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Pain's Subjectivities: Negotiating Complexity in the Research and  
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by

Sara Rubin

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in

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By  
Sara Rubin

# Pain's Subjectivities: Negotiating Complexity in the Research and Treatment of Pain

Sara Rubin

## **ABSTRACT**

Throughout much of clinical history, those working within the arena of pain medicine have conceptualized pain as a musculoskeletal problem. Clinicians adhered to biomechanical explanatory models of pain, seeking out an underlying corporeal source and targeting the body as a site of intervention. Recently, however, some pain specialists have begun to promote the notion that pain is an output of the brain, rather than an input of the tissue. This shift is occurring in relation to both an opioid-related overdose crisis, in which the biomedical community is searching for new solutions to chronic pain, and a neurocognitive turn, in which neuroscientific explanatory models of pathology are gaining popular and clinical authority. In this dissertation, I trace the ways in which pain is being newly biomedicalized, or neuroscientized, alongside these trends. I follow neuroscientific understandings of pain as they travel through the overlapping biomedical domains of production, dissemination, and uptake, arguing that a neuroscientization of pain repositions patient agency and responsibility.

Drawing upon interviews with pain neuroscientists and clinicians, as well as ethnographic observations conducted in a neuroimaging pain laboratory, two medical schools, and three clinical pain groups, I trace the policies, discourses, and subjects that both constitute and are constituted by these transformations occurring in pain medicine. I first explore the domain of production, demonstrating the means by which pain is produced as a neuroscientific object. Here, I argue that the structures of the scientific process of inquiry necessarily limit and restrict the various subjectivities inherent in pain by describing how pain scientists go about disciplining

complexity. Next, I examine the domain of dissemination, drawing on descriptions of the opioid crisis and its proposed solutions in order to characterize them as thoroughly biopolitical in nature, attending to its focus on risk and production of specific subjectivities, the surrounding politics of knowledge production, and the flattening of complexity as policies and clinical discourses simplify both opiates and pain patients. Lastly, I attend to the domain of uptake, examining the ways in which neural and plasticity discourses are taken up in clinical settings, shaping notions of patienthood by invoking a simultaneous opportunity for optimization and obligation for self-regulation. Taken together, this dissertation asserts that a biopolitical transformations in pain medicine are producing new understandings of what pain is, how it should be managed, and who stands to benefit from these new configurations.

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## **CHAPTER ONE: INTRODUCTION**

### ***I. Overview***

Pain is one thing that ties us all together. As personal and individual as pain is, it's also a universal experience, and therefore, thoroughly social. It is this juxtaposition—between pain's private interior and pain's shared commonality—that sets it apart from other conditions and renders it a biopolitical object, invested with valuations and judgments. Pain is political not only in that it lies upstream of intensely heated debates about its treatment, but also because it calls up questions of whose suffering counts and whose is rendered invisible.

This dissertation describes the layers of pain's complexity, attending to how pain is studied and treated within the current configurations of biomedicine. In considering how changes in pain medicine are occurring via a neuroscientific reframing, I argue that pain is being newly biomedicalized, or *neuroscientized*, shifting responsibility away from the health care system and onto the individual. These changes are occurring alongside and through reactions to the opioid-related overdose epidemic, as the biomedical community grapples with how to address pain without relying upon risky pharmacological interventions. As our conceptualization of what pain *is* are being transformed, new subjectivities emerge along with new understandings of our capabilities and corresponding obligations.

Through this dissertation, I sought to address three related aims: (1) examine how emerging neuroscience produces and constructs understandings of the nature of pain in the body; (2) evaluate the ways in which neuroscientific knowledges about pain are taken up in different biomedical arenas; and (3) analyze the scientific, social, political, and cultural influences that shape the production, dissemination, and uptake of the neuroscience of pain. In tracing

neuroscientific understandings of pain as they traveled through the overlapping biomedical arenas of production, dissemination, and uptake, I identified the ways in which these understandings were taken up and the various subjectivities and notions of personhood that they produced. I also ascertained the biopolitical forces that are co-constitutive of these processes. Collectively, the chapters of this dissertation attend to the ways in which power circulates through these biomedical spaces, focusing specifically on how shifting conceptualizations of pain rearrange notions of agency and responsibility.

### ***A. Background: Pain, Opiates, and Neuroscientization***

Chronic pain affects one-fifth of the US adult population (Kennedy et al., 2014), and evidence points to the possibility that this number has been steadily rising since 1992 (Zimmer & Zajacova 2018). Increasingly, pain is being framed as a significant public health problem, with social, psychological, and economic costs (Blyth et al., 2015; Croft et al., 2010). Despite these increases in prevalence and concern over its impacts, pain remains shrouded in uncertainty. Disagreements amongst the biomedical community over what pain is and how it should be measured and addressed persist, and relatively little is known about how pain maps onto other conditions, both physical and psychological, and how pain varies across populations.

Conceptualizations of pain and its import have shifted over time. In other historical and cultural contexts, pain has been interpreted differently, as proof of vitality (Cohen 2015), for instance, or as a spiritual phenomenon (Mellor and Shilling 2014). However, in the prevailing cultural and political narratives of the contemporary US, pain is invariably constituted as a problem whose solutions lie in the purview of biomedicine. Until somewhat recently, pain was exclusively considered to be a symptom of a broader disease and therefore not treated as a

condition in its own right (Baszanger 1998). Advocacy on the part of patients' rights groups, the pharmaceutical companies, and various regulatory bodies succeeded in repositioning pain as a condition in and of itself, worthy of sometimes aggressive treatment, and reconceptualized as a vital sign (GAO 2003). I argue in this dissertation that pain is undergoing yet another transformation, a *neuroscientization*, predicated upon two conditions.

First, a national emergency has been declared over rising rates of opioid-related overdoses, prompting those within the biomedical community to search for new solutions to chronic pain. As a result of pain being reconceptualized as a vital sign in 1996 (American Pain Society 2018), clinicians were encouraged to drastically increase their prescribing of opiate medications, ushering in what I term a logic of opiate proliferation. As described in detail via the accounts of pain specialists in Chapter Three, a host of political, economic, and social forces drove a marked increase in opiate prescribing between the 1980s and mid 2000s<sup>1</sup>, resulting in an iatrogenic crisis in which opiate-related overdose deaths have dramatically increased since the turn of the century (Rudd 2016)<sup>2</sup>. This crisis has been termed an epidemic, with pundits citing that death toll figure rival those of gun violence, car accidents, and HIV (Levitz 2017). The White House has declared this crisis to be a public health emergency (White House 2018), though little has been done to redirect resources to reduce its reach (Ehley 2018).

In response to this crisis, national regulatory bodies such as the CDC have launched efforts to curtail prescribing practices, issuing guidelines for safe treatment of pain and educating both patients and providers about the perceived risks of opiates (CDC 2016; US Surgeon General

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<sup>1</sup> By 2010, a national study revealed that 19.6% of all office-based physician visits for new musculoskeletal pain resulted in an opioid prescription (Daubresse et al., 2013).

<sup>2</sup> Public debate exists some disagreement over whether these overdose deaths were strictly opiate driven or resulted from opiates combined with other sedative agents, and whether or not the figures were measured consistently over time.

2016). These efforts have deeply impacted clinical conversations about the efficacy and safety of opiate medications, and have resulted in what I term a logic of opiate prohibition, wherein opiates are increasingly being removed from what is considered to be an appropriate analgesic strategy. To describe the changing standards in opiate prescribing, some pain specialists have invoked the language of the pendulum (Knight et al., 2017; Frieden et al., 2016; Atkinson et al., 2014), likening the shifts in guidelines for opioids to the swinging of a pendulum. The result of this latest pendulum swing is that clinicians are increasingly searching for non-pharmacological solutions to chronic pain, harkening the shift in pain medicine that this dissertation seeks to describe.

A second condition driving the neuroscientization of pain has been the proliferation of neuroscientific understandings of pathology both within biomedicine (Buchbinder 2015a/b; Rollins 2014; Buchbinder 2011; Dumit 2004) and in the broader social sphere (Pickersgill et al., 2011; Harris 2000). We are ever more situated within a neurocognitive era (Pitts-Taylor 2014; Rose & Rached 2013; Dumit 2004), whereby society's ailments, as well as the solutions to these ailments, are being discursively located within the brain-as-mind. Neuroreductionism, or "the belief that human beings are essentially their brains" (Vidal and Ortega 2011:7), "has the potential to dominate the understanding of health, wellness, and personal identity in everyday life" (Pitts-Taylor 2016:5), with implications not just for personhood but also for social knowledge (Vidal 2009). From meditation apps to personal biofeedback devices, consumers are faced with numerous opportunities to self-regulate, enhance, and "hack" (Schiller 2017) their neural patterns. Along with these new possibilities comes the imperative to optimize, as these emergent neuronal subjects are armed with the skills necessary to become increasingly better producers and consumers.



Pain falls squarely in the center of this neurocognitive turn. Despite the changes in biomedical understandings of pain that occurred in the 1980s and 1990s, pain remained discursively situated in the body. Clinicians adhered to biomechanical explanatory models of pain, seeking out an underlying corporeal source and targeting the body as a site of intervention. More recently, however, some pain specialists have begun to promote the parlance of “pain in the brain” (Kwon 2016), as opposed to in the tissue (Schopmeyer 2015). Countless courses, seminars, and therapeutic interventions draw upon the trope of neuroscience in order to bolster claims that an individual can utilize “science based” approaches to “retrain pain” (“Retrain Pain Foundation” 2016). Such interventions have begun appearing at top research hospitals, and emphasize re-educating patients to think about their pain as “an output of the brain, not an input of the body” (Schopmeyer 2015), as described in Chapter Four. The proliferation in neuroscientific understandings of pathology promote a shift in the types of discourses that shape and frame the mechanisms of pain.

In order to understand the changes occurring in pain medicine as a result of the opioid crisis and the rise of neuroscientific explanatory models, this dissertation traces the neuroscience of pain as it travels through the overlapping biomedical sites of production, dissemination, and uptake. I argue that a neuroscientization of pain is occurring, in which clinical explanations of pain, its consequences, and its solutions are shifting away from biomechanical models and towards neuroscientific models. Pain as a neuroscientific object is multifaceted and malleable, open to interventions that draw not upon external, but *internal* processes. I examine the production of neuroscientific knowledge about pain, describing the ways in which the structures of the scientific process of study design limits the amount of subjectivity, or human variability, that can be included in a study of pain. In describing the current situation of pain medicine, I map

the configurations of power operating through decisions about opiates, positioning the opioid crisis as an historically specific post-modern epidemic in its focus on risk, its shifting of responsibility to the individual, and its leveraging of moral panic in the absence of a biological contagion. Lastly, I attend to the ways in which neuroscientific discourses, imparted with agentic notions of plasticity, produce particular subjectivities; namely, patients who are capable of, and thus responsible for, self-managing their own conditions.

### ***B. Theoretical Frameworks***

This dissertation draws on several theoretical frameworks to analyze the shift towards neuroscientization occurring within pain medicine. I have approached these frameworks as sensitizing concepts (Strauss 1987; Bloomer 1954), or concepts that heighten awareness of particular lines of inquiry, allowing them space to adapt or fall away as themes emerged from my data. I draw heavily upon social theories on pain, social studies of science and technology, theories of biopower, critical neuroscience studies, and biomedicalization theory to understand changing conceptualizations of pain and its treatment. I engage with these overlapping theoretical frameworks in order to make sense of how power operates within and through the biomedical spaces addressed here, arguing that pain is constitutive of key processes and practices that are situated within a particular socioeconomic and political moment. I apply these frameworks in order to understand how shifting conceptions of pain present new opportunities and corresponding obligations for patients, considering the kinds of subjectivities that are produced via these neuroscientific explanatory models of pain. Taken together, these frameworks allow me to demonstrate that current changes in pain medicine are representative of biopower in action, whereby sovereignty over life itself, at the level of both the individual and the population,

is enacted via everyday practices and proliferated through discursive formations regarding the nature of pain and suffering (Foucault 1976/1978).

### ***1. Social Theories of Pain***

The interiority of pain makes it difficult to measure, study, and treat (Rubin et al., 2018; Pryma 2017; Crowley-Matoka & True 2012; Buchbinder 2011; Throop 2010; Kempner 2006; Barker 2005; Greenhalgh 2001; Charmaz 1999; Baszanger 1998; Bendelow & Williams 1995; Good & Brodwin 1994; Zola 1991; Scarry 1985). A rich area of sociological and anthropological inquiry revolves around this subjective nature of pain, and the implications that this has for biomedical treatment. Indeed, as Crowley-Matoka and True (2012:508) point out, pain is “simultaneously incompletely medicalized and ineffectively medicalizing.” Here, the authors are alluding to the dual nature of pain as a condition that you have to “fight to get”<sup>3</sup> (Dumit 2006), as well as a condition that is squarely under the purview of biomedical intervention. The literature on pain as an ambiguous and intersubjective condition, thus plagued by clinical uncertainty, highlights the tensions that surround pain and its treatment, at both individual and institutional levels (Crowley-Matoka & True 2012), thereby rendering it an entry point for stratifying processes.

Elaine Scarry’s (1985) book on torture highlights the inexpressibility of physical pain. She focuses on the ways in which pain destroys worlds, attesting to how pain evades language and thereby renders it unsharable. “Physical pain does not simply resist language,” she states, “but actively destroys it” (1985:4). This claim about pain as a destroyer of worlds has been more

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<sup>3</sup> The authors here allude to Dumit’s (2006) exploration of the leveraging of “facts” within cases of chronic fatigue syndrome and chemical sensitivity. He demonstrates that these conditions, as well as a host of other contested illnesses, are enshrouded in medical, social, and political uncertainty. Therefore, bureaucratic processes impugn upon a patient’s ability to acquire a diagnosis, and in turn limit their claim to legitimate suffering.

recently refuted by the work of several social theorists (e.g., Buchbinder 2015b; Mellor and Shilling 2014) who assert that the experience of chronic pain is not always destructive, but can often be generative of new social connections. The pain groups described in Chapter Four of this dissertation and by Ariana Thompson-Lastad (2018) add weight to these claims, revealing the ways in which pain can be a generator of relationships for many patients who otherwise struggle with social isolation.

Scarry (1985) also asserts that pain exists at the opposite poles of a spectrum, in which it is an object of absolute certainty on the part of the person experiencing pain, while at the same time being an object of uncertainty for those looking on from the outside. This account has been complicated by more contemporary explorations of painful conditions and their treatment, in which the patient himself experiences self-doubt and uncertainty with respect to the veracity of his symptoms. For example, Barker's (2005) work on fibromyalgia patients reveals the ways in which *patients*, alongside providers, often grapple with uncertainty about the verity of their *own* painful symptoms. Pain can therefore be seen as one of many contested illnesses for which there are no clear biomarkers (Brown 2011), leading to clinical and often self-inflicted doubt as to the "realness" of embodied sensations. The neuroscientization of pain further complicates pain's position as an uncertain and contested condition, with neuroscientists working to develop a biomarker for pain. However, as is made clear by their accounts, the subjectivity inherent in even these biomarkers raises suspicions as to their utility within scientific and clinical settings.

The uncertainty that still surrounds pain renders it a condition for which there is often no institutional legitimacy. In other words, chronic pain patients often have to work hard to receive the diagnoses that are so inextricably linked to bureaucratized forms of care (Dumit 2006). Certain patients are better able to make a case for the legitimacy of their painful conditions, and

thereby have greater access to medical intervention. Several scholars highlight the disparities and stratifications in care that exist in pain management (Rubin et al., 2018; Pryma 2017; Hoffman et al., 2016; Crowley-Matoka 2013; Crowley-Matoka & True 2012; Buchbinder 2011; Kempner 2006). I theorize that new stratifications in pain management are occurring alongside and via a neuroscientization of pain, with certain patients being framed as increasingly risky and systematically denied opioid medications based on their demographics and social histories. These same patients often do not stand to benefit from the neural techniques described in Chapter Four, as structural inequities, frequently coupled with ongoing trauma, do not fit neatly alongside many of these techniques.

This dissertation takes these collective works as its foundation, building upon questions of uncertainty, legitimacy, stratification, and subjectivity. In particular, I analyze pain as a condition that exists at the boundaries of subjectivity and objectivity, attending to the ways in which this complexity renders it a difficult condition both to study and to treat. Further, I draw upon these texts in analyzing the ways in which chronic pain patients are described in biomedical spaces, attending to the types of subjectivities that are produced via the current shifts in pain medicine. When pain is produced and taken up as a neuroscientific object, it carries with it differently configured implications for agency and responsibility.

## ***2. Social Studies of Science and Technology***

Social studies of science and technology (STS) is an interdisciplinary area of scholarship that attends to the social and institutional dynamics surrounding the practices of scientific knowledge production and their implications. The theoretical and empirical tools that STS provides are particularly useful for this project, in that they allow for pluralities and non-universalistic, non-linear claims about the origins and movement of knowledge systems. By

approaching the study of pain neuroscience through the theoretical frameworks of STS, I was able to remain open to the messy, complex, and often-cacophonous nature of scientific meaning-making.

My stated intention to “follow the science” emerged directly from a rich history of STS methodology. Early studies offered accounts of scientific practices as observed in the laboratory setting, detailing the processes by which scientists produced and disseminated their work (Lynch 1985; Knorr-Cetina 1981; Latour & Woolgar 1979). These works provided the foundation upon which future STS studies (Shostak 2013; Rajan 2006) could explore the taken-for-granted assumptions about the purity of scientific production, revealing localities, heterogeneities, and temporalities that exist within these spaces. Studies of laboratory and scientific work have sought to ensure that the practices of scientists are not black-boxed, uncovering the means of production by which knowledge comes to be, and bearing to light the value-laden conjectures that occur at each step of the scientific process. Drawing upon this theoretical tradition, this project illuminates the mechanisms through which knowledge production occurs, thereby making known the subjectivities embedded within these practices.

Other STS accounts have left the laboratory, exploring the multi-sited nature of knowledge production by attending to where and how these processes arise in education (Underman 2015; Prentice 2012; Mody and Kaiser 2008), policy (Benjamin 2013; Epstein 2008), biomedicine (Nelson 2016; Shim 2014; Bliss 2012; Murphy 2012; Timmermans & Berg 2010), and a host of other institutionalized (Vertesi 2015) and non-institutionalized (Weir 2009; Nightingale 2003) spaces. A portion of these works have revealed the inequitable distributions of the risks and benefits of research, and upended the assumption that knowledge is produced for the good of all (Benjamin 2013; Tallbear 2013). STS scholarship has exploded apart categories

(Shim 2014; Bliss 2012; Epstein 2008) and disrupted the taken-for-granted linearity of information flow from laboratory to bedside (Timmermans 2015). Much of this literature speaks to the work that science does in the world, attesting to the ways that rationalistic, positivist epistemologies inform and shape our every possibility. In diverse ways, many of these scholars are taking up Emily Martin's call to "wake up sleeping metaphors in science" (1991:501). This dissertation builds upon these works in demonstrating how neuroscientific ways of knowing have left the laboratory and shaped the conditions of embodied possibility. Further, it addresses the multi-directional movement of knowledges, challenging the notion that the laboratory is the ultimate adjudicator of truth. While neuroscientific understandings of pain could be found in clinical settings, so too could alternative epistemologies be found in the laboratory, with scientists drawing upon their own lived and embodied experiences in the design and execution of their studies.

Those exploring the activities of scientists have demonstrated the ways in which complexity is obscured in the name of clear data points (Liboiron 2015), and have attended to what, specifically, science means by "complex" (Nelson 2013; Arribas-Ayllon et al., 2010). Within the purview of biomedical practices, pain requires hard edges in order to be actionable. By observing the ways in which pain gets "counted" by neuroscientific practices, I was able to discover more about this process of creating representations out of things that cannot readily be perceived. The ways in which neuroscientists went about measuring, defining, and inscribing pain into discrete categories has implications for the meanings we ascribe to pain and pain patients, and in turn, the way that we experience pain as embodied subjects. This dissertation attends to the scientific disciplining of complexity, illustrating the ways in which the subjectivity inherent in pain is systematically circumscribed in order to produce clear data points.

Building upon these conversations in STS scholarship, this dissertation demonstrates the means by which the current structures of scientific knowledge production negotiate complexity and subjectivity in the study of pain. By describing the disconnects and fluidities between these three biomedical arenas of production, dissemination, and uptake, I point to the gaps in the flow of knowledges about pain between the laboratory and the clinic and back again. STS scholarship provides an important framework through which to make sense of the hierarchies that exist between heterogeneous knowledge systems, with some ways of knowing being privileged to the extent that other epistemologies remain obscured (Tallbear 2013; Harding 1995; Haraway 1988). Although by virtue of studying those in powerful positions, this particular project does not explicitly provoke a multitude of voices, meanings, and perspectives, through my analysis I point to places in which the inclusion of diverse ways of knowing would better the pursuit of knowledge about pain.

### ***3. Biopower***

In tracing the production, dissemination, and uptake of neuroscientific understandings of pain, I argue that the neuroscientization of pain is an example of biopower in action, in which “power is situated and exercised at the level of life, the species, the race, and the large-scale phenomena of population” (Foucault 1978:137). Within each of the three domains taken up in the following chapters, we see illustrations of Foucault’s concept of power over life, in which the bipolar technology of disciplined bodies and regulated populations is operating through biomedical epistemologies, institutional arrangements, federal and local policies, clinical and educational discourses, and neural techniques. Foucault traces the emergence of this power over life, noting the two poles of discipline and regulation. “This great bipolar



technology...characterize[s] a power whose highest function was...to invest life through and through” (1976:139). This new power is not simply interested in the extension of life, but the management of life at every angle.

Foucault describes the two poles of biopower, first centered on the body as a machine, disciplining, regulating, and optimizing so as to be “integrat[ed] into systems of efficient and economic controls” (1978:139). This disciplining of the body is illustrated in Chapter Four, which describes the clinical practice of teaching pain patients to self-regulate through neural techniques. These patients are thus transformed into optimized, low-risk, low-utilizing biomedical subjects, applying self-knowledge as a form of discipline, co-optative and normative (Turner 1997). The second pole centers on the species body, the regulatory controls of the population. These controls are operating through the regulations that first propagated and are now aiming to remedy the opioid crisis as described in Chapter Three. Numerous state and biomedical interventions are enacted to control the population and guard against the risk of an epidemic, which is the greatest threat to this biopolitical dominion over life (Foucault 1972).

Foucault also describes the medical gaze (1976), a process of transforming an individual experience into an abstract knowledge that then gets reflected back onto the individual. He delineates the process of collecting information, creating regulations, and educating people about how to care for themselves. Foucault describes a constant movement back and forth between these two levels—from individual to collective back onto the individual. The first part of this process is represented in the biomedical domain of production described in Chapter Two, in which neuroscientists gathering data from individual subjects that is then transformed into collective medical knowledge, which is then refracted back to the individual. The second aspect of this process is represented through evidence on opiates described in Chapter Three and the

neural discourses described in Chapters Three, in which scientific knowledge is translated into regulations and self-care techniques. Further, Foucault (1970) established that the ways in which life gets studied in turn shapes that very life, a theme that I join others in extending up on by demonstrating the ways in which neuroscientific discourses produce particular subjectivities in their proliferation.

#### ***4. Critical Neuroscience Studies***

Social scientific inquiry into the neurosciences is occurring across disciplines, and a growing collection of works offer up models through which to consider the implications of neuroscientific practices and discourses (Pitts-Taylor 2016; Buchbinder 2015b; Rollins 2014; Rose & Abi-Rached 2013; Hansen & Skinner 2012; Malabou 2012; Vidal and Ortega 2011; Vidal 2009; Dumit 2004). Many of these frameworks build upon the work of Foucault described above, engaging with his theories of biopower and the medical gaze. Fernando Vidal (2009:6) theorizes the cerebral subject, suggesting that the brain is the location of the “modern self.” Vidal also argues that neurocultural<sup>4</sup> imaginings operate as a “double reductionism of persons to brains, and of social and psychological knowledge to neuroscientific information” (2009:11; see also Vidal and Ortega 2011). This idea of neuroreductionism is one way of thinking through a social scientific critique of neuronal discourses. These are important considerations when it comes to questions of structure and agency as they relate to the neuroscience of pain, and how neuroscientific knowledge is leveraged across the biomedical arena.

Rose and Abi-Rached (2013) refute this idea of neuroreductionism, claiming instead that the advances in neuroscience open the brain up for interventions, providing opportunities for

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<sup>4</sup> “Neurocultures” emphasizes the capacity of neural discourses to produce new values, subjectivities, and practices (Pitts-Taylor 2010; Vidal 2009; Harris 2000).

self-understanding and self-management. It is not that we *are* brains, they claim, but that we *have* brains—and that those brains can be put to use for our own self-betterment. The authors trace the expansion of “neuromolecular styles of thought” (Rose & Abi-Rached 2013:41), or neuro-ontologies, into new domains, detailing the implications that these neuro-ontologies have on ideas of personhood. As an extension of Rose’s (2006) earlier arguments about contemporary practices of identity, here the authors invoke the ethic of social responsibility in urging us to become active participants in self-improvement by engaging in practices of “neurobiological self-fashioning” (Rose & Abi-Ached 2013:22). By becoming intimately aware of the processes of our biology, and in this case, our neurobiology, “we will no longer be passive subjects of those determinants, but learn the techniques to act on them in order to live a responsible life” (Rose & Abi-Ached 2013: 23). The authors elaborate upon this new neuromolecular landscape, in which the brain can be known, visualized, and modified through the use of neurotechnologies. They present a specific view on self-production, emphasizing individual obligation within a neoliberal paradigm.

In contrast to the optimism described by Rose and Abi-Rached, Victoria Pitts-Taylor (2010) uses the framework of governmentality (Foucault 1991) to understand and critique popular discourses of brain plasticity. Governmentality links the two poles of biopower described above, tying together regimes of discipline and the production of the self. The concept is taken up here by Pitts-Taylor in order to “illuminate how popular brain discourses on plasticity reflect the languages and practices of neoliberalism” (2010:639), thus attending to the power relations inherent in the making of neuronal subjects. She demonstrates that popular neuroculture, through the deployment of plasticity discourses, “situates the subject in a normative, neoliberal ethic of personal self-care and responsibility linked to modifying the body”

(639). Pitts-Taylor considers plasticity as it exists within a specific biopolitical economy, which produces patients-as-consumers who are obligated to self-manage and promote their own well-being (Clarke et al., 2010).

The neural discourses I analyze in the biomedical domain of clinical uptake are illustrative of both Rose & Abi-Rached's framing, in which new opportunities for personhood are embedded within neuroscientific knowledge and practices, *and* Pitts-Taylor's observations of the neoliberal ethics that are expressed through notions of plasticity. As detailed in Chapter Four, these neural and plasticity discourses carry with them the twinned opportunity/imperative to optimize, enhance, and self-regulate. While neural techniques are often positioned as empowering pain patients to self-manage their own conditions, such empowerment always comes with an obligation.

These theorists and others propose that neuroscientific practices and discourses produce certain notions of personhood. As mentioned above, Foucault (1970) theorized that the ways in which life is studied and understood have impacts upon that very life. Others have extended upon this theory (Pitts-Taylor 2016; Rose 2007; Mol 2002; Barad 1998) by enumerating the subjectivities that emerge out of epistemic regimes. Some have applied this concept directly to the field of neuroscience, highlighting the material consequences of neuroscientific discovery upon *how* bodies are understood as well as *what* those bodies become as a result of these discoveries (Pitts-Taylor 2016). Dumit (2006) describes how neuroimaging technologies produce values meanings about the nature of difference and normalcy. Buchbinder positions neurobiological explanatory models as productive in their capacity to legitimize pain patient's experiences (2015a), but also acknowledges their potential for casting certain patients as deserving of recovery (2011). The production, dissemination, and uptake of neuroscientific

knowledge about pain produces particular notions of subjectivity, evident in the laboratory, the medical school classroom, and the clinic.

### ***5. Biomedicalization***

Biomedicalization theory (Clarke et al., 2003; 2010) provides a final useful framework through which to conceptualize new subjectivities that emerge from an increasingly technoscientific biomedicine. Its focus on the complexities and multi-directionalities that occur between and within science and medicine speaks directly to elements explored within the three domains of this dissertation. In examining transformations occurring within pain medicine, specifically as neuroscientific explanatory models gain clinical authority, three processes constitutive of biomedicalization are particularly important to consider.

First, biomedicalization posits a new focus on health and risk surveillance, and particularly so within a commodified culture that strives for optimal bodies produced by self-regulation and a mandate to attend to individual and collective health. Optimization describes the ways in which biomedical regimes are increasingly organized to secure the best possible outcomes, where new technologies are engaged and developed to improve and better the lives of individuals and collectivities. Clarke and colleagues (2010) articulate how regulation through biomedicalization occurs from the inside out, wherein health becomes an ongoing personal and collective project involving continual self-surveillance. We have long seen evidence of this process occurring within pain medicine: once pain enters into the domain of clinical treatment, it becomes a disciplining project of constant monitoring, reporting, and quantification. This process is exacerbated under the neuroscientific model of pain, as brain-centered discourses are so often imbued with messages about self-enhancement and patient responsibility (Rose & Abi-Rached

2013). Placing pain under the purview of the brain has implications for patient agency, as the brain has been conceptualized as always-already plastic and flexible, and therefore open to neoliberal techniques of risk avoidance and modification (Pitts-Taylor 2010). Under neuroscientific explanatory models, then, chronic pain sufferers are called upon to self-surveil and regulate (Buchbinder 2015a/b). This dissertation attends to the ways in which the process of optimization is occurring within the biomedical domains addressed, with respect to the neuroscientization of pain — that is, the increasing application of neuroscientific claims to pain and its subsequent transformation.

Second, biomedicalization theory attends to the processes transpiring within the aspects of the biopolitical economy that inform and direct how we come to think about health, illness, and life itself. Clarke and colleagues use the term “Biomedical TechnoService Complex Inc.” (2003) to signal how biomedicalization occurs within a medical sector that is thoroughly and simultaneously social, economic, and political. Biomedicalization thus provides a sensitizing concept through which to consider questions of how current conceptions of the political and economic consequences of pain management shape and structure the types of knowledges that can be produced and disseminated within the biomedical complex. This dissertation speaks to how these political and economic processes impact the ways in which pain is being conceived of and acted upon within the laboratory and the clinic.

Finally, biomedicalization attends to the processes by which bodies are transformed via technoscientific and biomedical practices. Clarke and colleagues speak to the biopolitical potential of human and non-human actants to manipulate and transform bodies, creating “new forms of subjectification” and formulating “bioinflected individual and collective...identities” (2010:40). While pain has been a long-standing phenomenon within the human experience, pain

medicine—and, even more so, pain neuroscience—create the potential for people in pain to see themselves in new and different ways. Certainly, developments within pain neuroscience can lead to new forms of subjectification and provide opportunities in which people begin to think about themselves as “pain patients.” Therefore, it stands to reason that, given the relatively recent emergence of pain medicine, and the now shifting understandings and practices of the neuroscience of pain, these evolving ideas about pain may contribute to the construction of bodies in pain that are historically and culturally specific (Rubin & Zimmer 2015).

This study therefore engages with and seeks to extend biomedicalization theory in its exploration of the multivariate and complex transformations occurring within pain medicine. Specifically, this study analyzes pain as being newly or differently biomedicalized through the neuroscientization of health by means of these three processes. Inquiry into pain neuroscience contributes to theoretical understandings of the social, political, and cultural forces at play within the arena of biomedicine.

## ***II. Methodological Approaches and Data Collection***

I chose to apply both constructivist grounded theory (Charmaz 2014) and situational analysis methodology (Clarke et al., 2017; Clarke 2005) to the process of data collection and analysis, in hopes of capturing the heterogeneity of positions and perspectives taken with respect to changes in pain medicine. Constructivist grounded theory (Charmaz 2014) emphasizes the practices of gathering rich data, continuous coding and memoing, and the use of theoretical sampling. Unlike its Straussian roots (Strauss & Corbin 1998; Glaser & Strauss 1967), constructivist grounded theory encourages researchers to make use of inductive methods to develop ground-up, interpretive analyses, rather than rely on positivist approaches to analysis.

Further, Charmaz's approach to grounded theory maintains that the researcher is never a detached and neutral observer. Instead, the researcher herself is an instrument; her subjectivities are indeed *part* of the analysis. "Our imaginative renderings of what we see and learn are interpretations," Charmaz says, "emanating from dialectics of thought and experience" (2006:149). Keeping sight of this claim, I engaged in reflective practices throughout the various stages of this study, making use of my own lived reality to help shape my analysis, and making these positionalities clear in a subsequent section of this chapter.

Situational analysis, as a theory/methods package, seeks to bring grounded theory "around the postmodern turn" by addressing "demands for empirical understanding of the heterogeneous worlds emerging from this 'fractured, multi-centered discursive system' of new world orderings" (Clarke 2005:2). Situational analysis uses the situation as the unit of analysis in order to develop *sensitizing concepts* rather than pursue a formal theory. Situational analysis reflects Foucault's principle of capacious applicability (1972), staying committed to the complexities and heterogeneities of any given situation. Applying the tools of situational analysis to the consideration of transformations in pain medicine allowed for a nuanced understanding of the relationships and positionalities occurring between and amongst various actors situated in these three domains.

## ***B. Data Collection***

This dissertation draws upon data collected in three overlapping biomedical arenas: (1) production, (2) dissemination, and (3) uptake. These three arenas were selected to allow for insight into how neuroscientific research about pain travels, attending to the directionalities, connections, and interruptions in the movement of biomedical knowledges.



Prior to beginning ethnographic observations at each of the laboratory, educational, and clinical spaces, I completed all necessary paperwork for every institution. This included obtaining written approval from several Institutional Review Boards, Dean's Offices, and the Department of Public Health. A Study Information Sheet was distributed during observations, which detailed the study's purpose and procedures, as well as contact information for the PI, the Co-PI, and the Institutional Review Board for both UCSF and the respective institution where the observations were occurring.

Neuroscientists and clinicians interviewed here represented a range of professional backgrounds, institutional affiliations, and career stages. While throughout the analysis, participants are occasionally referred to as "scientists" or clinicians," in practice, many occupied both roles, simultaneously engaging in research activities and treating patients. Also, it should be noted that in Chapters Two and Three, I use the term "pain specialists" to collectively refer to all 30 of my interview participants; however, each were specifically situated within the broader arena of pain medicine, with some identifying as a leader in the field, and others tangentially affiliated by virtue of the fact that they treated pain patients. The following sections will describe selected characteristics of these participants, focusing specifically on their positions within the field of pain medicine.

### ***1. Domain One: Production***

#### ***Observation: Research activities in a neuroscience pain lab***

The laboratory, as the site of production of neuroscientific understandings about pain, is upheld by many pain specialists as the source of legitimate knowledge about their field. Further, as increased regulatory practices change the landscape of what types of therapeutic interventions

are available for those in pain, providers and patients alike look to the laboratory for alternative treatment options. Therefore, it is important to understand the practices and methodological approaches that shape the types of knowledges that get produced in these scientific spaces.

I conducted observations in a neuroimaging pain laboratory housed in an elite private research university. This lab, which I will refer to as the Regional Pain Neuroscience Laboratory (RPNL), was selected because of its reputation as a leading site of pain research on human subjects. Preliminary conversations with pain neuroscientists, attendance of lectures, and extensive evaluation of the neuroscience pain literature helped me to identify who the primary figures in the field might be, and led to the selection of RPNL as an exceptional site representative of the cutting edge in neuroscientific pain research.

Approximately 40 hours of ethnographic observations occurred in the laboratory between December 2016 and April 2017. All parties encountered in the lab during observations were read and/or handed a paper copy of the Study Information Observation Script and were asked for verbal consent to have their activities observed. If any person present declined to provide consent, observations in that space were ceased. This occurred several times through the course of my observations, and observations for that day were reoriented to attend to different scientist or group of scientists. Observations in the lab focused exclusively on the activities of neuroscientists, research assistants, and administrative support staff. No HIPAA-protected information was gathered.

When research practices involving human subjects were observed, my presence and role was first introduced by the scientist or research assistant they were working with. If the research subject agreed to have their activities observed, I then handed them a paper copy of the Study Information Observation Script and briefly explained my role and the broader purpose of the

study, emphasizing that the activities of the scientists, rather than of the research subjects, were the focus of my observations. The research subject was then asked for verbal consent to have their activities observed; all research subjects consented.

Handwritten fieldnotes were taken during ethnographic observations, which excluded all identifying information and only included general notes about the event and ideas discussed or presented. Where permitted and relevant, photographs that excluded any individuals were taken to document laboratory settings and supplement fieldnotes, such as photographs of office space, laboratory equipment, and presentation slides. At the end of each day of observations, fieldnotes were organized and completed. Audio memos were recorded in a private space and subsequently transcribed and deleted from the recording device. Fieldnotes of ethnographic observations and photographs were securely stored on an encrypted computer.

These observations focused on the research practices through which scientists sought to define, operationalize, and interpret measures of pain; how scientists constructed their studies and experiments; how they interacted with human research subjects and technological instruments; and the extent to which broader institutional factors, such as funding mechanisms or sociopolitical conversations about pain and its treatment, were weighed and considered amidst the production of research. Accordingly, I observed meetings between researchers; experimental procedures, including quantitative sensory testing and fMRI scans; interventions; consenting and recruitment practices; and informal conversations between staff and researchers. Such observations lent insight into the ways in which pain is constituted by the field of neuroscience. For example, observing how scientists elicited a pain response will provided an understanding of what, specifically, the discipline understood pain to be. Watching how those working in the lab

engage with human subjects revealed the ways in which neuroscience comes to define and describe the body in pain.

While I had originally intended to conduct 80 hours of observations in this first domain, a number of factors limited my access. First, the majority of the time that scientists spent researching did not involve collective activities, but instead consisted of hours spent alone at the computer, writing grants or conducting analyses. As I had been warned, there wasn't much to see at this phase. While I did spend some time engaged in informal interviews with these scientists as they worked, asking them questions about their analytic practices, for the most part, I opted not to spend time observing such solo activities so as not to disrupt their productivity. Second, many of the scientists were concerned with the fidelity of their research, and did not want an additional observer present during their experiments for fear that this would interfere with the comparability of their data. However, I was sometimes able to observe experiments involving subjects whose data would not be included in the final analysis. For example, as noted in Chapter Four, I was granted permission to observe the Cognitive Behavioral Therapy group specifically because it was a trial run, being conducted solely for the purpose of training a facilitator, rather than scientifically testing the intervention. Thus, the data collected from this group would be tossed out, and my presence would not impact the fidelity of the analysis. Third, some of the procedures of the various studies taking place involved sensitive questions or examinations, such as mental health screenings and physical exams, and many scientists chose not to have an observer present for such phases of the research in order to protect the privacy of the subjects.

Lastly, and perhaps most significantly, as much as I tried to convey the scope of my study, many of the scientists struggled to understand what exactly it was I was doing in their lab. Because qualitative inquiry is so far removed from the type of scientific study they were engaged

in, it was difficult for them to comprehend that what I was collecting were, in fact, data. When I described in detail my analytic strategy (to those who would listen), I often was dismissed as a journalist. Sometimes this worked to my favor, as a few scientists were either eager to have their work popularized or were so dismissive of the import of such an investigation that they couldn't care less whether I was there or not. Other times, scientists were wary of what data I was collecting, what conclusions I would be drawing, and what would be written about their projects. Other misconceptions regarding my methods included being asked if it would be better if I just recorded everything, given that I was sure to be missing content by taking notes by hand.

### Interviews: Pain Neuroscientists

In addition to observations within the laboratory, I conducted semi-structured in-depth interviews with 15 pain neuroscientists working in 11 different labs around the world. Interview procedures are detailed in the appendix A of this dissertation, and sample interview guides are included in Appendix B.

The 15 neuroscientists I interviewed for this study were either working or had very recently commenced working in 11 laboratories situated within 10 different institutions, located in three different countries, primarily the United States. Each focused their research on the neural mechanisms of pain. As described in detail in Chapter Two, the majority of these scientists worked either on the peripheral components of pain, or on the sensory components of pain, though some had experience working in both domains. Some scientists maintained a clinical practice in addition to carrying out their research, and several served as lecturers at their institution's medical schools. A range of professional trajectories were represented by this

sample, from postdoctoral scholars, to tenured professors, to professors emeriti. Many had served on national advisory boards and helped to develop policy related to pain and its treatment.

Neuroscientist interviews lasted between approximately 30-60 minutes; seven were conducted in person and eight were conducted over video conference. These interviews yielded rich accounts of the current state of pain neuroscience, its future directions, and the values embedded within its practices. Through these accounts, I gained insights into how various pain neuroscientists go about defining, measuring, and interpreting pain and its consequences; in other words, I was able to develop an understanding of the processes by which pain is produced as a neuroscientific object. These interviews shed light on the intersections between laboratory and clinical spaces, as well as the lines of communication that exist or are absent between various disciplinary environments. Interviews contained descriptions of the impacts of various institutional arrangements and bureaucratic structures upon the production, dissemination, and uptake of knowledge about pain. Further, through the accounts of these neuroscientists, I was able to identify some of the controversies surrounding the scientific evidence regarding opiates and their corresponding regulation. Lastly, the silences that emerged from these interviews, specifically regarding trauma and marginalized populations, contributed to the analysis presented in this dissertation as well as the generation of aims for future projects.

Taken together, ethnographic observations and semi-structured interviews conducted within this domain of production yielded rich data that contributed to the development of each of the arguments presented in these three chapters. Though the chapters are organized around the three domains of production, dissemination, and uptake, these are imperfect and somewhat arbitrary groupings, as the institutions of biomedicine are not so cleanly divided. Thus, data from

these three domains bleed into one another, providing context and perspective to each of the themes taken up. However, it should be noted that analysis of observational data from the laboratory is only directly discussed in Chapter Two, and analysis of neuroscientist interview data is limited to Chapters Two and Three.

## ***2. Domain Two: Dissemination***

### *Observation: Medical School Classrooms*

The majority of US medical schools include anywhere from zero to ten hours of mandatory instruction on pain (Mezei & Murinson 2011). The pain curriculum, as it exists within medical education, holds particular interpretations about pain and its treatment. In order to understand the means by which biomedical conceptualizations of pain are shifting, it is important to ascertain how messages about pain and its treatment are being communicated to aspiring physicians.

Observations in this domain occurred in two elite medical schools. I initially met with administrators at both institutions to map the boundaries of the pain curriculum, relying on their accounts to identify which courses focused primarily on pain and its treatment. While I had anticipated observing up to 20 hours of instructional content, I was informed early on that the 2016-17 academic year in which I was conducting observations was a transitional year for both institutions in terms of their respective pain curricula. Due to federal funding limitations and changes in the national requirements for pain education, both medical schools were overhauling their pain curriculum and consequentially were only holding two courses each that pertained specifically to pain and its treatment. Thus, observations of the official pain curriculum for medical school students totaled a mere 6 hours. These hours were supplemented by attending and

watching recordings of Grand Rounds and continuing education forums that were open to the public. Thus, between August 2016 and June 2017, I conducted approximately 15 hours of ethnographic observations of the pain curriculum and corresponding sites of dissemination. Observation procedures are detailed in the appendix of this dissertation.

At the beginning of each class session observed, instructors briefly introduced my presence and my role to the students in attendance, as well as those watching the video recordings of the class. Depending on the preferences of the instructor of each course, those attending courses observed were either read aloud a Study Observation Information Script or handed a paper copy of the Study Observation Information Script. I emphasized that the focus of my observations would be the course content, rather than the students in attendance. Those present in these courses were asked for verbal consent to have their activities observed; all students in attendance consented.

Handwritten fieldnotes were taken during the classes observed. These fieldnotes excluded all identifying information and only included general notes about the ideas discussed or presented. At the conclusion of each class observed, fieldnotes were organized and completed. Audio memos were recorded in a private space and subsequently transcribed and deleted from the recording device. Fieldnotes of ethnographic observations were securely stored on an encrypted computer.

The observations conducted in this domain allowed for insights into whether and how changing understandings of pain were being incorporated into educational and clinical spaces. Observations in this domain focused on the selection, packaging, and framing of biomedical models of pain, noting the ways in which pain was defined and contextualized. By taking note of what the pain curriculum consisted of, I was able to get a sense for what information these



institutions privileged with respect to pain and its treatment, as well as how individual instructors deployed various frames and models of pain. Observations of the pain curriculum lent insight into the ways in which biomedical knowledge travels, highlighting the “gaps and rifts” (Friese 2013:136) in the flow of research from bench to bedside (Marincola 2003). Data gathered in this domain contributed to an understanding of the types of subjectivities being produced via the shifts occurring within pain medicine. As noted previously, while data gathered in each domain provided context for all three chapters of this dissertation, analysis of the data collected in medical schools is limited to Chapter Three.

### ***3. Domain Three: Uptake***

#### ***Observation: Patient pain groups***

Throughout the US, group medical visits are appearing as an increasingly popular configuration of care; many of these groups focus exclusively on chronic pain (Thompson-Lastad 2018). Pain groups that promote self-management strategies often draw upon neuroscientific explanatory models of pain, or at very least premise their interventions upon these principles. Gaining an understanding of how these groups are structured, what messages are being conveyed to patients, and how group facilitators leverage neural and plasticity discourses is critical for analyzing changes occurring in pain medicine.

I initially intended to observe two separate pain groups occurring within two urban safety net clinics, which I call City Health System (City Group) and Neighborhood Primary Care Clinic (Neighborhood Group). As mentioned previously, through my observations in the Regional Pain Neuroscience Laboratory, I became aware of pain groups that were occurring at the lab as part of a larger study, and was granted access to one group (Lab Group). In total, I conducted

approximately 75 hours of observations across these three pain groups between November 2016 and April 2017. While the City Group allowed me to conduct observations every other week, so as to capture any changes to the group that occurred over time, the Neighborhood Group preferred that I observe the group every week so as not to disrupt the continuity of the group. Due to scheduling constraints, I was only able to observe half of the Lab Group sessions. During my first day of observations of each of the three pain groups, group facilitators introduced my presence and my role to all group members in attendance. I subsequently distributed paper copies of the Study Information Observation Script and read a summary of its main points, emphasizing: (1) the purpose of the study; (2) my role as a researcher; (3) the voluntary nature of their participation; and (4) the fact that the fieldnotes I was taking would not contain any information about their identities or their activities in the group, but would instead focus exclusively on the instructors and the curriculum of the group. Group members were then asked for verbal consent to participate in the study. During subsequent observations of the group, if I encountered new members of the group, I would repeat the above procedures with these new members. All group members verbally consented to participating in the study.

Fieldnotes were taken by hand during times when group facilitators were speaking, but not when patients were sharing. No information pertaining to patients' health statuses or other HIPAA-protected information was collected. All fieldnotes focused exclusively on the content of the curriculum and the activities of the group facilitators. Fieldnotes excluded any and all information about patients, and only included general notes about the activities of facilitators and the information conveyed during these groups. At the conclusion of each class observed, fieldnotes were organized and completed. Audio memos were recorded in a private space and subsequently transcribed and deleted from the recording device. Handouts distributed during the

group, both to group facilitators and to group members, were collected and stored in a locked desk drawer at a locked private residence. Fieldnotes of ethnographic observations were securely stored on an encrypted computer.

Importantly, as is detailed above, the agreements I set with various Institutional Review Boards and other relevant agencies stated that I would not be recording anything that patients shared or did in these groups. This was an important factor in my gaining entrée into these groups, both from facilitators and, perhaps, from patients themselves. While the content of these groups varied tremendously, as is described in Chapter Four, some groups focused on providing emotional support for patients and thus were often the site of intensely personal sharing. The absence of data on patients' reflections and experiences in these groups is a noted limitation, discussed further in the conclusion of this dissertation; however, attending exclusively to the facilitators and curricular content of these groups allowed for a more focused analysis that speaks directly to the discourses promoted in these spaces, rather than to the particularities of how these discourses were perceived.

#### *Interviews: Clinicians who interface with chronic pain patients*

In addition to observations of patient pain groups, I conducted semi-structured in depth interviews with 15 clinicians actively engaged with treating pain patients. Interview procedures and sample interview guides are detailed in the appendices of this dissertation.

The 15 clinicians interviewed for this study were actively engaged in treating pain patients, and were working within 6 different institutions. Eight were involved in facilitating pain groups; all five group facilitators of the three pain groups described in Chapter Four were interviewed, along with facilitators from three additional groups. Of the remaining 7 clinicians,

the majority were referring providers to various pain groups. Clinicians occupied a number of roles, including physicians, nurse practitioners, physical therapists, licensed social workers, and psychologists. Several clinicians were also engaged in clinical research, and some served as lecturers at their institution's medical schools or were responsible for training residents. While many of the clinicians I interviewed had been practicing medicine for over a decade (some for many decades), and thus had been exposed to the pendulum swing detailed in Chapter Three, some were newer to medicine and thus had not been in practice during the time of opiate proliferation. Some clinicians specialized in pain medicine, while others simply treated patients with pain conditions.

Clinician interviews lasted between approximately 30 minutes and one hour; all were conducted in person, with the exception of one that was conducted over video conference. These interviews provided nuanced and detailed accounts of the changes occurring within pain medicine and the ways in which these changes were playing out in clinical practice. Through these accounts, I gained insights into the ways in which the opiate crisis and the proliferation of neuroscientific models of pathology were shaping clinical practices, interactions, and policies. These interviews contained descriptions of the challenges clinicians are facing in making sense of this iatrogenic disaster of opiate-related overdose deaths. Through the various accounts of these clinicians, I was able to identify a range of positions taken on how to appropriately respond to this crisis. Further, these interviews provided color and context to my understanding of the various techniques deployed in the pain groups, allowing for a richer analysis of how, and for whom, they were being leveraged in the treatment of chronic pain.

Taken together, ethnographic observations and in depth interviews conducted within this domain of uptake contributed to an understanding of the implications of these shifts in pain medicine for biomedical practice. While data from all three domains contributed to arguments made in each of the following chapters, analysis of observational data from the pain groups is limited to Chapter Four, and clinician interview data is almost exclusively contained in Chapters Three and Four.

### *C. Data Analysis*

All data was coded and analyzed using both grounded theory (Charmaz 2014/2006) and situational analysis (Clarke et al., 2017; Clarke 2005). Analysis occurred concurrent with data collection, through the use of memoing and development of codes. Text from interview transcripts, fieldnotes collected throughout the duration of the observation period, and primary documents were coded and analyzed using Atlas.ti, a qualitative analysis software.

In addition to continual memoing and coding, I made use of Clarke's cartographic approaches to analysis as a way to make sense of the questions emerging from my data. Situational maps were useful in identifying and drawing connections between the various elements at play within the arena of pain medicine by asking the question, "Who are what are in the situation?" (Clarke 2005:87), and by providing spatial ways to think through these relationships. Positional maps were particularly useful in conceptualizing multiple areas of difference and controversy, highlighting the heterogeneities that exist within the field of pain medicine. Constructing these maps was, in essence, a practice of tracing discursive formations (cite), searching for their surfaces of emergence, or conditions of possibility.

#### ***D. Statement of Reflexivity: Situated & Embodied Knowledges***

Donna Haraway reminds us as researchers that “we need to learn in our bodies, in order to name where we are and are not, in dimensions of mental and physical space we hardly know how to name” (1988:582). I take her charge seriously, building my work upon a belief in situated and embodied knowledges. It is therefore important to name my own situatedness within this project, if only to acknowledge that, as researchers, we carry with us a host of experiences, roles, statuses, and values that inevitably shape every stage of the research process.

For the past twelve years, I have worked as a clinical bodyworker providing treatment for patients with chronic pain. I’ve witnessed my patients struggling with conditions of unknown etiology, trying in various ways to come to terms with uncertainties surrounding diagnosis and treatment. I have therefore been engaging with both pain and trauma from a very specific stance, which has lent a respect and curiosity to questions of embodied knowledge and agency. This background and (embodied) experience shaped the selection of my empirical site, the lens through which I perceived the field I was studying, and the subsequent analysis of the data collected. Indeed, as I’ve stepped into this field of study, my patients have been eager to hear not about my sociological analyses of pain, but instead about the neuroscientific interventions that I’ve encountered. These conversations with my patients about the neuroscience of pain have shaped the ways in which I approach my findings, as I try to keep in mind the hopes and desires of the patients whose lives are impacted by the ways in which pain is perceived, studied, treated, and regulated.

Further, my depth of experience as a bodyworker, and thus a purveyor of some of the values embedded within the neural and plasticity techniques described in Chapter Four, provides a complicated angle through which to consider these messages. One of the ways that alternative

medicine upends traditional biomedical systems is by positioning the solutions to physical and psychological problems as stemming from inside the individual patient. This regime of empowerment is present in my own approach to bodywork, as I have long encouraged patients to shore up their own capacity to heal themselves through self-care practices. Thus, encountering some of these same values in the field provided me with the opportunity to think critically about the messages of personal responsibility that I was sending to my patients.

Additionally, my own experience as a chronic pain patient has impacted the ways in which I think through and make sense of the current situation of pain medicine. While I did not develop my chronic pain condition until after selecting my dissertation topic, I certainly held up each piece of data against my own lived experience. My condition is by no means comparable to those of the patients I encountered in the field, in that I do not frequently experience it as debilitating and do not find that it impacts my life to the extent that it needs to be regularly and actively managed. However, I very much perceived the arena of pain medicine, and the meanings and values expressed within, through the lens of someone with a persistent pain condition.

Lastly, and perhaps most importantly, my position as a white, middle class woman undoubtedly shaped the questions I posed, the means through which I sought to answer them, and my capacity to do so. In the field, I was constantly aware of my embodied privilege and the difficulty I may have faced in gaining entrée into these spaces if I held a different social position. In analyzing my data, I was also made aware of how partial my view is on the inequities of pain and suffering, and can only hope to continue to learn from those with divergent standpoints and experiences.

### *III. Overview of Dissertation*

In this dissertation, I argue that a neuroscientization of pain is occurring that produces particular subjectivities and repositions risk, agency, and responsibility within the patient. This process is occurring in first response to an opioid-related overdose crisis, in which the biomedical community is searching for new solutions to chronic pain, and second, in relation to an increased proliferation of neuroscientific explanatory models of pathology. I contend that these changes represent biopolitics (Foucault 1978; Rose 2007; Turner 1997) in action. Control over populations and a disciplining of the body are being enacted through the production and dissemination of biomedical knowledge, the regulation of opioids, and the uptake of plasticity discourses in the treatment of pain.

#### *A. Chapter Two*

Chapter Two examines how pain is produced as a neuroscientific object by attending to the structures of knowledge production within the field of pain neuroscience. I argue that, in order to produce clear and actionable data points (Liboiron 2015), scientists must engage in practices that circumscribe complexity (Nelson 2013) and discipline subjectivity. I begin the chapter by describing the multiple components of pain as they are demarcated through scientific study: the objective/sensory/peripheral aspects of pain are delineated from the subjective/emotional/central aspects of pain. I attend to debate within the field over which aspect of pain is more useful, relevant, and possible to study. Through describing the practices of scientists working with human subjects, I argue that much of the work of studying pain involves negotiating the boundaries between subjectivity and objectivity, finding ways to make the subjective ratings of their subjects as objective, and standardized, as possible. Scientists struggled over questions of whether studying pain in healthy samples would limit the relevance



of their findings for clinical, patient populations. While many expressed faith that advances in technology and incremental scientific inquiry would eventually lead to breakthroughs in pain, others expressed concern about the disaggregation of pain that resulted from the structures of science itself.

### ***B. Chapter Three***

In Chapter Three, I assert that the opioid crisis and its proposed solutions constitute a biopolitical, post-modern epidemic (Boero 2010) in its focus on risk, its shifting of blame to the patient, and its proliferation of chaotic discourses in the absence of a biological contagion. I outline a host of social, cultural, economic, and political forces that pain specialists identify as driving the proliferation of opiate prescribing that resulted in the opioid crisis, characterizing the genesis of this crisis as biopolitical in nature. I then map the heterogeneous positions taken by specialists on how to interpret the current evidence base on opiates, revealing the impacts of undone science (Decoteau & Underman 2015; Hess 2013; McGoey 2012; Kempner et al., 2011; Frickel et al., 2010) and the politics of knowledge production (Clarke et al., 2010), and attending to the disagreement that exists within the field of medicine regarding what should be done about chronic pain and opiates. I then argue that the complexity of both opiates and pain patients is flattened in the development and implementation of policy and the discourses that circulate through clinical practice and medical education about pain and its treatment. I demonstrate that the opioid crisis and its proposed solutions produce particular subjectivities, specifically the “chronic pain player,” characterized as always-already at risk in the current biopolitical moment in pain management.

### *C. Chapter Four*

In Chapter Four, I attend to the ways in which neuroscientific explanatory models of pain are taking root in clinical settings, asserting that the plasticity techniques that are premised upon these models invoke particular notions of patienthood and require specific subjectivities. I describe three pain groups that operate under a neuroscientific model of pain management, teaching pain patients neural techniques, such as Cognitive Behavioral Therapy and Mindfulness-Based Stress Reduction, to self-manage their painful conditions. These neural techniques invariably carry with them notions of plasticity, wherein patients are encouraged to think of themselves as malleable, capable of transformation and enhancement. The structures, primary purposes, and settings of each of these groups shape and are shaped by the techniques they deployed for intervening upon their patients' pain levels, and also impacted their engagement with neural and plasticity discourses. These discourses, then, are situational and the distribution of their benefits stratified, as some techniques necessitate patients who are already engaged and activated.

## **CHAPTER TWO: PRODUCTION**

### **I. Introduction**

*“So (a pain neuroscientist) told this story about how he was at the museum with a friend of his who was a vision neurologist...they're standing there in front of a Mondrian looking at the painting. His friend says, ‘You pain people, you know nothing about the biological experience of pain. In the vision field, we understand where these lines and colors are happening in the retina. We understand what pathways they follow to get to the thalamus and how the thalamus decides what's linear and what's curved and what's moving still and how it goes to the occipital cortex. We understand what's happening in the occipital cortex. It turns into pictures and then into the hippocampus for memories. We understand vision. You guys are nowhere in the field of pain. You don't understand that.’ (The pain neuroscientist) said, ‘You show me where in the brain you're having the experience of beauty when you look at this painting and then we can talk about the experience of pain because that's how complex the experience of pain is.’” —Pain Specialist<sup>5</sup>*

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<sup>5</sup> Throughout these chapters, I use the term “pain specialists” to refer to the collectivity of my participants, whose focus on pain, either in the field of neuroscientific research or in medical practice, renders them a specialist in my estimation. At other times when relevant, I specify whether I am referring to a neuroscientist or a clinician.



Figure 2.1. Piet Mondrian, New York City 2 [unfinished, formerly New York City III], 1941 (SF MOMA)

The above story was repeated to me by a physician who had heard it told by a pain neurologist while in medical school. Now charged with training residents about pain, this physician tells this story on the first day of the residents' pain module. The story had inspired her to go into pain medicine, where she saw a gap in the field around "engaging complexity appropriately." When I later interviewed the pain neurologist who had originally told her this story, he told me that the story was about beauty. He added details in the retelling, remarking on how two people can look at the same painting and have an entirely different reaction: "One person looks at it...walks right by. The other person looks at it...they're stunned, it's beautiful...their whole brain is lighting up." In this retelling, the vision neurologist acknowledged that, while his field knows everything about the pathways, the processing, and the location of vision, they do not know where *the experience* of beauty resides in the brain. "It's right next door to pain," joked the pain neuroscientist, implying that, like the experience of beauty, pain also resides in a mysterious, unknown part—or, more accurately, parts—of the brain. This juxtaposition of pain and beauty hints at the multidimensionality, complexity, and subjectivity of pain as a neuroscientific object.

Pain is a complex phenomenon that is not fully understood within the biomedical arena. As opposed to vision, pain is complex, subjective, and multi-sited; while the vision neurologist can claim that “we understand vision” by pointing out the how, what, and where, those who study pain cannot yet claim this level of certainty. What stands in the way of understanding the how, what, and where of pain, is, at least in part, the subjective experience of pain itself. Like beauty, pain is something that is interpreted, and this interpretation can vary tremendously from person to person. So, while the vision neurologist can explain the *mechanisms* of seeing a painting, the pain neurologist points out that little is known about the *experience* of looking, feeling, and reacting to something that is seen, that is just as complex as the experience of pain. Pain neuroscientists, then, must go about the difficult task of reducing the complexity of pain in order to understand it.

The following chapter draws upon 30 in depth, semi-structured interviews with pain neuroscientists and clinicians, as well as approximately 40 hours of observations in a neuroscience pain lab, to describe how pain is produced as a neuroscientific object. Analyzing the accounts of neuroscientists’ systematic investigation of pain through scientific practices and technologies, I argue that much of the work of scientific meaning-making when it comes to pain involves managing the intersections between the subjective and objective, and finding ways to circumscribe or limit the subjectivity inherent in the pain experience. This negotiation between the objective and the subjective is part of what sets pain apart and renders it so challenging to both study and treat. The subjectivity inherent in the experience of pain is disciplined through a number of techniques, resulting in a disaggregated and abstracted notion of what pain is and who it impacts.

This chapter engages with the social studies of science and technology (STS) literature, following the rich tradition of laboratory studies (Lynch 1985; Knorr-Cetina 1981; Latour & Woolgar 1979) to reveal the social nature of scientific knowledge production. Disrupting notions of science as being an impartial, rational, and purely objective institution, I join others (Shostak 2013; Rajan 2006) in describing the localities and heterogeneities that exist within scientific spaces. Specifically, I attend to the ways in which the structures of scientific inquiry itself, and not just the preferences of individual researchers, shape the very object of study. I argue that the means through which pain is produced as a neuroscientific object limit what can be known about the holistic, lived experience of pain as it appears in clinical settings.

I build upon previous inquiries of scientific practices (Benjamin 2013; Tallbear 2013; Epstein 2008) that point to the inequitable distribution of its benefits. Pain neuroscience's focus on developing a basic understanding of pain itself, rather than investigating how pain operates alongside other conditions, limits the generalizability of findings to clinical populations. In analyzing how pain researchers design their sampling strategies, I draw heavily upon Steven Epstein's "inclusion-and-difference paradigm" (2007:17) to make sense of the absences of particularly "complex" patients in these studies of pain. As scientists describe their sampling practices, some notions of difference are made to count while others are obscured. By extension, I position neuroscience as a technology of the medical gaze (Foucault 1976), perpetually engaged in the practice of transforming individual processes into abstract knowledge.

Further, I engage with STS scholarship that points to the means by which complexity gets obscured in the name of producing clear, actionable data points (Liboiron 2015; Nelson 2013; Nelson et al., 2013; Arribas-Ayllon et al., 2010). These works attend to the scientific practices that do the work of claims-making by negotiating complexity and systematically carving out

simplicity, and bring to light what gets accomplished by rhetorically leveraging “complexity” itself. By describing the practices through which pain neuroscientists go about defining, measuring, and inscribing pain, I demonstrate the ways in which pain’s complexity is disciplined and circumscribed within the laboratory. It is this disciplining that produces an abstracted understanding of pain and who it impacts.

## **II. Pain’s Complexity: The Binaries of Pain**

The International Association for the Study of Pain (IASP) defines pain as an “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP 2018). While this definition has been heavily debated (Williams & Craig 2016), it remains the gold standard for how scientists are trained to approach the study of pain. Important for the purposes of this chapter is the inclusion of the words “sensory *and* emotional experience.” The sensory components of pain are framed as distinct from the emotional components of pain, and much of the work of studying pain involves isolating these two components from one another. As we shall see, this practice of isolating the sensory from the emotional is one way in which pain scientists negotiate the intersections between objectivity and subjectivity in their research practices.

As the researchers and clinicians I studied understand it, pain represents a unique interplay between the subjective and objective, and much of the work of studying pain revolves around managing and understanding this relationship. Scientists frequently referenced numerous intersecting components of pain, with some naming this complexity of pain as part of the appeal of studying it. For instance, one scientist shared what drew him to the field of pain neuroscience:

Pain is really fascinating, because it's affective, sensory, cognitive, it's all these different things ... You can precisely quantify it, do psychophysics on it, and yet it's still something that's kinda mysterious, because it's a subjective experience that's created.

These component parts of pain—the “affective, sensory, and cognitive” elements—can be distilled apart and precisely quantified. He referenced being able to “do psychophysics” on pain; psychophysics is the practice of quantifying physical stimuli and the perceptions they produce. In other words, this scientist was attesting to his ability to quantify, or objectify, the perceptive or subjective aspects of pain. Yet this subjective experience is what renders pain “mysterious,” despite efforts to understand it via these objective measures.

Another scientist described in more detail efforts to objectify the subjective:

As a model of affect, just emotional responding, [pain is] better than any other system because we actually know objectively what we're giving the participant. We use a device called a Derma that heats up to different temperatures and we know objectively speaking what temperature we're giving somebody but psychological factors can actually modulate perception all around. Any other modality, if you're interested in emotion, people have studied monetary rewards or they use gruesome images or something. There's no objective truth there, whereas with pain, I think what's really interesting is ultimately it's the subjective experience that matters but we know quantitatively what the person's actually experiencing. I just find that to be a compelling system.

She described a process that I observed repeatedly in the lab, whereby a participant receives a controlled stimulus and is asked to rate different components of how they perceive that stimulus. The heat coming from the Derma is quantifiable, and is thereby seen as an “objective truth.” The participant’s “psychological factors,” however, can modulate that truth, and, according to this scientist at least (though we will soon see that she did not hold a universal perspective in this respect), it is this subjectivity—or truth modulation—that ultimately matters. This delicate interplay between the subjective and objective is part of what sets the study of pain apart from that of other conditions, and understanding the practices of managing this relationship lends nuance to current considerations of biomedical knowledge production.



However, despite their acknowledgment that pain was constituted by this interplay, many of the scientists I spoke with had chosen to focus their research career *either* on the sensory *or* the affective, depending in part upon which component of pain they felt was the most important to understand. This decision also depended upon professional configurations, methodological limitations, and structural influences. At the end of the day, even though nearly all scientists attested to the inability to develop a holistic understanding of pain and its potential solutions without considering both the subjective and the objective, most scientists expressed a preference for one area of study over the other. The following sections describe their positions, and in so doing elaborates upon both the tensions and the relationships between the binaries of pain.

#### ***A. Objective/Sensory/Peripheral Nervous System***

Scientists who focus primarily on the *sensory* components of pain are interested in the mechanisms of nociception. Nociceptors are sensory neurons in the peripheral nervous system that send alert messages to the central nervous system when potentially damaging stimuli is detected (Dubin and Patapoutian 2010). The study of nociception, then, is often described as being primarily focused on the sensory, rather than the emotional (or affective) components of pain. This research is often conducted using animal models, rather than human models, and it focuses on the peripheral nervous system, rather than the central nervous system. The study of the sensory aims to understand the objective components of pain: pure response to an objectified painful stimulus.

Some of the scientists I interviewed who focused on the sensory components of pain did so because they felt that this was the most important aspect of pain. They believed that understanding the peripheral aspects of pain—the objective, sensory component of pain—was

key to developing an effective intervention for pain. For example, one scientist shared his allegedly controversial opinion that blocking pain signals at the periphery was the most promising way to manage pain:

I still happen to believe ... —this is a controversial thing—I happen to believe that most pains are driven from the periphery, if not all pains...In fact it was Melzack [an historically significant pain researcher] who chided me at a meeting once. He said, "You're wasting your time. You're never going to help anybody. All you are studying is nociception." Which is true. I study the transmission of messages, but I think if you block those messages most pains will be controlled. So, long acting ways to prevent input going into the [central nervous system] is going to be very effective. He doesn't believe that. I think the data argues in my favor. Certainly, dentists have known it for years, right? Local anesthetics, they block pain, and they work.

Stopping the transmission of pain signals before they even get to the central nervous system—the site of affective pain processing that other scientists seek to understand—is what this scientist sees as being the most effective way of controlling pain overall. He believes that the majority of pain is driven from nociception, or from the peripheral nervous system that responds to sensory input. By providing the example of dentists, who apply local anesthesia as a simple, almost mechanistic way to interfere with the sensory processing of pain, that is also clearly effective, he bolsters his position that pain can be managed by blocking signals at the periphery. Thus, his research focuses on the sensory components of pain, investigating nociceptive mechanisms in animal models.

Another scientist supported this position on studying the periphery, though he himself had done work on both the sensory and the affective, using both animal and human models. The complexity of the central nervous system was too vast, he attested, and scientific effort is wasted on trying to solve its puzzles rather than looking for simpler solutions to pain. He told me:

When you start to look at the underlying architecture and the complexity of the underlying architecture ... I remember back in the '90s there was a slide that people were using a bunch that showed that there was something like... 70 neurotransmitters, neuromodulators, neuropeptides, neuro whatever, in the spinal cord that altered

nociceptive processing ... As a field ... I think understanding the central neuropharmacology is absolutely crucial, but at the same time trying to develop a centrally acting treatment for pain time and time again—it's just not working out. I think where we really need to redirect is go much more to the peripheral nervous system now...It's simply a much more constrained entity. When you've got huge numbers of parallel pathways in the central nervous system processing information at a very, very highly distributed fashion, engaging 70 or more different neurotransmitters, the probability that messing around with one is gonna stop pain is vanishingly small. Now, when you get out in the periphery and you've got stuff that you can do out there, I think that's where we need to start directing a lot more of our energy...So I think doing a lot more research on a system that's much more tractable and constrained is probably gonna be where we're gonna start to see a lot of the big breakthroughs.

The central nervous system, in this description, was portrayed as being intractable and unconstrained, rendering it extremely challenging to study. He described an intricate and ornate, “highly distributed” system, in which isolating functions is proving to be nearly impossible, in his assessment. By contrast, he made a case for focusing on the peripheral nervous system, which he saw as simpler and more discrete, and therefore easier to study.<sup>6</sup> “There’s stuff that you can do out there,” he said, as opposed to in the central nervous system, where consistent efforts to develop a “centrally acting treatment” have proven unsuccessful, in his estimation. In short, this scientist’s account of the peripheral nervous system was that it was easier to control, given its relative simplicity. The central nervous system, then, is described as being more complex, and therefore more challenging to draw boundaries around and systematically study. These scientists’ decisions to focus on the tractable, more simplified components of pain represents one way in which complexity gets circumscribed (Nelson 2013; Arribas-Ayllon et al., 2010) within the structures of scientific knowledge production.

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<sup>6</sup> This perspective was shared in the context of a broader discussion regarding pain interventions, and so part of his draw to the peripheral nervous system had to do with what he saw as its superior promise as a place to intervene upon pain without as many negative side effects as say, opiates, which act upon the central nervous system. These negative side effects occur because of the interconnectedness of the central nervous system, where it is difficult to isolate and act upon one neural structure without impacting others. The main problem with opiates is that they have a high side effect profile, which is a demonstration of these overlapping regions in the central nervous system.

While these scientists and others had chosen to focus on one component of pain—in this case, the peripheral, sensory component—most scientists expressed the position that pain is too complex to tease apart into component parts. These scientists felt that this exercise of breaking pain apart into discrete systems was done only for the sake of developing theoretical models, rather than arriving upon an all-encompassing understanding of pain. Despite having a preference for one system over the other, many attested to the need to consider *both* the peripheral/sensory/objective *and* the central/affective/subjective components of pain. Even the scientist above who chose to focus his study on nociception said the following at a different point during his interview:

I mean pain, what's so difficult about it is that people think of it as a sensation. It's not a sensation. It's a sensation ... [but] with emotions. With no emotions, all you have is sensation, so you experience the stimulus, but it doesn't really have the same impact.

Although he had chosen to take a controversial stance by only studying the peripheral, or sensory, components of pain, he clearly believed that the emotional components were just as impactful as the sensory components. Thus, although the process of scientific investigation calls upon scientists to circumscribe complexity, this is *not* necessarily a reflection of individual researchers' conceptualizations of pain itself.

Still other scientists chose to study the peripheral components of pain due to methodological issues, such as IRB compliance, NIH funding mechanisms, or technological constraints. For instance, many studies of the mechanisms of pain needed to be carried out using animal models, due to either ethical considerations or the limitations of current technology. Some of the scientists studying the periphery using these animal models acknowledged their frustrations with the lack of translatability between animal and human research. As one scientist said:

There's no way to measure signals in the spinal cord in humans. We have these animal models of chronic pain but we really don't ... They can't tell us everything because they're just models and we can't ask that animal why it's in pain. So we really need ways to measure these signals in humans so we can really look at the clinical pain condition.

He attested to the limitations of studying pain using animal models, importantly saying, “we can't ask that animal why it's in pain.” In other words, even those scientists studying peripheral components of pain recognize that they are bracketing the question of the subjective, experiential, interpretive components of pain. They acknowledge that this poses an inherent limitation of their research given that most readily attest to the simultaneity of the objective/subjective, sensory/emotional aspects of pain.

### ***B. Subjective/Emotional/Central Nervous System***

Those researchers who are more interested in the emotional components of pain focus on the *affective* elements of the pain experience. These affective components of pain<sup>7</sup> typically relate to the psychological interpretation and contextual features of the pain stimulus itself. Research into the affective, emotional components of pain is conducted primarily on human subjects, and investigates the central nervous system, rather than the peripheral nervous system.

Several of these scientists objected to a strict focus on nociception, or sensory (peripheral) components of pain, making a case for inclusion of emotional or psychological considerations in the study of pain. These scientists sometimes coupled their position with their concerns over the clinical relevance of pain research, which were made more pressing given the consequences of the opioid epidemic. Others within the biomedical community have called for stronger translational medicine with respect to pain management, pointing to the need for

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<sup>7</sup> Some of the affective components of pain under study, as described by the scientists interviewed, are expectation, motivation, emotions, and attention.

researchers to consider the bench-to-bedside pipeline (Gilron et al., 2013; Woolf 2008; Marincola 2003). As one scientist put it, “The thing that brings somebody to the clinic is what they actually perceive, not whatever their peripheral receptors are doing.” She made a case for studying the emotional or psychological components of pain, which involves conducting research on the central nervous system, rather than the periphery. She also drew a connection between laboratory research and clinical experience, something that many who focused on the emotional aspects of pain worried was missing from peripheral studies, which they saw as being less clinically relevant than their own work. She continued, slightly hedging her critique of those who focused on the periphery:

I don't mean to disparage their work. It's obviously important, and again, if they did find something that blocks [pain] for everybody, then that's great. I think with something that is ultimately conscious and subjective and has all these different sources and comes with every different kind of disease, then you're not going to have a one-size-fits-all kind of treatment. I think that's why working on the actual perception is important.

While she did acknowledge that work on the periphery might be a way to manage pain by blocking signals before they can even get to the central nervous system, she clearly does not believe that this type of one-size-fits-all treatment is possible. Pain “has all these different sources,” and it is this complexity that stands in the way of developing a universal approach to pain management. As opposed to the scientist quoted above who saw the complexity of the central nervous system as being a barrier to being able to identify a treatment that acts upon it, this scientist viewed the complexity of pain itself as a reason for focusing specifically on the central mechanisms: the holistic perception or experience of pain, that is, the subjectivity of pain.

Scientists who focus on the emotional components of pain worked with human subjects, and often felt that studying pain in animal models, as is often necessary for studies of the

periphery, limited their ability to understand the interpretive meaning that comes along with the sensory stimuli. As one scientist said:

The problem when you get to the sort of things that I'm interested in is that [animals] don't have the emotional and cognitive life that we have. One of the most important things if you talk to people who have pain, they'll tell you that what's really important is the meaning, as in, "This has changed my life. I used to be an athlete and now I'm a shut-in. I used to be somebody people depended on, now I'm a sickly weakling." And that's actually what matters to them and you have to anthropomorphize a little but I don't think that animals really go through that kind of process. It's just is it immediately threatening or is it not immediately threatening?

This scientist studies various affective components of pain, which he noted above are not possible to study in animals, who he felt do not experience the emotional and cognitive experiences that humans do. Indeed, the use of animal models in the study of human pathology has widely been criticized, both from within the social sciences for the oversimplification necessitated by these models (Nelson 2013; Ankeny et al., 2014), and from within the pain science community for the translational challenges they pose (Mogil 2009; Le Bars et al., 2001). However, animal models are often seen as necessary by pain scientists given ethical and technological constraints. The scientist quoted above pointed to one shortcoming of using animal models for pain research, highlighting the importance of the meaning that pain patients ascribe to their conditions; he specifically referenced the impacts on self-identity that have been well established in the literature (Charmaz 2006; Paulson et al., 2002). In so describing his position on the limitations of animal models, he advocated for a focus on the emotional, subjective components of pain, emphasizing the importance of the meaning ascribed to pain. He further highlighted his belief that the emotional, interpretive components of pain are distinctly human, and therefore can only be understood by investigating pain in human subjects.

One scientist's definition of what pain actually is—and what is necessary in order to sufficiently explain it—emphasized the complex interplay between these various dualistic

components of pain: sensory/emotional, objective/subjective, animal/human. He began by zooming way back, to his fundamental definition of pain:

So first of all, what is pain? Pain is generated by a pattern of activity in the central nervous system that includes activation of what's called the pain pathway ...you may or may not have activation of peripheral nociceptors. They're not necessary, we know that. So on the one hand ... pain is the pattern of activity. Or, you can say, pain is the subjective experience ... The IASP defines it as the subjective experience ... [But] the problem with that is, there's no objective way to study a subjective experience, right? It's all inferential. It's all correlative ... So you can do things in the brain that will cause people to feel pain, but that doesn't mean that you've explained it, right? You have a cause, right, but do you have an explanation? I know that mumps is caused by this virus. Does that explain the disease? Not really. To fully explain the disease, you've gotta know a lot more. We could know a lot more, but the people working on rats, the rat's never gonna tell you what they feel, right?

He positioned pain as an activity that occurs in the central nervous system, rather than the periphery, thereby refuting the claims of those studying the periphery by directly saying that “we know that” the peripheral nociceptors are “not necessary.” He pointed to the IASP definition, problematizing its emphasis on subjectivity by stating that there is no way to objectively study subjectivity. He made a distinction between a cause and an explanation, correlating that with the difference between a virus and a disease. He claimed that to understand the disease, scientists need to know more—and this more lies in the domain of subjectivity. His statement made the claim that the work that remains to be done within the pain research arena concerns the central nervous system, not the periphery—the emotional rather than the sensory. Understanding the subjective components of pain, in his perspective, is where the real work remains: “The rat’s never gonna tell you what they feel, right?”

Another scientist who focused on the emotional components of pain shared a similar sentiment about the need to study these emotional components in human subjects, rather than focus on peripheral components in animal models:



In the end, if somebody believes they have pain, it doesn't matter what's going on in the periphery if their brain is telling them that they're experiencing pain. The fact that we have this addiction crisis is because there are psychological components to it and you can't understand something that is ultimately a conscious experience simply through animal models and nociception. There's something about the conscious experience. We have looked at brain pathways and we can separate out the subjective experience from kind of the pure response to temperature. I just believe there's a certain amount of understanding that we can only get from actually asking somebody what they're experiencing.

She rejected the notion that pain is something that can be adequately studied using animal models or by looking simply at the sensory components of pain, emphasizing that pain is something that can only be fully understood by “asking somebody what they’re experiencing.”

This stance departs from other perspectives in that she was not simply making a case for using the right tools for the job—choosing a research design that fits the questions posed. She went further than this, claiming that the peripheral components of pain are irrelevant if a subject’s “brain is telling them that they are experiencing pain.” Limiting the study of pain to the study of nociception ignores, then, the subjective experience of pain, which she held as primary.

Interestingly, she noted that the subjective experience of pain can be separated from the “pure response” or objective, components of pain and studied systematically. Her choice to focus on the subjective, emotional components of pain meant that she had to ask her subjects about their subjective experience. In order to systematically leverage this subjective data into objective measures, scientists must do the work of managing, limiting, and circumscribing subjectivity.

### **III. Circumscribing Subjectivity**

Those who study the affective components of pain in human subjects must find ways to negotiate and make sense of the subjectivity inherent in pain itself. Many scientists concluded

that in order to do so, they must measure, quantify, and otherwise objectify the experience of pain, but paradoxically, also acknowledged the inherent limitations of such an approach. As one scientist explained:

That's the tricky thing, one of the paradoxes of pain is that it's entirely private. If you tell me you're in pain, I don't have a way to demonstrate that you're not in pain. I can show that you're not injured but I can't rule out that you're not in pain...you are always stuck with this thing and this really comes to bear in when it comes to measuring pain...how is it that we measure pain? In my opinion, none of our objective measures are any good. You still have to ask people.

There are not always physical traces of pain, and researchers are not able to demonstrate whether someone is in pain or is not in pain. As other scientists told me frequently during fieldwork, you have to believe what your participant tells you. This raises questions when it comes to measuring or quantifying pain: “you are always stuck with ... hav[ing] to ask people.” Thus, pain neuroscience has developed methods for disciplining subjectivity, leveraging technoscientific practices that limit and circumscribe the subjective assessments of their research subjects in order to make them as objective and standardized as possible.

### ***A. Quantifying Subjectivity (QST)***

Scientists grappled with this methodological “paradox” of the balance and trade-offs between subjectivity and objectivity in a variety of ways. One method for transforming the subjective into something more objective involved measuring an individual participant’s baseline pain. This is one of several techniques involved in the practice of Quantitative Sensory Testing (QST), which attempts to standardize the subjectivity inherent in the experience of pain so that perception can be compared across subjects. Throughout the course of one experimental study I observed, this baseline pain measurement occurred prior to intervention, during the intervention, and after the intervention was completed. This procedure could last up to four hours, with

participants being exposed to various sensory stimuli and rating different components of the sensation.

For example, a heat test was conducted as a way to establish the participant's pain response. A black box called a thermode<sup>8</sup> was strapped to either the participant's hand or to their low back, and a range of heat was applied to their skin using this thermode. Participants were instructed to rate the intensity of the pain resulting from the heat using a sliding device. The temperature of the affected skin was measured immediately afterwards. This procedure was repeated multiple times during one visit at five-minute intervals, with researchers engaging in unscripted small talk with the subjects while the skin recovered enough to repeat the procedure. This is one way that scientists studying human subjects managed the messy heterogeneity of their participants by creating uniform, standardized measures that can be compared across subjects.

While QST represents one of several practices for interacting a subjective pain rating with an objective, or quantifiable, stimulus, some scientists had doubts as to how reliable the information produced by these procedures actually was, given the subjective foundation of these measures. For example, one has this to say about the practice:

It's not very good. It's basically just subjective asking questions, what's your pain today? There's no really good objective measure... So during the baseline visit, we do a [physical] assessment. And so that does just make sure that they have [the pain condition we are studying]... We touch them and see if that hurts. "Use a tiny little pin and prick them very gently, see if that hurts. Assess their sensitivity to hot and cold, assess range of motion." So that's as objective as we get. But even with a pin prick, you say, "Does this hurt yes or no?" If they say yes, you say, "On a scale of 0-10? What's your pain rating?" That's objective. But it's still subjective.

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<sup>8</sup> A thermode is a device used to apply heat or cold (in this case heat) to the body, usually for research purposes (Wong et al., 2010).

The physical exam is both subjective *and* objective, with the subjectivity posing a barrier to doing good research. Thus, this scientist and others felt as though she was compromising the rigor of her research by relying upon subjects' subjective assessments as her data points. However, this reliance upon subjective ratings was typically viewed as a necessary limitation, given the currently available technology.

### ***B. The Search for a Biomarker***

With pain's subjectivity posing so many methodological (and, as we will explore in subsequent chapters, political and clinical) challenges, some stakeholders are eager for scientists to develop a biomarker for pain. A biomarker has been classically defined as “a characteristic that is objectively measured and evaluated as an indicator of normal biological processes” (Strimbu and Tavel 2010), and has come to be used as a way to describe biological evidence of a condition, such as pain. The lack of clear biomarkers, or biological traces that can be detected using traditional biomedical tests such as bloodwork or imaging, is the hallmark of contested illnesses (Brown 2011) like fibromyalgia and chronic fatigue. These conditions are understood to be contested because they cannot be validated via a biomarker. Pain is similarly contestable in that it cannot be objectively measured—there is no way to verify whether or not someone is in pain using presently available biomedical technology. Instead, as is made clear by the accounts of neuroscientists above, “you still have to ask people.”

Some scientists have begun work to develop a biomarker for pain, or an objective measure of pain, using a combination of imaging technology and machine learning. While most scientists I interviewed acknowledged that this project was far off from being able to replace (or even augment) subjective ratings of pain, some were optimistic that a brain-based neurologic signature of pain could significantly extend scientific understanding of pain and its effects. However, one

point of skepticism among some scientists I interviewed was that these biomarkers, or neurological signatures, are typically a composite measure drawing on fMRI data as well as a host of “clinical measures,” many of the latter being data from self-report. As one scientist put it, “Pain is a challenging topic. All we rely on is subjective report, essentially, and we have no biomarkers. I don't know if we'll ever have really strong biomarkers for pain.” His assessment of pain as “a challenging topic” that has to resort to “subjective report” seems to suggest that biomarkers that include self-reported clinical measures might not satisfy those searching for robust and outwardly verifiable biomarkers.

In fact, work that has already been done on biomarkers or neurological signatures seemed to be dismissed by this scientist, who affirmed that “we have no biomarkers.” Another scientist echoed this account when I asked about the status of developing biomarkers for pain:

Well, I mean, there are none. There are none. Imaging is providing some measure. The best biomarker is that somebody tells you how much pain they have. But ... that's not the kind of objective measure we look at. There's no blood level measure. There's no molecular level marker of it. There's some genes that associate with, but that's not a predictor.

The data that can be derived by asking someone how much pain they have is subjective, and therefore not the kind of objective measure that scientists are interested in. He continued his account when I asked about a specific research program developing neurological pain signatures:

Well I mean, [those working on it] believes that there is a kind of signature of pain ... But I'm not convinced and I don't know that the world is convinced that it will. It's the kind of thing, put it this way, when the insurance companies believe that they can use that to tell me that somebody has x amount of back pain, then you know you've got a biomarker.

Another scientist told me, “I'm skeptical as to whether we will ever get [a clinically relevant biomarker] but...I'm skeptical we'll ever have world peace but that doesn't mean we shouldn't aim for it.” In this framing, the eventual development of a biomarker or objective measure of pain is

seen as almost as elusive as world peace (the importance of pursuing them notwithstanding). According to the accounts of these scientists skeptical about the development of a biomarker, if there were a way to subtract subjectivity out of the pain equation, then science might be that much closer to solving the pain puzzle.

### ***C. Healthy and Standardized Subjects***

Another way that scientists were able to manage the complexity of pain was by choosing in whom or what to study pain. While clearly some scientists chose to study pain in animals, thereby limiting the subjectivity and complexity of their object of investigation, those scientists interested in the affective components of pain needed to decide which humans would serve as appropriate research subjects for the study of pain. The majority of these pain scientists elected to study pain in healthy samples, or samples of subjects with no confounding health conditions or comorbidities. This is one way of circumscribing the complexity inherent in the clinical population. As one scientist told me, when asked about complicated pain patients:

All the really complicated patients? We didn't want them anywhere near that study. What I'm looking at...[are] proton interactions...in a cubic volume the size of a brain on a timescale of milliseconds when I put on the stimulus and take it off. I don't want a complicated patient—it's already more complicated than I can figure out. I want the simplest situation possible. I want the nicest, least complicated patient I can get. That's the ones we chose. Anyone who had any hint of complexity we didn't even touch them. And that was the right decision. [Those complex patients are] out of luck until we get to a point where we can understand their complexity.

The complexity of his equipment and procedures was complex enough—he did not want to further complicate his experiments by studying patients who carry with them a host of clinical and social conditions. Those complex patients were, according to this scientist, “out of luck” until science can arrive at a better understanding of their complexity, which, given the

incremental process of scientific investigation detailed above, might wind up being “a very long time.”

This scientist, like others, was interested in developing a basic understanding of pain itself, rather than understanding how pain operates alongside other conditions. They were working on developing a theoretical model, one that might not necessarily map onto the clinical population, but could instead serve as foundation for understanding the basic mechanisms of pain. For instance, one scientist told me that he prefers to work with healthy samples in order to get a basic understanding of brain mechanisms:

I think working with healthy people can inform you about general mechanisms of how the brain works and what the non-pathological state is, how the system should work. ...There's very practical aspects if you start working with patients you have to control for lots of chronic factors. They take drugs, they have other conditions, they're harder to get.

The clinical population is studied far less frequently because of the need to control for a host of conditions that complicate the data, such as comorbidities and pharmaceutical use. Another scientist described some aspects of the “noise” that can come from studying clinical populations:

You take [the intervention you're studying] to patients, you have to deal with the fact that, number one the patient group is gonna be very heterogeneous, so they might have different underlying biological problems and issues, they're gonna report pain in different ways and they're gonna use scales differently. So that's another problem. If you want to sort of say, "Did my treatment work or is my pain measure working to identify CRPS pain, yes or no? Does this measure? Then all that stuff, people take different numbers of drugs, they don't always tell you what they take. Many people are on drugs. People are in different places in the aging spectrum. So if they have a different vasculature even, so in the brain scanner their brain responses are different. If you're doing a treatment study people can selectively drop out and that can make your treatment look better or worse than it really is, and it's really hard to correct for that statistically. That's a sum set, those are some that come to mind.

He listed complications that could be quantified, such as underlying health conditions, pharmaceutical use, and age differences. Even these, however, could only be adequately controlled for in studies with large sample sizes, which is rarely the case in neuroimaging

studies. As many scientists pointed out in their justification for studying healthy samples, the more “noise” that needs to be controlled for in analysis, the more statistical power you lose.

The scientist quoted above also described a number of complications that could not necessarily be regressed out of a model, such as his sense that subjects are not always forthcoming about the medications they take. In addition to this, his reflection that patients “are gonna report pain in different ways and use scales differently” touches upon the perhaps messier subjectivity of a patient population. It is unclear whether this variation in pain reporting is specific to, or exacerbated in those with a disease condition, as opposed to healthy subjects.

Another scientist shared a similar perspective:

Even in the sort of uber healthy samples that I'm been working with... If I do a study on 20 people with say 48 degrees Celsius heat, there's a high probability that one of them will give me a one out of ten, and there's a high probability that another one will give me a nine out of ten. That type of variation even in extremely healthy populations is just massive.

The subjectivity of even healthy samples is therefore a challenge, with each subject rating their pain in different ways. This particular quote calls to mind the story of the museum at the start of this chapter, where one person sees the Mondrian and walks right past, and another sees it and “their whole brain is lighting up.” This variation of subjective experience, though, proves problematic in the systematic study of pain, even in healthy samples. In order to manage this, subjects are carefully primed for the research process so that their data can be comparable across the sample.

### ***1. Training Subjects***

All subjects, healthy or not, who participate in pain studies first undergo a training process. Particularly when preparing to enter the expensive and time-intensive scanner functional



magnetic resonance imaging (fMRI) machine, research subjects are trained in how to recognize the components of pain that they will be asked to report upon, and how to perform well in the scanner so as to produce clean, artifact-free images.

As a part of my fieldwork, I observed the activities of neuroscientists in one neuroimaging pain laboratory, including the process of gathering brain neuroimaging data from subjects via an fMRI machine. The training process was lengthy and repeated during each visit. Subjects engaged in several practice rounds before changing into a hospital gown, removing any metal (including hair ties and glasses—the lab provided visually impaired subjects with a set of plastic glasses), and being placed inside the scanner.

During the scan that I observed, a research assistant prepared the subject while a researcher prepared the scanner itself. The assistant read from a script, describing the events that would unfold over the next several hours, including some educational information about pain itself:

The assistant read aloud: “Pain has both physical and psychological components. Pain perception can be significantly altered by one’s physical or mental state, and by the circumstances under which pain is being experienced. This alteration in pain perception can go in either direction; the sensation of pain may be increased or decreased depending on the context surrounding the experience.”

According to this research study’s protocol, subjects were cued to think about pain as having multiple components, and to focus on the psychological components specifically. They were also prompted to think about pain as something that can be modulated, a process that occurs via the central nervous system, and which will be discussed in more detail in Chapter Four. The script continued, detailing the subject’s instructions while in the fMRI:

The assistant continued reading, “After each temperature you will be asked to rate your pain intensity and pain unpleasantness on a scale from no pain to worst imaginable pain. The reason why we ask you to rate your pain twice is that we’re interested in two slightly different aspects of the pain. For pain intensity, we are interested in the objective amount of pain you are experiencing. Whereas for pain unpleasantness, other factors may come

into play. So we are interested in how uncomfortable or bothersome you find the pain – the subjective component of the pain.”

Subjects were being trained to assist in the practice of breaking pain down into component parts—separating the unpleasantness from the sensation itself, in this instance. The phrasing of this particular script places subjectivity and objectivity side-by-side: subjects were told to first rate the “objective amount of pain you are experiencing,” then, presumably separately, to consider the subjective “unpleasantness” component of pain. Intensity and unpleasantness are parsed apart, with intensity serving as a stand in for objective sensation and unpleasantness signifying subjective interpretation.

Due to the high research costs associated with placing participants in the scanner, it was important that subjects perform well and produce good data from their scans. I observed researchers frequently joking with one another about “horrible subjects” who were difficult to train and who didn’t follow instructions while in the scanner. Apart from being trained in how to attend to different components of the painful stimuli, subjects were also instructed to stay entirely still for the duration of time that they are in the scanner. Any movement could result in an artifact, or something that occurs in a scientific investigation that is not naturally present but instead results from the investigative procedure. Movement is a major source of artifacts when it comes to imaging, and can sometimes render a scan unusable.

Other scientists complained about subjects who could not adequately complete the requisite tasks, or were difficult to train. One scientist shared with me her frustrations working with human subjects, recalling a subject who had fallen asleep during her visit:

I'm going to have to toss her data. She fell asleep during every visit she came in for... So I can't say whether or not her treatment was even effective... She showed up half an hour to an hour late to every appointment, all four. Which was pretty frustrating, and fell asleep at everything and was days late doing the surveys that I sent. It's the frustrations. Getting them to actually do what they say they'll do.

Subjects were required to self-regulate in order to participate in the research process—they needed to control their movements, perform the tasks assigned to them, recognize the different components of their pain experience, and stay awake.

These were requirements set not necessarily by individual researchers, but by the principles of controlled experimental design, that demand that investigators control everything that is not the experimental variable. Despite scientists' acknowledgments that pain is a holistic experience, containing both subjective and objective components, the structures of the scientific process of study design limits the amount of subjectivity, or human variability, that can be included in a study of pain. Through the process of training and parsing apart the components of the pain experience, subjects' subjectivity is inherently circumscribed, or made as objective as possible.

## ***2. Generalizability***

While many scientists limited their studies to healthy samples—made up of subjects who did not have compounding medical or social conditions, and who could typically be relied upon to perform well during the research process—some worried that the findings from these studies would not be relevant to the general population. As one scientist shared:

You have to have a broad sample of the population as a whole because otherwise if you're just looking at perfectly healthy people, there are very few perfectly healthy people running around. Most people have some issues going on, so you want to be able to generalize the data as much as you possibly can.

This notion of the “perfectly healthy” person was one that was discussed frequently when I asked scientists about sampling challenges. Many scientists lamented that they studied pain in “college sophomores,” the population most commonly available for biomedical studies at academic

research institutions (Prescott 2002). They felt that working with this population exclusively limited the ability of their findings to be translated to a broader segment of society.<sup>9</sup>

Some scientists described the ways in which these healthy samples differed from the population they were really interested in, and in so doing, made clear which differences are made to matter in scientific inquiry. For example, one scientist confessed:

We need to do more to study real world patients...one of the dirty little secrets that we all have in clinical research...is that on average, we enroll one person for every ten that we screen. And the secret is that one person we enroll doesn't look like a real-world person. They're very homogeneous. They're so clean and vanilla because we want to do good science. But the problem is, we do research on these people and we draw inferences. We draw conclusions, and then we go and apply to the other 90% for whom they were never studied. We find that in fact, may not apply.

He pushed back against the notion that findings from homogenized samples—subjects void of the messiness that can stand in the way of their ability to be compared to one another—could be applied across the broader population. He pointed to axes of heterogeneity and difference that he felt must be accounted for in order to make his findings generalizable. In his articulation of the “inclusion-and-difference paradigm” (2008:17), Steven Epstein traces the ways in which increased attention to health disparities has promoted a rise in difference-finding research, in large part motivated by critiques of the limited generalizability of scientific findings generated from studies with homogeneous samples. The neuroscientists I spoke to reiterated similar concerns about the applicability of pain research involving only “clean and vanilla” research subjects, rather than “real-world” populations. Interestingly, by describing his sample as “vanilla,” he invokes racialized dynamics that were occurring within the laboratory but were

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<sup>9</sup> Despite the difficulties of studying clinical populations, some scientists were committed to taking on the task by recruiting a much larger sample than is traditionally studied using neuroimaging technology. These studies were expensive and posed a number of methodological challenges—recruitment and retainment of clinical subjects being high on the list. However, some scientists felt that studying pain in patients added relevance to their work that otherwise might not be there.

rarely discussed and never systematically accounted for. Other scientists described what they felt was missing from their healthy samples, frequently referring to racial categories, but none were able to articulate why these differences mattered and others did not. By conceiving of differences in terms of race, and not in terms of structural conditions, these scientists were perhaps suggesting that there is something biologically distinct about racial groups, and that this is the axes of difference that is most important to consider.<sup>10</sup>

Another scientist grappled with the relative value of studying patients versus studying healthy subjects. He said, of his recent efforts to study patients:

I think it's just such an incredibly important question. What makes one person experience a stimulus as a one out of ten and another person experience exactly the same stimulus as a nine out of ten. I think there's potential clinical importance, how are those individuals gonna respond to post-surgical pain, what are their potential risks for chronic pain, but then maybe at a basic level of, by looking at what makes one person give us a nine out of ten versus another person that gives us a one out of ten, that can really show us how the central nervous system is actually building this individually unique experience of pain.

Determining the mechanisms behind variation in the subjective experience of pain motivated this scientist's research, as it probably motivated the research of many of the scientists quoted here.

However, while most scientists who were searching for a theoretical model, or fundamental ontology, of pain chose to study healthy subjects so as to reduce the complexity of their samples, this scientist saw the potential for developing this fundamental understanding by studying patients, despite—or perhaps because of—their messy complications. Studying pain that is not disaggregated from clinical complexity could, according to this scientist, still result in advancing a fundamental understanding of pain's mechanisms and subjectivity.

#### **IV. The Quest for a Fundamental Ontology of Pain**

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<sup>10</sup>The ways in which race and racism operates within neuroscientific settings is something that will be explored in a future project.

The scientists described above were searching for a fundamental understanding of pain itself, trying to identify the neural mechanisms involved in the pain experience in order to determine what pain actually is. Clearly, the subjective nature of pain poses a riddle for scientists, who were often charged with removing subjectivity from their investigations. After all, from their perspective, the entire endeavor of scientific inquiry was premised around the search for an objective finding, one free from the subjective values, interests, and perspectives of its practitioners. If, as one scientist's quote pointed out earlier, "there is no objective way to study a subjective experience," and robust, widely agreed upon biomarkers for pain do not yet exist, how do pain neuroscientists—particularly those who work with human subjects—set about studying pain? How much faith do they place in their methods being the appropriate tools for the job? Does the process of scientific inquiry get at the questions that they hold as primary about pain and its consequences?

### ***A. Faith in Incremental Science***

Most scientists I interviewed expressed faith in the strength of the scientific method and the development of technology as a means to answer difficult questions about pain. They viewed the systematic study of phenomena as the key way of understanding the world and of solving its problems. As one scientist put it:

There's definitely [questions about pain] that are hard to come up with how you would design [studies that would answer them]. I don't believe that anything is unknowable though, I think it would just take lots of incremental steps to get to the answer and lots of tweaking and adding on studies. It would take a long time. I think, and as technology gets better too and we get new things that we can actually use to answer these questions, that will also help and they'll add in other ways that we can look at the questions.

This practice of breaking things down into incremental steps is one way of managing the complexity of pain: scientists certainly separate the sensory from the emotional, as described

above. Considering the complexity of pain described above, this breaking down of pain into component parts can, as quoted above “take a long time.” However, they believed that scientific investigation, combined with advances in technology, would eventually get them to the answers, and many expressed faith that all biological phenomena can be understood via these practices.

As one scientist said:

It's just a matter of time...I don't think there's anything that is unknowable...To make that connection and understand how a particular life experience is influenced as the experience of pain by that individual, that's going to be really tough. But it's not totally intractable...If I believe, and I do, that we're a product of chemicals and electrical wires that evolve and change, and synapses form and break constantly—I'm a big believer in that—then it's a matter of science eventually figuring these things out.

While pain’s complexity and subjectivity create unique challenges to the general scientific process of breaking down complex phenomena into incrementally smaller parts and systematically investigating each of those parts, this scientist, like his colleagues, ultimately believed in science’s capacity to manage, circumscribe, and limit subjectivity so that a basic ontology of pain could be developed.

Several scientists identified barriers to advancing knowledge about pain, but never were those barriers located in the scientific process itself. Instead, they identified bureaucratic structures and institutions that impeded the progress that they and their colleagues were able to make using the systematic tools available to them. Several scientists pointed to funding mechanisms and the ways in which the current structure of academic research restricts scientific advancement. For example, when asked about whether there were aspects of pain that were unknowable, one scientist responded:

No, they're knowable ... the problem is NIH. The problem is how research is funded and the problem is how people get hired and promoted in academic circles and the difficulty of supporting physicians who are seeing patients that also do research. NIH just hasn't figured out how to do that...There are a lot of animal models, and what I tell people is,

these animal models are not like what people get...we're not doing as much as we could do to study patients.

He affirmed his faith in science as a system of knowing, and pointed instead to the ways in which the structures of academic research promote an over-specialization and a separation of laboratory and clinical research. By dividing up those who work with human subjects and those who work with animal models—or those who work on the peripheral nervous system and those who work on the central nervous system—this scientist felt that the field of pain science is “going backward.” He later complained that these groups of scientists “never talk to each other,” and pointed to the increase in scientific specialization as the main impediment to advancement of knowledge. As we will see in the following section, this scientist’s critique points to a much more fundamental issue, one that questions the ultimate utility of scientific disaggregation as the way forward for pain medicine.

### ***B. Powdered Milk: Doubt in Scientific Disaggregation***

While the perspective that science could and would eventually solve the problem of pain was shared by nearly every scientist I interviewed, several scientists also described feeling limited by this incremental method of investigation. They worried that by breaking pain down into component parts, a comprehensive and holistic understanding of pain may be obscured or lost along the way. As one scientist expressed:

We lack still a fundamental ontology of pain. And a way of languaging it, describing it in a systematically detailed way. That's a little bit of a challenge. We are also still burdened by our preconceived notions about what to measure, and what not to measure.

The field of pain medicine, according to this account, is still struggling with defining what pain is and how to go about systematically studying, measuring, and talking about it. This is reflective



of much of the analysis above, in which scientists relay their challenges over which components of pain are most pressing. These concerns are expressed slightly differently in the following quote from a scientist about the process of breaking pain down into component parts:

If we're trying to tease those things apart, you're always left with the question of, if you isolate these unique things, is that what makes pain distinct? Is pain still pain if you take, for instance, the unpleasantness out of it? ...We tend to think that experiences that are perceptually different from each other should have absolutely unique representation in the brain. I think that's very unlikely to be true because if I put a thermode on my arm and give myself a very hot stimulus, it's also a sensory stimulus, it's also an emotional stimulus. There's something about that experience that's unique from a pure sensory experience or a pure emotional experience. But, the experience of pain does involve those things and if you completely remove those things, you don't have pain anymore. The way I think of it is like if I said, "Well, I'm going to remove all the water from this glass of milk and what's left over is just milk." Well, it's not, it's a big pile of powder. It's nothing. So, the difficulty is knowing, okay, if we do isolate these things experimentally, what do we say about those things that are left over?

If you systematically break pain down into its component parts—sensory, emotional, subjective, objective—and study each part separately, as is in line with current scientific practices, are you actually still studying pain? Can a scientist investigating pain at just the periphery or just the central nervous system really understand what pain actually is? Perhaps the field of pain neuroscience has yet to develop a fundamental ontology of pain because of this very process of breaking pain down into component parts that, when examined separately, may not add up to something that looks like pain at all. By removing or circumscribing pain's subjectivity, then, is what's leftover pain, or just a "pile of powder"? The very process of producing pain as a neuroscientific object, then, runs the risk of reducing it to an abstracted phenomenon that no longer resembles the messy, complicated experience of pain itself.

## **V. Conclusion**

The findings in this chapter point to the capacity of neuroscientific practices to produce particular notions of pain, and more broadly, of personhood (Pitts-Taylor 2016; Rollins 2014; Rose & Abi-Rached 2013; Dumit 2004). As pain is produced as a neuroscientific object, the structures of scientific meaning-making necessarily limit the complexity inherent in the experience of pain. Through the process of training and parsing apart the components of the pain experience, subjects' subjectivity is inherently circumscribed, or made as objective as possible. Although some scientists expressed faith that incremental investigation and advancements in technology would eventually lead to breakthroughs in pain neuroscience, some also worried that these very processes were limiting their potential to develop a holistic, comprehensive understanding of pain.

I argue that the disaggregation of pain for the purpose of scientific inquiry results in an abstracted and overly simplified understanding of what pain is, who it impacts, and how it operates alongside other physical, psychological, and social conditions. As we shall see in Chapters Three and Four, the clinical pain population looks much more complex and heterogeneous than the healthy samples studied in the laboratory, and this has implications for who stands to benefit from scientific research. As the scientist quoted above remarked, "all the really complicated patients...[are] out of luck until we get to a point where we can understand their complexity." In other words, the models of pain produced in the laboratory are not necessarily meant to be applied to the complex, clinical population. As is made clear in Chapters Three and Four, understandings about pain circulate and construct particular subjectivities, regardless of whether or not these understandings were developed by studying pain in those with complex and overlapping conditions. The highly specified subjectivities that are constructed in

the laboratory are thus taken up and applied to the broader population in other biomedical arenas, such as the medical school classroom and the clinic.

This chapter describes a divide between those scientists who focus on the peripheral, objective, sensory components of pain, and those who instead focus on the central, subjective, affective components of pain. This theme is revisited in Chapter Four, which describes a shift from biomechanical explanatory models of pain to neuroscientific ones. These neuroscientific models build upon the work of those scientists focusing on the affective components of pain, with clinical uptake of these models emphasizing the interpretive, emotional components of pain that take place within the central nervous system. By contrast, the peripheral components of pain are more in line with a biomechanical approach to pain management, wherein signals are blocked at the periphery, frequently via surgical interventions. As elaborated upon in Chapter Four, these neuroscientific models leverage the flexibility of the central nervous system to intervene upon pain at the very site of subjectivity.

## **CHAPTER THREE: DISSEMINATION**

### **I. Introduction**

Changes in conceptualizations of pain are occurring alongside and through a national crisis of opioid-related overdoses. Fatality figures from this crisis are being said to rival those of the AIDS epidemic, gun violence, and car accidents (Levitz 2017); the situation has been deemed a public health emergency (White House 2018). Amidst this crisis, the biomedical community is struggling to make sense of their role in this iatrogenic catastrophe, and is questioning how to appropriately address pain given the risks associated with opiates.

This chapter draws upon interviews with 30 pain neuroscientists and clinicians and observations of the pain curriculum at two leading medical schools in order to illustrate this struggle. I analyze the claims of clinicians and scientists about the social, political, and economic forces that led to the current crisis, arguing that the opioid crisis should be considered a biopolitical, post-modern epidemic, historically specific and reflective of the values and structural arrangements of the moment. I trace the surfaces upon which this crisis emerged, pointing to the ways in which its genesis and proposed solutions are thoroughly social. Further, I describe the various positions taken by pain specialists regarding the current evidence base on opiate safety and efficacy, demonstrating that a heterogeneity of perspectives exist on how clinicians should move forward with their analgesic strategies. Lastly, I attend to the subjectivities that emerge from the opioid crisis, pointing to the flattening of complexity that occurs in both messaging about pain patients and opiates, as well as in the development of universal treatment protocols.

### ***A. Background: History of the Pendulum & Chronic Pain Players***

Beginning with the first reference to opium in 3500 B.C., clinical judgements about the use of opioid compounds for chronic pain have repeatedly shifted back and forth, at times celebrating opiates for their efficacy, and at other times dismissing them for their risks. Post-WWII revisions in disability policy resulted in changes to the national protocol for pain management (Wailoo 2015; Crawford 2014; Baszanger 1998), with pain being newly framed as a clinical problem in and of itself, rather than a mere symptom of another underlying condition. As described by pain specialists in this chapter, a number of social, political, and economic forces contributed to a drastic increase in opiate prescriptions from the 1980s to the mid-2000s, marking the prevalence of what I refer to as a logic of opiate proliferation. Subsequently, as a result of ever-growing numbers of opiate-related overdose deaths, opiate prescriptions for chronic pain decreased beginning in the mid-2000s as a result of opioid pharmacovigilance (Knight et al., 2017; Cesar et al., 2016) on the part of local and federal agencies. The current period, then, is characterized by what I term the logic of opiate prohibition. To describe the changing standards in opiate prescribing, some pain researchers have invoked the language of the pendulum (Knight et al., 2017; Frieden et al., 2016; Atkinson et al., 2014), likening the shifts in guidelines for opioids to the swinging of a pendulum.

This logic of opiate prohibition produces particular subjectivities, such as the over-prescribing physician (Freidman 2015) or the accidental addict<sup>11</sup>. Relevant to this chapter is the “chronic pain player,” or drug-seeking patient, that is so often invoked both in biomedical and

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<sup>11</sup> Many popular narratives of the opioid crisis center upon idealized notions of otherwise law-abiding patients who quickly and inadvertently become “addicted” or “hooked on” opiate medications, usually following a surgery or accident for which they were prescribed opiates. These narratives are typically racialized (Hansen & Netherland 2017, Hart 2017) and classed, and typically cast judgements about which types of patients are deserving of sympathy and care.

political spaces. Numerous publications in the medical literature outline strategies and techniques for identifying and managing drug-seeking patients (Kolodny et al., 2015; Hansen 2005; Compton et al., 1998), including the use of urine-toxicology reports, opioid risk assessment tools, and awareness of certain behavior patterns<sup>12</sup>. Social scientists have attended to the discriminatory practices that occur alongside and through such efforts to “identify and manage” drug seeking patients, often occurring along racial lines (Rubin et al., 2018; Netherland & Hansen 2017; Hart 2017; Crowley-Matoka & True 2012; Rouse 2009). Thus, characterizations of certain pain patients as always-already drug seeking provide another point of entry for stratification processes in pain medicine.

### ***B. Theoretical Frameworks***

In his introduction to the medical gaze, Foucault outlines a “medicine of epidemics,” distinguishing an epidemic from a disease, the latter of which is a purely physiological process, general in form. He holds that an epidemic is constitutive of a “particular process which varies according to circumstances...peculiar to this moment in time and this place in space” (1976:24). It is thus this historic specificity that sets an epidemic apart from a disease, situated in time and space, and thus reflective of the values of that particular moment. Considering the opioid epidemic as historically specific and reflective of current logics of care, this chapter draws upon the accounts of pain specialists as they construct a narrative of how this epidemic emerged, pointing to the political, social, cultural, and economic forces that created its conditions of possibility.

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<sup>12</sup> The behavior patterns of drug-seeking patients that clinicians should be aware of, as described by one publication, include “drug-seeking behavior,” itself, defined as “manipulative, demanding behavior to obtain medication” (Longo et al., 2000:2406). These vague definitions have propagated discriminatory profiling practices in biomedical practice (Hansen & Netherland 2017; Crowley Matoka & True 2012; Hansen & Skinner 2012).

These accounts frame the opioid epidemic, its impacts, and its proposed solutions as biopolitical in nature, pointing to the ways in which various biomedical apparatuses exercise power over life itself (Foucault 1978; Rose 2007). Previous social scientific works have elaborated upon the opioid epidemic as being biopolitical in nature, highlighting the ways in which the crisis has been racialized via inequitable treatment of both pain and addiction (Netherland & Hansen 2017; Netherland & Hansen 2016; Hansen & Skinner 2012), attending to the stigmatization of addiction (Fraser et al., 2017), the valuation of some lives over others (Bartozsko 2018), and the social controls and structural violence imparted upon those who engage in drug use (Treloar 2013; Bourgois & Schonberg 2009). These works situate the mechanisms of power at play surrounding the opioid epidemic, articulating some components of how both individuals and populations are continuously regulated through state apparatuses (frequently biomedicine) in the name of health. This chapter aims to extend some of these arguments by pointing not just to the biopolitical genesis of the opioid epidemic, but also to the ways in which biopower continues to operate through efforts to redress this crisis and restore the safety of pain patients via the institution of safe prescribing practices.

Natalie Boero extends Foucault's theorizing of epidemics by casting certain epidemics as "post-modern epidemics" (2007:41), which are characterized by a focus on risk, a shift in responsibility from the public to the individual, and a moral panic that is distinct from the presence of a biological contagion. Boero and others (Fletcher 2012; Brandon & Pritchard 2011) have used the concept of a post-modern epidemic to characterize biomedical claims of an "obesity epidemic," pointing to phenomena that are unevenly medicalized and lacking a clear pathological basis. I argue, through the accounts of these pain specialists, that the opioid crisis constitutes another such a post-modern epidemic, wherein risk is a central focus, responsibility

for managing that risk is shifted onto the individual (both the patient and the provider), and a “epidemic of signification” (Treichler 1999:19 as quoted in Boero 2010:309) is occurring alongside the actual epidemic, via moral panic and increased political discourses. By taking up this concept to describe the opioid epidemic, I do not intend to imply that opioid-related overdoses constitute anything *but* a clear pathological basis. However, I do hope to signal that a moral panic is occurring that is discursively tying pain to addiction, and producing pain patients that are always-already at risk and thus responsible for self-management of their own conditions.

Lastly, I aim to situate the uncertainty and disagreement regarding the evidence base on opiate safety and efficacy for chronic pain within the literature on non-knowledge, or undone science (Decoteau & Underman 2015; Hess 2013; McGoey 2012; Kempner et al., 2011; Frickel et al., 2010). Sociologists and STS scholars have theorized the systematic nonproduction of knowledge (Frickel et al., 2010), strategic ignorance (McGoey 2012; Gross 2010), forbidden knowledge (Kempner et al., 2011), and the ways in which uncertainty can be tied to social capital (Decoteau & Underman 2015). Though none of these frames fits perfectly with the situation described in this chapter, in which long-term scientific evidence on opiates is not available, each frame raises questions about why some knowledge is produced, and for whom. Others have considered the ways in which the “gaps and rifts” (Friese 2013) in biomedical evidence are filled in via the process of translation from laboratory to clinic. Those concerned with biomedical systems have interrogated the standardization work that supports the evidence-based medicine enterprise (Knaapen 2013; Timmermans & Berg 2010; Epstein 2008; Goldenberg 2006; Dopson et al., 2003), articulating the social landscape of clinical claims-making and describing the interrelationships that standards create between the local and the



universal. I build on these accounts in order to understand how the pain specialists here navigate scientific uncertainty regarding long-term use of opiates.

## **II. How We Got Here: Looking Back on The Logic of Opiate Proliferation**

Many of the pain specialists<sup>13</sup> I interviewed and observed had been involved in the field of pain medicine (through clinical practice and/or scientific research) during the period of opiate proliferation. They reflected on the mistakes that were made during this time, listing the structural forces that were pushing the pendulum towards a logic of opiate proliferation. Through these accounts, we see a description of a biopolitical situation that fostered the rise of opiate prescribing for chronic non-cancer pain, wherein a number of institutional, political, and cultural dynamics collided to lay the groundwork for an overdose crisis. This history, with its overlapping influences and multiple drivers, is part of what makes opiates so complex for specialists to assess, and in turn policy responses and clinical practices regarding their prescription so challenging to determine. It also renders the opioid crisis biopolitical in nature, co-constitutive of institutional power arrangements that shape and control life at the level of population.

Specialists pointed to a host of economic, social, and political influences they felt tipped the balance towards a drastic proliferation of opiates. From the impacts of social movements and the pharmaceutical industry, to the effects of regulatory and accrediting institutions, to the traces of undone science, specialists described a convergence of pressures that shaped the prescribing patterns of clinicians in the 1990s and 2000s, resulting in an extreme increase in opiates and a

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<sup>13</sup> As noted in the introduction chapter of this dissertation, the term “pain specialists” is used to indicate my collective sample, including clinicians, scientists, and those who occupy both roles.

subsequent opiate-related overdose crisis. This section details some of these influences identified by specialists, and in so doing positions the crisis as a biopolitical, post-modern epidemic.

Several specialists named the American Pain Society's push towards conceptualizing pain as the fifth vital sign in the 1990s (American Pain Society 2018) as a major driver of increases in opiate prescribing. This move was prompted by the efforts of patient advocacy groups that themselves were funded by the pharmaceutical companies, and required clinicians to ask patients about their pain levels during clinic visits, regardless of the medical reason for the visit. Most of the specialists I spoke with and observed expressed disapproval of this move, citing the ways in which it "interfered" with clinical practice. For example, one clinician described the impacts of the pain-as-the-fifth-vital-sign movement:

That you had to ask every patient every visit, "Do you hurt?" And "How much and where?" I can't tell you how many primary care visits this ruined. How many times patients came in for nothing related to whatever their pain disorder, but people hurt. If you asked me right now, I can tell you where I hurt. Most folks can...Doesn't matter, you have to address it. Every single visit came with this piece of paper for years.

His irritation at having had to address pain seemed to stem from its capacity to derail or "ruin" his interactions with patients, regardless of whether pain was the motivation for their primary care visit. Yet patient groups in the 1990s advocated to include pain as a vital sign because they felt it was undertreated, and to raise awareness that pain itself constituted a significant medical condition. That is, they argued for this shift precisely because "people hurt," as this specialist put it, but most people were not being treated for that pain. It is interesting to note, then, that the specialist diminished the need to clinically address that pain because he felt it was unreasonable to require clinicians to ask patients about their pain levels when pain is not the main motivation for seeking care for every visit, even though it is so prevalent. In this specialist's view, the very

ubiquity of pain, and the new mandate to ask about—and therefore to treat—it, had the consequence of increasing prescriptions of opiates.

Another specialist went even further, to suggest that the new guidelines were directly responsible for facilitating addiction. In a medical school lecture, she told her students, using an incredulous tone:

It's not a vital sign, you guys. It's a very subjective rating, right? For a very objective sort of thing. Vitals are objective things. People can't fake their vitals, right? They're not faking their heart rate. They can't fake their blood pressure. But a pain score? We all know that that is so darn subjective.

This lecturer went on to explain that the fifth vital sign mandate to ask patients about pain allowed “chronic pain players” to fake their pain scores in order to procure an opiate prescription. By drawing a distinction between the subjective and the objective, and saying that vital signs can only be measures of objective things, this lecturer implicated both what she viewed as flawed clinical practices and inappropriate professional guidelines in the proliferation of opioid addiction.

The move to elevate pain to the fifth vital sign in turn effectively changed what constituted the standard of care, and clinicians who were deemed to have undertreated pain came under the threat of malpractice suits. Specialists described several highly publicized suits in which clinicians lost their licenses, several of which were documented at the time in the medical literature (Furrow 2001). As one specialist said, these suits “sent a real shockwave through the community” and drove up prescribing rates as clinicians feared being driven out of medicine.

These fears of undertreating pain also rippled through regulatory bodies and accrediting standards. Several specialists referenced the impacts of the Joint Commission on the Accreditation of Healthcare Organization's (JCAHO) efforts to hold physicians accountable for treating pain by privileging patient approval ratings, including assessments of how thoroughly

their pain had been addressed. In 2001, JCAHO introduced standards aimed at improving pain management by increasing the prescribing of opiates. Some specialists pointed to these measures and standards as a primary driver of the opiate crisis, stating that patient satisfaction ratings and pain scores—which were linked to hospital accreditation requirements—were tied to patients’ abilities to obtain opiates. As the lecturer quoted above told her students, in reflecting on the JCAHO standards:

So you get to go home and tell us, write a survey and tell JCAHO and CMS how well or unwell we did as a team during your hospital visit...and ultimately 30% of your hospital payments could be withheld for a crappy rating. So who’s in control now, them or us, right? They are clearly in control. We need money for this hospital to survive, right?

According to her perspective expressed here, the introduction of the JCAHO standards that tied hospital reimbursements to patient approval ratings placed the control in the hands of patients, including pain patients more specifically. Like the complaints about elevating pain to a vital sign, this specialist and others connected patient assessments, either of their pain levels or of how effectively hospitals and providers were managing those pain levels, to the rapid rise of opiate prescribing at the turn of the century.

The move to classify pain as a fifth vital sign, and the subsequent lawsuits and regulatory changes to reflect this move, are representative of biopolitical struggles over who gets to decide what constitutes significant pain. As described by the lecturer above, these regulatory changes represented a shift in “who’s in control” when it comes to the treatment of pain, placing blame and pinning responsibility upon patients for the development of this post-modern epidemic. As other scholars have pointed out, changes in pain medicine are often reflective of our national dialogues around whose suffering counts (Wailoo 2014; Baszanger 1998). In this shift towards conceiving of pain as a condition in its own right, worthy of sometimes aggressive treatment, we see traces of political judgments about who is deserving of what kinds of care.

Alongside federal standards, local policies and the cultural values of certain clinics also seemed to reflect a fear of undertreating, according to the accounts of some specialists working in pain medicine in the 1990s and early 2000s. This was perhaps felt particularly acutely in safety net settings, in which many of the specialists I interviewed had been practicing medicine at the time. These clinics served patient populations that were, and continue to be, systematically dismissed as high risk for opiate abuse and frequently denied pain medication. As Knight and colleagues (2017) point out in their account of providers' perspectives on changes in attitudes towards opiates, clinicians were being warned in the 1990s of the dangers of undertreating pain, particularly in women and racial minority groups. Similarly, many of the specialists I interviewed described having been acutely attuned to this risk of systematically denying pain medicine to patient groups who were routinely seen as high risk for misuse of opiates. One specialist described her clinic's stance towards opiate prescribing among those diagnosed with substance use disorders at the time:

I think that back then, a lot of the thinking was that, people with substance abuse disorders tended to be stigmatized and considered not candidates for opioid treatment for chronic pain. We wanted to make sure that they were not sort of routinely, or as a matter of fact, not considered at all for opioids.

Another specialist who had been working within the same institution at the time experienced these fears of undertreatment as being detrimental to her efforts to provide good care. She recounted, with a sense of dismay, her experiences of being pressured by peers, superiors, and institutional bodies to increase her prescribing of opiates, even for patients who she had deemed to be at high risk for abuse:

We had a pain specialist at the [public hospital] that you could send your patients to, but, unfortunately, my experience was often that I would have my patient return to me and the assessment would be undertreated pain. What looks to you like addictive behavior to or drug seeking behavior—it's under treated pain and you should just double the dose ... I was getting patients who were on incredible doses.

She pointed to her clinic's concerns over disproportionate and potentially discriminatory under-consideration and undertreatment of pain as paradoxically encouraging an almost opposite response on the part of her clinic. Fears of misuse were often overpowered by fears of undertreating pain. This resulted in what she saw as an influx of patients on "incredible doses" of opiates. Considering these two accounts side-by-side—that of the specialist who had felt compelled to guard against discrimination of certain groups, and that of the specialist who had felt put upon by this very logic—reveals the widely variable perspectives surrounding concerns of undertreating pain during the time of opiate proliferation. While many saw such concerns as pushing the pendulum towards increased prescribing, some felt this was clinically appropriate.

Operating alongside—and, in some cases, through—all of these forces were the actions of the pharmaceutical companies who developed and promoted new opiate formulations during the 1990s and early 2000s, pointing to the economic forces driving the opiate crisis. Many specialists referenced the now highly publicized connections between the pharmaceutical companies' marketing of opiate formulations at the turn of the century and the current opioid-related overdose crisis. One lecturer called "the rise of big pharma" one of the major influences as to why we are now facing a public health emergency. He referenced Purdue Pharma's 1996 erroneous marketing of oxycontin as "abuse resistant" and the pharmaceutical industry's efforts to market directly to physicians via "physician details," or what he called "payment to physicians," such as "lectures, continuing education, promotions, food, gifts, et cetera." Other accounts echoed this, describing the grand rounds and CME courses on safe opiate prescribing that were developed and funded by the pharmaceutical companies in the 1990s. One specialist reflected on the inaccurate information provided via this marketing:

Having read about how the marketing was done, that [the extended release compound] actually doesn't last 12 hours, but that they were specifically told to market it that it lasts 12 hours because that was their prescribing niche, and so then if patients had pain, the clinicians were just told to increase the dose. Then, it seems like it set itself up to drive this crisis of addiction.

Another specialist went further, specifically naming the harms produced by such marketing:

I believe that the pharmaceutical industry has done a lot of things to sell and market opioids really against the best interest of people...I think in a number of cases in different industries including the opioid one, there have been some things that really have been unethical and illegal that people have done in order to promote widespread use of these drugs. And so I think there's a lot of shared responsibility for that and I think there are some things that were really bad.

While he referenced “shared responsibility” for those unethical acts, it is unclear whether or not he is claiming some of that collective responsibility.

In contrast, other specialists more directly invoked their membership in a biomedical community that, at least in part, helped propagate the current crisis. As one put it:

We were just giving opiates out like candy. And I also think that...managing pain is really uncomfortable for the practitioner. So there was this, just trying to get the pain to go away for both people involved, not just the patient. And opiates were an easy magic bullet that then we had the green light, and of course there's all this stuff that has emerged about where that green light came from, with the history of the pharmaceutical industry's input into all of that, into persuading us that pain should be the fifth vital sign, et cetera.

By referencing “we” at the outset of the quote above, this clinician specifically signals his sense of shared responsibility for decisions that may have contributed to the current crisis. While earlier accounts placed blame for the crisis on drug-seeking patients, regulatory bodies, or pharmaceutical companies, this specialist acknowledges the clinician’s role in drug-seeking, in that managing pain is uncomfortable for the practitioner, and thus the practitioner is also motivated to reach for a quick fix. This inability to find a singular driver or source of blame for the current crisis is part of what makes the opioid crisis so complex.

In recounting their experiences studying and treating pain around the turn of the 21<sup>st</sup> century, several specialists pointed to the undone science underlying the logic of opiate proliferation. When reflecting on the emergence of this logic, specialists who were directly involved in formulating opiate policy described their sense that there was a lack of scientific evidence about opiate safety and efficacy at the time of proliferation. For example, one specialist said the following while reflecting on the current opioid crisis:

The fact is, this [crisis] is a complex issue requiring a complex set of solutions...The pain field screwed up back in the late 90s and the early 2000s because the pain field inappropriately thought that if you had chronic pain, and you were put on opioids, that your likelihood of becoming addicted was very, very low. That was a notion driven entirely on belief...the reality is we all share the responsibility of that insofar as it was all based on belief. There was no data. There was simply no data available.

According to this telling, decisions about opioid safety were based on “belief” as opposed to “data,” juxtaposing tacit and encoded knowledge (Greenhalgh 2008). In reflecting on how we arrived at this national emergency of opiate-related overdoses, then, this specialist pointed to the undone science, and the ways in which these gaps in the evidence base were not acknowledged nor adequately addressed under the logic of opiate proliferation. This undone science is, itself, a reflection of the biopolitics of knowledge production, wherein some questions are more readily answered than others (Decoteau & Underman 2015; Hess 2013; McGoey 2012; Kempner et al., 2011; Frickel et al., 2010).

Thus, specialists named a host of political, economic, and cultural forces that they perceived to be drivers of the opiate crisis. From scientific uncertainty, to cultural values, to an economy that drove the marketing efforts of big pharma, the genesis of the opiate crisis as described by these specialists is illustrative of biopolitics in action, in which biomedical and state institutions were exercising power over life itself (Clarke et al., 2010; Rose 2007; Turner 1997;



Foucault 1978). These accounts construct the opioid crisis as a biopolitical “epidemic” (Foucault 1976), constitutive of a specific moment and place. Through these accounts, we see how specialists pointed to a confluence of sociopolitical events, structures, and values when attempting to locate responsibility and attribution for the overdose crisis. The complexity of the current opioid crisis, with its various drivers and causes, creates a situation in which today, specialists are still unclear about how to interpret the evidence on opiates, and how they should be handled clinically.

### **III. Opiate Prohibition: How Should We Proceed?**

Despite the agreement among pain specialists that mistakes were made in the 1990s and 2000s that led to the current opiate crisis, consensus as to how to remedy or respond to those mistakes has yet to be reached. While many specialists advocated for a total prohibition of opiates for chronic pain, others did not feel as though the current evidence supports such an extreme stance. The following section describes the range of positions taken with respect to the current evidence base on opiate safety and efficacy. It should be noted that it is not my aim to adjudicate the science on opiates, but rather to demonstrate the positionalities of multiple specialists regarding the evidence upon which opiate policy is predicated.

In the initial weeks of my time in the field, the CDC released guidelines for safe opioid prescribing. These included lower dosage recommendations, suggestions for identifying high risk patients, and an encouragement to avoid opiate prescribing for chronic pain, or pain that persisted longer than three months. Shortly thereafter, the US Surgeon General issued a letter to all clinicians asking for help in curbing the opioid crisis by engaging in responsible prescribing practices. For many of the specialists I observed and spoke with, these events signaled a sea

change in approaches to pain management. At the national level, opiates were being positioned as unsafe and ineffective for chronic pain within national discourses and policies, and clinicians were being called upon to help curb the addiction crisis.

Not only was the biomedical community recognizing and acknowledging opiate addiction, but at first glance it appeared as though a clear course of action had been established within this community. A surface reading of the CDC guidelines and the Surgeon General's warning seems to indicate a consensus that opiates were unsafe and ineffective for treating chronic pain. The Surgeon General's letter, for example, described the increase in opiate prescribing since 1999, then said, "Yet the amount of pain reported by Americans has not changed," suggesting that these opiates had done nothing to treat the national epidemic of chronic pain, and had only resulted in an increase in overdoses. The letter called for a clinician-led "turning of the tide," away from the proliferation of opiate prescribing experienced in the 1990s and early 2000s, and towards a stance of opiate prohibition. This logic was reflected in the CDC guidelines, as well as in political discourses over the need to curb the opiate crisis, as the 2016 presidential campaign picked up heat.

However, on the ground, in interviews with specialists about opiates, and in observations of the pain curriculum, specialists expressed a range of positions regarding this logic of opiate prohibition. While many scientists, clinicians, and instructors echoed the concerns over opiates voiced by the CDC and Surgeon General, others did not, or did so with caveats. Some challenged the documents' claims that opiates were unsafe and ineffective for treating chronic pain. Others expressed with certainty that these were "bad drugs" that needed to be phased out. That is, rather than a uniform stance on opiate safety and efficacy, what emerged from these interviews and observations were heterogenous positions, taken in the midst of contentious transformations

around pain medicine resulting from the opiate crisis. This section describes this complex landscape of positions on opiates held by the scientists and clinicians I interviewed, as well as the lecturers I observed.

Consonant with their heterogeneous perspectives on the logic of opiate prohibition, pain specialists discussed their interpretations of the current evidence base on opiate safety and efficacy in divergent and conflicted terms. For instance, one clinician opined:

I still think people have this extraordinary urge to simplify something this complicated. The most common and concrete way [that people simplify] is the way that people have simplified the question about opioids. Like suddenly they're bad. And people will spout this nonsense like, "Well, evidence shows that opioids don't help with chronic pain," which is not true. The evidence does not show that. It would be nice, it would be simpler if it did, but it doesn't. It's more complex than that. It probably is right for some people and probably is wrong for other people. And knowing who it's right for and wrong for is actually impossible. And let's just be real with that. You don't know.

She attests to the complexity of the current evidence on opiates, highlighting two central dimensions of this complexity: opiates are *variable* in their effects, “right for some people and wrong for others,” and predicting those effects is inherently *uncertain*, that is, “knowing who it’s right for and wrong for is actually impossible.” In detailing what made these drugs and the current situation so complicated, many specialists would refer to these two specific aspects of complexity—uncertainty, or lack of data, and variability, or the inability to develop a universal, one-size-fits-all approach. This section argues that the evidence base regarding the uncertainty and variability of opiates are two central dimensions of complexity around which pain specialists had very different opinions.

### *A. Complexity of Opiates: Uncertainty*

Not everyone agreed on how much uncertainty remained regarding the safety and efficacy of opiates for chronic pain. Findings in this section center around two positional maps (Clarke 2005) representing specialists' claims on how best to interpret the current evidence base on opiate safety and efficacy. Positional maps are cartographic approaches to analysis that allow for spatial representations of various elements at play in a situation. In the situation of pain medicine in the midst of the opioid crisis, these maps provided a way of making sense of the heterogeneous and sometimes conflicting discursive positions taken in the data. Positional maps attend to the spaces between positions, and allow for an identification of "sites of discursive silence" (Clarke 2005:126). They focus not on particular actors, but on the positions themselves, and in so doing, create the possibility for a fresh and empirically-driven analysis. The process of developing a positional map out of positions taken in the data is iterative, and what emerged from my data was not one, but two maps, each representing positions taken by specialists in similar but distinct ways. The map depicted in Figure 3.1 is more traditional, with two axes charting the range of positions; the map in Figure 3.2 is more representational, plotting positions along a continuum. Both are intended to convey the complexity and heterogeneity of positions held with respect to opiates.

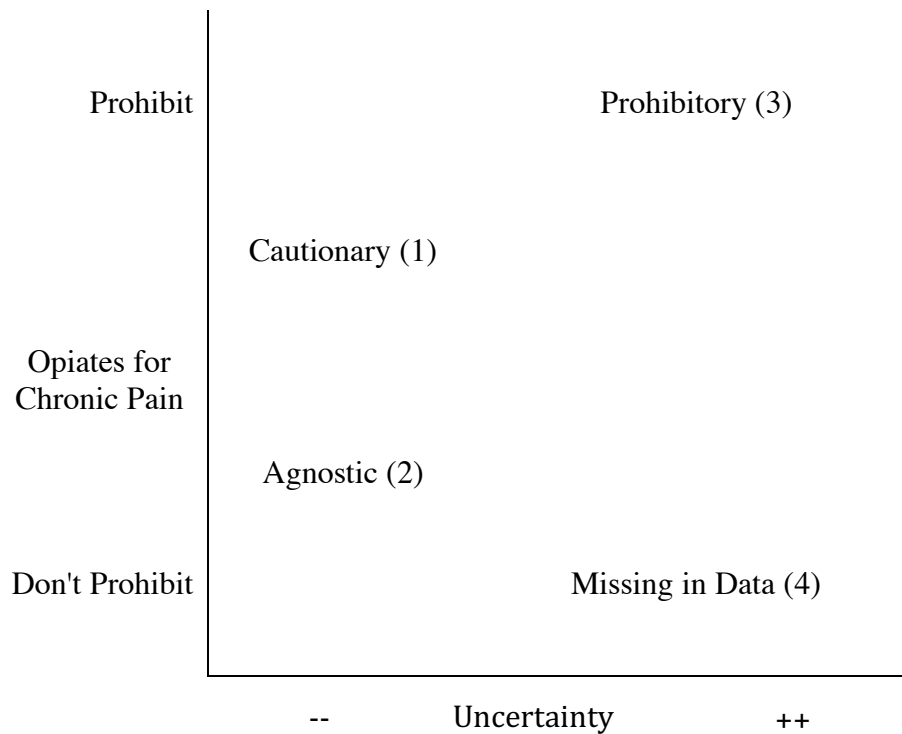


Figure 3.1. Traditional positional map of claims of how to interpret current opiate evidence

Figure 3.1 maps positions held by specialists in relation to the current evidence base on opiate safety and efficacy. Some specialists felt that uncertainty remained about how safe and how effective opiates are for chronic pain. Among this group, some expressed beliefs that this uncertainty necessitated that opiates should be prohibited for chronic pain, holding what I refer to here as a *cautionary* stance (the position marked as 1). In contrast, others within this group felt that this uncertainty rendered a policy of prohibition premature, thereby holding an *agnostic* stance (position 2). Still other specialists felt the evidence base regarding opiates was more certain. This group invariably held a *prohibitory* stance (position 3), in which they believed that opiates should not be prescribed for chronic pain. Lastly, no specialists held the position that evidence sufficiently demonstrates that opiates should not be prohibited, and this constituted a position missing in the data (position 4).

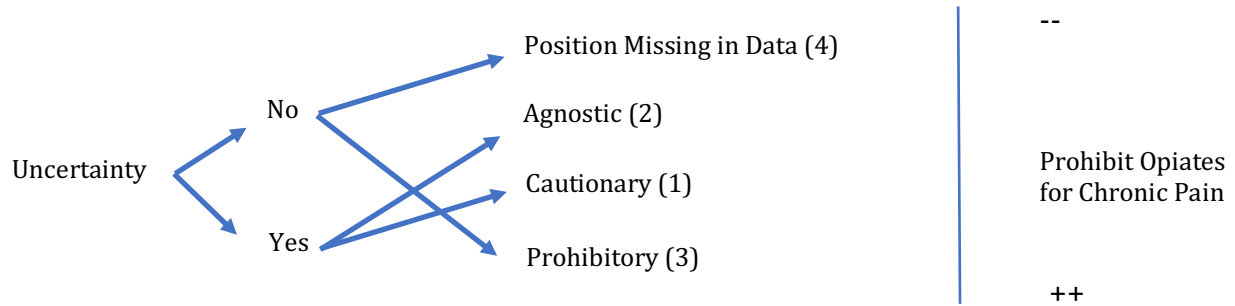


Figure 3.2. Representational positional map of claims of how to interpret current opiate evidence

Figure 3.2 also maps positions held on opiate safety and efficacy, but uses an alternative schema in order to represent the overlapping and contingent nature of these positions. Among those who contended that uncertainty remained regarding the evidence on opiates, some held an *agnostic* stance (position 2), stating that a policy to prohibit opiates was unfounded, and others held a *cautionary* stance (1), expressing the belief that this very uncertainty necessitated a policy of prohibition. All of the specialists I interviewed who believed that no uncertainty remained in the evidence on opiates held a *prohibitory* stance (3), stating that opiates should not be prescribed for chronic pain. The position that uncertainty does not remain in the evidence base, *and* opiates should not be prohibited, was not represented in the data (4).

These positions represent the diversity of perspectives that existed regarding how to appropriately proceed in the treatment of chronic pain with opiates. Rather than a homogeneous logic of opiates, what emerged from these interviews and observations was a range of positions were held by pain specialists regarding how to interpret the evidence on opiate safety and efficacy. I describe each of the positions below.

## *1. Data Remain Uncertain*

The scientific evidence on opiates upon which today's policy is based was described by some specialists as being limited, especially with regard to the long-term effects of opiates on pain beyond three months. By extension, then, these pain specialists believed that there were insufficient data, and therefore continued uncertainty, on the use of opiates for chronic pain (defined as pain that persists beyond three months). As one specialist put it:

The data now is getting there, but we're still a long way away. One of the biggest challenges, I think one of the biggest questions that we have in society is what is the safety and effectiveness of long term opioids for chronic non-cancer pain?

In his view, uncertainty existed regarding the long-term evidence on opiate safety and efficacy. This belief was echoed by several other pain specialists, some of whom described structural reasons for why this longitudinal science remains undone, and why we might be “a long way away” from having answers about the long-term effects of opiates. Several pointed out the logistical challenges of studying opiates in general, given their complexity, as described in Chapter Two. Others focused specifically on the difficulty of designing longitudinal studies on opiate efficacy:

Imagine the clinical trial data you would need to study something like [long-term efficacy]. It's temporally really complicated. And nobody can do a huge trial like that and what would the intervention be? How would you have control groups? So we're in a super data-free zone.

Yet another specialist echoed this account of undone science, describing in a lecture the challenges of making clinical decisions in the absence of data. He told his students, “We don't have long term studies on these drugs for chronic pain...this is a problem that we have throughout medicine, we need long-term studies.” These specialists highlighted the scientific uncertainty surrounding long-term opiate use, tying this to a larger problem within biomedical research regarding the lack of prospective studies.

Other specialists went further, attributing the lack of long-term data on opiates to funding limitations and lack of economic imperatives on the part of the pharmaceutical companies. As one specialist put it:

I think there's a big lag in what we know about drugs in the long term in general. Especially for opiates, it's really critical, because the side effects are so massive and that needs to be more studied, but then again that takes time and it's really expensive. The pharmaceutical companies don't need it to get approval so nobody's going to do it unless you have a big crisis.

According to this specialist, despite the high side effect profile of opiates, such as the well-documented respiratory depression that can result in overdose, particularly when combined with other medications, scientific investigation into the long-term effects of opiate use is unlikely to be funded without support from pharmaceutical companies. Other pain specialists also pointed to the lack of incentives for pharmaceutical companies as a barrier to funding long-term studies:

I think it's partly because, if you're a pharmaceutical company, it's really, really expensive. If you could already give people opioids and manufacture them and sell them, everybody already knows they're good, you don't need to do more science that might tell you that they're not so good. I mean so the society's beliefs are already on your side, so there's just no incentives for drug companies to ever fund studies that could undermine the basis for their selling drugs, right?

Like the specialist quoted above, this specialist pinned the hope of long-term opiate data on whether pharmaceutical companies will fund this research, but acknowledged that they would have little financial incentive to do so. These accounts of undone science attest to the biopolitical economy of knowledge production, in which commercial interests and institutional structures penetrate scientific investigation (Clarke et al., 2010). Frickel and colleagues (2010) put forward the concept of undone science to theorize the politics of knowledge, pointing to the inequitable distribution of power and resources within science. Within the arena of pain medicine, some questions can be asked and answered, and others cannot, for economic and political reasons.



Many pain specialists held this position of uncertainty, attesting to a lack of sufficient data about the long-term effects of opiates. Given the gaps in the data, disagreement remained about how best to proceed from a policy standpoint. How should the data be interpreted, given the uncertainty regarding long-term effects of opiates? How should those gaps be filled as policy on opiate prescribing is developed and implemented? While some specialists supported the current logic of opiate prohibition, reflected in the CDC guidelines, others questioned the soundness of that determination, challenging the evidence supporting those guidelines.

a. Cautionary (1)

Given the risks associated with opiates, and the fallout of a major crisis of opiate-related overdose deaths, most of the pain specialists I spoke with were reluctant to endorse the continued prescribing of these drugs, evidence or no evidence. One pain specialist said the following:

I think that the main message with treatment of chronic pain right now is that, we really don't know what to do. There's no strong evidence for any treatment, medication or non-medication. Generally the evidence is not good. And so I think given all of the information we have about the risks of opioids, if it's not clear that there's a benefit, it doesn't make sense to be using them much.

This stance represents a cautionary position on opiates, one held by many of the specialists I interviewed, particularly clinicians who had themselves witnessed the risks related to opiates. That is, they perceived that the asymmetry of information, in which a preponderance of evidence on opiate risks is weighed against what is perceived to be a lack of data on opiate efficacy, calls for a cautionary position against prescribing opiates.

Some of the specialists who expressed this cautionary position did so by extrapolating from the data that do exist, either on short-term use of opiates or on the long-term effects of opiates on animals. These specialists leaned towards phasing out opiates for chronic pain

management, pointing to what they perceived to be evidence that suggested that opiates were not producing positive outcomes. Even if this body of evidence did not speak *directly* to the effects of opiates for chronic pain, because they were not longitudinal and/or drawn from research on animal and not human subjects, these specialists felt that the *potential* (even though not yet fully demonstrated) risks of opiates outweighed the potential benefits. One pain specialist, speaking about a recent animal study that found negative outcomes from long-term opiate use in rats, said the following:

And so, obviously these [rats] aren't humans, and I don't know of any studies in humans that are comparable...but, you know, if I had to guess I would say that humans should stand a good chance of being similar in that regard. And plus clinical evidence basically suggests that people who are on opioids for long-term had terrible outcomes overall.

He pointed to a gap between what is known and not known in the scientific literature and what can be intuited by practicing medicine in a clinical setting. Despite a lack of human subject research on the long-term effects of opiates, this specialist felt that animal models combined with clinical evidence provided sufficient support for a cautionary stance. Given the intensity of the current opiate-related overdose crisis, the majority of those who felt that the evidence was still uncertain held a cautionary stance, operating under the premise that, despite gaps in the evidence, it's better to be safe than sorry.

#### b. Agnostic (2)

Several specialists who held that there was a lack of long-term evidence about the safety and efficacy of opiates did not take a cautionary stance, but instead remained agnostic about the potential risks and benefits of long-term opiate use and therefore did not advocate for a prohibition on opiates for chronic pain. This position was often expressed with the phrase, “we don't know.” Like the specialist quoted in the introduction of this section, who urged the

biomedical community to “be real with” the fact that “you don’t know,” some held more firmly to the stance of not presuming or extrapolating from what they felt was inadequate evidence on hand. As one specialist put it, “The reality is that yes, it’s true that there’s no evidence for long-term efficacy of opioids. [But] there’s no evidence that they don’t work long-term, you know?” In other words, opioids are innocent until proven guilty, and this specialist did not yet see convincing evidence demonstrating guilt.

The specialists I interviewed who held agnostic positions were often frustrated by the difficulty of remaining neutral regarding opiate safety and efficacy. As prominent researchers and clinicians, these specialists were frequently called upon to voice opinions about opiate safety and efficacy. As specialists in the biomedical community, they often felt an expectation to deliver a clear and simple response. In this sense, taking an agnostic position was not always easy. Speaking of the pressure he felt to deliver a simple answer to a complicated question, one specialist said the following:

The fact is, there’s no data. There’s just no data. We don’t have any information. And so as clinicians and researchers, we don’t like saying, “You know what? I don’t know. I really just don’t know if it’s effective.” We need to just put it out there and say, “I don’t know.” Unfortunately...the American public has an expectation that we know everything. That we’ve got this all figured out. That this is like a 30-minute TV show or 60-minute medical drama where at the end everybody is cured. And we don’t.

Without sufficient data, according to this specialist, the biomedical community is unable to provide a resolute answer on the question of opiate efficacy. Regardless, given the pressures placed upon pain scientists and clinicians by the American public in the midst of an iatrogenic crisis, such a clear and simplified answer is often demanded. His complaint mirrored the perspective expressed by the specialist in the introduction: pressure exists for a simplified, one-size-fits-all solution to the problem of pain and opiate addiction. Where these two specialists

differed, however, is in where they saw the pressure deriving from—the specialist quoted in the introduction saw it coming from within the biomedical community, while the one quoted just above felt it coming from without. Both, however, maintained an agnostic position on opiates, and advocated for making space within the biomedical arena for not knowing.

Many of the specialists who held agnostic positions referenced their concerns that the pendulum of opiate logic is currently swinging too far in the direction of opiate prohibition. All of the specialists in this group had been studying or treating pain since at least the 1990s, and described the pendulum of opiate logic as swinging from one extreme to the other, with no time in between. One lecturer shared this perspective with his students:

From a society standpoint for thousands of years, we keep slamming back and forth between these two extremes. We've been doing it for hundreds if not thousands of years. And what we're seeing here is that we did this [gesturing to one side] in the late nineties and now we're slamming over here to this side [gesturing to the other side]. And we're doing it rapidly... Ideally, we want to find a way in this central position.

Throughout his lecture, he frequently referenced the patients who he had perceived to be succeeding on long-term opiates, but who were being proactively transitioned off opiates by their primary care teams following these regulatory changes. Perhaps he held this agnostic position, then, as a reaction to having seen the deleterious effects of the previous swing, when in his assessment, opiate policy was similarly built upon an insufficient evidence base. In the face of uncertain data, this specialist and others in the agnostic group chose to remain in a place of uncertainty, complex as that position may be.

## *2. Data Are Now Certain*

As the above sections indicate, although many specialists I interviewed and observed spoke to the undone science on long-term opiate use, others did not perceive the same level of

uncertainty or insufficiency. Instead, they believed that the available evidence was clear and sufficient.

a. Prohibitory (3)

Invariably, these specialists felt that the evidence supported a prohibitory stance towards opiate prescribing. This position was similar to the cautionary stance described above, however, the specialists who held the cautionary stance did not feel as though the evidence was sufficient, but still believed that opiates should be phased out; in contrast, those who held this prohibitory stance felt that the evidence was clear enough to support a prohibition on opiate prescribing for chronic pain. This placed them in line with the national regulatory bodies, such as the CDC, whose position based on the 2016 guidelines could also be classified as prohibitory.

Those who held this prohibitory stance were less likely to describe opioids as complex, or to refer to the opioid crisis as complicated. Often, this position was implied, or presented as a given, rather than made explicit. As I describe below, specialists demonstrated the implicit nature of this position in a number of ways in the various settings I observed. Particularly in lectures, specialists who held this prohibitory stance did not name it directly or advocate for it, as those who held other positions did, but rather assumed that everyone in the room was on the same page with respect to opiates. These lecturers did not speak about the risks associated with opiates, but instead spent a good portion of their hour-long lectures discussing drug-seeking patients. By coupling these warnings about drug-seeking chronic pain patients with a lack of discussion about appropriate prescribing of opiates, these lecturers sent the message that opiates were bad medicine. Given that such a stance is in accordance with national opiate discourse, perhaps they did not feel the need to justify their position as others did.

These implied positions also emerged during my interviews. For instance, when asking one specialist about opiate prescribing, he responded that, “There are many, many options that are safer than opioids and that are more efficacious than opioids,” and proceeded to describe many of these options, such as spinal cord stimulators, NSAIDS, and behavioral therapy. When I followed up by asking about any controversy he had encountered around this position, he responded by saying, “I kind of see only one style, really...multi-modal management with an emphasis on function.” He saw an exclusive reliance on opiates as no longer being part of the traditional approach to pain management. He had not experienced any pushback on his position that opiates were not appropriate care, nor had he observed any variation in this prohibitory stance. Interestingly, others working within his same institution had expressed differing positions on opiates during interviews with me and lectures to medical students; possibly, he had not encountered this range of positions, or he did not feel comfortable discussing this range with me.

Some specialists who held this position used the phrase “we know that” to indicate consensus in the biomedical community; one such statement I heard was “we know that as we increase doses people's pain actually doesn't improve.” These specialists were expressing their certainty about the risks related to opiates, and were at the same time signaling agreement amongst the pain medicine community. One specialist, when asked about policy on opiates in her institution, replied:

Yeah, the party line is it's not good for long-term use. We have better medications. We now know that...long-term opioid use actually can increase your pain sensitivity...We know there are so many other different medications that can be more effective in the long run.

Like others who held this prohibitory stance, this specialist did not describe a situation of opiate complexity and ambiguity. Instead, she expressed certainty about the “party line” on opiates, that

they are not the most effective medication for long-term, chronic pain. Interestingly, she too worked in an institution in which I observed tremendous variation in positions taken, where some specialists took a prohibitory stance while others took an agnostic stance. Regardless, this specialist perceived consensus within her clinic that opiates are bad medicine. Thus, those in the prohibitory group did not perceive a diversity of valid perspectives regarding opiate safety and efficacy, but instead experienced their positions to be in keeping with the party line of the biomedical community.

#### b. Position Missing in Data (4)

Worth noting is the absence of specialists who expressed the position that there is sufficient data *and* we should not prohibit opiates for long-term pain. Ironically, this was the position held by many within the biomedical community in the 1990s and early 2000s, as described earlier in this chapter. However, given the fallout from the opiate crisis, both in terms of the political embarrassment of an iatrogenic crisis of this scale, and in terms of the “carnage” that many of the specialists described as a result of these mistakes, the position that opiate use is supported by the evidence is a highly unpopular one today. It is possible that some specialists did hold this position but did not feel safe to divulge this to me, despite my assurances of confidentiality. The professional repercussions for holding such a stance would be extreme in the current climate.

However, I have been surprised by the number of scholars who were *not* participants in my study who have pulled me aside at conferences, in clinic hallways, and at academic gatherings, and urged me to write about this pendulum swing based on their *own* experience of opiate efficacy for their own chronic pain conditions. Those who have successfully managed

their chronic pain with opiates seem to be living in fear of losing access to their main lifeline, despite perhaps conflicted feelings about the scientific evidence supporting their experience. Most of these conversations were hushed, and despite this position not being formally represented in my data, I feel it constitutes an important silence that should be analyzed in future projects.

### ***B. Complexity of Opiates: Variability***

A second way in which opiates were conceptualized as complex by pain specialists was that, for many, opiates were seen as highly variable. Instead of having a clear and straightforward assessment of their value, many specialists spoke about opiates as being both “good” for some conditions or circumstances and “bad” for others, or “right” for some people and “wrong” for others. As one specialist put it, “I think it's a little bit complicated because there's good uses of opioids and bad uses.” Here she was speaking specifically to uses of opiates, meaning that opiates are “good” for acute pain and “bad” for chronic pain. Others spoke more directly to variability in patient outcomes, such as the specialist quoted in the introduction: “It probably is right for some people and probably is wrong for other people” but that “knowing who it’s wrong for and who it’s right for is actually impossible.” Still others shared their perspectives on the challenges of determining who will succeed and who will not, such as this specialist, who spoke about her interpretation of the data on opiate safety and efficacy:

So I haven't taken a personal look at all of the data recently. But my understanding about it is that it's very heterogeneous based on the patient population which is very hard when you have a person in front of you and you're suddenly in that conversation. It's so much easier to have a single approach that you sort of take with everybody.



Again, opiates were positioned as complex—right for some and wrong for others—and this very variability proved difficult to navigate and ascertain both for pain providers and patients.

Interestingly, although the variability of opiates' effects was widely expressed, it was uncommon for lecturers to speak about variability in opiate outcomes. One lecturer did take time to tell his students about what he saw as a range of potential outcomes from prescribing opioids. Throughout his lecture, he described the complex situation of opiates, calling them “the good, the bad, and the ugly.” He spoke about the challenges of making decisions about who to prescribe opiates to, saying, “On the one hand, people are dying these tragic deaths from these overdoses. On the other hand, we've got these people who have chronic pain, who've been using opioids and in many cases using them appropriately.” His position was unique among the pain lecturers who I observed, in that he made reference not just to the risks of overdose, but also to the rising number of patients with chronic pain. He also was one of the few pain specialists I observed who specifically pointed to his experience of working with patients who are “in many cases” using opiates appropriately. Still, he highlighted the tension that he and other pain specialists have observed between the patients who do well on opioids and the patients who experience negative—and sometimes life-threatening—outcomes.

This tension between the “good” and the “bad,” and the inability to know which patients fall into which bucket, is one aspect of complexity inherent in opiate prescribing. This variability, or inability to develop a “single approach,” does not always fit neatly into universalized protocols. In order for guidelines and policies to be developed and carried out, this complexity must be flattened. Variability must be standardized, and uncertainty diminished, in the formulation of policy. The following section will explore this process of standardization—instances in which complexity is flattened in an effort to produce actionable protocols.

#### **IV. Flattening of Complexity: Policy and Messaging**

Despite the complexity of opiates described above—an intricate biopolitical history, a range of positions on sufficiency and uncertainty in the evidence-base, and an inability to determine who will succeed on opiates and who will suffer negative consequences—policy makers at the local and federal level are still called upon to develop clear and universal protocols for safe prescribing. Further, clinicians with limited time for office visits are faced with the difficult task of succinctly discussing opiate-related risks with their pain patients. Pain lecturers, many of whom are operating under the constraints of a scant two-hour pain curriculum, must convey to clinicians in training the appropriate way to approach opiate prescribing in their future practices. All of these acts—the development and implementation of policy, the messaging that occurs in office visits, and the curriculum delivered to medical students—necessitate some simplification, wherein the complexity of opiates described above is flattened in favor of clear, concise, and standardized policy and messages.

These processes emerged out of and reflect the biopolitical opiate crisis, in which policies and discourses are enacted to control, optimize, and enhance life itself (Rose 2007). Efforts to address this biopolitical, post-modern epidemic focus on minimizing risk, specifically the risk of opiate overdose, in the population. Foucault made clear that “death is power’s limit” in that “it testifie[s] to the individual and private right to die, at the borders...of power that [i]s exercised over life” (Foucault 1978:139). Thus, biomedicine as a system of state apparatuses is compelled to guard against the threat of death through the disciplining of the body (described in more detail in Chapter Four), and regulation of the population. This regulation occurs not only through policies developed to manage the population, but also via discourses that proliferate in

biomedical arenas. The following section describes these regulatory processes in turn, via the accounts of the specialists I observed and interviewed.

### ***A. Policy***

Several specialists I interviewed had once been involved in policymaking at the local and federal level, or had been in conversation with those who were. They relayed stories about how these policy decisions were made, often describing tensions or disagreements over how to interpret the available evidence. Most of the specialists who recounted these stories personally held the agnostic position described above, wherein they felt that there was not sufficient evidence to make a clear determination on the safety and efficacy of opiates. However, the *policy* perspectives they described encountering in their professional practice were largely reflective of the prohibitory stance detailed above, in which the evidence was seen as certain enough to prohibit opiates for chronic pain. For example, one specialist recalled a conversation that she had had with the head of a major branch of the public health department, during which they were trying to establish dose limits for opiate prescribing within their network:

I told her [the department head], “I don’t think the evidence is sufficient to support [dose limits] ...I just don’t think the data’s there.” And she said, “Well, there are people who say the climate change data isn’t there either, so you can make the data say anything. I think we need a dose limit.” The intensity of people’s opinions in the absence of data has been astonishing.

She saw this department head as filling in the gaps in the evidence with her own perhaps politically informed agenda. For this specialist, that a public health department head could liken those who hold an agnostic stance on opiates (which she saw as a legitimate position given the “absence of data”) to climate change deniers (which she implied are resisting a much higher

preponderance of scientific consensus) pointed to policy being dictated by politics rather than evidence.

Several specialists, whether agnostic or not, spoke to controversy surrounding the recently released 2016 CDC guidelines, which limited opiate prescribing for chronic pain. These specialists critiqued those who had developed and approved these guidelines, claiming that the scientific basis for their recommendations were scant. For example, one specialist recalled his experience sitting in on a meeting of the most prominent governmental agency on pain research, evaluating the current CDC guidelines on opiate prescribing:

The real question is how effective are opiates for non-cancer chronic pain, beyond 3 months. The fact is there's very few trials of that...Around the table, the uber-committee, the IPRCC [NIH Interagency Pain Research Coordinating Committee]. When the CDC report came out with the guidelines and said, "Less opiates, lower prescriptions, 3 days, blah, blah, blah," the whole bit. And so here was all the recommendation, the guidelines, and then beside them was the science. How strong is the recommendation based on science? Basically zero-zero-zero-zero. They admitted there was almost no good evidence for any of their guidelines, it was really more, almost fear and emotionally driven, understandably, that this is a problem. We've got to do something. We know that the evidence isn't there, but, clearly, there are people dying. The only way to solve the problem is to stop it. Kind of like Prohibition.

Although the IRPCC allegedly admitted to holding an agnostic stance, what was produced by the CDC was a cautionary stance, wherein even though the evidence was perhaps not seen as sufficient, the committee apparently decided that they had to "do something" in the face of so many overdose deaths. The two accounts relayed above, analyzing a department head's decision to impose dose limits and a governmental agency's adjudication the science behind the CDC guidelines, depict the kind of proliferation of chaotic discourses characteristic of a post-modern epidemic, involving "a rapid spread of fear and calls for vigilance" (Boero 2010:309).

The above specialist claimed that fear was motivating the decision of the CDC; however, other agnostic specialists blamed the same regulatory body for operating out of disciplinary

biases, rather than conclusive scientific evidence. They claimed that the CDC guidelines had been developed by addictionologists, rather than pain specialists, and that their professional experiences had biased their perception of the efficacy and safety of opiates. One such specialist said in an interview:

Unfortunately, the lens upon which they view things has got a lot of tunnel vision...Imagine you're an addictionologist. Do you think that you ever met an opioid that you thought was appropriate? Is there ever a patient that comes to you as an addictionologist that's doing well on opioids? They never will come to you doing okay on opioids. By definition, they've got a problem. So, they get a very skewed view, and it's hard for them to see beyond that skewed view. I think that causes real problems because there's a lot of emotional rhetoric out there around this. There are a lot of strong statements about opioids around pain.

The underlying complaint of many of these specialists was that the current standards of care are based on emotions, beliefs, and experience, rather than on what they perceived to be good evidence. In critiquing the oversimplification of opiates, then, some specialists drew a division between undone science, where no evidence may exist, and unreliable science, where evidence is predicated upon emotions, belief, and experience, rather than laboratory studies. The participants I portray here object to policy being made in the context of either of these situations.

### ***B. Clinical Practice***

While many federal and local guidelines were developed in order to produce a universal standard of care—a clear and consistent protocol that over-taxed clinicians could rely upon for safe prescribing recommendations, some institutions worked to develop a way to navigate the variability of opiates' effects described above. Operating upon the premise that opiates could be “good for some people and bad for others,” some policymakers attempted to develop tools and

committees that could help determine which patients were good candidates for opiates, and which patients were considered high-risk.

For instance, one specialist served on a committee at her institution that gathered regularly in order to weigh in on difficult clinical cases and make recommendations about opiate prescribing. The interdisciplinary team helped advise clinicians regarding opiates, and attempted to answer the question, as the specialist put it: “How do they manage the really difficult patients who have chronic pain?” In her interview, she described the complex patients that this team regularly consulted on, pointing to what she perceived to be contraindications for opiates:

A common complicated patient would be somebody who is maybe homeless, has some substance use issues, so maybe they are currently using cocaine and methamphetamine and also wanting to be on an opiate, maybe prescribed a benzo[diazepine]. So you have all of these things that are contraindicated. Also, a history of trauma and chronic pain from a gunshot wound and maybe limited mobility because they got hit in the spine or something. And so all of those complex factors, like on the one hand, they’re contraindicated for opiates. And certain conditions really shouldn’t be treated with opiates anyway, but providers tend to want to like try to fix and might prescribe opiates when it wouldn't be the best.

This specialist described trauma and substance use as being contraindicated for opiates, referencing the existence of an evidence base that demonstrates poor outcomes for patients with these characteristics. These contraindications and others have been collected into an Opiate Risk Tool (ORT), a checklist which some clinicians described consulting prior to prescribing opiates (see Figure 3.3).

## Opioid Risk Tool

This tool should be administered to patients upon an initial visit prior to beginning opioid therapy for pain management. A score of 3 or lower indicates low risk for future opioid abuse, a score of 4 to 7 indicates moderate risk for opioid abuse, and a score of 8 or higher indicates a high risk for opioid abuse.

Mark each box that applies	Female	Male
<b>Family history of substance abuse</b>		
Alcohol	1	3
Illegal drugs	2	3
Rx drugs	4	4
<b>Personal history of substance abuse</b>		
Alcohol	3	3
Illegal drugs	4	4
Rx drugs	5	5
<b>Age between 16—45 years</b>	1	1
<b>History of preadolescent sexual abuse</b>	3	0
<b>Psychological disease</b>		
ADD, OCD, bipolar, schizophrenia	2	2
Depression	1	1
<b>Scoring totals</b>		

Figure 3.3. Opioid Risk Tool (NIH 2018)

Among other traits, characteristics deemed to be high-risk for opiate abuse via this tool include a family history of substance use as well as a personal history of childhood sexual abuse, a conflation that some have critiqued as having the effect of producing gender gaps in the prescribing of pain medication. Thus, this tool draws upon epidemiological research to produce categories of risk, many of which map onto marginalized groups. Further, application of this tool creates the potential for systematically denying pain medication to certain populations, thereby shifting responsibility for pain management away from the health care system and onto the patient. This focus on risk and shifting responsibility onto the patient are two ways in which the opioid crisis, and its proposed solutions, can be characterized as a post-modern epidemic.

Some specialists I spoke with described embracing the ORT, heralding its ability to reduce uncertainty in the face of knowing which patients might be appropriate, or low-risk, for opiates. For example, one specialist conveyed her enthusiasm for this tool:

For some patients we're using an opioid risk tool, where you look at their past history of substance use disorders, their past history of abuse as children, their age, their gender, et cetera, and then you can kind of calculate how risky it is to prescribe opioids to that person.

The use of this tool, with its promises of effectively calculating risk based on demographic and psychosocial categories, represents another way in which the complexity of opiates—in this case, the variability inherent in their safety and efficacy—is systematically reduced in order to produce a clear and concise standard upon which to act. Given the constraints placed upon providers, who are often not granted the time with patients necessary to develop individualized assessments that would result from an in-depth relationship, the clinical reliance upon algorithmic tools such as this one is understandable. At the same time, such policies, guidelines, and tools run the risk of flattening the complexity inherent in not just opiates but in chronic pain patients as well.

While many clinicians that I interviewed held agnostic positions related to opiate safety and efficacy, this stance did not always translate into how they spoke to their pain patients about the risks of opiates. These clinicians described their uncertainty regarding what the currently available evidence concludes about opiate safety and efficacy; however, they also described speaking to their patients about their fears regarding the potential risks about opiates. This may be a reflection of an inconsistency between a theoretical, general position—their agnostic stance discussed with me—and a real-world, specific position—a prohibitory stance discussed with patients who they deemed high-risk for negative outcomes. Regardless, by examining their messages to patients regarding opiates, we see an illustration of how the nuance and complexity behind opiate evidence is flattened in the context of a brief office visit.

After discussing the contingencies of the available evidence on opiate safety and efficacy, two clinicians in particular described the ways in which they discuss opiates with their pain



patients. They spoke to me as they would their patients, and these enactments are placed side by side here:

Clinician 1: This is the dose where we really start to see an increase in the amount of people dying and we've had our own patients in this clinic die. I've had patients of mine die and this medicine has contributed to that. And I'm not talking about people who we knew were going to die who are in hospice. That's not what I'm talking about. I'm talking about other people who are very much like you who took this medicine and it contributed to them dying. So we're not going to. I'm not doing that for you. I don't want to hurt you.

Clinician 2: I know you haven't overdosed yet, but I worry every day that you're going to. Honestly, I don't know if you have an addiction yet. I don't know that, but I'm scared that that's going to happen to. I know that these medications aren't that helpful. They might help a little bit, but they don't help a lot. That I feel is true, as evidence has told us. I think we have better ways to help you. I think I can do better.

Despite the agnostic position expressed by both of these clinicians in other parts of their interviews, their individual clinical experiences had resulted in their feeling a need to safeguard against opiate overdose by invoking fear in their patients about opiate risk. The first specialist recounted opiate overdoses that occurred in her clinic, drawing a connection between those patients and the hypothetical patient sitting in front of her. The second clinician leveraged her therapeutic relationship in order to communicate her own misgivings about the potential for opiate addiction and overdose. In this hypothetical, she explained that the evidence of opiates' efficacy (that she had previously positioned elsewhere in her interview with me as being contested) could not trump concerns around addiction she had for the patient, and concluded instead that a prohibitory stance was warranted.

### ***C. The Pain Curriculum: Medical Education***

In interviews with clinicians, pain patients were often described as “complicated,” frequently carrying a host of overlapping conditions, such as trauma, substance use, and chronic illnesses that both contributed to their pain and made it more challenging to assess and treat. In

medical school settings, where the pain curriculum totaled 2-3 hours at each institution where I conducted fieldwork<sup>14</sup>, these complex patients were presented as tropes, with instructors frequently characterizing pain patients as “chronic pain players.” This term was used to refer to the stereotypical drug-seeking pain patient described earlier, who is willing to manipulate both clinicians and the health care system by providing false histories and doctor-shopping (Longo et al., 2000). While the term “drug-seeking” first appeared in the medical literature in the mid-1950s (Beach 1955; Rayport 1956), it was not until the emergence of the opioid crisis that this descriptor was pinned to particular kinds of pain patients. Thus, the chronic pain player is co-constitutive of the biopolitical, post-modern opioid epidemic, whereby a focus on risk manifests in the emergence of this particular subjectivity.

Case presentations are a common didactic in medical school, and instructors I observed would often draw upon the most extreme pain patients, either real or imagined, for their exemplars. For instance, one lecturer developed a fictional character to use for his case presentation, basing the imaginary patient loosely around Michael Jackson, whose silhouette was displayed on his slide. He narrated from the text on his slide:

A 51-year-old man with a long history of chronic back pain and a history of prescription opioid addiction. He comes to you asking to take over his care. Willing to pay you \$150k/month. Wants short-acting opioids, specifically demerol. Also having some difficulty sleeping and inquiring about this milky white substance called propofol.

This lecturer chose to leverage the public details of a well-known celebrity, thereby illustrating the ubiquity of opioid addiction narratives in the popular imagination. While the case described above did not necessarily resemble the typical pain patient that these physicians-in-training

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<sup>14</sup> This was below the average 9 hours that has been widely reported (Mezei & Murison 2011). Both institutions were overhauling their pain curriculum at the time of my observations, and told me that, during this transition time, they had cut the recognized pain curriculum significantly.

would most likely encounter, it is worth noting that this extreme example is demonstrative of the type of chronic pain player that students from this private, suburban institution were warned about. By contrast, we see that a case presentation at a public institution imagines a different kind of patient:

The lecturer described the details of his case presentation: “This is a gentleman with a failed back surgery and post-traumatic stress disorder and opioid use disorder.” He said to his students, “You’ve probably taken care of this patient cause they seem to come to [our institution] repeatedly.” They discussed the patient, identifying him as being “definitely not opiate naïve.”

Through such case presentations, the complexities of pain patients become standardized in the telling and retelling of their histories. Further, the chronic pain player is produced as a subjectivity, with the hidden curriculum (Hafferty & Gaufberg 2013) of medical school signaling to students that certain pain patients should be approached with skepticism.

The leveraging of complex patients for educational case presentations stems, in part, from efforts within pain medicine to embrace a biopsychosocial model of pain management (see figure 3.4), which holds that psychosocial interventions may prove just as effective as biomedical treatments (Gatchel et al., 2007; Turk & Monarch 1996) in addressing chronic pain.

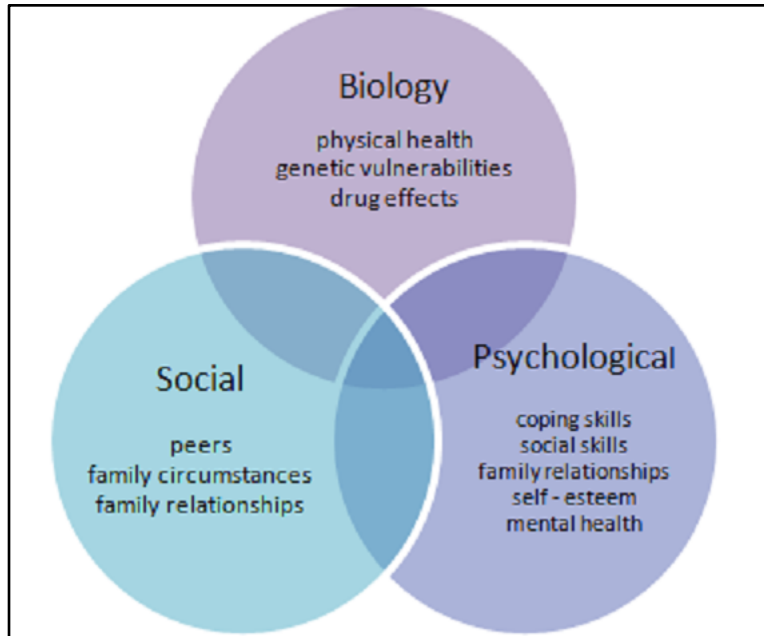


Figure 3.4. The biopsychosocial model

Advocates of the biopsychosocial model seek to draw attention to social and psychological components of pain, in part by including a social history in case presentations (see figure 3.5 for an example from a continuing education forum).

**Case 1 | Chronic Opioids | History**

52 year-old gentleman with h/o failed back surgery syndrome, PTSD, opioid use disorder, scheduled for repeat spinal fusion due to progressing neurologic deficits.

Soc:

- Divorced, living alone in an apartment
- 1 daughter (age 26y); 1 son (age 21y)
- Works as a wholesale distributor for a major grocery chain
- Occasional EtOH, non-smoker, 1-2 years of intermittent cocaine and heroin use in 1980s

Figure 3.5. Case presentation from continuing education forum

However, these social histories tended to draw upon extreme and totalizing patient narratives, as was demonstrated by the following case presentation from a Grand Rounds lecture:

So to summarize [the] case here, so we have a patient with opioid tolerance, heroin abuse, nerve injury, and lack of psychosocial support. We cannot forget that psychosocial support—remember, pain is an emotional and sensory experience and that’s a huge part of this guy...for these complex patients, we must think more broadly...and understand their social environment in order to help them.

This move towards attending to the biopsychosocial model of pain often resulted in each case presentation embodying many of the complexities of a stereotypical pain patient (“opioid tolerance, heroin abuse, nerve injury, and lack of psychosocial support”) all at once. These characterizations signaled to clinicians and clinicians-in-training that the majority of pain patients are messy, complex, and difficult to deal with.

Such essentialized descriptions of pain patients run the risk of priming clinicians to be wary of pain patients altogether. In extreme instances, pain patients are reduced to drug-seeking stereotypes. For example, one lecturer repeatedly referred to all of the pain patients she described as “chronic pain players,” describing the field of medicine as a battle between “us” (clinicians) and “them” (pain patients). She warned students about the various ways that she predicted pain patients would try to trick them into prescribing opiates:

They think they’re so tricky—if they don’t actually say the name of the drug they think we won’t realize that they know exactly what they’re looking for. ‘Oh the one that starts with a D.’ ‘Dimetapp?’ ‘No, that’s not the one.’ ‘Oh, Dilaudid?’ ‘Yeah, that’s the one!’

She primed her students to be wary of trusting pain patients, who, in her estimation, were all manipulative and cunning. While this was an exceptional example in my fieldwork, it represented the range of messages being conveyed to physicians-in-training about chronic pain patients, even within elite medical institutions.

## **V. Conclusion**

This chapter argues that the opioid-related overdose crisis, and its proposed solutions, constitutes a biopolitical, post-modern epidemic. Foucault theorized that an epidemic posed the greatest threat to a dominion over life (1976/1978), and thus described the ways in which the bipolar technologies of this power over life function to control populations and ensure longevity and health. The regulations and practices detailed above, which participants describe as both propagating the opioid epidemic and seeking to curtail it, are enacted by biomedical state apparatuses in order to guard against the threats associated with an epidemic. Further, this chapter accounts for the subjectivities produced via this crisis, attending to the consequences of constructing pain patients as always-already at risk.

Further, this chapter analyzes the politics of knowledge production, revealing the contested and partial nature of scientific evidence on opiates. By speaking to the various positions of specialists as to how the evidence on opiates should be interpreted, I contend that the field of pain medicine holds heterogeneous and complex understandings of both the scientific evidence on opiates and how this evidence should be acted upon. Further, by attending to the undone science that remains within this evidence base, I assert that biomedical knowledge is not, in fact, comprehensive and total, as Rose argues (2007), but rather is incomplete and inequitably distributed, subject to economic, political, and social forces.

Most of the clinicians and scientists I spoke with and observed described opiates, their evidence-base, and the current biopolitical situation around opiates, as “extraordinarily complicated,” “incredibly complicated,” or “extremely complicated” (sometimes accompanied by an exasperated sigh). Many specialists referenced the politically charged landscape of opiates

given the ongoing crisis, which was reaching its pitch during data collection, as the 2016 election leveraged the logic of opiate prohibition, placing blame and promising solutions. In fact, several specialists declined to answer questions about opiates during interviews, or requested to be off the record when weighing in on their perspectives about these drugs. Each pain lecture that I observed referenced the intensity of coverage of the opioid crisis, speaking to newspaper headlines and national concern over growing overdose deaths. Several specialists compared the intensity of the opioid crisis to that of the abortion debate, or climate change rhetoric, highlighting the political potency of the current biopolitical situation surrounding opiates. The opinions and perspectives of specialists reflected here were often conveyed with emotion and exasperation, and I am grateful to my participants for their candor and trust.

This chapter attends to the opiate crisis as a driving force behind the broader transformations in pain medicine described elsewhere in this dissertation. Within Foucault's conceptualization of biopower, the bipolar technology of sovereignty over life operates at the level of the population—as described here via the regulations, discourses, and interventions that control the species body—as well as at the level of the human body, which is disciplined, regulated, and optimized in order to integrate into systems of efficiency—a process which will be detailed in Chapter Four. While this chapter attended to proposed solutions to the opioid epidemic at the level of the population, the next chapter describes the solutions that are directed at the individual, shifting responsibility even further away from the health care system and onto to the patient.

## **CHAPTER FOUR: UPTAKE**

### **I. Introduction**

*“It is the brain that decides whether something hurts or not, 100% of the time, with NO exceptions.” –Explain Pain, p17*

The current shift from a biomechanical to a neuroscientific model of pain was premised upon the proliferation of neuroscientific discourses into everyday notions of the self, whereby pain and other ailments are increasingly positioned as neurocognitive in nature<sup>15</sup>. Neuroscientific discourses regarding pain are frequently imparted with notions of plasticity, highlighting the malleability of the brain and its responsiveness to environmental stimuli (Pitts-Taylor 2016). The neuroscientists I interviewed and observed celebrated this neural flexibility, basing many of the interventions they were studying upon the very principle of plasticity. For instance, one scientist said:

I think at this point we know that pretty much everything is plastic in the brain... anytime I'm doing anything, I think of my brain as, there's new neurons making new connections, there's new connections being strengthened in certain areas and other areas not... (In relation to pain), when you have... some maladaptive process going on where you have an injury, you're not responding to it the right way, you're not helping it move, helping it heal, there's going to be connections that are like pro-pain connections forming. If your thoughts are in that direction too, like, 'Oh my gosh, my ankle is totally broken, this happened to my mom, I'm never going to heal,' then those negative thoughts are working together too. It's creating pain memories and you're just going to keep moving forward in that bad way. If you can do everything, stop all those from forming... guard your thoughts and make them on the right way, then you would be forming good connections that

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<sup>15</sup> Additionally, this shift is occurring in relation to heightened concern over the opioid-related overdose crisis, which calls upon clinicians to identify new, non-pharmacological solutions to chronic pain. These new solutions often rely upon patients' self-management, and thereby leverage neuroscientific plasticity discourses that champion pain patient's capacity for change and self-regulation. While opioids—part of the biomechanical model—positioned pain's intervention outside of the patient, neuroscientific self-management techniques place the impetus for healing on patients themselves, imparting agency upon pain patients and positioning solutions as coming from within.



would be healthy connections that would hopefully...it wouldn't be turning chronic into this really strong rooted connections of pain.

Within neuroscientific understandings of pain, the brain is conceived of as always-already plastic, capable of change and open to manipulation. This guarding of one's thoughts described here is exactly what the interventions detailed in this chapter are premised upon. Pain patients are being trained in techniques that help them to self-monitor and self-surveil, thereby steering their perceptions of their pain towards "healthy connections" that will minimize their risk for developing and maintaining chronic pain. As chronic pain is framed as increasingly risky in light of the opioid crisis, the imperative to guard against this risk by engaging in "healthy" neural regulation is all the more heightened. Further, this framing of the brain as plastic and malleable produces particular subjectivities, namely pain patients who are both capable of, and responsible for, managing their own conditions. Thus, a neuroscientific configuration of pain places the onus of care on the patient, rather than on the health care system. This chapter describes this twinned imperative/opportunity embedded within these neural techniques, highlighting the complexities inherent in the subjectivities produced by their proliferation.

Data for this chapter is drawn from 30 in depth, semi-structured interviews with pain neuroscientists and clinicians, many of whom were group facilitators, as well as approximately 50 hours ethnographic observations of three pain groups which I call the Lab Group, the City Group, and the Neighborhood Group. In order to satisfy the agreements outlined in my Institutional Review Board approval, I did not collect data on the patients participating in the groups. This resulted in my being unable to analyze the positions of these patients, both in terms of their reactions to the material presented in groups, as well as their demographic or clinical characteristics. While this limitation did restrict the extent to which I could make analytic claims regarding power dynamics occurring across these spaces, the structure and setting of each group

still enabled me to draw inferences as to the types of patients who were included and excluded via these discourses.

Drawing on these interviews and observations, I first describe the plasticity techniques deployed in pain groups as a means to intervene upon patients' pain scores. I then outline the structure, primary purpose, and setting of each group, and attend to the ways in which these features both shaped and were shaped by the techniques deployed and their engagement with neural and plasticity discourses. I conclude by delineating the relationships between these two discourses, and by attending to the types of patients who are excluded in from the benefits this neuroscientific model of pain presumes, as they are presented within the current structures of the US health care system.

In this chapter, I characterize neural and plasticity discourses as disciplinary techniques, functioning to produce patients that are low-risk and self-managing. I argue that these techniques are simultaneously productive and oppressive, contending that they represent a twinned imperative/opportunity to optimize, enhance, and self-surveil. These neural discourses invoke particular notions of patienthood and produce specific subjectivities, specifically calling upon patients to conceive of themselves as plastic, malleable, and capable of transformation.

### ***A. Theoretical Frameworks***

This chapter engages with both biomedicalization theory and what I have termed critical neuroscience studies, the latter of which encompasses social scientific inquiry into neuroscientific knowledge production, dissemination, and uptake. Both of these bodies of literature draw heavily upon Foucault (1973; 1978) in theorizing both neuroscience and biomedicine writ large as institutions of power, which is itself “situated and exercised at the level

of life, the species, the race, and the large-scale phenomena of population” (1978:137). While the authors of these collected works take different positions regarding the productive aspects of these institutions, and the place of agency within them, all of them are engaging with the configurations of biopower, or the apparatuses that bring “life and its mechanisms into the realm of explicit calculations and made knowledge-power and agent of transformation of human life” (1978:143). By considering these arrangements of power over “life itself” (Rose 2007:3), these theorists make clear the stakes and implications for such a shift in conceptualizations of pain.

Biomedicalization theory (Clarke et al., 2010) applies the concept of biopower to considerations of the expanding jurisdiction of medicine over not just illness and disease, but health itself. While *medicalization* (Conrad 1992) implies a unidirectional pattern of influence, *biomedicalization* takes up a Foucaultian notion of power (Foucault 1978) in order to emphasize the circulative, co-constitutive nature of transformations occurring within and across biomedicine. Clarke and colleagues (2010) highlight the commodification of health and the shift to individual, rather than medical, responsibility for health. This chapter engages with biomedicalization theory in order to consider how technoscientific practices are transforming bodies and minds from the inside out, producing new conceptualizations of what it means to be in pain. Neuroscientific understandings of pain create the potential for pain patients to see themselves and their bodies in new and different ways, repositioning responsibility for suffering from the health care system to the patient.

Critical neuroscience studies extend these considerations of how biopower operates through neuroscientific discourses, considering implications for human agency, systems of knowledge, and corresponding power structures (Pitts-Taylor 2016; Buchbinder 2015; Rollins 2014; Rose & Abi-Rached 2013; Hansen & Skinner 2012; Malabou 2012; Vidal and Ortega

2011; Vidal 2009; Dumit 2004). These works collectively analyze the emergence of the neuronal subject produced via these discourses, taking different positions on the potential for “neuroreductionism,” or reducing persons to brains (Vidal 2009). While Rose and Abi-Rached (2013) emphasize the positive, productive features of these new subjectivities by pointing to the opportunities of self-knowledge and self-enhancement provided by advances in the neurosciences, Pitts-Taylor (2010) instead considers plasticity as it exists within the specific biopolitical economy of neoliberalism, which produces patients-as-consumers who are obligated to self-manage and promote their own well-being, emphasizing individual responsibility. Both of these accounts engage with Foucault’s concept of governmentality, considering the arrangements of power and knowledge in relation to neuroscientific understandings of the self, emphasizing different features of this concept. Rose & Abi-Rached invoke the ethic of social responsibility in urging us to become active participants in self-improvement, engaging in practices of “neurobiological self-fashioning” (2013:22). Pitts-Taylor, on the other hand, attends to the power relations inherent in the making of neuronal subjects by pointing to the ways that popular neuroculture, through the deployment of plasticity discourses, “situates the subject in a normative, neoliberal ethic of personal self-care and responsibility linked to modifying the body” (2010:639).

The following chapter engages with these ongoing conversations in the literature by illustrating how these discourses are enacted in clinical settings, specifically as they apply to the subject in pain. The neural discourses I analyze are illustrative of both Rose & Abi-Rached’s framing, in which new opportunities for personhood are embedded within neuroscientific knowledge and practices, *and* Pitts-Taylor’s observations of the neoliberal ethics that are expressed through notions of plasticity. Often, these two tendencies occurred side-by-side,

wherein pain patients were conceived of as neural subjects with both the opportunity and the imperative to self-regulate, optimize, and enhance. Further, neural and plasticity discourses were situated, showing up in various ways in relation to the setting, purpose, and structure of each group.

Both biomedicalization and critical neuroscience studies emphasize a trend towards enhancement, self-monitoring, and patient responsibility. By bringing together these two theoretical frames and applying them to pain medicine, I situate the neuroscientific shifts occurring within biomedical conceptualizations of pain. I argue that pain is currently being newly biomedicalized—more specifically, neuroscientized—vis-a-vis these neural discourses and plasticity techniques. This shift has broad implications not just for pain medicine itself, but also for questions of agency and responsibility.

## **II. Background**

In the following section, I briefly describe the three neural techniques deployed within the three pain groups I observed, including illustrative examples of each, and touching upon their application.

### ***A. Techniques***

The pain groups that I observed and heard described in interviews relied more upon a neuroscientific explanatory model of pain than a biomechanical one, promoting the notion that training pain patients to respond to their pain in new and different ways was a more promising intervention than medication or surgery. In order to train patients, group facilitators drew upon several related techniques, three of which I will briefly describe here: (1) Psychoneuroeducation;

(2) Cognitive Behavioral Therapy (CBT); and (3) Mindfulness-Based Stress Reduction (MBSR).

While each of these techniques was premised upon neural and plasticity discourses, the extent to which they were framed as such varied depending on the configurations of each group, as described in later sections of this chapter.

### *1. Psychoneuroeducation*

Psychoneuroeducation is based upon the premise that teaching patients about the neuroscience of pain is, in and of itself, an effective and safe way of reducing pain scores and improving function. This premise serves as the foundation for the Explain Pain movement, which promotes Therapeutic Neuroscience Education (TNE) as a means for managing chronic pain (Louw & Puentedura 2013). The Explain Pain movement occurs mostly via continuing education courses, wherein clinicians are trained and certified to teach patients to conceptualize pain as an “an output of the brain, not an input of the tissue” (Schopmeyer 2015). One clinician and group facilitator told me about her engagement with TNE in her group:

The first week is about, what is pain. There's a literature on neuroscience education and there's some things that have been written...we talk about the fact that pain is real. Pain is an important mechanism for the body to alert itself to harm and decide whether or not to act. Pain lives in the brain. It gets messages from the nervous system in the body. It also gets messages from other parts of the brain.

Training patients to reconceptualize pain as something that “lives in the brain,” rather than in the body was a common way to introduce the pain group to patients, as it served as a foundation for the other techniques. As I explore later in this chapter, however, this standard premise was sometimes complicated in practice.

Often, in the groups that I observed and heard about in interviews, the first session would lay the foundation for the rest of the curriculum by teaching patients about the “gate theory of pain” (Melzack & Wall 1965). Facilitators would draw a spinal cord and a brain on the white

board, usually joking about their inability to draw, and would describe the concept of “pain gates,” as is demonstrated in the following fieldnote:

The facilitator points to the brain she’s drawn and says, “The experience of pain happens here. Pain *is* in your brain. Pain *is* in your head. Gate theory says that other things can affect your experience of pain—the ‘open and close the gates’ piece. When we focus on the pain, we’ve *opened* the gates. If you distract yourself—if you become really engrossed—your brain directs its resources elsewhere. It *closes* the gates. We don’t even have to do it. Our brain does it for us.”

This concept of a pain “gate” that can modulate one’s experience and interpretation of pain served as a foundation for the rest of the course. Group facilitators would often claim that certain activities (such as MBSR or CBT) would close the gates, resulting in decreased intensity of the pain experience.

## 2. Cognitive Behavioral Therapy

Cognitive Behavioral Therapy (CBT) is premised upon the idea that patients’ reactions to the situations of their lives are influenced by their thoughts, or the things they tell themselves about these situations (Rothbaum et al., 2000). Identifying and examining these thoughts, according to this model, will better equip them to develop alternative thoughts, or different ways of conceptualizing their situations. The following quote is pulled from a fieldnote in which Sabine, a Lab Group facilitator, introduced this concept to the group:

Let’s get into the role of thoughts and feelings on pain! Pain has an impact on our thoughts, behaviors, feelings---the converse is true as well... There’s a scientific reason for why pain comes along with negative feelings—there’s overlap in the brain region for processing pain and emotions—they share real estate in the brain. When you have physical pain, you’ll also have emotional pain. The limbic system controls emotional pain. The same structures are activated when you have physical pain. It’s all a vicious cycle—that’s why pain psychology exists! You can’t address one without the other... The way we think about a situation is gonna determine how we feel. Sometimes you have a thought before you’ve gathered all the evidence. Our minds can be very powerful—we wanna make sure we use our minds in a way that’s helpful to us rather than sabotages us.

In conveying the principles of CBT, facilitators guide patients in developing “alternative thoughts” about their pain and life circumstances, with the goal of eliminating “negative” thoughts and feelings and thus reducing their pain scores. By engaging in this technique, patients are seen as capable of actively selecting what their framing of a situation is, and therefore changing the very experience of that situation.

### *3. Mindfulness-Based Stress Reduction*

Mindfulness-Based Stress Reduction (MBSR) was developed by Jon Kabat-Zinn (2003) in order to apply meditation practices, body awareness, and mindful movement to a host of physical and psychological problems, including chronic pain. It is traditionally taught in an eight-week class, however pain groups I observed incorporated elements of MBSR<sup>16</sup> as one of several techniques for intervening upon chronic pain. These elements ranged from grounding practices, to guided meditations, to body scans, to breathing exercises, and were all typically intended to bring patients into the present moment and to cultivate awareness of thoughts and sensations. The following fieldnote is pulled from a City Group session in which the facilitator, Veronica, led the group in a mindfulness exercise, speaking in a slow and gentle tone:

Get as comfortable as you can; allow your eyes to drift closed. If that doesn't feel comfortable, you can leave your eyes open and let your gaze soften. Take a few deep breaths just to land here, letting your attention come here, bringing your attention to your breath. Wherever else your mind is getting pulled, tell your mind, I'll go there later. Right now I'm here. Feeling your breath in your body—maybe you feel it in your belly, maybe in your chest or your nose...can you become so curious about your breath that you begin to notice a subtle difference from one breath to the next? Imagine there's a stream running in front of you; you're sitting at the edge of the stream, watching the water babble by. On that stream, there are leaves floating by. Maybe a few leaves, maybe many. Any time you have a thought distract you from this stream, place the thought on a leaf. Leaves may float by quickly or slowly; no need to rush them along. Let your leaves float

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<sup>16</sup> It is important to note that the pain groups I observed drew upon elements of MBSR, rather than teaching the entire series.



by whatever speed feels right. Same thing for emotions—worry, sadness, fear. For now you can place them on a leaf. Let them go. You may notice a thought keeps returning—that’s fine. Keep placing it on the leaf each time it comes back...watch the water float by, knowing there’s no problem with any thought you’re having; they’re all allowed.

Veronica’s meditation exemplified many of the key features of MBSR: she emphasized attention to the present moment (“land *here*...come *here*”), a focus on the breath, awareness of the body, and guided imagery. Recognition of physical sensations sets MBSR apart from other neural techniques, which are much more cognitively focused on thoughts. This attention to the body is part of the practice of cultivating mindfulness, or “presence” (Kabat-Zinn 2013) which proponents of MBSR claim will over time translate into increased agency over the activity of the mind: “Tell your mind, I’ll go there later.”

### ***B. Group Descriptions***

Table 4.1 describes the key characteristics of the three groups I observed, demonstrating the variation and similarities between each. While all three groups intended to train pain patients in how to self-manage their pain through a variety of techniques, other elements of each group differed significantly. The structure, primary purpose, and setting of each group both shaped and were shaped by specific techniques deployed for intervening upon patients’ pain levels. These specific techniques in turn necessitated a particular kind of patient, with groups calling upon patients to enact certain forms of self-management and engagement. Further, each group positioned itself differently with respect to trauma<sup>17</sup>, as some groups restricted access for patients with past and ongoing trauma conditions, and others focused their curriculum around these very

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<sup>17</sup> Throughout this chapter, I use the terms “trauma,” “patients with ongoing/a history of trauma,” and “PTSD” interchangeably, and often place these conditions alongside other mental health conditions. I place such mentions side by side because the content of what they refer to often overlap, though I do not mean to dismiss the distinctions between these classifications.

patients. These variations resulted in different configurations of each group’s structure, and led to facilitators taking up certain plasticity techniques in favor of others.

Table 4.1 breaks group characteristics into three sections: (1) Setting, which describes the geographic and institutional arrangements of each group; (2) Purpose, which attends to the primary interventions and intentions of each group; and (3) Trauma as Inclusion/Exclusion Criteria, which details how each group was organized with respect to trauma. Importantly, the setting of City Group and Neighborhood Group was quite similar and also quite distinct from that of the Lab Group; each group maintained a different balance between providing emotional support and psychoeducation; and each group held different positions with respect to including and tailoring to patients with trauma.

Table 4.1. Group Characteristics.

	<b>Lab Group</b>	<b>City Group</b>	<b>Neighborhood Group</b>
<b>Setting</b>			
Location:	Suburban	Urban	Urban
Institution:	Laboratory on a Private University Campus	Safety Net Clinic	Safety Net Clinic
Time:	Evening	Daytime	Daytime
<b>Purpose</b>			
Key intervention:	CBT only	CBT, MBSR, ACT—recent move to more CBT because of evidence-base	Focus on trauma—elements of CBT, ACT, and MBSR, but no allegiance to any one approach
Emphasis on Psychoeducation and Emotional Support:	Not support-based—entirely psychoeducational	Minimal support—mostly psychoeducational	Mostly support-based—limited psychoeducation
Manual:	Uses standardized manual developed for NIH funded laboratory study	Uses manual developed by facilitators and refined over the years	Uses manual originally designed for trauma & substance use

Table 4.1. Group Characteristics, continued.

	<b>Lab Group</b>	<b>City Group</b>	<b>Neighborhood Group</b>
<b>Trauma as Inclusion/Exclusion Criteria</b>			
Trauma:	No trauma/mental health conditions	No trauma	Trauma
Requirements for Enrollment:	Extensive—patients were screened for eligibility to participate in the study	Not be receiving overlapping services (i.e., no individual therapy); English speaking	High ACE <sup>18</sup> score; be on opiates
Gender:	Mixed gender	Mixed gender	Same gender (group observed was all women)

***C. Positional Map: Neural Techniques and Plasticity Discourses***

Figure 4.1 maps the positions taken by each of the three groups in relation to neural techniques and plasticity discourses. Positional maps are an analytic strategy that enable a spatial understanding of difference (Clarke 2005) by mapping positions held by various actors, concepts, or institutions. Analytic mapping strategies are a way of cartographically understanding and demonstrating the situational nature of these discourses. This mapping strategy allowed me to ascertain the distinctions that existed between neural and plasticity discourses, noting where they overlapped and where they diverged.

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<sup>18</sup> The Adverse Childhood Experience (ACE) scale is considered a standard assessment of childhood trauma (Felitti et al., 1998).

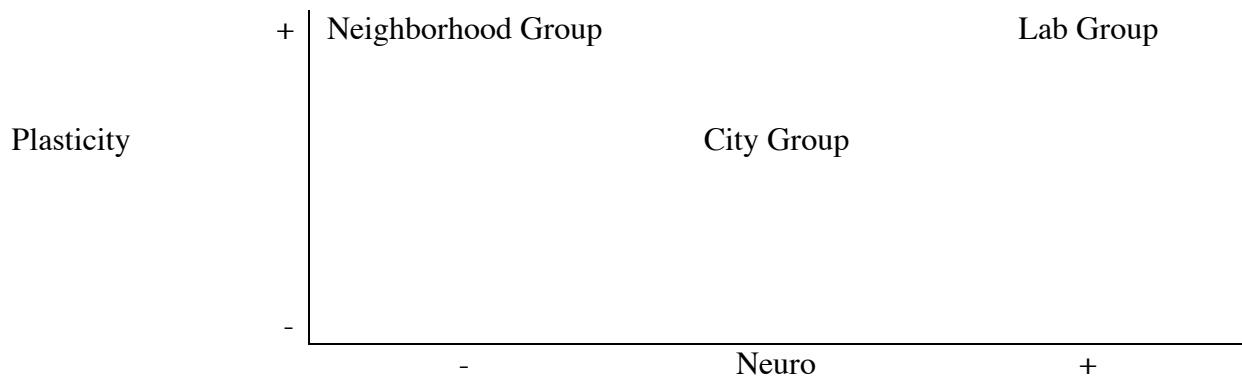


Figure 4.1. Positions taken by groups with respect to neural and plasticity techniques

Rather than a uniform leveraging of both neuroscientific models and plasticity techniques, each group held distinct configurations of these two discourses, situated in their structures, settings, and patient populations. The Lab Group evinced high levels of both neural and plasticity discourses. The City Group displayed medium levels of both neural and plasticity discourses. The Neighborhood Group, however, demonstrated low levels of neural discourses but high levels of plasticity discourses. These positions will be elaborated upon as the specific features of each group are described in turn later in this chapter. Positions not present in my data were high levels of neural discourses combined with low levels of plasticity discourses and low levels of both neural and plasticity discourses; the implications for these absences will be discussed in the conclusion section of this chapter.

### III. Lab Group

While the Lab Group did aim to help people with their pain, it was primarily intended for research purposes, as was made explicit via its positioning in a clinical research lab. Research subjects who enrolled in a broader neuroimaging study of non-pharmacological treatments for low back pain were placed in one of three interventions: CBT, MBSR, or acupuncture. The

particular group that I observed was intended to test the mechanisms of CBT's impact upon chronic pain. Group members were placed in an fMRI machine before and after this intervention in order to measure the effects of the intervention on their neural processing, as is described in more detail in Chapter Two of this dissertation. The facilitator of this and other Regional Neuroscience Pain Lab groups read from a script developed by the principal investigators and approved by National Institutes of Health, and were monitored by research assistants who were testing each group for fidelity.

The primary purpose of the Lab Group was to collect data on the mechanisms driving the effect of CBT upon chronic low back pain. In order to fulfill this function, the group was structured in particular ways, such as maintaining an exclusive focus on CBT and a rigid adherence to the scripted curriculum. This in turn promoted particular notions about both the neural nature of pain and what constitutes an ideal pain patient. The following section describes the ways in which the purpose and structure of this group co-constituted these neural conceptualizations of pain and these particular kinds of patients.

### ***A. Setting***

The Lab Group took place in a neuroscience pain lab that was a part of a private university, and was located in an affluent suburb. Group members had come to participate after enrolling in a heavily-publicized study of low back pain, often having learned about the study from advertisements placed in visible sections of the suburb's downtown district. This group was primarily intended to function as an engagement with scientific research, rather than to serve as a form of care.

The Lab Group was held in the evening so that participants could arrive after a full day of work. When a research assistant mentioned to Michelle, one of the group facilitators, that he thought this group was “mellow,” she nodded, saying:

They’re not a very psychiatric group. I think this might have something to do with them being evening people. They’re much different from the people who are like, ‘I’m free every Wednesday from 1-3.’

According to Michelle, Lab Group members were occupied during the day, and therefore, presumably employed, making the group less “psychiatric,” or less in need of emotional support than those who were not working, either for socioeconomic reasons or because their pain prevented them from regular employment.

Both the setting and the time frame of this group, then, presumed or even necessitated a certain type of pain patient. The Lab Group members were mainly white, English-speaking, and employed in highly skilled positions, traveling to the group from the nearby affluent neighborhoods. This impacted the ways in which neural and plasticity discourses were invoked; for instance, at one point Michelle discussed fears of homelessness, dismissing these fears as catastrophic thinking, and therefore out of the realm of realistic possibilities for these affluent group members. This assessment would not have been appropriate in either of the two safety net groups described later, in which many group members had, in fact, experienced homelessness.

### ***B. Purpose, Trauma, and Key Intervention***

The Lab Group was part of an ongoing study being conducted at the Regional Neuroscience Pain Lab and others around the country. The procedures of the study designated this group specifically as a Cognitive Behavioral Therapy (CBT) psychoeducational group. As the facilitator told students on the first day, reading from the script provided by the research assistants, “This program teaches how changing thoughts and behaviors can change your pain.”

Thus, unlike the other groups that combined a number of approaches in their curriculum, the Lab Group focused exclusively on CBT. The lab was co-currently running a mindfulness-based stress reduction (MBSR) group, which was designated as a completely different intervention that would be tested on a different test group. While the Lab Group did introduce group members to guided meditations, these were brief and the facilitator often softened the language around this, saying that group members could think of meditation as a “relaxation practice, if you like.”

One major way that the Lab Group was set apart from the other groups was that the primary purpose of this group was research, conducted in a controlled environment, rather than care. More specifically, the group that I observed was actually a trial run intended to evaluate a potential facilitator—while the data from this particular group was collected, it was not included in the analysis. If Michelle demonstrated that she could run this group in a manner in keeping with the intended curriculum developed by the PIs of the study, she would then be approved to facilitate other groups whose data *would* be counted in analysis. (I was permitted to observe this group specifically because it was a trial run—data would not be included in the final analysis, and therefore my attendance would not impact the fidelity of the procedures and the comparability of this group to other groups.) In other words, groups that were being run as an official part of the study had to be similar enough to be able to compare to one another. They had to be standardized. This process of standardization included, among other things, training instructors, maintaining fidelity to the script that was developed by the PIs, and ensuring that the only observers present were research assistants. As expected, then, this standardization process

did not—and could not—include all aspects of the group, such as the composition of its members and the ways they interacted with one another<sup>19</sup>.

This group's position as part of a scientific study to test the effects of CBT on chronic pain resulted in a narrowed and very specific level of engagement with both neuroscientific and plasticity discourses, wherein neuroscientific ways of understanding pain were held as primary, and patients' capacity to self-regulate and leverage what was often referred to as the "power of the mind" was taken as a given. This was not always the case, at least not to the same extent, in other groups. Frequently, the principles of CBT were presented via scientific discourses. In the illustrative example in the previous section of this chapter, Sabine drew a connection between thoughts, feelings, and pain, providing a "scientific reason" for why physical and emotional pain often co-occur by pointing to overlapping brain structures. In this particular group, even the introduction of CBT draws upon scientific rationales and neuroscientific education to anchor and provide support for the intervention. One of the key skills embedded within CBT is frequently termed "evidence-gathering," where patients are encouraged to examine their thoughts and, drawing upon scientific reasoning, look for evidence in their lives that either supports or negates that thought. The assumption is that our minds can either be used to help us or to "sabotage us," and it is only through careful, scientific evidence-gathering that we can harness the value of our brains and self-regulate our reactions to pain. Thus, CBT imagines a particular kind of pain patient: one who can leverage scientific practices to rationally weigh the evidence, and who is then capable of altering one's thoughts in order to optimize.

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<sup>19</sup> Often, members of the Lab Group looked at their phones while other group members shared, which no doubt impacted the experience, and perhaps efficacy, of the group.



Because the Lab Group took place as a part of a larger study whose eligibility criteria excluded those with mental health conditions, group members likewise had been previously screened and, at least theoretically, no one in the group had a history of trauma. As one scientist told me, mental health-related exclusion criteria served to preserve both the safety of study participants and the quality of the study data:

We want [a]very specific sample at this...we definitely exclude based on those inclusion/exclusion criteria, because we need to...draw finer grained inferences to define your data. Participants are asked [to fill out] a number of questionnaires. One of them is a psychological screening questionnaire that they answer before they are enrolled into the study...We make sure that there aren't any conditions that are going to interfere with the analysis down the road, if they're not going to be put in any harm's way in any way, shape or form.

The lack of group members with self-reported mental health conditions allowed for a particular configuration in the group, wherein support was minimal and the facilitator could focus more directly on the curriculum. Further, because creating a safe container was not a stated priority, the Lab Group was far less facilitator-dependent—so much so that, during one session, the facilitator was replaced with a substitute, Sabine, so that Michelle could attend another training.

This was the only group that did not specifically intend to provide emotional support for its members, either through peers or via the facilitator. This meant that the group members did not participate in check-ins or check-outs, sharing their pain scores and personal reflections, as was the case in the other groups. While the facilitator for this group was required to hold a degree in pain psychology, she was not expected to provide therapeutic support to the members of the group, although she frequently was called upon to navigate emotional content. When group members did raise emotional concerns related to their pain, Michelle—by necessity—had to quickly deflect and redirect the group back to the curriculum, as there were certain things that had to be covered during each session. Several times, I observed group members becoming teary,

or beginning to share more deeply about their emotional experiences. In response to this, Michelle would briefly acknowledge the patient's experience, and then quickly redirect to the course materials, often finding a way to connect the two. Michelle would often tell tearful patients that they could check in after class, and at that time refer them to individual therapy if necessary. If she noticed that a group member's emotions were getting overwhelming, she would invite them to step out of class, and then pivoted the conversation away from the patient's individual experience and towards the curriculum for that day. Finally, the facilitator engaged in far less personal sharing than in other groups, rarely talking about her own experiences—and, if she did, only discussing benign or inconsequential details about her life, such as her professional background and her aversion to cooking.

When I interviewed Michelle, she described how she would intervene when group members began to share too much, or became tearful during group:

Trying not to minimize her experience, but, 'We have a lot to cover in these few weeks. I want to make sure everybody gets the same experience, group to group. We want to keep it really consistent' ... .. I want to show that I and the group can tolerate their suffering and their experience. That's fine. It's hard to have pain.

In service of the science being conducted, Michelle frequently engaged in the difficult task of keeping the class moving along so as to maintain fidelity to the study protocol and the group's scripted curriculum, while also being sure to briefly acknowledge that emotions related to pain are valid. The rigidity of this structure limited the amount of personal sharing that members could engage in, and therefore allowed for a more primary focus on neural techniques and plasticity discourses. As opposed to other groups that aimed to provide more emotional support to its members, the Lab Group constrained the level of support available, and therefore was not an ideal environment for patients navigating intense feelings. Thus, the Lab Group necessitated a pain patient who could

already self-manage enough to not require resource-intensive emotional support, either from peers or from the facilitator. Again, because the primary focus of this group was research, rather than care, study PIs could develop inclusion/exclusion criteria that would restrict the group composition to just these kinds of self-regulating, healthy subjects<sup>20</sup>.

### ***C. High Neuro, High Plasticity***

As shown in Figure 4.1, the Lab Group evinced high engagement with both of neural *and* plasticity discourses. In the Lab Group, neural discourses were leveraged frequently throughout the curriculum. Unsurprisingly given the context of the group, the curriculum framed pain entirely in neural terms, describing it as an experience that “*is in your head*,” as Michelle said in an earlier quote. Pain’s position in the brain was never questioned or augmented with biomechanical notions of pain, but rather served as the central and sole foundation of the curriculum itself. Techniques were conceived of and described in terms of brain structures and supported with scientific evidence. For instance, the following fieldnote is taken from the session in which Michelle introduced CBT to the group:

“Let’s get back to the CBT stuff here,” Michelle says, telling the group to open their books. She reads from the manual about the emotional impact of “automatic thoughts,” or “thoughts that happen quickly and pop into our heads automatically.” Michelle summarizes, “This is just to remind you of the relationship between our thoughts and pain. Pain triggers the same kind of areas in our brain that certain negative emotions do. When you put someone in an MRI who’s experiencing physical pain, and you put someone in an MRI who’s experiencing emotional pain—sadness, anger, fear—the same areas of the brain light up.”

Even the introduction of the key intervention was premised upon neuroscientific understandings of pain, and referenced neuroimaging data to demonstrate the veracity of the claim. Further, these statements were rarely translated into lay terms, as we shall see examples of in future group

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<sup>20</sup> See Chapter Two of this dissertation for a more detailed account of how neuroscientists decide what types of samples to recruit for their pain studies.

discussions. Instead, Lab Group members are assumed to be of high enough literacy to be familiar with scientific terminology. (For example, Michelle once asked the group, “Fight or flight: remember this from high school biology? Our body’s original response to threat. Cortisol!”) Thus, the Lab Group exemplifies what a high level of neural engagement looks like within the context of these pain groups, and demonstrates what type of patient is imagined by leveraging this type of explanatory model.

In turn, plasticity discourses were also high in the Lab Group. Change was held up as the ultimate goal, both attainable via these techniques and preferable given the discomfort of group members’ current painful conditions. Agency was assumed, as group members were frequently told that they had control over their thoughts. The following fieldnote demonstrates this type of plasticity discourse:

“We don’t get to immediately change our emotions. We don’t get to say, ‘Turn that frown upside down,’ and then automatically feel good. But we do have command over how we think about our pain, our emotions,” Michelle says, in an optimistic tone, full of enthusiasm. “Then that trickles down into our thoughts. Research has shown us, we can alleviate some of that pain. Changing our thoughts can improve our emotions, our functioning, and our physical pain, too. We can learn to pull apart our thoughts and feelings.”

Again, founding her claims upon scientific research, the Lab Group facilitator based her intervention upon the assertion that pain patients “have command” over their thoughts and emotions. By exercising this command, or capitalizing on the agency inherent in “embrained subjects” (Rose & Abi-Rached 2014; Pitts-Taylor 2010), pain patients were conceived of as capable of altering their neural patterns, thereby actively participating in the process of plasticity.

While Michelle acknowledged that immediate change is not attainable, she contrasted this with the assumed capacity of group members to change their thoughts and thereby alleviate their own pain. This capacity was never questioned, nor was it ever positioned as difficult to

exercise, as was the case in other groups. Instead, Lab Group members were conceived of as the ideal pain patient: actively engaged in the practice of self-managing their own conditions.

#### **IV. City Group**

The City Group aimed to teach chronic pain patients self-management techniques, as well as to provide them with emotional support, both from peers and from facilitators. Further, the group served the purpose of providing training in pain management strategies to medical residents, while at the same time exposing these residents to the types of pain patients they would be encountering in this safety net hospital. These joint aims shaped the structure of the group, and dictated the types of techniques that would be deployed within the curriculum. The setting, structure, and purpose of this group also produced particular conceptualizations of pain and was constitutive of the type of pain patient best served by this kind of intervention.

##### ***A. Setting***

The City Group was embedded within City Health System, an urban safety net hospital that was connected to a public medical school. Group members came to participate after being referred by their primary care providers (PCPs), who were looking to augment care for their chronic pain patients. These PCPs had largely heard about the group from the mental health services department embedded within their clinic, or were residents who had been exposed to the group during their training. Veronica, the group facilitator, would often demonstrate do's and don'ts of a good referral to the visiting residents, emphasizing that patients should be assured that they were not being sent to the pain group because their PCP thought that their pain was "all in their head." The following fieldnote describes Veronica's suggestions to a resident of how to make a good referral:

“The trick is making a referral that people will accept,” Veronica tells the resident. “I usually frame it as, ‘I know that this pain has really impacted your life: your relationships, your sense of who you are, your emotions. It’s had a deep and broad impact. I’m not saying this pain isn’t real or that it’s in your head—it’s absolutely real. That’s why you need extra support—I’m not saying that talking is going to make it go away.’”

City Group facilitators frequently coached visiting residents in how to validate patients’ pain experiences, while at the same time promoting neuroscientific, rather than biomechanical, understandings of pain itself. Through Veronica’s suggestions, we see an example of how clinicians and facilitators hedged against the perceived risks of recommending psychosocial or neurological interventions to pain patients. Fearing that these suggestions would be interpreted by pain patients as being told that their pain was imaginary or psychiatric in nature, clinicians frequently over-emphasized the “realness” of pain, pointing to the biological reality of pain and its material consequences upon patients’ lives. This concern on the part of clinicians stands in interesting contrast to Mara Buchbinder’s (2015a) findings that the use of neurobiological explanatory models of pain had the potential for legitimizing pain patients’ experiences and thereby abating stigma. This departure could reflect the differing clinical contexts: while Buchbinder’s study drew upon data collected in a pain clinic for upper-class gifted and talented adolescents, wherein their social positioning was leveraged in their treatment (2015b), the clinicians interviewed and pain groups observed in my study were primarily situated in safety net clinics, serving a predominantly low-literacy patient population.

### ***B. Purpose, Trauma, and Key Intervention***

The City Group combined psychoeducation with support. As Veronica said to a resident who was observing the group:

The group is designed to target pain in three ways—or there are three ways in which they think it functions. One, help people reframe their relationship with pain. Still feel like

whole human beings in the experience. Two, through evidence based practices—reduce people’s pain score. Three, feel supported and understood.

Points one and two described above refer to the psychoeducational interventions deployed by City Group, such as Therapeutic Neuroscience Education (TNE), Cognitive Behavioral Therapy (CBT) and Mindfulness-Based Stress Reduction (MBSR). In addition to these practices, group members also received emotional support, ideally both from one another and from facilitators.

The psychoeducational interventions deployed in the City Group were wide-ranging, but facilitators mostly drew upon CBT and MBSR<sup>21</sup>, with a brief introduction to the group using TNE. Interestingly, following a change of facilitators, the group had recently shifted to emphasizing CBT over other techniques, rewriting its manual to include more CBT-based instruction. When I asked facilitators why this shift had occurred, I was told that CBT has a superior evidence base and is easier to protocolize than other techniques: as Hannah, a facilitator of the City Group, said in an interview, “It's a lot easier to have a manualized treatment when you have the same protocol that you do for everything.” CBT was seen as rooted in fundamental principles that can be conveyed by anyone, making it less facilitator-dependent than other interventions and therefore easier to scale. As Veronica shared in her interview:

CBT is coming to dominate all of medicine as the model that is proving to work. It's easy to study. You can do short studies. You can have protocol. You can have lousy therapists and it still works fine. It's the best model.

According to these facilitators, as well as other professionals I spoke with and observed in my study, CBT is simpler to study, disseminate, and scale than other techniques historically deployed in this group, and was therefore favored by hospital administrators who needed to demonstrate

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<sup>21</sup> Both the City Group and the Neighborhood Group also drew upon a technique called Acceptance and Commitment Therapy (ACT), which was premised upon teaching pain patients to accept the limitations of living with chronic pain without letting these limits keep them from enjoying the things they value. ACT is not taken up directly in this analysis because it proved more tangential than CBT and MBSR.

efficacy in order to justify the allocation of resources necessary to run the group. While the City Group still included other techniques, and still provided emotional support, its emphasis on a manualized curriculum meant that certain types of patients were better served by this group than others, and these patients were served in a particular way.

As is demonstrated by Veronica's guided meditation described in a previous section of this chapter, MBSR has some overlap with CBT: both practices focus on identifying thoughts and feelings. However, MBSR is differentiated in that it encourages acceptance, rather than revision, of those thoughts. "There's no problem with any thought you're having—they're all allowed," Veronica said during the meditation. Within the context of these groups, this acceptance of thoughts and feelings is imparted as a self-management skill that is distinct from the CBT practice of developing "alternative thoughts" in order to eliminate "negative feelings." Both CBT and MBSR, however, are intended to equip pain patients to self-regulate their own painful conditions, transforming them into active and engaged patients.

Several clinicians identified the focus on the present moment as the key intervention for chronic pain embedded within MBSR<sup>22</sup>. One clinician shared the following:

What I would say is, if you're sitting and you're being mindful, what you're doing is you're sort of withdrawing from worries about the future and ruminating about the past and you're able to focus. "Well, how bad is it right now? To what extent is my anticipation contributing to it?"...it gives you a more objective view, takes the fear of pain and dampens its power to actually produce more pain.

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<sup>22</sup> As referenced previously, the pain groups I observed drew upon elements of MBSR, without teaching it in its entirety. Thus, the analysis of this technique is not reflective of MBSR writ large, but speaks more to the ways in which an abstracted and condensed version of this technique frequently appears in clinical settings. Similarly, this analysis is not intended to serve as commentary on mindfulness practices as a whole: MBSR is itself an abstracted version of mindfulness meditation practices (Yahm 2018), and thus this paper is in essence analyzing an abstraction of an abstraction. However, it is this abstraction that is appearing as a technique within pain medicine, and should thus be attended to in its current form.



According to this account, mindfulness practices impart pain patients with a “more objective view” of pain by training them to focus on the present, rather than the future or the past. This practice looks similar to the “evidence-gathering” of CBT. Both techniques, at least as they are conveyed by facilitators I observed and interviewed, are premised on the notion that there is an “objective” way to conceptualize painful sensations, and that these techniques are the tools that allow pain patients to gain such objectivity. This implies that, if pain patients were able to perceive their situations accurately, their reactions to painful sensations would be diminished, and thus their pain would be reduced. Both MBSR and CBT can be conceived of as practices of perpetual surveillance in pursuit of self-knowledge (Foucault 1978), which pain patients are encouraged to engage in order to transform themselves into optimized patient-subjects.

The City Group’s focus on a manualized form of care such as CBT, instead of a less structured approach to providing support, often meant that the breadth of emotional content was more scripted and constrained. While the City Group had historically been more oriented towards providing emotional support, recent changes in facilitators prompted more psychoeducational aspects of the group to be emphasized, such as CBT. Still, each group session would begin with check-ins, wherein patients would share their pain level that day on a scale of 1-10, as well as what the week had been like for them emotionally and physically. These check-ins would often turn into long and emotional shares, and both facilitators worked to hold space for what was coming up for patients, while also ensuring that no one patient dominated the entire check-in time. Facilitators were slightly more forthcoming about their own life experiences in this group than in the Lab Group, though still mostly kept the focus on the patients, and on the curriculum.

Like the Lab Group, City Group facilitators had to walk a tightrope between acknowledging emotions and moving things along. However, because the purpose of the City

Group was not to impart a standardized intervention as part of a research study, and its structure was therefore much more relaxed, there was space and leeway to allow for more in-depth sharing than in the Lab Group. Similarly to the Lab Group facilitator, however, City Group facilitators frequently tried to tie individual shares to the broader aims of the group. For instance, during check-ins, facilitators would frequently interrupt, pointing out ways in which patients were incorporating the skills conveyed in the group into their day-to-day lives: “Sounds like you were doing a good job of pacing<sup>23</sup>,” Hannah would sometimes reflect during an emotional share. This signified one way that City Group facilitators constrained the emotional content of the group: rather than letting patients express their experiences without limitations, facilitators actively worked to redirect patients back to the overall lessons they were trying to convey.

Another way that City Group (and, as we saw previously, Lab Group) facilitators were able to constrain the emotional content of the group was by applying the very skills of CBT to those intensely emotive shares of various group members. One premise of CBT is that focusing on “negative” thoughts and feelings will promote more pain, and therefore should be avoided or replaced with “helpful” thoughts. Therefore, this form of interjecting and redirecting carried out by the facilitators was, in and of itself, a way of demonstrating the core practice of CBT. For example, in response to a long and tearful share, Hannah said, “Sounds like you were doing a really good job of identifying helpful and unhelpful thoughts,” praising the patient for taking up some of the CBT skills she had been learning in group. Hannah was simultaneously redirecting the group back to the curriculum and demonstrating how to engage in CBT: by replacing a

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<sup>23</sup> Pacing was one skill taught in each of the three groups, which involved realistic goal setting and structured productivity.

“negative” or “unhelpful” thought (one that leads to tears) with a “helpful” thought: “you’re doing a good job of applying this new skill to your problems.”

Both City Group facilitators, and a host of referring PCPs at City Health System, praised CBT for its scalability and efficacy—one clinician said, “CBT changes people’s lives.” At the same time, however, Veronica worried about this very potential for constraining emotional content. During an interview, she told me:

CBT feels like just brushing the outer layer of your hair, but not actually getting in and brushing your hair ... I do fear that the CBT model underestimates what people are capable of and has the potential to deprive people of a more rich lived experience. It really does pathologize. They say unhelpful and helpful instead of good and bad or whatever, but it pathologizes certain tendencies in life.

Veronica felt that CBT denied patients the opportunity to discover more about themselves. She critiqued CBT for its pathologizing of certain emotional states, such as anger, fear, sadness, worrying that the City Group’s emphasis on manualized interventions like CBT would limit the type of help that they could offer patients. She pointed to ways in which specific plasticity techniques, such as CBT, constrain the depth at which such interventions can engage patients. This constraint is a function of the limits of the health care system, in which reimbursement structures often restrict the time allotted to individual patients, particularly in safety net settings. CBT works well within such a system because it provides a means to offer protocolized, brief, and limited interventions to manage the emotional manifestations of much deeper and complicated life experiences. CBT, therefore, is itself co-constitutive of resource-poor system. As Veronica mentioned later, reflecting on the potential implications of a tailored or stratified approach to pain management techniques: “It’s been such an interesting juxtaposition of strategies. I worry that I’m teaching mindfulness to the rich people and CBT to the poor people

because I think that's what the poor people can handle or because our system thinks that's what they can handle. Maybe it's true.”

Veronica’s concern was reflective of a larger trend in the City Group, wherein eligibility requirements had recently shifted and adopted restrictions on patients with trauma and other severe mental health conditions. When asked about these new restrictions, facilitators stated that trauma was best saved for one-on-one therapy, given that its expression can be triggering for other group members. The hospital that housed the City Group apparently required that patients not be receiving double services<sup>24</sup>, which meant that no patients who were actively engaged in individual therapy were eligible to participate in the group.

Although this preference for avoiding patients with a history of trauma was stated several times to me and to other observers of the group, several episodes occurred during my observations in which facilitators or residents felt that patients’ trauma symptoms were activated. Facilitators and observing residents would stay after group to briefly discuss how the session went, and frequently the discussion revolved around a patient’s mental health condition or traumatic history. The following fieldnote describes a typical post-group check in:

After the last patient leaves, Hannah closes the door and Veronica says to the resident in attendance, “I know that you need to get to clinic, but quickly, we always ask the newcomer: What went well? What could we do better?” The resident looks stumped. She asks about the individual patients: “What are the causes of their pain?” Veronica hesitates for a moment before describing each patient in detail. She links their pain conditions to what she sees as the emotional factors that are contributing to their experiences of suffering; one patient deals with a lot of depression and lack of support from her family, she shares. She talks about one patient’s struggle with her family member’s kidnapping. “The new patient, she’s been in group before. She’s been married three times, each with a lot of domestic violence. Her last partner hit her in the head with a lead pipe. She’s dealing with a lot of trauma.”

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<sup>24</sup> This institutional policy wound up being more complex than presented here: While one facilitator and one referring MD said that not receiving double services was a requirement for the pain group, another facilitator said that this wasn’t a requirement of the group.

While the group explicitly excluded patients with active trauma symptoms, in practice, they wound up working mostly with patients with active trauma symptoms and other mental health conditions. Further, as many of the City Group members were immigrants and poor women of color, placing them at high risk for experiencing traumatic events, some developed active trauma symptoms *while* participating in the group.

Disagreement existed as to how rigorously they should enforce their policy of not working with trauma patients, given how much trauma was already presenting itself on a weekly basis. Previous iterations of the group had been much more focused on support, and therefore allowed more room for working with trauma symptoms. Veronica had been involved in those previous group iterations, and shared in an interview that navigating the trauma that came up proved difficult but possible:

When I first started doing group (I worked with a psychologist) who was super comfortable with messes. He'd take anyone...The messes that come up are really trauma related messes. One person triggering another is rough...When somebody can't stop themselves from telling a really traumatizing story, for example, that's rough for the group and can do harm. That's the mess that you have to watch out for. Even then, we used to handle it. I remember we had one guy... Every time we would do the deep breathing...he would tap his foot. Then I remember once we tried to do a meditation and he just left the room. [The other facilitator] kept going through the meditation and I followed the patient... I would spend the time with him in the hall and he'd say, "Yeah, every time I do that, memories come up that I don't want to have." I'd say, "What helps you? He'd say, "Thinking about music." We'd sing a song out in the hall and then we'd go back and have the rest of group, which was fine. In fact, a dozen weeks into the group, he announced, "I realize there's something I want to tell my family." Then he starts telling this story and I realize by "family," he meant the group. He tells us this story of having been raped when he was 8 years old and going home and wanting to tell his mom but his mom had just been beaten by his father. He felt he couldn't tell her. I mean, horribly traumatic experience for him that he had never told anybody. That's what was going on for him. I think those are the kinds of mess that, right now, the [clinical team that runs the group] doesn't want to have because they worry that it will disrupt the structure of the group. I feel like that's exactly the kind of disruption that helps people.

In her recollection of this moment with the patient in the wheelchair, Veronica was sharing a success that she had experienced as a result of making more space for trauma. But in the most

recent iteration of the group, facilitators stuck to the script and avoided taking on patients with traumatic symptoms in hopes of containing these messes, according to this account. She did not feel as though the current group's emphasis on evidence-based treatments, such as CBT, over more freeform emotional support, was as likely to result in "the kind of disruption that helps people."

### *C. Medium Neuro, Medium Plasticity*

As shown on Figure 4.1, The City Group occupied a midpoint on both neural and plasticity discourses. While the group was premised upon psychosocial or neurological interventions for chronic pain, and avoided biomechanical explanatory models of pain, there was less emphasis on positioning pain as a brain disease than in the Lab Group. Further, plasticity discourses were not leveraged to the extent that they were in the other two groups, as City Group members were not conceived of as being universally capable of, and therefore obligated to, change their neural patterns.

City Group began the curriculum with an introduction to the neural mechanisms of pain, drawing upon the principles of TNE described earlier. The following fieldnote encapsulates the entirety of that neuroscientific introduction:

Veronica goes to the whiteboard and draws a picture of a stick person smiling, making a joke about her drawing skills. "If you injure your toe, how does that pain signal get into your mind?" She draws a long nerve and explains that the pain signal gets passed from nerve to nerve along the spine until it reaches the brain. She explains that one part of the brain that gets signaled is the front: the part that helps us determine what to do with that pain. "This is the part that does all of our critical thinking—it's where we think. It starts to tell us stories about the pain. Where it's coming from, what it means." She explains, "There are other spots where we're having all of the emotions about the pain: 'I'm upset, I'm angry.' And of course, thoughts impact our emotions. They feed in and make them more intense. So there's the experience of the pain itself, our thoughts about pain, and our feelings about pain. All three of these things, when you put them together, can lead to suffering. The bad news is that this all happens really fast," she gestures at what she's just

drawn on the board. “The good news is that at every connection point, we can change the way that signal gets experienced.” She lists ways in which we can slow the signal down, including medication. She then says that the other way to slow down the signal is with our emotions: “All the things we’ve learned here in this group—if we can work on our thoughts, that can help with our emotions, and help with our pain.”

Similarly to the Lab Group, this facilitator used neuroscientific language and imagery in order to bolster claims about plasticity techniques. However, her description above included more contextualization and was slightly less technical than in the Lab Group, reflecting the presumed literacy levels of the City Group patient population. Further, there was no reference in this group to scientific evidence, as was the case in the Lab Group.

Most significantly, this was the City Group’s only engagement with TNE. Although facilitators had elected to begin the group with this neuroscientific overview, it did not serve as a foundation for the entire curriculum, as enrollment was rolling and group members could join at any point. This resulted each group session being stand-alone, meaning that Week One, the neuroscience week, was taught to different group members at different points in their trajectory. Thus, rather than continually referring back to brain structures, as was the case in the Lab Group, City Group facilitators rarely referred to the neural mechanisms of pain, other than occasionally mentioning the “pain gates” when describing the impacts of various techniques.

As is evident in the fieldnote above, the City Group did uphold notions of plasticity and change: “we can change that way that signal gets experienced.” This change was mostly conceptualized as occurring through the application of CBT, wherein patients were trained in how to rewrite their reactions to their pain. The following fieldnote describes how this practice was conveyed in the City Group:

Hannah goes to the board and begins to take examples from the group of thoughts they have had about their pain. She describes the difference between helpful and unhelpful thoughts. “Helpful thoughts tend to improve your mood and decrease your pain.” Together, they walk through some examples, labeling thoughts as helpful or unhelpful.

She says, “Once you’ve figured out that a thought is unhelpful, we can work together to see how we can change that thought.” She offers a suggestion for changing an unhelpful thought into a helpful thought: “Instead of, ‘What did I do to cause my pain?’ —that’s an unhelpful thought, right? It’s depressing! We can change that thought into: ‘I don’t know what caused my pain, but I’m going to work on managing it until it gets better.’ See? A helpful thought moves you in the direction you want to go.” Some group members are having difficulty coming up with examples of their thoughts, and Veronica jumps in, “Every time you say something, you’re expressing a thought.”

This group worked within the framework of CBT to “change” thoughts, thereby equipping group members with the tools of plasticity.

However, facilitators often struggled to convey the plasticity principles of CBT and MBSR, as is demonstrated by Veronica’s attempt to coach group members in how to identify a thought. City Group facilitators would often complain after group that the group members were not “psychologically minded.” When I asked in an interview what this meant, Hannah answered as follows:

Hannah: [To me, psychologically minded means] having an idea of your thoughts and your emotions and being able to identify them...If you ask [some people] how they're feeling, they don't even really know how to describe it... It's really hard for them to verbalize or even identify what the emotion is.

Sara: Where does that come from? Where do people gather those tools?

Hannah: I think to some extent it's taught, especially as you're growing up if you have a caregiver...who's very attuned and is able to help you with whatever the emotion is, that you're crying and you're really upset, being able to say "Wow, you're really upset, are you hurt right now? Are you sad?" Putting a name to that helps kids learn how to name it. In cultures or families where there's a bigger emphasis on shutting down emotion and putting on a brave face and just pushing through, those folks tend to have a much harder time being able to identify what emotion they're experiencing.

Patients raised with the skills of identifying thoughts and feelings are not necessarily “psychologically minded” enough to be capable of engaging in plasticity techniques, according to this account. Another referring PCP described the divide more sharply, speaking specifically to the gap between those who he saw potentially benefiting from CBT and those who might not:



Clinician: Cognitive behavioral therapy has a good evidence-base...Intuitively it's very appealing to me as well. It's not for everybody.

Sara: Why do you say that it's not for everybody?

Clinician: Well, because not everyone is a rational, thoughtful person.

According to these assessments, the initial steps of plasticity techniques are not accessible to certain kinds of patients: those who were not raised in environments that nurtured a specific kind of emotional intelligence. Hannah chooses her words carefully, being cautious not to place blame or essentialize the shortcomings of these patients. She does, however, point to a perceived parenting deficiency, which she may or may not see as being structurally produced. The patients in the City Group invariably occupied marginalized social positions; almost all were women of color, many were immigrants, and, by nature of being reliant on a safety net clinic for care, all were presumably economically disadvantaged. Thus, various axes of inequality were operating within this group, with the logics and values of the white, middle class facilitators sometimes fitting uncomfortably alongside those of patients.

Thus, within the context of the City Group and its network of referring providers, plasticity is seen as possible but not inevitable. Under this configuration, CBT and other plasticity techniques imagine a particular kind of patient—a rational, thoughtful patient who was brought up by sensitive and attentive (and perhaps culturally-specific) parents and consequentially developed the foundation for good self-management skills. While change is possible, it requires a particular starting point, and in order to benefit from these plasticity techniques, patients must always-already be “activated” (Van Natta et al., 2018; Bodenhemier et al., 2002), or primed for a particular kind of engagement. As alluded to above, these valuations about what types of patients are rational and thoughtful are racialized and classed, embedded with assumptions about what constitutes a healthy response to emotional discomfort.

## **V. Neighborhood Group**

Finally, the third of the pain groups I observed, which I call the Neighborhood Group, was developed specifically to address the intersections between pain and trauma. When I first spoke to Nicole, the facilitator who had founded the group, she shared with me that her experience as a clinician had allowed her to see how intertwined PTSD and chronic pain were in her patient population. She theorized that addressing trauma would help people manage their painful symptoms, and had found some literature that supported this theory. Nicole told me during an informal conversation, “My model is very practical. I want to make people suffer less, and I see these groups as doing that.”

At the time of my observations, the Neighborhood Group had been operating for seven years and Nicole lovingly referred to it as “her baby.” She had advocated for the group and had eventually been granted four hours a week for group facilitation and administration (the group itself was two hours long). Previous attempts to transfer facilitation to other providers had not proven successful, according to Nicole. Thus, the Neighborhood Group was the most facilitator-dependent model that I observed, and required a tremendous amount of time and dedication from both Nicole and her co-facilitator, Grace. Following the conclusion of my observations, the Neighborhood Group was cut by clinic administrators. “It’s not seen as productive,” said the clinician who broke the news to me in an interview. While the data I collected does not allow for a clear determination as to why the clinic’s administration ended the group, the interpretation shared by the clinician quoted here provides some insights.

The primary purpose of this group—to alleviate the suffering of chronic pain patients—shaped the structure and interventions offered. In turn, the group upheld particular notions of pain patienthood and the nature of pain itself. Below, I analyze the positions that the

Neighborhood Group held in relation to neural and plasticity discourses, and discuss the type of patient constituted by such configurations.

### ***A. Setting***

The Neighborhood Group was part of a small, safety net clinic located in a mixed-income neighborhood of a major city. The clinic largely served patients who could walk to their appointments from the nearby housing projects; the small parking lot in front held approximately ten cars, and all of the spots were reserved for patients. Patients came to group after having been referred by their PCP or their mental health provider. Most of the PCPs I interviewed and spoke with in the halls expressed enthusiasm for what they called “Nicole’s group,” describing the differences they saw in the patients they had referred, even after a few short sessions:

I see that there's this transformative thing that happens after they've come to [Nicole's] for even two times. It's really amazing. I notice that they're more confident, they're more comfortable in the clinic, that they have this sense of wellbeing that I didn't ever see in them before.

Another referring PCP told me, “There’s magic that happens in that group.” While the other groups were described by facilitators and referring PCPs as “helpful” or “beneficial for some,” the Neighborhood Group was typically described as “transformative.” Unlike the Lab Group and even the City Group, the Neighborhood Group primarily sought to intervene upon *suffering*, rather than pain scores. Nicole and Grace described their group as “healing”: “Pills don’t work for healing,” they told members of group. “You can not only recover from this but be stronger because of it.” This orientation towards healing, rather than “fixing”, shaped the structure of the group, the interventions selected, and the level of engagement with plasticity discourses. All of these factors in turn imagined a particular kind of ideal pain patient: one who desires and is prepared for transformation, or healing.

### ***B. Purpose, Trauma, and Key Intervention***

The Neighborhood Group was nearly all support-based, wherein group members provided one another with emotional support via sharing and listening, and facilitators did the same. Their engagement with trauma led the facilitators to utilize the Seeking Safety (Najavits 2002) manual, developed initially as a guide for working on trauma and substance use. The facilitators shared with me that they saw trauma and substance use as being frequently conflated with pain, and in the group, each time they would read a section of the manual that said, “trauma and substance use,” Nicole would typically add, smiling (and often looking at me), “and *pain!*” This was the only revision that they had made to the manual, aside from occasionally adding quotes and activities that one of the facilitators had discovered.

Even though this group followed a manual, they were the least rigid in their adherence to it, and therefore had more flexibility to allow patients to share without redirecting them. In fact, one facilitator estimated that patients spoke 80% of the time, and worried that, because I would not be taking notes on anything that patients shared, I would not have much to write down at all. Patients engaged in lengthy and personal check-ins and check-outs, sharing not just about their pain but also about the broader contexts of their lives. Notably, facilitators also participated in these, and would often share very personally about their own emotional lives, acknowledging when they had had a hard day, or when they were fighting with family members. Interestingly, although fieldwork in all three groups occurred simultaneous to the 2017 inauguration of Donald Trump, this was the only group where facilitators mentioned their feelings about the political climate, and their concerns for what these changes might mean for their patients.

Unlike the redirecting that occurred in other groups when emotions became high, the facilitators of the Neighborhood Group gave patients a lot of space to experience their

heightened feelings. Facilitators saw strong emotional responses as an opportunity for skill-building. This is made apparent from the following fieldnote, in which Grace worked with a patient who was struggling with intense emotions:

When one patient becomes tearful during her check-in, Grace pauses and asks her what her intensity level is, from 1-10. Together they talk about the tingly feeling that she's experiencing, and Grace says that this is good—it's telling her something about what's going on for her. "Can you describe something good that's happened to you?" Grace asks the patient. She encourages the patient to feel her feet on the floor, and to take a deep breath. The facilitator breathes with her. Then she says, "One more time. Where's your intensity level? Right now, 1-10?" When the patient reports a lower number than before, the Grace reflects, "Good. It went down. Right on."

Grace was not rushing through this exchange in order to cover more of the curriculum for that day, as might have occurred in another group. This moment *was* the curriculum, and she used it as a teaching moment, demonstrating how patients can go about regulating their emotions.

Neighborhood Group facilitators viewed these moments of emotional management as the key intervention of the group: helping patients to link their emotional states to their physical states, and giving them tools to manage both.

This group's wider intent to reduce suffering, rather than a narrower focus on lowering patients' pain scores, rendered it the least scripted group. In other words, while facilitators did have broad aims for each session, such as discussing boundaries, or talking about pacing, the patients led the way: facilitators were not following a script, and did not interrupt patients' sharing in order to 'get back on track' and move through the curriculum. The broad scope of this group, and its emphasis on support over education, meant that it was difficult to scale up or replicate; the success of the group, as was recognized by the facilitators, was entirely dependent on the skill of the facilitator in navigating emotional content. The type of patient that this group was constitutive of—a patient with high levels of trauma—required a high level of flexibility and

emotional support, and, in the end, this need may have proven unsustainable given the constraints of the currently configured safety net health care system.

This group was the only one I observed or heard about that required patients to have a score of 6 or higher on the 10-point Adverse Childhood Experiences (ACE) scale, which is considered to be a standard assessment of childhood trauma. This group was specifically intended to help patients understand and work with the connections between their trauma and their pain, and therefore necessitated patients with trauma and/or PTSD. Rather than managing or circumscribing the complexity that comes with trauma, as was the case with the other groups, this group sought to engage with that complexity directly. Neighborhood Group facilitators told me that they had seen ACE scores range from a low of 4 and a high of 10, the maximum score allowed by the scale. Nicole made it explicit in our initial conversations that the population they work with were all “exposed to a lot of trauma,” as many had grown up in, and were continuing to live in, structurally disadvantaged conditions that in turn made them vulnerable to the structural violence that proliferates under such circumstances. She and other providers working within this clinic listed examples, such as patients falling out of windows, being involved in gun violence, and experiencing ongoing physical and psychological abuse.

But while sharing and processing was encouraged, Neighborhood Group members were not allowed to share the historical details of their trauma, as the group was intended to focus on the present moment, rather than excavate the past. This was stated upfront, and was tied to the need for safety. The following fieldnote is taken from the initial session of the Neighborhood Group, wherein facilitators laid out the ground rules for the group:

Grace begins to talk about the agreements that they hold in this group. “First, this is a safe space. For our bodies, for our emotions. We need to have the ability to trust one another. One of the ways that we do this is—we don’t talk about the details of our past traumas. The way this group is designed, we won’t need to.” Nicole adds to this, saying to the

group, “Sharing details about what’s happening now — that’s perfect. Details about past nastiness — not helpful.”

Other precautions were taken in the Neighborhood Group to ensure safety for patients living with both ongoing and past traumas. For instance, outside observers were not welcome; I was allowed to attend the group only under certain conditions, and only after extensive negotiations with group facilitators. When I requested to attend only every other group meeting as my research procedures had originally stated, Nicole and Grace objected, stating that this would be disruptive to the safe container that they worked hard to create in the group. Rather than sitting quietly and observing, as I had done with the two other groups, the facilitators required that I actively participate in the group, sharing during check-ins and check-outs, and answering any questions that the group members might have about my experiences with pain, to the extent that I felt comfortable doing so. While I can’t be sure, I suspect that my background as a clinical bodyworker working primarily with patients with trauma histories created more willingness amongst the Neighborhood Group facilitators to allow me into the group. When other providers requested to sit in on the group so that they could develop their own comparable group at another clinic, Nicole objected, stating that they already had one observer (me), and that one was her limit. Further, pain groups held at the Neighborhood Primary Care Clinic were always gender-specific, either all male or all female, in order to maintain a feeling of safety for patients dealing with trauma; the group that I observed consisted entirely of female-identifying patients.

Despite these precautions, there were moments during my observation where the emotional content of the Neighborhood Group escalated and became intense in nature. These incidents were handled similarly to the way that high emotional content was handled in the other groups: if patients became triggered or emotionally activated, they were encouraged to step outside. One

facilitator would follow the activated patient while the other would stay with the group.

However, during one such instance, the facilitator who remained with the group was left with the challenge of restoring safety amongst the group after a potentially triggering experience, and this seemed difficult to do on her own; she later shared that she could have used some additional help in “anchoring” the group during such moments. As Nicole told me when discussing the history of the group:

We’ve had patients who we needed to send to the emergency room because they were having chest pains during the group, and another woman who started dry heaving because she was talking about her daughter and was having so many somatic symptoms.

After one particularly stressful session, I stayed to debrief with the facilitators, and Nicole reflected, “These patients are the hardest of the hard. Both pain and trauma. No one else wants to deal with these people.” This mirrored something she said later in her interview with me:

They don't teach trauma in medical school...Most of the medical students that I get coming through don't know about the ACE score...the way we like to do medicine, we like to have it nice and simple...I think that is why no one wants to touch trauma, it's considered to be too messy and they don't know it.

The messiness that comes along with trauma makes it difficult to study, teach, and treat via protocolized and evidence-based methods. Neighborhood Group facilitators were willing to take risks that other facilitators were not able or willing to take when it came to treating complicated trauma patients with creative and freeform emotional support; they were eager to try innovative approaches to managing the overlapping pain and trauma of their group members, given the suffering they saw (see also Thompson-Lastad 2018)<sup>25</sup>. While Nicole had hopes of establishing an evidence base around the type of care she was providing, she was also aware that she was a

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<sup>25</sup> As Ariana Thompson-Lastad (2018) found in her study of similar pain groups, some facilitators were more willing to be opportunistic when it came to the treatment of chronic pain, whereby the inherent uncertainty surrounding chronic pain invited a willingness to experiment with treatments that had corresponding uncertainty in terms of efficacy.



pioneer in this terrain, drawing more heavily upon her experiential knowledge as a provider than on the scientific literature.

While the Seeking Safety manual that the Neighborhood Group used drew loosely from CBT and MBSR, facilitators were skeptical about how these techniques would land with the type of patients that they served. Nicole told me early on that she did not feel that CBT alone was sufficient to treat the pain-trauma nexus, and believed that trauma had to be addressed directly; however, she still preferred CBT to mindfulness for “people with bad trauma and complex trauma...they’re the ones who can dissociate really easily. A body scan might not be such a good idea.” Grace expressed different concerns about MBSR techniques for patients experiencing ongoing trauma:

There are some situations where I think telling a person to just be mindful and in the moment and present and all of that might come off as being very trite or glib in response to a person's current situation. For example, a lot of people in the projects have long histories of community violence and are in constant threat. When I have a patient whose reality, whose current reality is that someone could shoot them or that two of their family members have been shot right in front of them, and that they're going right back to the place where their family members were shot. For instance, I have a patient that I'm working with right now who was shot three years ago and was nearly killed. The perpetrator is still at large, so for me to say to be in this present moment and feel safe is not appropriate because nobody knows who did it, and nobody knows where the person is or why that person did it. We can guess, but the bulk of the work with him, he's got agoraphobia and severe trauma. The mindfulness pieces that I do bring into a case like that might switch the focus to give yourself an opportunity to take a breath right now. Give an opportunity to look around when you're waking up from a nightmare. Everything still feels intense, to take a breath and touch the walls and look around the room and say, "These are my belongings. This is my place. The door is locked. This is my reality. My reality in this space right now is grounded and safe." I'm not sure if [telling them to be in the moment] makes sense.

Grace’s version of MBSR incorporated bringing patients into the present moment, which she felt, for many of the patients she worked with in group, was not a safe or useful intervention.

Neighborhood Group facilitators felt that CBT was a safer technique for addressing the

intersections of trauma and pain than MBSR, which had bearing upon the ways in which they engaged with plasticity discourses, as is described in the following section.

### *C. Low Neuro, High Plasticity*

Neighborhood Group facilitators deliberately avoided engaging with neuroscientific explanatory models of pain. However, as I explore below, this did not translate into a dearth of plasticity discourses; quite the opposite: the Neighborhood Group forefronted the notion of change, and more so than any other group, pinned an imperative or obligation to that capacity to change.

The Neighborhood Group was the only group that I observed or heard described in interviews that did not include a discussion of the neurological components of pain, or even the “pain gates.” In fact, they told me that they specifically avoided “medicalizing pain” in order to develop trust with group members. “With this population, the details about the neuro and the bio loses people,” Nicole told me in an informal conversation. Thus, decisions how to navigate neural discourses had more to do, perhaps, with customizing to their population than with their general approach to conceptualizing pain. The very culture of biomedicine was rejected for fear of alienating patients. For instance, when the Seeking Safety manual included medical terminology, such as “cortisol” or “PTSD”, the facilitators laugh and call out, “Medicalese!” or “Alphabet soup!” They thereby dismissed the relevance and authority of biomedical terminology. While other group facilitators frequently used the phrase, “we know that,” simultaneously signaling their inclusion in the biomedical community and positioning their knowledge as fact, Neighborhood Group facilitators only once used a similar phrase, but did so in reference to the collective and embodied knowledge of the group: “We know about fat and sugar—it calms us down! So it’s a way of coping. But not the best way of coping.”

However, the one time that Neighborhood Group facilitators did mention brain mechanisms in the group, they did so in order to speak emphatically about the brain's capacity to change:

Nicole says, “the way the brain works—the brain is used to repeating the same patterns—like a car going down the super highway. But sometimes it takes parking that car by the side of the road, walking across the grassy field a new way. And the first time you walk across that field, you're not gonna know where you are. And the next time, you won't either. But our brain is always changing, our whole lives.” Grace says, “It's easy to get stuck, like a record—you know there are grooves in the record, it gets stuck—it happens to everyone. I call it my critical self—every single one of us has it—our job is to not get stuck in it.”

Rather than relying upon biomedical descriptions of the brain and its correlates, these facilitators drew parallels to everyday objects and actions: driving a car, listening to a record. While they did emphasize the brain's capacity to change, and therefore were still in conversation with plasticity principles tied to self-improvement, they did not bypass the challenges inherent in making these changes, and therefore they did not simplify the process of enhancement, as other facilitators frequently did. They positioned plasticity as a process that is difficult for everyone, including themselves. However, even within this framing, patients (and, presumably, facilitators) were still responsible for transforming themselves, self-disciplining in order to optimize.

Within the Neighborhood Group, plasticity discourses were presented alongside and through principles of self-compassion. More so than any other group, the Neighborhood Group emphasized the need to be kind to oneself, demarcating this practice as the key to “healing” or “transforming.” Facilitators positioned group members as always-already strong and resilient, often reflecting on personal accounts of resilience in the face of adversity that they had witnessed amongst group members. Thus, patients were conceived of not as damaged or inadequate, but as already containing the skills that they need to transform. These depictions were frequently coupled with a sense of personal responsibility or obligation to transform. For instance, at the

start of the group session on self-compassion, patients were asked to read aloud the quote at the top of their handout:

*“You are not responsible for being down, but you are responsible for getting up.”—Jesse Jackson*

Facilitators had patients read it twice, commenting on how powerful the statement was<sup>26</sup>. This was representative of one the underlying principles of this group, sometimes stated explicitly, sometimes not—each patient was seen as strong and resilient, entirely capable of transforming, evolving, and therefore, obligated to get up. Another quote read from the manual demonstrated another aspect of plasticity discourses:

The facilitators, Nicole and Grace, ask who wants to read the quote, and one patient volunteers. “Watch your thoughts; they become your words. Watch your words; they become your actions. Watch your actions; they become your habits. Watch your habits; they become your character. Watch your character; it becomes your destiny.” Nicole says, “Wow.” Everyone else echoes her wow. Grace asks, “What’s the main point of that?” Nicole notes, “What comes first? Your thoughts!” Grace remarks, “What if I just read first sentence and last sentence: watch your thoughts, they become your destiny. But the idea is, that we can intervene at any point. We have that power. If we get to a point where our habits aren’t what we would like, we can change them—we have that power. We have choice points—all the way along the line. We can change our destiny.” She is speaking with intensity, preaching.

This quote, and their unpacking of it, was directly aligned with plasticity principles, and while it did not directly reference CBT or MBSR, it suggested very similar techniques and processes. However, this quote goes even further than CBT and MBSR in its promises—by monitoring ones’ thoughts, one can change her destiny. Grace emphasized the “choice points” at each step of the way—highlighting the agency implied by this statement. In this quote and the facilitators’

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<sup>26</sup> This quote is pulled directly from the Seeking Safety manual, and might well have been selected in part because Jesse Jackson’s social position as a black politician advocating for civil rights and his message of racial equality would resonate with the Neighborhood Group’s members, who were largely African American.

reactions to it, we see traces of the double edged sword of patient empowerment: the twinned capacity/imperative to transform, enhance, and optimize.

While the two quotes above were pulled directly from the Seeking Safety manual, which the facilitators opted into but did not themselves create, there were sessions where Neighborhood Group facilitators inserted their own material, often quotes or parables. One quote included by the facilitators directly leveraged the language of plasticity and optimization, but was couched in folk wisdom, put forward as a Cherokee story:

A patient reads, “A grandfather is talking with his grandson and he says there are two wolves inside of us which are always at war with each other. One of them is a good wolf which represents things like kindness, bravery and love. The other is a bad wolf, which represents things like greed, hatred and fear. The grandson stops and thinks about it for a second then he looks up at his grandfather and says, “Grandfather, which one wins?” The grandfather quietly replies, the one you feed.”

Embedded in this quote are principles of plasticity: the more you “feed” a set of neural pathways, the stronger it becomes, and the more likely those pathways are to “win.” Assuming that this truly is a Cherokee teaching, it was clearly not developed in reference to neuroimaging studies on plasticity. However, it was picked up and utilized in this group in order to illustrate the same principles described in more scientific terms in other groups. By couching this narrative within the language of folk wisdom, the facilitators were (perhaps inadvertently) naturalizing and thus further validating twinned potential/imperative to self-surveil and optimize. The message was not overtly neuroscientized, but was nonetheless carried the same values embedded within the neural discourses described in other groups.

While I do not believe that these inclusions were demonstrative of the facilitators’ desires to transform their patients into self-regulating, low-risk biomedical citizens, I do think that they had every intention of teaching their patients skills that would empower them to survive within

this particular biopolitical economy. In fact, Nicole shared the following reflection with me during an interview:

I mean, I think we are overly simplistic in our thinking about things because we live in a society where the unspoken assumption is if you are poor, it means you're doing something wrong. If you're not happy and you have adversity in your life, it's because there is something wrong with you, not that that's the way life is. Given that all of my patients are poor and have a lot of adversity, it's a very hard culture to live in. That absolutely contributes to the reality and the experience of pain and self-efficacy and how to approach problems.

In acknowledging these adversities, she brought to light the neoliberal ideology of individualism that permeates our culture, naming the principles of personal responsibility that place the burden of emotional and material success on the individual. Both Nicole and Grace frequently referenced this cultural constraint in the group, criticizing “bootstrap” mentalities and acknowledging the discrimination that many of their patients experience as a result of their class, race, and gender characteristics. Thus, while these facilitators are enacting a neoliberal regime through their curriculum, they are doing so while recognizing the structural constraints that *require* patients to self-regulate and optimize.

## **V. Conclusion**

The following section begins by outlining positions that are missing in the data, tracing the relationships between neural and plasticity discourses. I then attend to the patients who are excluded under these models of care, speaking to the ways in which the possibility of healing, as presented via these discourses, are inequitably distributed. Lastly, I provide a summary and discussion of key findings from this chapter.

## *A. Positions Missing in Data*

In the map depicted in Figure 4.1, two positions were not represented in the data, both analytically significant: (1) Low Neuro, Low Plasticity and (2) High Neuro, Low Plasticity.

### *1. Low Neuro, Low Plasticity*

None of the groups I observed demonstrated low levels of both neural and plasticity discourses. This position is representative of a biomechanical model of pain described above, one that is best addressed through musculoskeletal interventions and pharmacological solutions. It is telling that this position was not taken by any of the pain groups described here, but not surprising. Given the shift towards neuroscientific explanatory models, which in and of itself is evidenced by the very existence of this group, it is difficult to imagine a group reliant upon biomechanical explanations of pain. However, one clinician who facilitated a different group (that I did not observe) did describe aspects of her group that drew more upon biomechanical models than neuroscientific models. While her group did cover a neuroscientific explanation of pain, she relayed that her patients would often get confused by the language deployed here, and so she focused more on a biomechanical description of what pain is:

We don't go down to the nitty gritty, but we bring in a skeleton, and we show ... We just teach the anatomy of the bones, so we ... The vertebrae, the disks. And we show how the spinal nerve roots come out because a lot of people have sciatica. And then we show ... We have a skeleton with muscle overlay on one side, so we show the muscles. We go into the most common diagnoses that we get for back pain, so disk problems, the different causes of sciatica, the muscles, things like that. It's not intended for medical residents.

This focus on vertebrae, discs, and muscles replaces the neural discourses that were so evident in other groups. Similar to the Neighborhood Group, this clinician made efforts to avoid biomedical concepts that might be difficult for low literacy patients to grasp.

However, nowhere in this biomechanical explanation of pain are traces of plasticity discourses; if pain is positioned in the musculoskeletal system, rather than the nervous system or brain, the opportunity to rewire one's neural pathways and thus address pain via the "power of the brain" is nowhere to be seen.

## *2. High Neuro, Low Plasticity*

The other position not evident in my data is one that leverages high levels of neural discourses and low levels of plasticity discourses. I argue that this did not appear in my fieldwork or interviews because it does not exist: plasticity is part and parcel to neuroscientific explanatory models. While it is possible to have plasticity discourses without neural discourses, as we saw in the Neighborhood Group, it is not possible to have neural discourses without plasticity discourses, because they are so intrinsic to one another, particularly in conceptualizations of pain.

### ***B. Who's Excluded?***

As mentioned previously, the structure of each group and the systems they were embedded within, the techniques conveyed, and the neural and plasticity discourses leveraged through the curricula imagines a particular kind of pain patient. Specifically, in order to maximize the benefits of these group interventions, pain patients are required to be "activated" (Van Natta et al., 2018; Bodenheimer et al., 2002), or primed for such an approach. Patients with trauma or other mental health conditions did not fit easily into the types of groups described here, and when facilitators attempted to make space for them, as was the case in the Neighborhood Group and earlier iterations of the City Group, their funding was pulled or their manuals were rewritten. These changes were made not to purposefully exclude this group of



patients, but rather to stay afloat within an increasingly constrained public safety net, where outcomes need to have sharp edges in order to be actionable (Liboiron 2015).

### *C. Summary*

This chapter described the ways in which a shift towards a neuroscientific model of pain management is resulting in a proliferation of neural and corresponding plasticity discourses in the treatment of chronic pain. I argued that this framing of the brain as plastic and malleable produces particular subjectivities, namely pain patients who are both capable of, and responsible for, managing their own conditions. Neuroscientific understandings of pain create the potential for pain patients to see themselves and their bodies in new and different ways, repositioning responsibility for suffering from the health care system to the patient. By showing patients that their neurobiology is capable of change, it places the onus upon them to heal themselves. This onus is simultaneously an opportunity and an imperative, as pain patients are faced with questions of what to do with the new knowledge about themselves and their neurological capacities gained via exposure to these discourses. I described three pain groups, detailing how the structure, primary purpose, and setting of each group both shaped and were shaped by specific techniques deployed for intervening upon patients' pain levels. These specific techniques in turn necessitated a particular kind of patient, with groups calling upon patients to enact certain forms of self-management and engagement. Thus, the deployment of these discourses and techniques was situational and inequitable, with certain settings being more equipped to leverage them appropriately and sufficiently.

## **CHAPTER FIVE: CONCLUSION**

### **I. Summary of Dissertation**

This dissertation attends to the various subjectivities of pain. Pain is subjective in its interiority; pain also produces particular subjectivities in its situatedness. As pain medicine undergoes a neuroscientific shift, these multiple subjectivities are repositioned. Biomedical actors must navigate these subjectivities when studying and treating pain, and when developing policy around its treatment. Pain medicine has undergone a number of historical shifts in orientation and values; I argue that the transformation occurring presently is a product of both the opioid crisis and a proliferation of neuroscientific explanatory models of pathology. I describe the current shift as a *neuroscientization*, in which pain is being newly biomedicalized as a neuroscientific object, raising questions of agency and individual responsibility.

In tracing pain as it travels through the overlapping biomedical domains of production, dissemination, and uptake, I describe the ways in which power operates within and through the arena of pain medicine. I argue that pain, as a neuroscientific object, is co-constitutive of key processes and practices that are situated in a specific social, political, and economic moment. These processes and practices represent techniques of biopower (Foucault 1978) in action, simultaneously disciplining bodies and regulating populations in service of life itself.

#### ***A. Key Findings***

Chapter Two examined the structures of scientific knowledge production and their impacts upon the ways in which pain is studied and produced as a neuroscientific object. Despite scientists' acknowledgement that pain is a holistic phenomenon, containing both objective and

subjective components, their accounts also described a necessary process of breaking pain apart into its component parts, specifically drawing a divide between the objective/sensory/peripheral aspects of pain and the subjective/emotional/central aspects of pain, for purposes of incremental scientific study. Much of the work of producing scientific facts about pain, then, involved managing this relationship between subjectivity and objectivity, and circumscribing subjects' subjectivity as a way of managing the complexity inherent in pain itself. They did so by finding ways to measure, quantify, and otherwise objectify the experience of pain, through quantitative sensory testing, developing biomarkers, carefully selecting healthy and standardized subjects, and training those subjects to perform well during experimental procedures. Even given these techniques for limiting subjectivity, many neuroscientists working with human subjects still felt as though the very foundation of their data—subjective ratings of pain—was represented an inadequate compromise in the pursuit of objective, scientific facts. As one scientist put it, “You still have to ask people.”

While many scientists expressed faith in the process of incremental scientific inquiry, claiming that technological developments coupled with slow, methodical investigation would eventually lead to breakthroughs that would solve the problem of pain, some worried about the disaggregation produced by the process of scientific study. They voiced their concern about studying pain in healthy subjects who do not resemble the clinical population of pain patients who carry with them a host of complicating physical, psychological, and social conditions. In order to produce a basic understanding of pain mechanisms, then, many felt that it was necessary to study pain in these healthy subjects, rather than in actual pain patients, who they believed were difficult to work with. However, this meant that they worried about the generalizability of their findings and the clinical relevance of their work. Some also expressed concern about the ways in

which the structures of scientific investigation may produce abstracted, disaggregated understandings of pain.

This chapter built upon STS studies of laboratory and scientific work (citations) to bring to light the value-laden conjectures made at each point of the scientific process: the decisions made about what components of pain to study, who to study pain in, and how to circumscribe subjectivity so as to limit the amount of complexity. These judgements were not necessarily reflective of the ethics and preferences of individual researchers, but instead spoke to the logic of scientific meaning-making and its ability to constrict both the subject and object of study. I argued that the structures of scientific inquiry necessarily discipline complexity (Nelson 2013) in the name of clear data points (Liboiron 2015). I contended that pain science's focus on developing a basic understanding of pain itself, rather than investigating how pain operates alongside other conditions, limits what can be known about the holistic, lived experience of pain as it appears in clinical settings. By primarily choosing to study pain in healthy samples, neuroscientists were drawing divisions and producing particular notions of difference and normalcy (Epstein 2008; Dumit 2004). In doing so, they produced a body of biomedical knowledge that may not be relevant to the complicated pain patients seen in clinical settings. This upended claims that science is produced for the good of all (Benjamin 2013; Tallbear 2013), and instead pointed to the inequitable distribution of the benefits of scientific investigation (Frickel et al., 2010).

In Chapter Three, I analyzed the claims of pain specialists about the social, political, and economic forces that propagated the opioid crisis, as well as their heterogeneous positions on what the current scientific evidence on opiates implies about how to appropriately move forward

in relation to the prescribing of opiates for chronic pain. I argued that the opioid crisis and its proposed solutions represent a biopolitical, post-modern epidemic (Boero 2007/2010), with its focus on risk, its shifting of responsibility to the individual, and its proliferation of chaotic discourses distinct from a biological contagion. In attending to the ways in which policy and biomedical discourses produce simplified notions of both opiates and pain patients, I demonstrated that particular patient subjectivities (Foucault 1978/76) are emerging out of both the opioid-related overdose crisis and its proposed solutions.

I traced the structural forces that specialists named as contributing to the genesis of the opioid crisis, such as the rise of the pain-as-a-fifth-vital-sign movement and the shifting values of regulatory and legal systems, each of which privileged patients' assessments of their pain over clinicians' judgments about what pain was deserving of treatment. In pointing to the impacts of these changes, many pain specialists made claims about patients' responsibility in propagating the opioid crisis. Additionally, these specialists identified the influences of the pharmaceutical industry and the undone science (Decoteau & Underman 2015; Hess 2013; McGoey 2012; Kempner et al., 2011; Frickel et al., 2010) as economic and political forces driving the opioid epidemic. Thus, the origins of the opioid crisis were depicted as being thoroughly biopolitical in nature, with numerous biomedical apparatuses exercising regulatory control over the population.

I described the complexity of opiates, specifically accounting for their uncertainty and variability. With respect to their uncertainty, I mapped a range of positions taken by pain specialists regarding the current evidence base on opiate safety and efficacy. Many specialists felt that uncertainty remained within the evidence, pointing to the lack of longitudinal studies on opiates. They pointed to institutional and economic reasons for this undone science, highlighting the politics of knowledge production, whereby the processes of scientific inquiry are penetrated

by commercial interests and institutional structures (Clarke et al., 2010) and some questions are more readily answered than others.

Among the specialists who felt that uncertainty remained in the evidence on opiates, some held a cautionary position, claiming that the insufficiency of evidence suggested that opiates should be prohibited for chronic pain, while others in this group held an agnostic stance, claiming that this insufficiency of evidence meant that opiates should *not* be prohibited for chronic pain. Still others felt that no uncertainty existed in the current evidence base on opiates, and all of these specialists held a prohibitory stance, saying that evidence clearly indicates that opiates should be phased out in the treatment of chronic pain. No specialists held that uncertainty did not remain and opiates should not be phased out, and this represented an analytically relevant absence in the data. These various positions depicted the field of pain medicine as heterogeneous and conflicted about how to proceed when it comes to prescribing opiates for chronic pain, augmenting other accounts of clinicians' perspectives on opiates (Crowley Matoka & True 2012; Knight et al., 2017).

The variability of opiates, or difficulty of developing a one-size-fits-all model, proved challenging for local and federal policymakers who struggled to come up with universal protocols and guidelines for the use of opiates, and for lecturers and clinicians with limited time for contextualizing their messages regarding opiates. I argued, then, that the complexity of opiates, specifically their uncertainty and variability described above, is flattened within this process of dissemination. I attended to the subjectification of pain patients, frequently characterized as drug-seeking or stereotypically complicated within medical education. The policies and discourses enacted in response to the opioid crisis further render it a biopolitical,

post-modern epidemic, in which a focus on minimizing risk of overdose often translated into shifting responsibility and blame for the crisis onto patients.

Chapter Four illustrated another means by which responsibility is shifted onto pain patients, in this case via neural techniques intended to empower patients to self-regulate, optimize, and enhance. I argued that the neural and plasticity discourses that are appearing as interventions in pain clinics are embedded with a twinned imperative/opportunity for pain patients, simultaneously embodying the productive potential for new identities (Rose & Abi-Rached 2013; Rose 2007) and the obligations for self-management and personal responsibility (Pitts-Taylor 2010). I also contended that engagement with these discourses is situational, and distribution of their benefits is stratified, with some techniques requiring patients that are always-already “activated” (Van Natta et al., 2018; Bodenheimer et al., 2002), and the conditions of possibility for overcoming pain being consequentially produced for some, but not others.

This chapter positioned the shift towards neuroscientific explanatory models of pain as being imbued with notions of plasticity, highlighting the malleability of the brain and its responsiveness to environmental stimuli. Within plasticity discourses, then, pain patients were encouraged to think of themselves as capable of change and optimization (Pitts-Taylor 2016; Rose & Abi-Rached 2013). This framing of the brain as plastic and malleable produces particular subjectivities, namely pain patients who are both capable of and responsible for managing their own conditions. Thus, a neuroscientific configuration of pain places the onus of care on the patient, rather than on the health care system.

I detailed how different pain groups had varying structures, primary purposes, patient populations, and settings that shaped and were shaped by the specific techniques deployed for intervening upon patients’ pain levels, and that impacted their engagement with neural and

plasticity discourses. While neural discourses always invoked plasticity discourses, the inverse was not true: notions of plasticity could be, and were, deployed in the absence of explicit neural explanatory models. I argue that this is demonstrative of the inherent values of neuroscience itself, which invariably holds that the brain is plastic and malleable, capable of change and enhancement. However, all of the techniques disseminated in the groups were premised on neural, rather than biomechanical, understandings of pain, and correspondingly held particular notions of patienthood and agency (Pitts-Taylor 2016; Buchbinder 2015a/b; Rose & Abi-Rached 2013; Buchbinder 2011). These specific techniques in turn necessitated a particular kind of patient, with groups calling upon patients to enact certain forms of self-management and engagement. These findings extended previous examinations of neural discourses and their implications for agency, personal responsibility, and arrangements of power.

### ***B. Theoretical Contributions: A Neuroscientization of Pain***

In the past several decades, scholars have analyzed the ways in which pain has undergone a process of medicalization (Kaufman et al., 2016; Farrell and Cacchioni 2012; Conrad and Munoz 2010). These scholars contend that the development of scientific theories of pain, as well as disciplinary settings for its treatment and study, have resulted in pain being thoroughly medicalized, or, in the case of Crowley-Matoka and True (2012), incompletely medicalized in that it still represents a site of clinical uncertainty. However, few accounts have applied the framework of biomedicalization to pain and its treatment. Biomedicalization theory (Clarke et al., 2010) extends medicalization theory (Conrad 1992) by focusing not solely on medicine's jurisdiction over illnesses and diseases, but also considering the expansion of medical jurisdiction over *health itself*, highlighting the commodification of health and the shift to



individual, rather than medical, responsibility for health. While medicalization implies a unidirectional pattern of influence, biomedicalization emphasizes the circulative, co-constitutive nature of transformations occurring within and across biomedicine.

I argue that pain is being newly biomedicalized, or neuroscientized, as a result of both the opioid crisis and a proliferation of neuroscientific discourses. This dissertation considered how technoscientific practices are transforming bodies and minds from the inside out, producing new conceptualizations of what it means to be in pain. Neuroscientific understandings of pain create the potential for pain patients to see themselves and their bodies in new and different ways, repositioning responsibility for suffering from the health care system to the patient. Further, I argue that the opioid crisis and its proposed solutions is biopolitical (Rose 2007; Turner 1997; Foucault 1978) in nature and constitutes a post-modern epidemic (Boero 2007/2010) in its focus on risk, its shifting of responsibility from the health care system to the patient, and its promotion of chaotic discourses in the absence of a biological contagion. As pain is indelibly tied to opioids, a new focus on risk and surveillance emerge as the biomedical state apparatus seeks to guard against the threats inhered in an epidemic (Foucault 1976). Out of this crisis emerges particular subjectivities, such as the “chronic pain player”—the drug-seeking, complicated pain patient, always-already at risk given their social and medical histories.

This focus on risk is directed not only through control over the population, via regulations and interventions aimed at extending, protecting, and optimizing life itself (Rose 2007), but also at the individual, who is newly subject to a host of disciplining and self-regulating techniques. These techniques are centered upon leveraging the brain’s plasticity, or malleability, and pain patients are presented with the twinned opportunity/imperative to self-regulate, enhance, and apply self-knowledge to the task of optimization. Risk is thus repositioned

as occurring within the brains of pain patients, who are capable of either forming healthy or unhealthy neural patterns. As opposed to a biomechanical model of pain, which located solutions such as surgeries and medications within the health care system, a neuroscientific model of pain places the onus of care upon the patient herself, simultaneously empowering her with the tools of self-care and placing responsibility on her to regulate her own conditions.

### **III. Implications for Social Scientists and Policymakers**

Findings from this dissertation suggest that the “gaps and rifts” (Friese 2013) that exist between the domains of production, dissemination, and uptake of biomedical knowledge are persistent and consequential. While efforts from within translational medicine continue to examine and improve the bench-to-bedside pipeline (Marincola 2003), work remains to be done if the knowledge produced in the laboratory is to be relevant for the clinical population. Pain specialists pointed to the structures of scientific practice that limited collaboration between different types of pain neuroscientists, and identified economic and institutional barriers to conducting longitudinal studies. Scientists expressed concern about the lack of generalizability of their studies of healthy samples, worrying that findings from these studies may not be applicable to the clinical population. In fact, the patients I encountered in the clinic were nothing like the research subjects I encountered in the laboratory.

Several critics have pointed to neuroscience’s tendency to overpromise (Rollins 2014; Button et al., 2013; Pitts-Taylor 2010; Harris 2000) when it comes to the generalizability of their findings. Neuroimaging studies typically rely on small sample sizes of 15-20 and are thus intended to serve as theoretical, rather than clinical, models, aimed at developing an understanding of the basic mechanisms of pain, rather than how pain maps onto other conditions.

The tendency for findings from these studies to be extrapolated and taken up in clinical settings and through popular discourses is troubling.

Further, the complexity of pain itself has bearing upon the potential for scientists to develop a universal, one-size-fits-all approach to its treatment. As scientists made clear, pain “has all these different sources,” and the central nervous system is extraordinarily complex, so identifying a compound that will work on all types of pain and can act upon pain seems unlikely. As was explored in Chapter Three, the allure of a universal treatment for pain is strong, and promises of such a treatment have led the biomedical community astray in the past. Most likely, any new intervention, pharmacological or not, will work well for some, and not for others.

These findings open up opportunities for sociological and STS inquiry, given that many scholars are interested in the work of scientific translation and standardization within the evidence-based medicine paradigm. Work remains to be done around the ways in which biomedical knowledges travel between overlapping yet distinct arenas, attending to the mismatches between how medical conditions are studied (and in whom) and how they are treated. Further, those working within what Steven Epstein (2008) has termed the discipline of “recruitmentology” need to take up the task of identifying which categories of difference are invoked, and which are obscured, in biomedical research, specifically interrogating the ways in which complexity is conceived of and modeled in scientific settings.

Policymakers advocating for stronger translational medicine would do well to develop strategies for removing the institutional barriers that exist between practitioners of science and practitioners of medicine. While these categories are often collapsed (Clarke et al., 2010), many of the pain specialists I interviewed still pointed to hyper-disciplinarity and the ever-increasing specialization and siloing of expertise as an obstacle to progress within pain medicine. Creating

more opportunities for science and clinical medicine to interact and converse would do more to create holistic understandings of both patients and the conditions they live with. While some such collaborative spaces do exist, few if any invite the participation and perspectives of social scientists. For an institution that has begun celebrating the biopsychosocial approach to health care, biomedicine is negligible in its conceptualizations of “the social” within medicine (Rubin et al., 2018). At a fundamental level, ethnographic accounts such as this one should serve to sensitize scientists and clinicians about the disconnects evident in the bench-to-bedside pipeline.

In addition to the need for clinically relevant research, findings reveal that the production of pain as a scientific object renders it an abstraction, and meanings that are produced in the lab may not be reflective of the holistic nature of pain itself. By circumscribing the subjectivity inherent in pain, scientific practices necessarily limit pain’s complexity in its effort to produce clear data points. This raises the possibility that pain science may be strengthened by finding ways to be more inclusive of subjectivity, allowing for a diversity of perspectives and epistemologies around the experience of pain. In previous papers, I have argued that ethnographic research methods are well-positioned for capturing embodied, subjective data (Rubin 2016), a claim that builds upon a wide body of embodiment literature (Haraway 1988). I contend that an interdisciplinary approach to pain medicine—one that combines multiple (including qualitative) methodologies and thus makes space for heterogeneous understandings of pain’s complexity—is called for.

Further, the ongoing embrace of neuroscientific explanatory models of pathology creates an ever-expanding opportunity (and obligation) for social scientific scrutiny. Questions remain about how these discourses are produced and disseminated, and how they are taken up and applied across different populations. Medical sociologists interested in power and agency, as

well as STS scholars studying the mechanisms and practices of knowledge production, will find ample empirical sites through which to consider these questions, given the continued proliferation of neuroscientific epistemologies into popular culture and clinical contexts.

These findings imply both discursive and material consequences of a shift towards a neuroscientized model of pain. By imagining pain patients as always-already capable of self-managing their own painful conditions via neural techniques, responsibility for pain's impacts is placed upon the individual patient, rather than the health care system. The biomedical community, in trying to make sense of what to do about pain in the midst of the opioid crisis, has found a way of managing risk under the framework of patient empowerment. Thus, clinicians and policymakers should keep in mind the downstream consequences of deploying neural discourses that carry with them ideas of agency and responsibility, namely, that these techniques require patients that are always-already engaged, activated, and capable of self-management. Not all patients are equally positioned to leverage and benefit from these plasticity techniques, with structural inequalities that are often coupled with ongoing trauma rendering many of these techniques inappropriate for marginalized patient populations. The current configurations of the health care system limit the amount of support patients can expect from providers, either in group settings or individual appointments. Chronic pain and its treatment, unfortunately, require a vast amount of support. Policies targeted at improving patients' access to mental health services and complementary and alternative health modalities are needed if we are to successfully address the opiate crisis and the upstream problem of rising levels of chronic pain.

#### IV. Future Directions

A range of future inquiries would strengthen and add nuance to these collected contributions. First, this dissertation did not directly attend to racial dynamics occurring across these three spaces. I see this as a major limitation, that informs my own plans for future research. Investigations into the ways in which race impacts the experience of pain are called for in order to address persistent racial inequities in the treatment of chronic pain (Hoffman et al., 2016).

Race has been referred to as a ghost variable (Jordan-Young & Cardazis 2017), in that its traces are often difficult to detect and perceive, its boundaries are porous, and operationalizing studies into racial difference necessarily dredges up a complicated and violent past (Dudley 2012; Washington 2006). I found this to be true in my interviews with pain scientists and clinicians, as well as my observations in the lab, the medical school classroom, and the clinic, as participants rarely named race directly. When asked about racial differences in pain, many expressed confusion about conceptualizations of race, often slipping between biological notions of race and conceptions of race as a social construct. While some pain neuroscientists attested to the importance of studying differences between racial groups, few could articulate why these differences mattered, and most were at a loss for how to include racial differences in their experimental designs.

Future studies will address the ways in which race is conceptualized and operationalized within neuroscientific settings. Oliver Rollins found that neuroscientists were unwilling to acknowledge or examine the ways that race influenced violent behaviors. While an avoidance of examining racial difference along biological lines is understandable, neglecting “the *social experiences* with race that their participants both live with and within” (Rollins 2014:212) unnecessarily (and, most likely, unintentionally) imbues their research practices with what some

scholars have termed colorblind racism (Bonilla-Silva 2017), in which the complexities of living as a person of color are erased, thereby naturalizing and individualizing stratification along racial lines. In other words, in an effort to avoid explaining racial differences through biology, neuroscience has largely ignored the effects of racism upon the object they seek to understand.

Next, the lack of patient voices in this dissertation represents a significant absence. Including the accounts of how these policies and discourses are impacting the lived realities of pain patients would add nuance and depth to this analysis. I plan to attend to the experiences and perspectives of pain patients in future studies, taking into consideration the material consequences of this neuroscientization of pain. Further, as referenced in Chapter Three, a significant silence emerged in my data: not one of my participants supported the position that the evidence base on opiates is certain *and* opiates should continue to be prescribed to chronic pain patients. However, in my professional and personal life, I frequently encountered chronic pain patients who were succeeding on opiates long-term, and were deeply concerned that regulatory measures would soon prevent them from accessing this lifeline. In future studies of pain patients, I aim to gather accounts from long-term opiate users about their perspectives on the shifting sands of opiate logic.

Lastly, I consider it an oversight that this dissertation focused on pain without inquiring specifically into addiction. In the current biopolitical moment, with the opioid crisis raising concern about both pain *and* its treatment, these two conditions are discursively entangled. Talking about pain in clinical settings inevitably invokes fears of addiction, and I feel that future studies should consider these two conditions as they are produced alongside one another.

## V. A Final Word

Studying pain and its solutions means that, no matter where you go, you will hear deeply personal reflections about the nature of suffering and what it means to people. I began this line of inquiry because, to me, pain represented so many of the questions that I have carried with me my whole life about subjectivity and the ways in which social values and ethics are inscribed onto bodies: how do we know what we know, and how do we separate our own lived experience from the social narratives and discourses we are swimming in?

When I first caught sight of this neuroscientific shift in conceptualizations of pain—clinical discourses that declared pain to be an output of the brain, not an input of the body—I grew concerned. I care deeply about the body, in all of its corporeal, nonlinear messiness, and I worried that, through these discourses, we were being encouraged to think of ourselves as neuronal subjects: distrusting the wisdom of our bodies in favor of the rationality of our brains. I was surprised to discover, both through my time in the field and through countless conversations with friends, colleagues, and my own bodywork patients (many of whom struggled with debilitating chronic pain), how few people seemed to worry about this. Instead, many found these neural discourses empowering—they invested chronic pain sufferers with a sense of agency, a feeling that they were not out of control. Having now lived with chronic pain myself, I can see how this sense of efficacy can be life changing: the real suffering, for me, often comes not from the sensation, but from the stories that get overlaid on top of the pain, about what that pain means for who I am and what I am capable of. If I can interrupt those stories, as these neural techniques encourage me to do, my suffering is greatly reduced. So after living with these techniques—through my data, through my conversations, and through my own body—I have personally landed somewhere in the middle: yes, neuroreductionism is happening, via these and



other techniques, but thinking that this somehow renders us separate from our fleshy bodies implies a divide between the flesh of the brain and the flesh of the musculoskeletal system. As is often the case, it's not either/or, it's both/and. We can expand our notions of what we are capable of without sacrificing the humanity that I feel resides below our necks. Even if our meanings and interpretations of our sensations are thoroughly social, this does not mean that they are not also material and embodied.

Coupled with these deeply personal reflections about pain that are so frequently shared with me is the omnipresence of a single question: what should be done? What can we do—as individuals, as health care providers, as policymakers—about the problem of pain? I can't honestly say that I have a very definitive answer. Usually my response is, "It's complicated." As this dissertation makes clear, pain is a complex phenomenon made up of intersecting components and overlaid with social, political, and economic forces. What I can say, though, is that taking an interest in the pain of others is one way to diminish the severity of one's *own* pain. Those who are able to put themselves in a place of curiosity and care when it comes to the suffering of others are far better positioned, in my experience, to manage their own embodied discomfort.

## **APPENDIX A: INTERVIEW PROCEDURES**

Scientists and clinicians were identified as potential interview participants via encounters during ethnographic observations, snowball sampling, and the use of professional networks. In order to be eligible to participate in interviews, scientists needed to be working within the field of neuroscience, focusing primarily on the study of pain, and clinicians needed to be actively practicing medicine and working with a chronic pain patient population. For both study populations, participants were required to be 18 years of age or older and be proficient in the English language. Potential participants were sent an Invitation Letter and a Study Information Sheet via email, and if they expressed interest in participating in an interview, they were screened for eligibility using a 2-minute screening guide. All potential participants met the eligibility requirements. Subsequently, a time was arranged for either an in-person or video conference interview.

Prior to the interview, participants were encouraged to review the Study Information Sheet and contact me with any questions they might have. At the beginning of each interview, I explained the research study, the study procedures, and risks and benefits to participating, stressing that participation was voluntary and may be stopped at any time, including during the interview, and that the participant could decline to answer any questions. Participants were encouraged to review the Study Information Sheet and ask any remaining questions. I used a Verbal Consent Script to obtain verbal informed consent from all participants in order to ensure further confidentiality by removing the need for a paper trail. Informed consent information included: (1) the purpose of the study; (2) assurances of confidentiality, such as the fact that no identifying information will be associated with responses provided by participants; (3) a

reminder that all participation is voluntary including answers to any questions, and that participation can cease at any point with no penalty; (4) a statement that interviews will be audio-recorded and transcribed upon consent; and (5) the terms for compensation, which in this case were that participants were not compensated for their time, given that this was an unfunded student project. Once scientists were consented, they were given the option to be either “On the Record” or “Off the Record.” Clinicians were not given this option in order to maintain the safety and confidentiality of their patients. Though some scientists did elect to be “On the Record,” I subsequently decided to anonymize all accounts, given the intimate nature of the field of pain neuroscience and the risk that “Off the Record” scientists could easily be identified by their colleagues. Participants were asked if the interview could be audio recorded and all agreed. Digital recordings of each interview were professionally transcribed. Transcriptions and audio recordings were stored on an encrypted computer.

At the conclusion of each interview, participants were asked to recommend any colleagues or peers with similar work experiences and/or knowledge who might be interested in participating in the study. If recommendations were made, snowball sampling procedures described above were followed to reach out to these individuals. All participants will be sent a thank you email following their interview. Many participants requested to be kept informed of findings; thus, following successful defense of this dissertation a three page summary of findings will be sent to each participant.

## **APPENDIX B: SAMPLE INTERVIEW GUIDES**

Note: These interview guides were developed in advance of data collection, and were subsequently modified to reflect the ongoing analysis of incoming data.

### *I. Neuroscientist Interview Guide*

- Can you please tell me a little bit about your current projects?
  - What are your hypotheses around these studies?
  - How did you arrive upon this particular set of questions?
- What do these projects entail, as far as procedures?
  - Are you working with human subjects, or secondary data analysis?
- Tell me a little bit about the instruments that you/your team uses.
  - What information do these devices capture?
  - How is that information conveyed to you (i.e., images? Quantitative data?)
- To what extent is it possible to actually see pain, using this equipment?
  - What are some of the limitations of this equipment?
  - Have there been recent technological advancements that you see as being really crucial for the acceleration of our understanding about pain?
- I'm really interested in the ways in which your team simulates painful stimuli. Can you describe to me some of the mechanisms that are typically used?
  - Is there a debate over which mechanisms are most reliable, or most closely related to pain?
  - Are you familiar with any of the theories as to why these mechanisms are used (for example, how did heat/anal balloons/pressure become proxies for pain)?
- How then, do participants/patients report their experience of pain in the midst of these studies?
  - Do they use the pain scale?
  - How was this pain scale developed and validated?
  - How is the pain scale explained to them?
- What are some of the conversations that occur within your field, broadly speaking, about the subjective nature of pain?
  - Is there disagreement around this?
  - Have people been proposing solutions to this?
- Can you tell me about some of the ways that you see/hear pain being talked about in the broader public that conflict with what you know to be true?
- What are some of the funding mechanisms available to someone working in pain within the neurosciences?
  - Have those changed much in the past several years?
- How, if at all, have you seen the landscape of pain science changing as the opioid crisis has gotten more public attention?

## *II. Clinician Interview Guide*

- Can you tell me a bit about your training around pain and its treatment?
  - How was pain handled in your first three years of medical school?
  - How about during residency?
  - Have you taken any continuing medical education around pain?
- Do you feel as though your training in pain prepared you for what you would come across in practice?
  - How so? How not?
- What types of things do you do to make sure that you are staying up-to-date with the science around pain?
  - How has the generally-accepted clinical conception of pain changed since you've been in practice?
- What are your options when it comes to treating your patients' chronic pain?
  - How have those options changed since you began practicing medicine?
  - How difficult has it been for you to adapt to those changes?
  - What effect do these changes have on your patients with chronic pain?
- What are some of the ways that you explain chronic pain to your patients?
  - How much does this vary depending on the condition? Depending on the patient?
  - Have these explanations changed over time?
- Can you describe a situation in which you experienced some uncertainty with regards to a patient's chronic pain?
  - In that instance, how did you communicate with that patient about their experience of pain?
- Do you have conversations with your colleagues about how to work with chronic pain patients? What do those conversations usually entail?

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