troubles problematic rhetorics that insist chronic pain is an isolating, individual, and alienating experience and speaks to this dissertation’s political-relational-rhetorical methodology, which argues that chronic pain is experienced in and through relationships.

Selections featured in the exhibit include art images of paintings, photography, sculpture, mixed-media, and found art. A few pieces also incorporate alphabetic text, seemingly used for emphasis and to depict thoughts. The multiple modes (image, text, color) and materials (paint, canvas, clay, glass) used in the artwork afford the artists with more means to render their pain and their audience with greater opportunities to access the lived experience of pain being

conveyed.³¹ Access to the artists' works and their pain experiences is also increased given the fact that the exhibit's website offers multiple points of entry into the eleven art galleries resulting in visitors having more agency over how they wish to experience the exhibit.³² Such agency would not be possible for readers of a traditional, linear, print-based text on chronic pain. Thus, PainExhibit.org enacts an alternative rhetoric of chronic pain not only through its messages but also through its hybrid form.

One multimodal composition that exemplifies this enactment is Judy Cowan's "Pieces of Me." The art image contains an exaggerated form of a head, arms, and torso of a human figure painted in black. Inside the figure are scattered puzzle pieces of photographs painted, cut out, and glued onto its surface. The images on the puzzle pieces seem to act as symbols that capture the artist's lived experiences of chronic pain: broken hearts, the word Love torn apart, the blue waves of an ocean, black crosses, and a teddy bear wearing a pink ribbon. Cowan's choice to include the image of the teddy bear in her artwork serves as a critique of the tendency to infantilize women with chronic pain considering the fact that teddy bears and other stuffed

³¹ Although multimodality as it is theorized and practiced in writing studies is beyond the scope of this chapter, it is worth noting that multimodal rhetoric scholars advocate for the use of multiple modes in the composition process in order to increase accessibility (Arola and Wysocki; Butler; Shipka; Yancy). For example, in "Where Access Meets Modality," Janine Butler writes: "I connect multimodality to accessibility to reflect the potential for communicating through multiple modes to engage more senses. When we express meaning in more than one mode—when we go beyond the spoken work in isolation, for instance—we increase the number of ways that others might access our message" (n.p.).

³² However, it is important to note that despite these increased opportunities for access, persons who do not have the means to afford personal internet service will still have limited access to the exhibit. Also, the exhibit is not universally designed. For example, although there are artist statements describing the artists' interpretation of their images, there are no text captions to describe the artwork to those visitors with visual impairments. Also, missing from the exhibit are trigger warnings that indicate that an image could evoke trauma. Although, the ability to communicate pain effectively is still challenging, Collen has made an important start.

animals are often given as “get well” tokens to sick women, especially during hospital stays. The pink ribbon wrapped around the teddy bear is indicative of how the color pink permeates sick women’s hospital rooms and bedrooms because of its associations with femininity (see especially Ehrenreich). On the outside of the figure are discriminatory remarks that are all too familiar to persons with chronic pain, such as “it’s all in your head,” “oh, but you look so good,” and “you’re just being lazy.” Cowan’s positioning of these problematic rhetorics outside of the black figure speaks back to the demand that persons with chronic pain internalize and individual their pain. In addition, the space outside of the body can be imagined as a shared public space in which these dismissive comments circulate socially, thereby drawing attention to how chronic pain and other forms of disabilities need to be theorized as political-relational-rhetorical. Also, the hybrid form of the composition allows for multiple opportunities to access her experiences with chronic pain. As a result, Cowan offers an alternative rhetoric of pain that validates and values the lives of persons with chronic pain and demonstrates the communicability of chronic pain by acknowledging the material realities of living with chronic pain and by disrupting attempts by commonplace rhetorics to devalue a life in pain.³³

As a person with chronic pain, I know I am more able to connect with and understand Cowan’s and the other artists’ experiences with chronic pain through their art images than those visitors coming to the exhibit without this shared experience of pain. I know I am more likely to understand the symbols Cowan uses to express her struggles with chronic pain than those

³³ It is important to note that this line of inquiry intersects with work being done in visual and digital rhetorics (i.e., Buehl; Frost and Haas; Graham; Teston). Although investigating these connections is beyond the scope of this dissertation’s methodology, future iterations of my methodology will be more heavily influenced by visual cultural rhetorics invested in embodiment and social justice.

without the shared experience of undergoing numerous hospital stays in rooms filled with teddy bears, pink balloons, and pink flowers. Like Cowan, I have also felt the loss of faith and the losing of love, and the betrayal of voices shouting that my pain is not real. We both know deeply the marginalization and stigmatization that comes from being othered by problematic rhetorics of chronic pain. For these reasons, Cowan’s artwork speaks to me because it speaks to my own pain as well. I know this sense of solidarity is not available to those visiting PainExhibit.org without the lived experience of chronic pain, and that, as an effect, the pain communicated to these visitors by “Pieces of Me” and the other art images might not be the same as that which is communicated to me. However, the pain that is communicated to those visitors who do not share the artist’s lived experience can still be one that opens a space for questioning, thus leading to possibilities for different kinds of connection and relations. These possibilities then offer different, and no less important, understandings of pain. Also, there is value in becoming aware of the pain of others, of being able to cultivate empathy for those who struggle in ways we cannot truly know. And it is this empathy, this willingness to imagine other people’s pain, which draws us all together.

The Galleries

The art images featured in PainExhibit.org’s eleven galleries include approximately twelve images in each gallery. When selected, the images are enlarged and accompanied by the artist’s name, the title of the artwork, a list of the materials used in the creation of the artwork, and an artist statement.³⁴ The titles of the galleries—“Portraits of Pain,” “Pain Visualized,” “But

³⁴ The artist statements are a few sentences-to-two paragraphs in length. They read as though they are journal entries produced by a writing prompt. Each statement tends to have similar components: a description of the pain condition, an explanation of the artwork, what the artwork is meant to convey, and the impact of pain on the artists’ lives. It is important to stress that the artist statements do not appear simultaneously with the artwork in the gallery; rather, they only

you Look so Normal,” “Healthcare,” “Escape from Pain”—in and of themselves are noteworthy since they reflect the artists’ awareness of problematic rhetorics of chronic pain, such as: since pain is invisible, it must not be real, and therefore persons with chronic pain are illegitimate. These titles also suggest that visitors of the exhibit might experience a disconnect between reading about the exhibit and actually viewing the collection. This disconnect is the result of the congenial tone used in describing the exhibit and the artists’ expressed desire to help “educate healthcare providers” about chronic pain without giving an indication of the darkness, anger, and despair evoked by the images, especially those directed at the medical industry, the healthcare professionals “treating” them, and the pharmaceutical industry.

The artists’ distrust and frustration are felt most in the “Healthcare” gallery where pills, multicolored and in various sizes and shapes, are set loose: crashing down fences, scattering on plates for an evening meal, and stacking high on a wall in Dilaudid pill bottles (a commonly prescribed narcotic pain killer) where a shiny stethoscope hangs. Other striking images include a tower-high cylindrical image visualizer plastered with X-rays and a pill bottle whose label has been replaced with a hundred-dollar bill. These images not only express the artists’ frustration

come to the screen after a visitor clicks on the art image. As a result, the artist statements seem secondary in importance to the art image on display and give the impression that they were written after the artwork was already composed. In fact, given that as part of the submission process artists have to explain “how each piece of art relates to you and your chronic pain,” I would argue that most, if not all, of the artist statements were written for the submission process rather for the artists’ themselves or visitors to the exhibit. I make this important distinction in order to explain why my analysis of PainExhibit.org as an alternative rhetoric of pain focuses solely on the artwork displayed and not the artist statements. Also, the fact that the artist statements are not integral to experiencing the artwork might also explain why many of them not only undermine the complexity and nuances afforded by the art images, but also re-inscribe some of the problematic rhetorics of pain discussed in previous chapters (e.g., pain is uncommunicable and not survivable) and, in so doing, become an example of the pervasiveness of these rhetorics.

and disillusionment with biomedicine; they also serve as an alternative rhetoric of chronic pain by providing a counter-narrative to the self-indulgent, doctor-shopping, and drug-seeking chronic pain patient by revealing how medical professionals overprescribe medications and undertreat their patients and how the pharmaceutical industry profits from patients' pain. Thus, we see in this example how PainExhibit.org aligns with the commitments of alternative rhetoric to make apparent how those in dominant positions of power oppress marginalized populations and how such populations challenge discourses of power and, in so doing, begin to upset the status quo. As an effect, the artists become active agents in their healthcare management rather than passive victims of a hegemonic medical system. In turn, exhibit visitors are invited to question the "authority" that the medical and pharmaceutical industries seemingly have over their bodies. In such a way, PainExhibit.org also participates in what Susannah Mintz describes as the larger project of disability studies, which is to provide a counter-discourse to commonplace narratives of disability by finding "a way of articulating the body that challenges the authority of medical narrative and allows the individual to emerge as a self-authored, rather than a chart-noted, being" (6).

In addition to revealing how the medical industry fails to effectively and ethically treat persons with chronic pain, the artwork in the Healthcare gallery also troubles the medical model of disability, which locates disability in the individual rather than acknowledging that disability is created by political, societal, economic, and relational factors. For example, the proliferation of medications in these art images illustrates the great cost of pain management, the stethoscope hanging on the wall with the Dilaudid pill bottles points to the fraught and suspicious relationship between pain specialists and their patients, and the image visualizer plastered with X-rays points to the great amount of time and energy that persons with pain must undergo in

order to receive treatment. Lastly, these criticisms of the medical model of disability speak to the necessity of a political-relational-rhetorical model of disability that accounts for the above material realities of living with disability and chronic pain.

Before moving on to the next section and continuing my analysis of the PainExhibit.com's artwork, I first wish to revisit an argument I presented in chapter 1 of this dissertation. In that argument, I made a distinction between two types of rhetorics: problematic rhetorics of pain and the new, generative rhetorics of chronic pain,³⁵ and I now realize that the distinction between the two is no longer necessary. I wrote that the former (problematic rhetorics of chronic pain) defines rhetoric as the persuasive use of language, wherein language induces audiences to accept certain versions of reality, which can thus be interpreted, contested, and revised, while the latter (the new, generative rhetorics of chronic pain) defines rhetoric as the study of how embodiment produces knowledge, identity, and ways of being-in-the-world. Now I have come to understand that for persons with chronic pain and other "marginalized, ghettoized, neglected or overlooked" populations, the act of critiquing problematic rhetorics is also an act of survival. Thus, the art images in the "Healthcare" gallery, as is true of all the art images in the exhibit, simultaneously critique problematic rhetorics of chronic pain and invent a new generative and productive rhetoric of chronic pain that honors and values their lives. Hence, the artists' critique of problematic rhetorics of chronic pain is also what allows them to survive.

³⁵ The new, generative rhetoric of pain is also what I refer to as alternative rhetorics of chronic pain in this chapter.

The Visibility of Chronic Pain

The issue of knowledge location is central to the struggles of people experiencing pain. The physical location of pain within bodies' tissues is ambivalent, its materiality questioned by practitioners who point to the lack of organic traces of chronic pain.

—Petra Kuppers, *The Scar of Visibility*

As discussed in previous chapters of this dissertation, many chronic pain conditions are considered invisible because they do not appear in most imaging testing studies, such as X-rays, Cat Scans, and MRIs (Foreman, *A Nation*; Wendell). As Petra Kuppers notes above, the fact that chronic pain conditions cannot be detected in biomedical tests leads to medical professionals' skepticism about the chronic pain patient and to their questioning of the validity of their patients' symptoms. This skepticism is also felt by family and friends of persons with chronic pain who, after time, start to question why their loved ones' pain does not improve in spite of countless doctors' appointments, medications, and a lack of physical evidence to support reports of suffering (Foreman, *A Nation*; Morris). As a person with chronic pain, I have often wished and prayed for a broken bone, a fracture, swelling, bruising, scarring, even a tumor, anything that would make my pain visible, and, therefore, believable and treatable. The supposed lack of visibility of most chronic pain conditions is also what leads to chronic pain being labeled as "bad" and "dirty" pain (Cervero; Schleifer), since unlike acute pain it is said to reveal no indication of danger or a threat and instead leads to what pain scholar Ronald Schleifer describes as "the destruction of a person's sense of her life as a whole" (8).

Schleifer's words serve as an example of how the belief that chronic pain is invisible leads to problematic rhetorics of chronic pain. His use of such rhetorics also points to the need for alternative rhetorics of chronic pain that are more nuanced and generative. Such a rhetoric

can only come from refusing to accept the commonplace belief that chronic pain is invisible and by interrogating who decides and what defines the invisibility of chronic pain. This can be done by questioning the authority and objectivity of the “evidence” most used to discount the chronic pain patient—the medical photograph.

The ethos of the medical photograph is a topic of conversation amongst disability studies scholars and medical rhetoricians (i.e., Buckland; Garland-Thomson; Hall; Helle; Hevey; Siebers). For example, in “Zip Zip My Brain Harts,” Alice Hall asks us to consider what it means “to name, diagnose, and make disability visible on a literal level” (266). She argues that medical portraiture is “based on a momentary fantasy of transparency” in which

X-rays turn the body inside out, not only in the sense that technology allows doctors to make the hidden interior visible, but also in that they suggest that an external viewer can “read” or “decode” an individual’s interior state from a single image. (267)

By questioning the ability of the medical photograph to name and diagnose, Hall complicates the one-dimensional view of the body and the authority of biomedicine, reminding us that “the X-ray cannot be seen as culturally neutral or simply as a technical-medical image” (267). Hall also argues that the medical photograph “captures views of a body at a particular moment and does not take into account the complex layering of cultural associations, power relations, and wider, intersecting histories of oppression that construct and complicate the way that we see” (268). Hall’s work challenges the invisibility of “invisible” disabilities, such as chronic pain conditions, by showing the limits of medical knowledge as well as the limits of the photographic image. Additionally, Hall’s work speaks to the need for alternative rhetorics of disability to reveal how those in dominant positions of power construct restrictive identities of the disabled and how the disabled resist such identity constructions.

In *Disability Aesthetics*, Tobin Siebers also questions the ethos and objectivity of the medical photograph by explaining that

the medical photograph is its own aesthetic genre, an aesthetic genre determined not to be seen as one: it obeys a number of aesthetic rules, such as the use of full body profiles, changing postures, and serial shots of the same subject, comparative anatomy between subjects, and close-ups, but its primary aesthetic imperative is the pretense of objectivity for the purpose of medical understanding and diagnosis. (45)

In addition to questioning the credibility of the medical photograph, Siebers also points out what is at stake when the medical photograph is taken as truth when he writes that “there is no better example with which to think of human disqualification than the medical photograph” (45). He explains that the medical photograph “may enfreak any deviation from the baseline, however slight,” considering that “the baseline in medicine is perfect health” (45). He concludes that the danger of the medical photograph is its power to “represent a person as a medical oddity,” and, in so doing, “disqualify the medical subject as inferior” (46). Rather than give the medical photograph the power to define normalcy, Siebers instead turns to modern art for more realistic and complex representations of disability. By challenging the ethics and omnipotence of the medical photograph, both Hall and Siebers ask us to consider how other ways of seeing make disability visible.

Consider, then, a pair of a woman’s feet. Side-by-side images of a pair of clay paper-mache woman’s feet jut out from a pinkish-red spray painted cardboard box resembling a slab of heavy brick. The toes and tops of the feet are painted the same pinkish-red color as the cardboard box. Thick shards of glass gather at the middle of the woman’s feet and then cascade over the brick creating a waterfall of ice. In the second image, the back of the woman’s feet are inflamed

red, small rocks are embedded in the skin, and more glass shards pierce the tender flesh before falling to the floor in a heap. Consider then a charred and cracked hand lit up with bright red-orange flames. Wisps of smoke surround the decaying hand in a landscape of darkness. The damaged hand rests atop an artist's notebook with a pencil-drawing of a healthy hand. Consider then a woman's back. The gentle curving interlocking vertebrae of her spine is replaced by jagged heavy metal black and red anvils that crumble at the base of her back. Beside her is a tall ladder. Across each rung of the ladder is the word *Pain* written in red ink.

Pain *is* visible in each of the PainExhibit.org's art images described above. In Deborah Ann's "Pain Without Words," the pinkish-red areas of the feet indicate the rawness, sensitivity, and burning sensation that are often symptoms of chronic pain conditions. The shards of glass that fall over the feet and the small rocks embedded in the soles represent chronic pain's contradictory sensations of sharpness and numbness. In "Suffering for Art," Tanya Paterson's digital manipulated photograph of the charred and cracked hand bursting in flames makes it almost possible to feel the scorching heat of the fire burning up the flesh. The juxtaposition of the decaying hand atop the artist's notebook with the drawing of the healthy hand is a visualization of the trauma that many persons with chronic pain feel when disembodied from what they believe to be their former "healthier" selves (see especially Wendell). In KJ William's "My Reality," the ink drawing of the woman's back makes visible an injured spine that has seemingly undergone numerous surgeries to repair pierced nerves or dislocated discs. The heavy metal anvils along her spine show the pressure, muscle spasms, and stiffness that many persons with chronic pain feel with incurable and unexplainable back pain. The ladder with the rungs of pain climbing upward into the sky can be seen as a variation of the pain scale found in most

medical professionals' offices that attempts to quantify the often subjective experience of chronic pain from 0-to-10, and fails to do so.

Unlike the medical photograph with its limits, dehumanizing mechanisms, and questionable ethics, the art images above invite us to consider and witness other ways of seeing that make disability visible. Rhetorically, they trouble the unknowability of chronic pain and offer an alternative rhetoric of chronic pain to the one presented to us in the static, one-dimensional, snapshot of an X-ray of a body part at a particular moment. Instead of attesting to chronic pain's invisibility, the art images, like pain, breathe and pulse with life. They reveal the artists' humanity—their vulnerabilities, struggles, determination, and perhaps even their hope, which is often the result of channeling difficult emotions and experiences into art. These images do not portray the “destruction of a person's sense of life as a whole” nor other such problematic rhetorics of pain; rather, they are testaments to the resilience of the human spirit.

It is also important to note that the alternative rhetoric of chronic pain that these art images express neither deny the hardships and other terrible realities of living with chronic pain, nor do they put their audiences at ease and placate them with rhetorics of overcoming. What they offer are nuanced and generative rhetorics of chronic pain that produce new insights and knowledges about the richness and vastness of the embodied lives of persons living with chronic pain, while opening up moments of difference and new alignments of power. In creating these works of art, the artists also resist the medicalization of their bodies and, as an effect, challenge the restrictive and stigmatizing identities forced upon them by the medical industry and others in dominant positions of power. Consequently, these artists empower not only themselves, but also the viewers of their work who also live with chronic pain by reclaiming their voices, their bodies,

their minds, their feelings, and their sensations from objectification and victimization to transformation and healing.

Cracked Voices and Narrative Medicine

In the opening of this chapter, I vowed to listen to the “cracked voices,” the “cries and rants,” and the “teases and taunts” of those who live with chronic pain and have different stories to tell, and move away from the voices of those in dominant positions of power who have occupied this dissertation for far too long (Wallace 3). Thankfully, I began to do this listening as I viewed the galleries at PainExhibit.org. Such listening can lead to positive social change for the disability community, persons with chronic pain and other disabilities, and even practitioners of medicine.

The practice of medicine, “despite such technical progress,” argues physician and narrative medicine specialist Rita Charon, is populated by “doctors that often lack the capabilities to recognize the plights of their patients, to extend empathy, and to join honestly and courageously with patients in their struggles toward recovery, with chronic illness, or in facing death” (24). Charon argues that narrative medicine, which she describes as “medicine practiced within the narrative competence to recognize, absorb, interpret and be moved by stories of illness,” will “lead to more humane, more ethical, and perhaps even more effective care” (8). I wish to propose that as an alternative rhetoric of chronic pain, PainExhibit.org is also a site of narrative medicine with the potential to positively change the way medical professionals treat chronic pain and the persons who live with these conditions. Such a proposal aligns with the mission of PainExhibit.org, which is to “educate healthcare providers” about chronic pain, and with founder Mark Collen’s own personal experience of receiving improved medical treatment as a result of using his art to communicate his pain to his physician. The stories of resilience,

suffering, desperation, and hope that the artists offer in PainExhibit.org can have an extraordinary impact on the future of pain medicine that too often overprescribes opioids and nerve blocks rather than encouraging patients to share their experiences of living with daily, unrelenting pain.

In “When the Photograph Speaks,” Anita Helle notes that contemporary narrative pedagogy in medicine has expanded to include visual media by realizing its importance to “our evolving understanding of the sick” (297). This fact points to the possibility that the art images featured at PainExhibit.org will be received and accepted as legitimate forms of medical knowledge production and lead to the increased communicability and visibility of chronic pain amongst healthcare professionals. As a consequence, problematic rhetorics of chronic pain will lose the power they once had to marginalize and stigmatize persons with chronic pain and new productive rhetorics of pain will continue to emerge. In addition to being of vital importance to the improved healthcare treatment of persons with chronic pain, narrative medicine also is said to have healing powers for those patients who tell their stories. Charon explains that the proliferation of illness narratives, or pathographies, “demonstrate[s] how critical is the telling of the pain and suffering, enabling patients to give voice to what they endure and to frame the illness so as to escape dominion over it” (86). While reading Charon’s words, I am reminded of the ways in which the PainExhibit.org’s artists expose themselves, open up to their pain, and then release their hurt, and of the alternative rhetorician’s responsibility to listen.

This responsibility to listen, especially to those voices that are appropriated by persons in dominant positions of power claiming subject-positions that are not their own, is powerfully expressed in Jacqueline Jones Royster’s “When the First Voice You Hear is Not Your Own” and Krista Ratcliffe’s “Rhetorical Listening.” Both feminist rhetoricians urge scholars in the field of

rhetoric and composition to incorporate listening as invention into their research and pedagogies as a transformative process that can lead to deeper understanding of cross-cultural differences. Ratcliffe offers that “perhaps through listening we can avail ourselves with more possibilities for inventing arguments that bring differences together, for hearing differences as harmony or even as discordant notes, (in which case, at least, differences are discernable)” (203). Royster similarly urges us “all to be awake, awake and listening” (40). In addition, she asks us to take care in our listening, especially when “strangers outside of our communities” speak for us. She cautions us to recognize that although these strangers offer “interpretive views,” these views still “tend to have considerable consequences in the lives of the targeted group, people in this case whose own voices and perspectives remain still largely under considered and uncredited” (32).

When I listen to Royster’s warnings, I am reminded of how the voices of persons with chronic pain are appropriated by institutions of power—medical experts, the pharmaceutical industry, popular news outlets, and legislative bodies that claim to speak for and know of the embodied lives of persons with chronic pain. For example, they claim to know that laziness is what keeps persons with chronic pain unemployed and in search of Social Security Disability benefits, they claim to know that since chronic pain “indicates no harm” that it must be meaningless, they claim to know that “a life in pain is not a life worth living.”³⁶ But then I stop and listen.

Royster is still speaking. She is speaking about Audre Lorde’s wisdom and how it has encouraged her to come to voice:

³⁶ This quote is from Tobin Sieber’s article “In the Name of Pain.” In that article he explains that the able-bodied consider that a “life in pain is a life not worth living,” (184) and how this belief is used as a reason for ending the lives of persons with disabilities.

Lorde teaches me that, despite whatever frustration and vulnerability I might feel, despite my fear that no one is listening to me or is curious enough to try to understand my voice, it is still better to speak. (36)

By listening to Royster's words I am reminded of PainExhibit.org's artists and the bravery that resides in each of their art images. I listen to Royster explain that stories act as "vital layers of a transformative process," and I hear her call for those whose voices have been displaced and erased by "authorities" to join their stories with hers:

My sense of things is that individual stories placed one against another build credibility and offer, as in this case, a litany of evidence from which a call for transformation in theory and practice might rightfully begin. My intent is to suggest that my stories in the company of others demand thoughtful response. (35)

I realize then that Royster is calling for alternative rhetoricians to rewrite the stories and reinscribe the voices that were taken without permission. In response, I offer up the stories hanging up in the galleries of PainExhibit.org and, when I listen close enough, I can almost hear those other voices disappear.

CHAPTER VI

COLLECTIVE AFFINITIES: NORMALCY, INTERSECTIONALITY, AND MULTIMODALITY IN DISABILITY-THEMED WRITING COURSES

Three years have passed since I published the article, “Investigating Students’ Reception and Production of Normalizing Discourses in a Disability-Themed Advanced Composition Course,” in a special issue of *Disability Studies Quarterly* that welcomed contributions from disability studies scholars who integrated disability studies into their pedagogies. In those three years, I have finished all but this chapter of my dissertation, relocated twice, slowly embraced my disability identity, and become a mother. I mention all of this to account for the changes in my subjectivities, embodiment, knowledges, and beliefs that now inform my work as a teacher-scholar, and I realize that I am no longer the same woman who wrote that article.

Exposure in these last three years to the core commitments of the fields in which my work resides—disability rhetoric, disability studies, and feminist rhetorics—has pressed upon me the ethical imperative to acknowledge one’s own positionality in relation to one’s research and teaching (Kerschbaum; Kirsch and Royster; Oliver; Price; Wallace). This awareness has also allowed me to recognize that all of the students who enter my classroom are unique and diverse because they are shaped by the multitudes and limitations of their embodied experiences. Although, at the time of developing the course, I had made a commitment to practice an inclusive and accessible pedagogy, I failed to recognize the diversity of all my students, seeing instead their similarities: they were mostly white and came from rural and working-class backgrounds. Now I realize I made assumptions about their capabilities, strengths, and weaknesses based on rigid identity categories and, by doing so, limited their potential to develop

and contribute to the course.³⁷ In effect, I normalized my students in a class devoted to disrupting normalizing discourses.

Although it is disheartening to realize how some of the pedagogical choices I made when teaching the course and writing “Investigating” were problematic, I welcome this opportunity of looking back so that I can move forward. In this penultimate chapter of my dissertation, it seems apt to be doing this work. In “Investigating,” I came to a conclusion regarding pedagogy that I believe still has value. I wrote that “pedagogy is not a static category to be fit into, but rather a philosophy that emerges from our subject positions, identity formations, and our ways of being-in-the-world” (Selznick). Given the fact that three years has passed since I wrote “Investigating” and taught my “Discourses of Normalcy” advanced composition course, and that my ways-of-being-in-the-world have changed, I can expect to continue to have new insights similar to those I describe above. This chapter, then, is devoted to analyzing “Investigating Students’ Reception and Production of Normalizing Discourses in a Disability-Themed Advanced Composition Course” and the class that informed that article through the lens of this dissertation’s political-relational-rhetorical methodology, both to improve the course I created three years ago and to gain insight into my evolving pedagogy and teacherly identity.

Desiring Normalcy

I always wanted to be normal, so much so that I began “Investigating” with this declaration and designed a disability-themed composition course that asked students to question

³⁷ In *Toward a New Rhetoric of Difference*, Stephanie Kerschbaum warns of this tendency among writing teachers to fix students in static identity categories. Instead, she explains the necessity of how “recognizing the contingency of identity and remaining vigilant toward our own orientations to difference is important for us as teachers because our vantage points lead us to see our students in particular ways—some of which can be harmful and damaging” (9).

what it means to be “normal” and to consider how the concept of normalcy threatens the lives of persons deemed “abnormal.” The impetus for developing a course on the “Discourses of Normalcy” emerged from my reading disability scholar Lennard J. Davis’s *Enforcing Normalcy*, which revealed the social construction of the norm. From Davis, I came to understand that normalcy is a fiction, or rather an ideology, constructed by those in dominant positions of power to suppress difference. As an effect, the concept of the norm separates the desirables from the undesirables, the normal from the abnormal, and the abled from the disabled. In “Investigating,” I concluded that despite reading and doing work in disability rhetoric, “I still carried around a normal measuring stick,” knowing that “the most powerful narratives are the hardest to resist.” I also wrote that one of the reasons I decided to teach a course that looked at the terrible material consequences of discourses of normalcy on marginalized populations was because I did not want my students “to wait until they are my age to realize that being normal is a façade and that trying to fit in with the norm suppresses our unique identities.” Put more simply, I did not want my students to become me. Now as I revisit the article, I am relieved to realize that in doing the work of this dissertation—analyzing, critiquing, and disrupting dangerous problematic rhetorics of normalcy—my desire for normalcy has lessened, and I am coming closer to accepting myself as I am. This is what I want for my students. And yet, by making the above claim, I do not wish to negate how powerful and insidious is the ideology of the norm; rather, I realize from my research that being aware of such an oppressive ideology can reduce the power it has over our lives. This is also what I want for my students.

In addition to the above realizations, I also know now that normalcy is a concept more complicated than I had once thought and presented in my teaching. My dissertation’s methodology has shown me that normalcy is not only a rhetorical, social, and cultural construct

but also influenced by political, socioeconomic, and relational factors. As such, any explorations of normalcy must include discussions of how power dynamics, class structures, institutions, legislative bodies, relationships, and the politics of identity contribute to the norming process. Without this more nuanced understanding of normalcy, I did not give my students the knowledge necessary to interrupt and disrupt normalizing rhetorics, which was one of the core aims of the course. For example, although as a class we spent much time considering how language and rhetoric shapes the norms associated with disability and other stigmatized populations and how such rhetoric affects the ways these populations are represented and treated, we did not discuss how institutions (educational, medical, rehabilitative) that are meant to support persons with disabilities participate in the norming process, and, as a result, to the systemic oppression of the disabled (see especially Ben-Moshe, et al.; Kafer). In addition, class readings and discussions paid little attention to how the eugenics movement, right-to-die legislation, and debates over selective abortions for fear of birthing disabled children are also products of rhetorics of normalcy. Conversely, we did not address how the norms associated with poverty, such as poverty is the result of laziness, are used to deflect from real social inequities such as the inaccessibility of quality healthcare to low-income populations.

Although it would be difficult to cover this much content in a single semester, and perhaps suggesting that I should would be setting myself up for disappointment, I want instead to focus on how realizing that normalcy is influenced by political, socioeconomic, and relational factors, in addition to being socially and culturally constructed, changes my orientation to normalcy and affects how I will teach future iterations of this course, and how other disability rhetoric scholars might also think through the complexities associated with teaching a course on rhetorics of normalcy. For instance, knowing that disability cannot be divorced from politics, as

is also true of gender, race, class, and sexuality, makes it possible for a future discourses of normalcy course to address Alison Kafer's call to understand disability differently by "making room for more activist responses" and "seeing disability as a potential site for collective imagining" (9). One way I can implement Kafer's call in a future iteration of a discourses of normalcy course is by incorporating an activist unit into the course syllabus. In addition to continuing to assign an academic paper that asks students to analyze, critique, and disrupt discourses of normalcy as they relate to disability and other marginalized identities (which is a form of activism), I might also task my students to work in groups to develop a public writing project or create and implement a proposal that does activist work by addressing a social justice issue related to their lives on campus, such as the inaccessibility of dormitory life and the gendered stereotypes used in marketing advertisements posted around campus. Another possible project for this unit could ask students to investigate a local or online activist group that problematizes normalizing stereotypes and have students participate in these groups by using writing to further the aims of these organizations. Incorporating these types of assignments into a future syllabus, I believe, will not only show students how discourses of normalcy are contingent on political factors, but also encourage students to realize their agency as social actors to enact change.

Similarly, coming to understand that disability and other marginalized identities are relational because they are "experienced in and through relationships" (Kafer 8) has profound implications for how I would teach a disability-themed advanced composition course in the future. This is especially true since it has caused me to reconsider some of the conclusions I made in "Investigating" in regards to student work. For example, in "Investigating," I spoke of a student who "ends up reifying the narrative of overcoming and inspiration" in her life-writing

paper, in which she wrote that her blind uncle “made the people around him, especially me learn to appreciate and simplify life at times.” I had concluded in the article that this student reinscribed normalizing discourses in her writing by situating her uncle as the “moral compass for which she judges herself and others” and, in so doing, “reduced his life.” However, now that I am aware that disability is relational, I realize that I was not in the position to make such conclusions, considering that the student understood disability through her relationship with her uncle—a relationship that I was not privy to. Without knowing more about my student’s relationship with her uncle, I made a generalization about my student’s perception of disability based on my research and experience at the time that may have been inaccurate and unfair. In retrospect, it would have been best to talk to my student about my concerns and also ask her to spend more time in the revision of her life-writing paper developing her relationship with her uncle. As an effect, her readers would have more insight into how she came to understand disability through that relationship. As the above example indicates, by understanding that disability is relational, I now realize that when analyzing student responses to normalizing discourses, I need to pay more attention to the contexts in which they are written.

Understanding that normalcy and disability are relational has also given me insight into a troublesome interaction that took place during a group discussion during my normalcy class. In “Investigating,” I spoke of how a student exhibited a “forcibly negative reaction” at another student’s disclosure that she had A.D.H.D and took medications for her symptoms. The student with the negative response explained that his younger brother with A.D.H.D was “ruined” for years from taking similar medications. Although I tried to “mitigate the conversation by making it less personal,” both students left class that day frustrated, and the student with A.D.H.D told me later that her classmate’s reaction was the reason why she usually did not self-disclose her

disability. I concluded in “Investigating” that I felt terribly that “I failed to protect her from normalizing discourses and I wonder what I could have done differently.” I realize now that I need to reconsider my perception of the situation. Now that I know that normalcy is relational and that disability is experienced in and through relationships, it is clear to me that my first mistake was in thinking that their discussion was not personal. In fact, both students had very personal relationships to A.D.H.D, and it would have been impossible for them to ignore their subjectivities in such a discussion. Perhaps instead of trying to mitigate the conversation, it would have been more valuable to both students and the class if I allowed them to continue their discussion but then shifted their attention to the ways in which our relationships shape our perceptions of normalcy and disability. By doing so, my focus would move away from trying to shield my student from normalizing discourses (which would not be possible no matter how much I wanted to) and move more productively to enabling her to better understand them.

As I hope the above discussion demonstrates, my dissertation’s political-relational-rhetorical methodology has allowed me to develop a more complex understanding of normalcy and of my own desire to be normal. By incorporating this understanding into my teaching practice, I can with more confidence create a future discourses of normalcy course that better equips students with the knowledge and awareness they need to analyze, critique, and disrupt oppressive and discriminating normalizing rhetorics not only in their compositions, but also in their own lives. This is what I want for my students.

Intersectionality and “White Disability Studies”

One of the issues I grappled with during the planning of my “Discourses of Normalcy” course was whether I should develop an advanced composition class that focused exclusively on disability studies content, or whether I should broaden the scope of the class to look at issues of

normalcy as they related to race, gender, sexuality, class, and other minority identities. When I reflected on this decision in “Investigating,” I came to the realization that I chose to look at issues related to other minority identities including disability because I was unsure if seemingly nondisabled students would be receptive to an entire semester of disability studies content and would rather take a course that considered multiple identity categories. Therefore, I decided that I would use disability studies theory as the foundation for the course and then apply that theory to disability and then to the other marginalized identities mentioned above.

The decision worked out well. However, I was wrong about my assumption regarding student resistance to disability studies content. Most of my students had never taken a class that addressed disability and remarked in reading responses that they appreciated being introduced to the field. The normalcy theme also energized my students, and subsequent class discussions were animated and compelling. Hence, in “Investigating,” I wrote that “the course theme was effective” and that after being exposed to critical disability studies earlier in the semester my students were “more open and willing to discuss other social justice issues relating to race, sexuality, religion and class” (Selznick). Yet, despite these successes, when I look back at the question I posed—whether to focus the course on disability or also include other minority identities—through the lens of my political-relational-rhetorical methodology, I realize I was operating on a fallacy that all minority identities are discrete categories of difference rather than understanding them relationally as also intersecting identities. Given this new lens, I realize that it is impossible, and perhaps even unethical, to develop a course on disability that does not also attend to race, gender, sexuality, class, and other minority identities. In addition, by not recognizing these identity categories as also intersecting identities, I foreclosed consideration of what Akemi Nishida describes in “Understanding Political Development through an

Intersectional Framework” as the “ways in which various social injustices intertwine and interactively affect our daily lives.” Thus, I find myself looking at how the concept of intersectionality, which disability studies scholar Stephanie Kerschbaum describes as “a rich consideration of how different factors shape identity and identifications” (64), might address my concerns and offer my students a deeper understanding of how rhetorics of normalcy oppress stigmatized and marginalized populations. In order to this work, it seems necessary to review some of the scholarship on intersectionality, apply that scholarship to a reflection of “Investigating,” and then consider how intersectionality can invigorate a future iteration of a disability-themed composition course.

Developed by critical race feminist scholars, the concept of intersectionality is described as a way of understanding “the relationships among multiple dimensions and modalities of social relations and subject formations” (McCall 1771). By understanding these relationships, it becomes possible to analyze the experiences of people who are located at the interstices of multiple differences and to better address the social injustices they face. For example, in “Mapping the Margins,” Kimberlè Williams Crenshaw advocates for intersectionality as a “way of framing the various interactions of race and gender in the context of violence against women of color” by considering that

many of the experiences that Black women face are not subsumed within the traditional boundaries of race or gender discrimination as these boundaries are currently understood, and that the intersection of racism and sexism factor into Black women’s lives in ways that cannot be captured wholly by looking at the race or gender dimensions of those experiences. (1244)

As an example of the above, Crenshaw illustrates how an intersectional analysis is crucial to understanding the plights of battered women, which she explains is the result of “when systems of race, gender, and class domination converge” (1246). Without such an analysis, Crenshaw concludes, “intervention strategies based solely on the experiences of women who do not share the same class or race backgrounds will be little help to women who because of race and class face difference obstacles” (1246).

Disability scholars Nirmala Erevelles and Andrea Minear similarly describe how an intersectional analysis is essential to understanding the “historical context and structural conditions within which the identity categories of race and disability intersect”³⁸ (357). They pay particular attention to ways in which these categories have intersected in the U.S. education system to cause multiple forms of oppression. For example, in “Unspeakable Offenses,” they describe how the association of race and disability led to

a large number of students of color (particularly African American and Latino males) being subjected to segregation in so-called special educational-classrooms through sorting practices such as tracking and/or through labels such as mild retardation and/or emotional disturbances. (357)

As an effect of putting disability and race into conversation with one another, Erevelles and Minear also make it more possible to recognize when such convergences happen in the future and to develop more effective ways to intercede in them.

The work of the above scholars has shown me that presenting race, sexuality, disability, class, and gender as separate entities and not also as intersecting identities limited my students’

³⁸ It is important to mention that Erevelles and Minear are cautious of critical race feminist theory’s characterizations of intersectionality that do not account for disability in their analyses and/or understand disability as a biological condition rather than a social construction. (356-59)

understanding of how the ideology of the norm is used to silence, punish, and eradicate difference. For example, when I look back at my students' Normal Commonplace Books³⁹, I notice how an understanding of intersectionality could have enriched their analyses.

This is particularly clear in the instance of my student who produced a Pinterest board for his commonplace book, which I discussed in "Investigating," by using a mix of images and texts to disrupt the norm that "real men" do not need to be stereotypically masculine—muscular, strong, and athletic, without including a single image of a man of color. The fact that I never noticed that all of his images were of white men until now is rather shocking to me since I teach a course on normalcy! With this new awareness, I now think of how much more insight my student could have gained about masculine normativity had he also considered race in his analysis. Similarly, as I look back at the Art as Representation papers that my students produced, in which they were asked to analyze a piece of "art" that used normalizing stereotypes, I realize that students who chose to analyze disabled characters in film did not also take into account how race, class, gender, and sexuality also affected the characters' experiences of disability. For instance, in her paper on *Avatar*, a student produced an astute analysis of how the main character's disability, portrayed as a defect in need of an eradication, motivates him to endanger his life at the promise of a new functioning leg; however, she did not also consider how his desire for a cure might have been impacted by the hyper-masculinized norms of the military and the character's fear of losing his career and military status. These examples not only show me how an intersecting analysis could have meaningfully impacted my students' understanding of

³⁹ Throughout the semester, students were asked to take notice of some of the societal commonplace assumptions in regards to normalcy, stigma, and stereotypes and arrange them in a "book." This was a semester-long project and the students used various material and digital technologies to create the books.

normalcy, but also how such an analysis could have enhanced their ability to disrupt normalizing rhetorics and imagine different futures for stigmatized populations.

The above explorations of the concept of intersectionality have also made me aware of the fact that, as Chris Bell warns, my advanced composition disability-themed course was actually a white disability studies-themed course. In “Introducing White Disability Studies,” Bell writes that the field of disability studies is not inclusive since it fails to “engage issues of race and ethnicity in a substantive capacity, thereby entrenching whiteness as a constitutive underpinning” and focuses only on the “work of white individuals and is itself largely produced by a corps of white scholars and activists” (275). After providing compelling examples of how the above is true, Bell writes that if “Disability Studies as a field had taken a reflexive look at itself at some point, particularly with regard to its failings in examining issues of race and ethnicity, there might not be such a glaring dearth of disability-related scholarship by and about disabled people of color” (278). When I take a reflexive look at my own teaching of disability studies, I notice that although I talk about race and ethnicity in my normalcy course, in particular in regards to white privilege, I did not consider these identity categories in the context of disability. Also to my dismay, when I review my “Discourses of Normalcy” course syllabus, I notice that every critical disability studies reading and disability life-writing excerpt I assigned was written by a white author. As a consequence of not bringing the scholarship and stories of disabled persons of color into the classroom, I participated in the silencing of marginalized voices. In retrospect, I can easily see how I could have incorporated these voices into the course and how the course would have been more valuable because of that inclusivity. For example, my students were particularly engaged with the disability studies use of the concept of “passing,” which I introduced through white disability studies scholar Brenda Jo Brueggmann’s “Lend Me

Your Ear,” who discusses passing in reference to her deafness. Although I would not strike the reading from the course since Brueggmann does such interesting work incorporating her personal experiences with critical scholarship, I could have also assigned black disability scholar Dea H. Boster’s “I Made Up My Mind to Act Both Deaf and Dumb,” which tells of how slaves “pass[ed]” as disabled in order to gain agency over their masters. By including Boster’s essay in the course readings, we could have discussed how race and disability intersect and gained a much richer understanding of the complexities of “passing.” In addition, I could also have assigned Nirmala Erevelles’s “Disability in the New World Order,” in which she discusses the intersections of Third World feminism(s) and disability, and, as a result, we could have moved our examination of normalcy outside of the U.S. and into the context of globalization and transnationalism.

Lastly, I realize from this discussion of intersectionality that bringing the concept into a future normalcy course can also enable students to explore their own subjectivities, embodied experiences, and the ways in which they self-identify and identify with others. In doing so, they will better understand themselves in relation to normalcy and be more aware of their own use of normalizing discourses. In “Investigating,” I thought it was my responsibility to intercede in their uses of these discourses rather than discovering ways in which students might realize for themselves when they reified in their writing the same normalizing rhetorics that they critiqued in class. Now, through this analysis, I can see how making intersectionality a part of the content of the course can assist students in acts of self-discovery. Such acts, in turn, can allow them to notice when they use normalizing rhetorics and choose for themselves how to respond.

Reconsidering Access and Multimodality

In these last three years, since developing and teaching “Discourses of Normalcy” and writing “Investigating,” my work in disability studies has allowed me to recognize that access means creating spaces where human difference is not only valued but encouraged. This realization is crucial to reimagining a course on normalcy that celebrates difference. In particular, disability scholar Tanya Titchkosky’s scholarship on disability and access has shown me that access is an act of perception, “a form of oriented social action that organizes the socio-political relations between bodies and social space” (3). Questions of access, she writes, reveal which bodies belong and which need to fight for legitimization. Under this framework, then, access has become a privilege rather than a basic human right. By looking at access as a questioning orientation rather than reducing access to accommodation or simply viewing access as inclusion, I am more able to develop a pedagogy that honors the strengths and contributions of *all* bodies.

Prior to reading disability studies scholarship on access, when I designed and taught “Discourses of Normalcy, my understanding of the concept of access was limited to discussions of the ways in which students could make their compositions more accessible to diverse audiences. Although having students consider the accessibility of production, delivery, and reception of their texts is fundamental to their work as compositionists, it would have been best to first consider whether the design and approach of the course were accessible to my students so that they would be more able to do such important work. Also, a more nuanced understanding of how access is political, relational, and rhetorical could have enriched my students’ awareness of the subtle ways in which norming operates by masking discriminatory practices as natural exclusions under the guise of “unreasonable” accommodations. In addition to being valuable to

students, a more in-depth understanding of access would have allowed me to witness the fact that I was norming my students by not practicing an “ethic of accessibility.” For the remainder of this section then, I will use Cynthia L. Selfe and Franny Howes’s conceptualization of an “ethic of accessibility,” described below, as a heuristic for understanding how I practiced an accessible pedagogy during the development and teaching of “Discourses of Normalcy” as discussed in “Investigating,” and how I might improve upon this pedagogy in *all* future composition courses⁴⁰.

In the multi-authored webtext, “Multimodality in Motion,” Selfe and Howes ask composition teachers to practice an “ethic of accessibility.” Such an ethic, they explain, includes teaching students “how to create texts that allow the broadest possible range of people to make meaning in ways that work best for them,” in addition to “expanding our understanding of the physical and material conditions needed for learners” and acknowledging “the responsible and respective attention we need to pay to the differences people bring to the educational spaces of composition programs, classes, and assignments” (qtd in Yergeau). After rereading “Investigating,” it is clear to me that I only considered access in relation to the first part of Selfe and Howes’s explanation of an “ethic of accessibility” since I only spoke of accessibility in terms of developing texts for multiple audiences, especially in relation to disabled users. As I said earlier, although considering the accessibility of texts is crucial to developing usable and effective compositions, ensuring that the course was accessible to my students needed to be my first priority. I realize now that I could have made my class more accessible by inviting students to join me in developing course projects; selecting course “readings” (including digital texts,

⁴⁰ My decision to italicize “all” reflects my belief that enacting an accessible pedagogy should not be restricted to disability-themed composition courses.

print texts, and multimodal compositions); and designing assessment criteria. In addition to ensuring that all materials and assignments were accessible, students would also have had the opportunity to become more active participants in their own knowledge-making. Furthermore, by involving my students in creating accessible pedagogy, I would be heeding Margaret Price's call in "Multimodality in Motion" that we composition teachers build academic infrastructures through participatory design that are accessible to all bodyminds⁴¹. Without paying attention to access in this way, Price warns that infrastructures will "continue to be designed for normate⁴² bodyminds, and non-normate bodyminds (those that are gendered, classed, raced, disabled in particular ways) will disappear" (qtd in Yergeau). This is an important consideration in a class on normalcy.

My review of "Investigating" has also revealed that I believed I was addressing issues of access by simply assigning multimodal projects. I explained this belief by concluding in "Investigating" that "multimodal assignments unlike strict, linear, rule-based writing assignments allowed students to access more aspects of themselves and their abilities in the composing and delivery process" and that "the audience of multimodal compositions have greater opportunities at accessing these compositions." Although I still agree with these conclusions, and a plethora of scholarship supports my belief that many multimodal projects are more accessible than traditional print-based papers (see especially Ball; Dolmage; Shipka; Selfe; Yancey), I also know now that I need to be more careful when equating multimodal projects with access since many of these projects still remain inaccessible to a variety of users. For example, in

⁴¹ Margaret Price uses the term bodyminds, which is a term sometimes used in trauma theory and psychotherapy, to "emphasize that although 'body' and 'mind' usually occupy separate conceptual and linguistic territories, they are deeply intertwined" (qtd in Yergeau).

⁴² Normate is a term coined by Rosemarie Garland-Thomson that represents a "mutually constituting" figure existing opposite the disabled figure.

“Multimodality in Motion,” Stephanie Kerschbaum explains that “many multimodal texts are not commensurable across modes” and that “this lack of commensurability means that for many multimodal texts, if someone cannot access one or more of the modes, the entire text is inaccessible” (qtd in Yergeau). Kerschbaum’s warnings have me reconsidering the accessibility of some of my “Discourses of Normalcy” students’ multimodal projects, which I assumed were accessible because of their use of multiple modes.

I am thinking specifically of a major course project in which students had to create a multimodal remix of their print-based, traditional life-writing narratives that described their personal experiences with normalization. Although many of the projects were insightful and inventive, I realize now that most of them privileged some modes over others and, as a result, were not accessible to many audiences. For instance, many of my students who composed videos for the life-writing multimodal remix projects used auditory modes (narration, music, dialogue) and visuals, but did not include closed-captioning, rendering their projects inaccessible to deaf and hard-of-hearing audiences. Another student produced an interesting and provocative sound essay that depicted her experiences with eating disorders and disrupted gender norming. Although the student used a variety of auditory modes, she never turned in a script for those who could not access sound. Also, I recognize now that when students were using Pinterest boards for their Normal Commonplace Books, neither my students nor I conducted any research beforehand on Pinterest’s compatibility with screen readers. In addition, in many class discussions I spoke of access as a retrofit⁴³, rather than considering from the onset how to develop and construct a

⁴³ In “Mapping Composition: Inviting Disability in the Front Door,” Jay Dolmage explains that “to retrofit is to add a component or accessory to something that has already been manufactured or built. This retrofit does not necessarily make the product function, does not necessarily fix a faulty product, but it acts as a sort of correction” (20).

multimodal project for a variety of users. Although I do not expect future students to produce fully accessible projects in a one semester course, especially since my own skills are limited in this area, I do believe that integrating the concept of access in the course content would have at least pressed upon my students and myself the urgency to de-normalize composition by discussing and implementing, as best as possible, universal design principles. By doing so, I would have come closer to practicing an “ethic of accessibility.”

In addition to assigning multimodal projects following readings on and discussions of access and its relationship to normativity, I now realize that another way I can practice an “ethic of accessibility” in all of my future composition courses is by making access a part of our everyday classroom experiences. For example, students can routinely analyze the accessibility of digital spaces, texts, and other materials that they encounter through their research practices and strategize how to improve the accessibility of these resources to make them more useful to a wider range of persons with differing needs. In addition, students can analyze the accessibility of spaces around campus and in their communities and incorporate their findings into a multimodal project of their own choosing. Also, by assigning more group assignments and projects, I can help students become more aware of the different insights and perspectives that each group member brings to the table and of each other’s access needs.

Lastly, before closing this section, I want to address the final part of Selfe and Howes’s “ethic of accessibility,” which stresses the importance of paying “responsible and respectful attention to the differences people bring to the educational spaces of composition programs, classes, and assignments.” Although I would have said at the time I developed my normalcy course and wrote “Investigating” that I practiced an accessible and inclusive pedagogy by doing the above, I know now that I would have been mistaken. It is only through this reflection on the

concept of access seen through the lens of my dissertation's political-relational-rhetorical methodology that I have come to understand that all students who enter my classroom are unique and diverse because they carry with them their own truths and beliefs, vulnerabilities and strengths, and ways of knowing and expression. I also know now that by fixing rigid identities on my students and by not acknowledging the intersections of their identities, the class I designed worked for some bodies and not others. Thus, I normed my students and, in doing so, restricted their access to class materials, class content, richer understandings of discourses of normalcy, and, most importantly, to realizing their full potential as thinkers and writers.

Looking Forward

Instead of ending this chapter with the narrative of all the "mistakes" I made in developing my "Discourses of Normalcy" course and in "Investigating," which I am dangerously close to doing, I want to instead close this chapter by looking forward. And yet, it is important to note that in looking forward I do not mean to reify the normative rhetoric of improvement that is so often expected from teachers in pedagogical reflections. Rather I wish to look forward in a way that honors the important work of teaching my discourses of normalcy class and writing "Investigating," while also accounting for the new knowledge and awareness I have gained by looking back. In order to make this possible, I am letting go of the normalizing rhetorics that tell teachers to "fix" the errors of the past in order to move forward. Instead I look forward to developing and teaching a future iteration of my normalcy class that is not motivated by regret, but rather invigorated by my dissertation's methodology, evolving subjectivities, and political commitments. I look forward to witnessing my students become more empowered by a course that theorizes and practices intersectionality and how the collective affinities that come from intersectionality can challenge stringent and fixed categories of difference that contribute to the

power of discourses of normalcy. I look forward to the multitude and diversity of voices that will echo through the walls of my classroom and spill out into the hallways and beyond.

EPILOGUE

For twenty years, I have filled notebook, upon notebook, upon notebook—perhaps hundreds—with my pain. It began after my first emergency room visit when the sharp spasms in my belly caused me to collapse on the floor of my tiny dorm room. Since then I've come to the page when I have nowhere else to go. I used to buy fancy journals, the kind that you can still find on the shelves of Barnes and Nobles and independent stationary stores, with gilded pages and striking Asian-inspired designs on the covers: long-stemmed crimson flowers, burnt orange sunsets, intricately-painted mandalas, all accompanied with Chinese proverbs encouraging me to find courage and faith in myself and in the world around me. Next I turned to classical literature and sought out journals whose covers carried the words of William Blake, Emily Dickinson, and Elizabeth Barrett Browning, with the hope that their oft-quoted passages would ease some of my pain. Then I tried Italian leather-wrapped journals, some with and some without lines. But I often found it difficult to allow myself to write of such ugliness in places meant for beauty.

Later I read Natalie Goldberg's *Writing Down the Bones*, in which she urged me to write instead in spiral notebooks with unadorned or whimsical covers to give myself the freedom and permission to write imperfectly, ignore the censor, and let go of the fear that often comes from writing about the self. Sometimes I wrote to G-d and prayed for him to take the pain away. Sometimes I wrote about the things I missed about myself and my life before chronic pain, especially the curiosity and spontaneity. Other times I wrote about the pain itself—how it moved inside of me in fits and starts, stiffened my muscles and weakened my limbs, burned and cooled my skin—as I tried to make sense of its messages. And I think now of all those notebooks: piled high in my basement, stacked away in cardboard boxes, leaning on one another on my bookshelves, and how I can't get rid of them. I take them with me each time I move to a new

home, even though the words inside are illegible, slanted so heavily that they run into each other, rushed in swirls and loops, and left with uncrossed Ts and sentences with missing words. The result of sleepiness, an opioid-addled brain, and the achiness of my hands. I take them with me because more than any treatment, medicine, or specialist, these notebooks have kept me alive. And I remember that day at the Disability Studies Conference, when the patient-advocate at my Q&A asked me if pain destroys language and of how silly it was that I had to search for an answer.

And yet I am grateful for her question, for it has allowed me to understand the necessity of arguing that chronic pain is communicable to persons without the lived experience of chronic pain. It has also made me realize that if we were to continue to invest in the theoretical and commonplace belief that pain is unknowable, we would lose the valuable insights into the human condition that a life in pain affords. Additionally, by employing this dissertation's political-relational-rhetorical methodology to reveal the ways in which pain is communicable, I have made it possible to provide a presence for persons with chronic pain in the fields of rhetoric and composition, feminist rhetorics, disability studies, and disability rhetoric, in which this dissertation resides. By beginning this work, I hope that persons with chronic pain are more able to claim a disability identity, and, as a result, have increased access to the resources and benefits that make living with chronic pain more manageable, while also experiencing the solidarity that comes from being a part of a community that has a shared understanding of oppression and marginalization. Pursuing the question of the communicability of chronic pain has also led me to discover how normalizing rhetorics are used to punish and silence persons with chronic pain for supposedly threatening the health of the nation-state and how to intercede in their proliferation. Perhaps most importantly, exploring the relationship between language and pain has made it

possible to witness alternative and generative rhetorics of chronic pain that account for and honor both the loss and the wisdom that comes from living with chronic pain.

However, as is true of all explorations, my study has yielded almost as many questions as answers. Although attending to these questions is beyond the scope of this dissertation, I want to take the time to identify what some of these questions are and briefly consider how they open up future inquiries into the study of chronic pain, rhetoric, and disability for myself and other teacher-scholars invested in this work. The majority of these questions relate to the concept of crip, intersectionality, alternative rhetorics of chronic pain, and access as it relates to chronic pain.

The first time I encountered the term “crip” was that same day when the patient-advocate asked me about the communicability of chronic pain. It was at that Indian restaurant after I explained how chronic pain made it difficult to make and keep friends since no one could understand how I could appear perfectly healthy one day and then claim I needed to stay home the next because of pain and fatigue. In response, the women around the table had told me that I needed “crip” friends. When I wrote of this conversation in this dissertation’s prologue, I marked it as the moment that I felt part of and let into a community that shared similar struggles and understood the pain of alienation. Throughout the rest of the conference, I heard the term crip evoked in numerous presentations and pop up in casual conversations between conference attendees. And yet, I still did not quite understand what the concept meant.

From what I gathered at the conference, crip seemed to suggest an identity that somehow merged queerness with disability, while simultaneously resisting identity categories. Also, crip seemed to be just another word for disability, yet it problematized some of the aims of the disability movement. I could not make sense of its contradictions. However, since my

dissertation argues that chronic pain is a disability and needs to be theorized as such in the fields of disability rhetoric and disability studies, it made the most sense to use disability theory as the theoretical framework for the dissertation and not engage with the concept of crip. But now that I have made these arguments, I find myself coming back to crip and embracing its contradictions, especially because it reminds me of how chronic pain defies easy explanations.

Specifically, I wonder how crip theory, which Robert McRuer defines as “the study of how bodies and disabilities have been conceived of and materialized in multiple cultural locations, and how they might be understood and imagined as forms of resistance to cultural homogenization” (33), might lead to a greater and more nuanced understanding of chronic pain, and of how persons with chronic pain problematize culturally imposed binaries such as healthy/sick and abled/disabled. In addition, I also wonder if the term crip, which crip theorist Carrie Sandahl refers to as “fluid and ever-changing,” rather than the term disability, which is more fixed and restrictive, might better represent the shifting and fluctuating nature of chronic pain conditions. If so, might persons with chronic pain benefit from claiming a crip identity, rather than, or in addition to, a disability identity since crip theory includes illness and impairments that are not usually recognized as disabilities (see especially Kafer; McRuer; Sandahl)? Conversely, how might taking up chronic pain in their scholarship further the aims of those working in crip studies? Likewise, how might the inclusion of persons with chronic pain in the crip community empower crip movements? Another line of inquiry that might be of interest to teacher-scholars concerned with chronic pain and disability is an exploration of “crip time.” Specifically, would crip time, which Alison Kafer describes as “flex time not just expanded but exploded . . . [which] requires reimagining our notions of what can and should happen in time, or recognizing how expectations of ‘how long things take’ are based on very particular minds and

bodies” (27), be useful in challenging stigmatizing representations of persons with chronic pain as lazy and deceitful? As all of the above suggests, a consideration of the concept of *crip* offers rich and robust avenues for future study into the relationship between chronic pain and disability.

Now that I have considered future inquiries into how the collapsing of identity categories can potentially benefit persons with chronic pain, it seems prudent to also consider possible inquiries into how recognizing and maintaining identity categories can lead to a more nuanced understanding of chronic pain. In order to do this work, I turn to the concept of intersectionality, which has been used in critical feminist race studies and disability studies to analyze how the intersections of multiple identity categories can lead to increased experiences of oppression for minority groups. Although I attended to intersectionality in my dissertation in relation to my pedagogy (see chapter 6 “Collective Affinities”), I limited my engagement with the concept knowing that I needed to first theorize chronic pain as a disability in order for persons with chronic pain to claim a disability identity. Now that this work has begun, it becomes possible to explore the ways in which chronic pain intersects with and is affected by race, ethnicity, gender, sexuality, class, and other identity categories. This exploration seems particularly necessary considering that pain research indicates that “a disproportionate number of persons with chronic pain come from traditionally disempowered groups” (Graham) and “chronic pain greatly exasperates already existing inequality in our society” (Bourke 300).

Future research on intersectionality and chronic pain might look at the demographics of the chronic pain population and analyze how cultural rhetorics influence why certain minority groups are more likely than others to report high levels of pain.⁴⁴ Other explorations into race,

⁴⁴ In a recent National Institute of Health’s (NIH) study on chronic pain, women, older individuals, and non-Hispanics were more likely than Asians to report pain. In “I Don’t Feel

ethnicity, and chronic pain might consider why minority groups receive less pain management treatment than white pain patients and are less likely to get their prescriptions for pain medication filled at pharmacies (Foreman, *Why*; Graham; Wailoo). A specific inquiry might address how racial stereotypes and colonizing rhetorics are being used to justify giving black pain patients less pain medicine than white males. Additionally, future research on intersectionality and chronic pain could examine the intersections between gender and chronic pain, which seems especially important given that recent statistics indicate that a much larger number of women are diagnosed with chronic pain conditions than men.⁴⁵ Disability rhetoricians and feminist rhetoricians might wish specifically to study how the rhetoric of the “hysterical female” (see especially Segal; Vidali) leads to the feminization of chronic pain, skepticism over chronic pain as a legitimate disease, and the under-treatment of persons with chronic pain. Also, those interested in doing work on intersectionality and chronic pain might wish to pursue the connection between chronic pain and low-income populations, especially in regards to access and healthcare and the policing of opioid medications. Clearly, as with *crip*, the

Your Pain,” Ruth Graham reports that among pain patients, blacks and Hispanics are likelier to report their pain as severe.

⁴⁵ According to a recent article in *the New York Times*, women are twice as likely to have multiple sclerosis, two to three times more likely to develop rheumatoid arthritis and four times more likely to have chronic fatigue syndrome than men. As a whole, autoimmune diseases, which often include debilitating pain, strike women three times more frequently than men (Edwards). Similarly, in “Why Women are Living in the Discomfort Zone,” Judy Forman informs that “women are both more likely to get chronic painful conditions that can afflict either sex and to report greater pain than men with the same condition, according to studies over the past 15 years” (n.pag.).

concept of intersectionality has much to offer future scholarship on chronic pain, disability rhetoric, disability studies, and feminist rhetorics.

I wish to turn now to speculate on how future work on alternative rhetorics of chronic pain might further emphasize the communicability of chronic pain. In an earlier version of chapter 1 of this dissertation, I discussed how I would be exploring several alternative rhetorics of chronic pain that would offer productive and generative rhetorics of chronic pain that need not be restricted to linguistic forms of expression. I also wrote that these alternative rhetorics would offer persons without the lived experience of chronic pain multiple ways to access and experience chronic pain. As a result, these alternative rhetorics of chronic pain would challenge the prevailing belief that pain is uncommunicable, while also complicating what counts as language. Due to the time and space constraints of a dissertation, I was only able to analyze one example of this type of alternative rhetoric of chronic pain: a non-profit visual art exhibit on chronic pain titled PainExhibit.org. Thus, I am left wondering how other forms of alternative rhetorics of chronic pain might offer different engagements with chronic pain and also provide unique insights into the lives of persons with chronic pain.

One possible line of inquiry might be to consider how disability performance art challenges the invisibility of chronic pain, considering that “performance is a conscious placement of one’s body into the visible, tangible scene of a show” (Kuppers 2). Doing so could complicate the belief that chronic pain is unknowable. Also, it would be interesting to analyze how the aims of disability performances, which Petra Kuppers describes as “creating unexpected encounters, fleeting moments, and puzzles and unanswerable questions” (1), mirror the experience of living with chronic pain. Another alternative rhetoric of pain worth future study is autobiographic disability comics, especially for multimodal rhetoric scholars. A specific inquiry

could explore how autobiographical disability comics capture the trauma of living with chronic pain by utilizing visual, gestural, spatial, audio, and multimodal modes (see especially Jacobs and Dolmage). In addition, disability-life writing, including memoir, the lyric essay, and disability blogs, might offer multiple inquiries into the communicability of chronic pain and provide realistic and genuine representations of living with chronic pain. Lastly, I propose that studying crip poetry, which Jim Ferris explains as poetry that “centers the experience of disabled people [and] shows disabled people taking control of the gaze and articulating the terms under which we were viewed,” might be useful in challenging rhetorics of suffering that view chronic pain as tragic and shameful, while also complicating normative expectations of form and language.

Contemplating how alternative rhetorics of chronic pain offer more access to understanding lived experiences of chronic pain has been an important part of the work of this dissertation. In addition, exploring access as a concept and a practice has allowed me to identify the reasons why persons with chronic pain are often denied access to quality medical care and other much-needed services. This exploration had led me to the conclusion that access should be considered a fundamental human right and not a matter of privilege. I also studied access from a disability studies perspective, and in doing so I was able to reimagine how to develop a more inclusive pedagogy that supports the needs of *all* students. However, now that I have come to the conclusion of this dissertation, I am surprised to realize that I did not consider issues of access in the context of chronic pain.

One line of inquiry I wish to explore in the future, then, is how to develop an accessible pedagogy in the composition classroom that would speak to the needs of students with chronic pain. One question that comes to my mind readily is how I can make the physical environment of

the classroom more accessible for students with differing chronic pain conditions. Attending to this question is especially necessary considering that many college disability services offices do not consider students with chronic pain disabled and therefore do not offer them accommodations. Given that chronic pain conditions can fluctuate in severity almost daily, other inquiries might explore how stringent attendance policies, mandatory face-to-face teacher-student conferences, and the demands of group projects might make it difficult for students with chronic pain to be successful in their courses. Consequently, what changes to class policies might need to be made in order to accommodate students with chronic pain?

Perhaps students could Skype or Zoom into class on high intensity pain and fatigue days? Maybe instead of meeting in person with their professors for conferences, students with chronic pain can arrange Google Chats as an accommodation? Similarly, might it be possible for students with chronic pain to use Google Hangout in order to “attend” peer-group meetings? And most importantly, how can all of this be done while still practicing universal design for *all* students? Although these questions are important, I realize that they are focused more on accommodation than access. Thus, maybe future research into making composition classes more accessible to persons with chronic pain and all students should instead, or in addition to, concentrate on thinking of access more conceptually. For example, an avenue for future work might focus on how to change perceptions of “participation” and “time,” instead of thinking of access in terms of a retrofit.

This inquiry could also expand to include other spaces of academia and consider faculty in addition to students. Specifically, one future study might look at access issues as they relate to chronic pain in what Margaret Price calls the “kairotic spaces” of academia. Price defines kairotic spaces as the “less formal, often unnoticed, areas of academe where knowledge is

produced and power is exchanged” (*Mad* 60). She identifies one of these spaces as the academic conference. I know personally the difficulties of participating in academic conferences when access for persons with chronic pain is not a consideration. Although I value and look forward to academic conferences to share work and hear the work of my colleagues, I am often in so much pain the last day of the conference because of all the sitting, navigating the long hallways at conference centers, and too short in-between session times that I almost regret attending the conference at its close or have to leave early, and yet I am expected to participate in them in order to be successful in my profession.

Price explains that kairotic spaces tend to be understudied because they go unnoticed by those who “move through them with relative ease” (“Multimodality”). I am interested in Price’s work on the inaccessibility of kairotic spaces not only because it considers access issues beyond the classroom, but also because it points to an even larger concern: that the expectations of our profession are predicated on the assumption that all of us have normative bodyminds. Perhaps, then, the best way to make the work of our profession accessible to persons with chronic pain and other disabilities is to recognize our diversity as a community of teacher-scholars and to approach our work relationally through collaborations. These kinds of investigations into access and chronic pain are worth advocating for and can lead to much-needed change in our classrooms, profession, and other areas of academic life.

Tonight, as is true of all nights, before I go to bed I will lie down with one heating pad on my belly and another one on my back, and I will write in my notebook. However, I no longer feel the loneliness of my pain and get lost in my suffering. This dissertation has changed my pain, as it has changed me. I used to believe that I would never get better, but perhaps I didn’t

understand what better meant. I realize now that my pain is not useless or invaluable and that neither am I. Rather, I have come to accept that pain is a part of my life and although it stays with me this night and all nights, I can use it to channel change by continuing to do the important work that this dissertation has begun.

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