

QTBIPOC Interventions in Fibromyalgic Presents: Critically Exploring Gendered, Racial  
and Neoliberal Regimes of Knowledge in Medical Understandings of Fibromyalgia

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## ABSTRACT

This dissertation asks how fibromyalgia, a chronic illness that is admittedly unknown, unknowable, and undetectable by medical knowledge and technologies comes to be known *as fibromyalgia* by the medical system. By prioritizing critical theory and the experiences and knowledges of queer and trans Black, Indigenous, and people of colour (QTBIPOC), I explore the ways that gendered, racial and neoliberal regimes of knowledge are central to medical understandings of a chronic illness that largely impacts marginalized people. The interventions that I make ask us to rethink the relationship between race and health/illness, to be attentive to the presence of past violences in fibromyalgic presents, and to deeply question the role of the medical system in scientifically legitimizing and sustaining systems of power. I interrogate how the reverence of medical and scientific knowledge provides the medical system the epistemological power to participate in institutional gaslighting and in producing what I call good “neuroliberal” subjects, all justified through the association it makes between irrational bodies and irrational minds. Above all, this dissertation asks us to take QTBIPOC seriously as theorists in their own right, and to recognize their leadership in disability and healing justice as generative of theory and practice that demands us not to rehabilitate sick bodies, nor to reform the medical system, but instead to dismantle the medical system and reach for notions of healing that resist rather than uphold systems of power.

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## **PREFACE**

I started this project by asking, quite simply, how do we come to know an unknown and unknowable condition? In other words, not: what is fibromyalgia? But, rather, how does fibromyalgia come to be fibromyalgia, the same fibromyalgia that opens up histories, that recalls an arsenal of medicalized knowledge, that elicits visions and practices of psy interventions, the fibromyalgia that is both everywhere and nowhere, that is apparently irrational and that apparently makes us irrational?

I was guided by what I early on identified as an epistemology of absence, inspired by the debate around fibromyalgia's invisibility. It centered absence as an entryway into knowing, and practically speaking, it made me prioritize subjugated subjects, historical considerations, invisible structures, and the body to better understand how racial, gendered, and neoliberal regimes of knowledge inform how fibromyalgia becomes fibromyalgia.

Each chapter was dedicated to a different theme, and taken together, they intervene in fibromyalgia studies, but more importantly they point us to the ways that marginalized bodies are pathologized across time and space, and in the service of structures of power, through the scientific justifications offered by the medical system. Along with the QTBIPOC I interview, I argue that our only option for healing is to break free of the use of our bodies to sustain the very structures that oppress us and make us sick in the first place.

And it took revisiting the relationship between race and illness, and interjecting mad studies into making sense of the psychologization of fibromyalgia, and writing about structures of power and history and regimes of knowledge, and introducing the concepts

of institutional gaslighting and neoliberalism, to return to the fact that this project is actually about flesh and bones and blood, and throbbing, piercing, constant, relentless pain, and death, and daily grinding.

It is about an epidemic of chronic illness and “premature deaths” (Wilson Gilmore 2007) and precarious living among a multiply marginalized community that is psychiatrized and sick, often from youth. Not only when we are underserved by the medical system or do not have access to medical care, but often when we do, or precisely because we do. It is about invisible illness not really being that invisible, and how all absence is a product of dispossession, erasure, displacement and violence; absence is a sign that something present has been erased.

I think back to my interviews, and can hear us speaking, while turn by turn our bodies ache, shift, readjust, inhale, lean back and forward, push through, stretch, and become unavoidable. These movements are so familiar to me. And I ask myself, is it so difficult to see fibromyalgia? How are medicalized understandings of fibromyalgia really, mostly, not about fibromyalgia at all?

This project is about bodies that are pushed and bodies that ultimately fail in a system that was not made for them to thrive in in the first place. It is also about the ways in which “being affected” by violence or dealing with violence in ways that do not support its reproduction have been constructed to be maladaptive, pathological, and ultimately, reasons for further violence.

I am a theorist pulled to lean into the experience of my body, an activist excited by the emergence of times and places that I can rarely physically inhabit. You might ask, if my goal is not to fix us or better diagnostic processes, or find a cure, why attempt to

know illness at all? And, I would answer that perhaps the whole point is that I already know illness. I do not need to look far to know illness. I live illness. The participants in this research do not need me or anyone to tell them what illness is. We feel it, so we know it, even though this feeling itself is targeted by the medical system. For many of us, illness is not even a new rupture in our lives; it is a continuation of the medicalization of our bodies and minds; of our histories, even.

In this project, far from trying to know illness, what I am doing is trying to understand how the medical system knows it, or in other words, how an institution granted with epistemological supremacy and which is at the basis of how we know mostly everything we know, comes to know illness, and so by extension, comes to know us, and how we come to know ourselves through it. It is a project about the workings of the production of medical meaning makings, how they relate to structures of power and what impact this has on our lives. It is recognizing that these institutions and systems that infiltrate our lives are always governed or supported by a medical ethos, which has long grappled with, but also long constructed our strangeness. Because it was needed. Because it still is.

Illness cannot be separately read or known from the conditions of our life, from the histories that shape us, and the structures that reach into the most intimate parts of our experience. For many QTBIPOC, fibromyalgia is not our first entry into a relationship with the medical system and the world of psychiatry. It is, in fact, a continuation of the permeation of medical violence into our lives and across generations.

It does not take a visit to a clinic to know and experience medicalization, though clinical encounters can break open our awareness of the presence of medicalization in all other areas of our lives and in the lives of those who came before us.

This project is thus about how our encounter with fibromyalgia concretizes how our bodies are sites of battle, and also sites that are productive of regenerative rationalities for racial violence beyond their time and place. In this sense, fibromyalgia is used here as a starting point for understanding the medical system's encounters with irrational bodies – by which I mean bodies that challenge the limits of medical rationality by escaping its grid of intelligibility, and thus threaten all systems supported by medical knowledge - and irrational minds - those of us who are always already read as crazy, and thus always already necessary for the constitution of racial hierarchies and the perpetuation of racial violence. Our sickness is thus no mistake.

Though this dissertation is about fibromyalgia, it is also about the pathologization of bodies that do not survive in ways that are productive to systems of power. Of bodies that are targeted by power and then fail not to be affected, that malfunction by failing too greatly. Of bodies whose response to power is seen as a threat to power. Of bodies who are in danger but are read as dangerous.

This dissertation is about fundamentally shifting the taken for granted assumptions in fibromyalgia studies and letting fibromyalgia studies be moved by the scholarship, organizing and theorizing of mad, sick, and disabled QTBIPOC, but it is also about understanding the limited ability of medical research to produce theory and incite practices that benefit us. For this would ask that it work against itself. QTBIPOC bodies

have always been against science, and to be against science, I argue in this project, is to be pathological, is to be irrational, is to be targeted by medical violence.

Across this dissertation, I reiterate the ways that the medical system has devised to scientifically legitimize the pathologization of the effects of power and of the techniques of survival we create. I remind us to be wary of systems and institutions that, by design, understand resistance as pathology. Systems that pretend to heal the intended results of their own violence.

Beyond all, I make the case for seeing irrational bodies and minds as openings for paths to healing that do not sustain systems of power but instead resist them. QTBIPOC imagine healing beyond reestablishing a “good moral character” (in Caplan’s words), beyond being reasonable, or aligning and rewiring our behaviours and thoughts to fit the needs of structures of power. In these pages, I share a QTBIPOC invitation to shift the way we live; a shift that is not only desirable, but needed to ensure our survival. A shift that positions healing as a refusal of the systems that wear the body down, rather than a rehabilitative project of forcing the body back in.

## INTRODUCTION

For fifteen years now, I have relied on medical professionals to read, understand and treat unrelenting widespread chronic pain and unexplained fatigue, and a host of other symptoms, such as cognitive difficulties, numbness and digestive issues, that come in unpatterned ebbs and flows. I am not sure exactly when they started, but I distinctly remember bringing them up to a family physician in my teens, when they began to creep into my daily experience of moving through the world. Later, during my undergraduate degree, I saw a new doctor when these symptoms began to interfere more markedly with my life. By then, I had heard of a condition called fibromyalgia that seemed to describe my bodily experience. I casually mentioned the word to this doctor, asking simply, could this explain what is going on with my body?

My memory of this experience is visceral. From that point forward, the doctor would not look at me. He averted his eyes, became cold and brusque, glanced at my medical history in his computer files, and rushed through the rest of the appointment. He wrote me a prescription for an antidepressant and sent me on my way.

I was finally diagnosed with fibromyalgia in 2013, during my last bout of intense illness, after moving to Toronto to pursue my PhD studies. Both prior to and after diagnosis, these types of medical experiences have been quite common in my life for the last decade. My encounters with medical professionals have sustainably shared some common experiences: first, when they have agreed to perform tests, doctors have not found medical evidence (such as through blood tests or x-rays) to orient their diagnosis; second, doctors have always leaned towards psychological explanations for my condition, regardless of whether they knew about my mental health history. I have often felt like the

medical system and its practitioners make up their minds about me and my body in the first minute of any given encounter.

Fibromyalgia is a chronic medically unidentified illness (MUI), in that it has no determined cause, no consistent diagnostic process and no proven treatment. In other words, doctors and medical researchers do not know what fibromyalgia is exactly or how to treat or cure it, and it cannot be found using blood tests or other medical technologies. Yet, theories on fibromyalgia abound. I have closely studied over a hundred medical journal articles in fields from rheumatology to psychiatry. I have consulted numerous health care professionals, including general practitioners, chronic pain specialists, massage therapists, chiropractors, acupuncturists, physiotherapists, psychiatrists, pharmacists and therapists. I have read blogs about fibromyalgia that discuss its symptoms, the diets and exercise plans and other healing strategies said to help with those symptoms, and the despair people with fibromyalgia feel when these strategies and their experiences with the medical system fail them. I have read how-to books and self-help books, and I have listened to podcasts, friends and even random strangers who were uncomfortable with the idea of a young person presenting with so much pain. Still, I, too, cannot say what fibromyalgia *is*.

Thus, the central question guiding this research is, how does the medical system come to know an illness that is apparently unknown and unknowable? More specifically, I ask how gendered, racial, and neoliberal regimes of knowledge shape medical understandings of fibromyalgia and MUIs, generally speaking, and particularly when they relate to marginalized bodies. This dissertation thus also centres queer and trans Black, Indigenous, and people of colour (henceforth, QTBIPOC) experiences,

contributions, and knowledge on this subject. I ask how QTBIPOC could shift our understanding of fibromyalgia and fibromyalgia care. Though my analysis mainly focuses on Canadian texts and on the Canadian medical system, some of the QTBIPOC I interview are based in other settler-colonial societies, namely the United States and Australia, and thus this dissertation presents careful possibilities to generalize to other non-Canadian contexts, though still holding in mind their differences and specificities (such as the privatized medical system in the United States).

I developed my approach to answering these questions during my time in Toronto, beginning in 2013. That year, and in the years that followed, when not at school or at home, I was often in clinics. It was a trying time, to say the least.

That first year, I took a Critical Disability Studies course at York University that gave me a new toolset and theoretical perspective through which to interrogate and understand my experiences. At the same time, I was in community with QTBIPOC, many of whom were discussing chronic illness, disability, the relationship between these and structural violence, and what it would mean to live in ways that supported our bodies. These discussions built upon a long history of disability justice activism in the city, and a highly politicized culture of activism among QTBIPOC, but it was also born out of necessity, as many of us were sick. Although their specific experiences of fibromyalgia were absent from medical literature, QTBIPOC around me were struggling with fibromyalgia as well as other chronic illnesses, many of which were medically unidentified, such as multiple chemical sensitivities, chronic pain and chronic fatigue.

Knowing that many of us have histories of psychiatrization or mental health struggles and diagnoses—by way of our race, sexual orientation, and gender and class

marginalization—I wondered about the relationship between the psychologization of MUIs, such as fibromyalgia, and subjects like us who have had a long and fraught history with medical and psychiatric systems. I also saw a real need, and myself felt curious about what research that centred QTBIPOC—an ignored community in medical literature in general and in fibromyalgia studies in particular, and a community that is spearheading organizing and thought around disability and illness (Piepzna-Samarasinha, 2018)—could tell us about how fibromyalgia and the bodies it inhabits are made sense of in the medical system.

Fibromyalgia is an interesting starting point from which to explore the meanings made through the medical system’s encounters with irrational bodies due to the threat such bodies pose to systems of power. By “irrational bodies,” I mean both bodies that test the limits of medical rationality by escaping its grid of intelligibility, and subjects that have historically been deemed irrational by the medical system, namely gendered, racialized and working-class people (see, for e.g., Kanani 2011 for a historical review of the association of racialized people with madness). Thinking through the psychologization of fibromyalgia by centring QTBIPOC can tell us more about the racial, gendered and neoliberal regimes of knowledge that underpin medical understandings of fibromyalgia, chronic illness and health more broadly.

Finding literature on QTBIPOC health that, similarly to this project, considers structural factors in its analysis was incredibly difficult. Even on the well-known Rainbow Health Ontario research database—which features literature, posters, academic and medical studies, and conference presentations on QT health—work about or by QTBIPOC formed a miniscule minority of the resources available. Many studies on

QTBIPOC health are the first of their kind, and thus end up focusing on discrimination in medical settings and their impacts, but leave out theoretical and structural analyses that could potentially shed light on practices of discrimination. For example, Trans Pulse Project—one of the better-known and larger-scale studies on the health impacts of transphobia and discrimination on trans people in Ontario, which included 433 trans-identified respondents—focuses on incidents of trans discrimination but does not truly analyze structural factors beyond acknowledging them; considering this is the first study of its kind, this seems to be by research design as structural analysis was beyond the goals of the project (Longman Marcellin et al 2013). I did, however, come across a community-based study by Ristock, Zoccole and Passante (2010) on Aboriginal Two-Spirit health, which emphasized how an analysis of settler-colonialism and other systems of power must be made central to studies on health in this community. As obvious as it may seem, this type of perspective remains absent in most of the literature on QTBIPOC health, when there is any, though, like Ristock, Zoccole and Passante, I believe it is essential to understanding the reality and experience of chronic illness in QTBIPOC communities. High rates of trauma, abuse, homelessness, psychiatrization, poverty, and incarceration - and particularly so of Indigenous people (Rainbow Health Ontario 2016) - in QTBIPOC communities have health consequences that have thus far been largely ignored, and are largely tied to the workings and consequences of structures of power.

Medical and academic literature on QTBIPOC and fibromyalgia is nonexistent. Yet, certain factors point us to the high probability of this condition's prevalence in QTBIPOC communities. Fibromyalgia mainly affects women and working-class people (Fitzcharles et al. 2012). This points us to the prevalence of fibromyalgia among people

of marginalized gender identities, which includes QTBIPOC, but also drives home the trouble with cis-heteropatriarchal medical research that continues to rely on gender binaries and the exclusion of those of us who may not be captured by this category of “women.” Furthermore, studies on the economic well-being of trans people have revealed that they are often working-class, and experience more poverty and homelessness (e.g., Dénomme-Welch, Pyne and Scanlon 2008; Vancouver Coastal Health et al. 2016). We also know that socioeconomic status is intimately connected to gender, sexual orientation and race.

While I cannot confirm that QTBIPOC are more affected by fibromyalgia than other groups of people, my own research points to a concern with high incidences of chronic medically unidentified symptoms and illnesses, as well as chronic pain, in this community. I consider this seriously, and read it along with the important observations made by participants in relation to the impacts of gendered, racial and neoliberal knowledges on QTBIPOC health, to propose a critical perspective currently nonexistent in fibromyalgia research. Other studies (e.g., Vancouver Coastal Health et al. 2006) have circumvented lack of statistical data by using a similar approach to warn of the prevalence of some illnesses among queer and trans people. They highlight how the proof of the commonality of risk factors among this community is enough to investigate prevalence. In relation to cancer, for example, the availability of evidence on trans socioeconomic marginalization, high rates of alcohol use and smoking, hormone use, surgery and risky sex, have been used to suggest that trans people might be at risk or might particularly be affected by cancer, and that transphobia and medical disregard for

this context possibly increases the negative outcomes and prevalence of cancer among this community (Vancouver Coastal Health et al. 2006).<sup>1</sup>

Several QTBIPOC participants I interviewed referenced the commonality of chronic illness among their QTBIPOC friends and the communities they belong to, and everyone in the room during the group interviews I conducted agreed that they had noticed this too. Participants asked questions such as, “Why are we all sick?” A passage from my interview with E, one of the participants in this research who belongs to an online group for QTBIPOC who are disabled or sick, illustrates this point. When I asked E if many people around them had unidentified chronic illnesses resembling fibromyalgia, they said, “Yeah, it’s, like, everybody I know.” This observation was reflected in the interviews I conducted in Toronto, too. When I asked participants what was on the forefront of their minds in terms of unidentified chronic conditions, mge said, “I think there’s a conversation to be had around POC with fibro, and mitigating factors and trauma, and, like, why do we all have it? [laughter].” This remained a theme throughout this interview, and was later brought up again by Arti, as reflected in our dialogue below.

Arti: I don’t really know any Black, Indigenous or people of colour who don’t have chronic pain. I know lots of people who don’t talk about it but I don’t know any who don’t have it. That feels relevant. [laughter]

Ghaida: At home, it’s just a part of life.

Arti: Exactly.

Further, many of the factors that are said to justify fibromyalgia’s overrepresentation among women (mental health, trauma and, when structural factors are

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<sup>1</sup> A similar approach was used in relation to poor cardiovascular health (Vancouver Coastal Health et al. 2006).

considered, gender inequality) are common in the experiences of QTBIPOC. For instance, one report provides evidence of alarming rates of trauma, violence and abuse experienced by Indigenous Two-Spirit people (Rainbow Health Ontario 2016). Another notes that “compared to straight people, lesbian, gay, and bisexual people have double the risk of exposure to traumatic experiences over their lifetimes” (Sharman 2016: 18). Further, research has pointed to the significance of race in terms of prevalence of chronic pain and discomfort (e.g., Green et al., 2003; Levy, Ansara and Stover, 2013; Ramage-Morin and Gilmour, 2014), one of fibromyalgia’s most common and pervasive symptoms. While this subject has been shown some attention, as Green et al. note, “the significant impact of chronic pain on health and quality of life in racial and ethnic minorities has been largely overlooked” (2003: 281).

QTBIPOC remain mostly absent from medical research overall, as well as more specifically from medical studies on race, sexuality, gender and fibromyalgia. When we do appear, it is rarely as theorists, but rather as objects of study. What is more, the medical system has been an important source of violence in the lives of many QTBIPOC, making us necessary thinkers to include and prioritize in a scholarly conversation that reflects on the impacts of medical violence, such as the one I undertake in this dissertation. Indeed, medical violence was often brought up during my interviews, with participants disclosing that they have avoided seeking medical help or medical explanations for their physical symptoms, particularly in relation to the experience of pain. The distrust participants expressed towards the medical system often stems from the tense and violent (ongoing) history of racialized and queer and trans people’s encounters with it. This research accounts for this distrust, and thus stands apart from more

mainstream health research. Rather than excluding those who chose to absent themselves from the purview of the medical system, or were forced out of it, in this project I decided to address the reasons for these exclusions, and people's experiences of them. While the widespread evidence of chronic illness and chronic pain - oftentimes invisible and medically unidentified - within communities of queer Black, Indigenous and people of colour is apparent for those within these communities, this reality is not even on the radar of the literature I consulted.

To consider QTBIPOC as theorists in their own right is particularly fitting for a research that questions the revered epistemological power of medical knowledge. It is an act of scholarly resistance to challenge institutional gaslighting (see Chapter 3) by choosing to believe, value and consider QTBIPOC to be worthy enough to narrate the conditions of our lives and offer a unique theoretical vantage point for understanding the structures of power that govern them.

### **Chapter breakdown**

In light of this literature, in this dissertation, I interrogate fibromyalgia's relationship to gendered and racialized bodies by evaluating how fibromyalgia is produced by the medical system. Thinking about the medical system as a medical-industrial complex involves recognizing it as an institution of state and market-sanctioned violence that manipulates, coerces, targets and intervenes in non-normative bodies, and that plays a central role in determining these bodies to be non-normative in the first place (Wall 2016).

After a review of my methodological, epistemological, and theoretical approaches in Chapter 1, in Chapter 2 I introduce and briefly analyze literature on health and race. In Chapter 3, I solidify our understanding of processes of psychologization, and introduce the interventions of (QT)BIPOC mad studies scholars. In Chapter 4, I challenge past research's narrow understanding of fibromyalgic bodies as the latest incarnation of Victorian hysteria. Along with the QTBIPOC I interviewed, I suggest that this limited genealogy obscures racial and settler colonial power, for which the medical system has long provided scientific justifications, and I instead propose a new set of ancestors. It is in this chapter that I begin to use the term "fibromyalgic" - which until now has only been used as a modifier for the nouns "pain" or "disease" or "patients" in other studies - in association with "bodies," "encounters," and timeframes, like "pasts" and "presents." Though, of course, I use "fibromyalgic" to mean "related to fibromyalgia," I also offer it as a concept to think through subjects, times, and meetings that highlight the tensions between bodily knowledge and experience and medical epistemologies and the systems of power they sustain.

Chapter 5 and Chapter 6 jointly make the case that irrational bodies—bodies that cannot be known through medical rationality—have a strong association with what the medical system considers to be irrational minds, and that the production of the two are intertwined. In Chapter 5, I develop the concept of institutional gaslighting to discuss how this process is mobilized to discredit the epistemological threat of fibromyalgic bodies by suppressing body knowledge, psychologizing QTBIPOC, and masking the role of the medical system and other institutions and structures of power in producing illness in the first place.

Chapter 6 builds on the work of previous chapters to evaluate how a specific practice of institutional gaslighting—cognitive behavioral therapy—is used in pain management courses for people with fibromyalgia to discipline failed neoliberal subjects. In this chapter, I closely read and analyze the latest Canada guidelines on fibromyalgia (Fitzcharles et al. 2012) and a pain management course workbook (Chronic Pain Service of Toronto Rehab Rumsey Centre 2014) through the concept of “neoliberalism.” I develop this concept as a tool that is useful to attend to the ways that the medical system acts as a supportive institution for neoliberalism by developing and applying interventions that combine neuroscience and the interests of neoliberalism. I also highlight the ways in which QTBIPOC I interviewed propose new ways of living and being that resist “neoliberal” approaches to fibromyalgia. To end the dissertation, I offer a conclusion that reflects on my own journey as a researcher that has been moved by this process, I review some key concepts introduced in this project, and I propose some new paths for future research.

## **CHAPTER ONE: QTBIPOC EPISTEMOLOGIES AND METHOD-ILL-OGY**

In this dissertation, I offer a critical lens that is currently missing from, and desperately needed within, fibromyalgia studies and studies on medically unidentified chronic illness more broadly. Changing our starting point to begin by inquiring with those most affected by medical intervention—in this case, QTBIPOC—can change the direction of these studies, leading us, ultimately, elsewhere. This elsewhere not only urges us to understand illness differently, but helps us identify and challenge the power of oppressive knowledges, the institutions that produce them, and the structures they sustain. Health and illness are the areas that I chose to explore here, but this dissertation is simultaneously an exploration of how structures of power reach into the most intimate parts of our lives. It demonstrates how meanings made by medical authority that aim to uphold gendered, racial and neoliberal structures shape our understanding of our bodies, our sense of reality, and the way in which we interact with the world. Exposing the effects of these systems on what is generally thought of as the most objective truth—science and medical rationality—opens up the possibility that we can trace the lineage and sources of illness and pathologization to violent interventions. In these pages, I also hope to incite new paths to healing and to reclaiming our bodies, thoughts and knowledges.

In this first chapter, I draw the contours of this dissertation and discuss the methodological and epistemological approaches that have guided me throughout this project. Primarily, my interventions into fibromyalgia studies are theoretical and they draw from critical theory in health, disability, race, and gender studies. Included as well

in this theoretical framework are the interventions, theories, and experiences of the QTBIPOC with whom I conducted semi-structured individual and group interviews.

Framing my dissertation are three overarching structural approaches I have developed. The first, which I have named “method-ill-ogy,” reflects my consideration of the impact and influence of illness on my research process. The second is what I call an “epistemology of absence,” and it has not only served to intervene in medical positivist and empirical epistemologies, but has also guided me in identifying the theoretical work necessary for this project. The last is an intentional decision to centre critical work on illness and disability from interdisciplinary fields, and particularly the work of QTBIPOC, who I consider to be theorists in their own right. In what follows, I outline the overall structural approaches that inform this project as a whole, and then discuss in greater detail the theoretical underpinnings of this dissertation.

After setting up these overarching approaches, I dedicate the final part of this chapter to a review and discussion of the details of the methods I used, namely the interviews I conducted and the content analyses I performed, as well as to a reflection of the ethical considerations that emerged and the guidelines I followed.

### **“Method-ill-ogy”: Illness-led research**

While this research is *on* illness, it is also *of* illness. My illness and that of participants shaped this research in a notable way, which I inevitably had to reflect on throughout this project. I call this process of shifting, adjusting, listening, of holding and being held by illness during a research project, “method-ill-ogy.”

Traditional methodology often refers to a rigorous set of rules that orient how one does research; a method-ill-ogy troubles this consistency. I could not, after many attempts, separate illness from this research about illness. While I was trying to shape this research, the force of illness often took this agency from me, and the real director at times was illness itself. Illness dictated the flow, rhythm, pauses and complete halts of this research. Illness interfered with my ability to think conceptually, to remember long enough to type, to leave the house to make it to interviews and relevant events or talks. It restricted how widely and for how long my body could stretch into the outer world to gather evidence. Because of these limitations, my body also forced me to listen to it: to view it as a site and author of knowledge in its own right. Days and weeks aside, for one whole four-month stretch and for one year-and-a-half stretch, I was mostly bedridden while writing and researching. On a daily basis in the seven years I have been writing, my body has pulled me to the bed and to the clinic, rather than to the world and to my computer. I have had over one hundred encounters with healthcare professionals since I started writing my dissertation, including four family physicians, walk-in and hospital doctors, laboratory n/professionals, nurses, massage therapists, ultrasound and MRI technicians, rheumatologists, chronic pain management group facilitators, energy healers, acupuncturists, audiologists, pain specialists, and cognitive behavioural, narrative, and somatic experiencing therapists. I have had blood work done on at least twenty occasions, ultrasounds on five or so, MRIs and X-rays on more than ten, and undergone six hearing examinations, innumerable consultations, and appointment upon appointment with doctors and specialists.

In these meetings and appointments, my research was occurring, taking shape before me. My body, too, was being shaped, probed, tested, changed; it was reacting, shrinking away from these interventions. We are continuously taught—as racialized people, as QTBIPOC, as women, as people with chronic illness, as marginalized students, as patients in the mental health and physical health systems—that our body- and experience-based evidence is not enough. But my illness kept pulling me back inwards, and I was forced to rely on this body knowledge, this body *of knowledge*, more than I initially intended or anticipated.

There are times when, bound to bed and home, my body’s limits meant that I missed occasions to do research. All of the events, meetings, performances, classes, appointments and other obligations that I have missed came to *mean* something and offered me a perspective on this subject. My body oriented me elsewhere, into itself. The presence of my body, the absence of my body: these came to reflect back to each other and began to create meaning. This meaning became increasingly apparent as I struggled to perform the role of researcher, as my body stood in the way of my ability to show up and to connect with others, to think clearly enough to write, to archive the wide range of online writing by QTBIPOC on illness and disability (an element of this project I was ultimately unable to do as much as I would have liked), to keep pushing despite the limits of my synchronization with timelines and deadlines. My body’s limits became the limits of this dissertation, too. I was repeatedly asked by doctors if I was “still going to work,” as though this was the defining marker of the extent of my illness. Yes, I was, most days, and sometimes not, but what they did not ask is how my work was being shaped and moulded by my illness.

Fibromyalgia not only defies the logics of the medical-industrial complex but also, as I came to know painfully, the logics of most systems, including the academic-industrial complex. Fibromyalgia answers to no one; it does not chase progress or linear movement, achievement or over-achievement. On days when not finishing, not sending, not replying, not writing felt like the end of the world in my mind, my body simply did not care. To find this out three quarters of the way through my doctoral degree was a hard blow to me as a student who up until that point was not only proud of being on time, but also to me as a human being who had designed an identity around resilience. Bouncing back, beating the odds, surviving: these were central tenets of who I thought I was. Fibromyalgia forced me to investigate what was behind this sense of identity, what regimes of knowledge guided my own understanding of illness and myself, what histories shaped my becoming and my undoing, and what made me resist other understandings, some of which were taught to me by the participants in this dissertation. These questions and reflections have guided how I approached this research. They are my method-ill-ogy.

I situate this method-ill-ogy in a long line of decolonial, anti-racist, and feminist methodologies spearheaded by feminist and anti-racist scholars that have centred the body as a site of knowledge and as a way of knowing as early as the 1980s. My method-ill-ogy is connected to and builds on the concepts and methodologies of implicit, bodily, and embodied knowledges set forth by women of colour scholars such as Hill Collins (1990) and the authors featured in the collection edited by Bordo and Jaggard (1989). Not only have these scholars valued embodied knowledges but they have offered ways to centre the body as a key methodological approach and tool to research and processes of knowing. I expand on the importance of reclaiming felt and embodied knowledges in the

following section, which I will turn to now, as I introduce the “epistemology of absence” guiding my work.

### **Epistemology of absence**

My interest in how the medical system comes to know fibromyalgia is without a doubt an epistemological question. In fact, currently, fibromyalgia is, in and of itself, an epistemological question; its very existence is contested because medical technologies cannot see it. Thinking through this context inspired me early on to frame my dissertation around what I call an “epistemology of absence.” This epistemology motivates the two levels of inquiry at the heart of this research. The first is the value I give to QTBIPOC knowledges, which have traditionally been subjugated both in the academy and in medical research. The second is my interest in interrogating the gendered, racial and neoliberal knowledges and invisible structures that inform how fibromyalgia is understood and treated. The epistemology of absence at the heart of this research forces us to look beyond what can be seen, calculated or measured, at the same time as it allows us to ask: What unseen forces are in play when we attempt to understand what cannot be seen?

Valuing subjugated knowledge, challenging the primacy of medical knowledge, and critically interrogating the role of systems of power: these approaches are interconnected. For example, historically, the depreciation of women’s knowledge and increased medicalization have gone hand in hand; medical technologies gained empirical power over women’s experiences of themselves as these technologies became available on the market (Munch 2004). An epistemology of absence allows us to seek out the

connections between the approaches I note above by looking beyond, behind, underneath and above current contexts.

These levels of inquiry lend themselves to Foucauldian and feminist standpoint epistemologies, as they interrogate the relationship between knowledge and power (Foucault 1970, 1980), and understand dominant groups as “scientifically and epistemologically disadvantaged for generating knowledge” (Harding 2004: 43). Rather than adopting one or the other, or both, in this dissertation, I view them as examples of an epistemology of absence; Foucauldian epistemology has a specific interest in interrogating invisible structures, and feminist standpoint epistemology values subjugated, invisibilized knowledges. Taken alone, each one is limiting. For example, postmodern Foucauldian epistemology explains identity as a product of power, yet authors using this conceptualization do not always intervene in the power of privileged subjects to produce (valued) knowledge. In other words, revealing that identity is a construct does not make identity-based power disappear (see, for e.g., Gilroy 1993; Puar 2007). Data about health disparities in terms of race, for instance, are still needed, whether race is understood as constructed through power or not. Identity politics are often dismissed using such social constructivist arguments. Yet, Mullings and Shulz (2006) explain that data on race is necessary, if only “in order to measure the biological effects of the social construction of race” (12). As Geiger (2006) points out, we must “count race until race no longer counts” (280). As well, while feminist standpoint epistemology helps justify my interest in QTBIPOC knowledges as valuable and useful toward understanding power relationships, I consider that QTBIPOC knowledges, too, exist in a historical, economic and socio-political context that does not separate them from power, even while

these knowledges challenge it. Like some before me (e.g., Etowa et al. 2008; Malterud 1999), though, I agree that medical knowledge is limited in attending to the experiences of people who are racialized or of marginalized sexualities and genders precisely because it fails to consider how power operates within this system, a point made by a feminist standpoint epistemology approach. On gender, for example, Malterud (1999) writes:

Medical theory and practice have, for a long time, been constructed by men, with the clinical gaze of men, the cultural templates of men, and the perception and language of men. It is therefore not unexpected that the clinical signs presented by women patients are not always adequately embraced within the scope of contemporary medical epistemology. Theoretical and empirical evidence remind us that the interpretation of clinical signs depends on the position of the reader—even the gendered ones. From such a perspective, it is not surprising that medical signs in women have been denied medical validity.

Although I view Foucauldian and feminist standpoint epistemologies as epistemologies of absence, they remain insufficient for discussing fibromyalgia. It is important to transcend the debate between social constructionist or postmodern epistemologies on the one hand, and standpoint epistemologies on the other, particularly in relation to fibromyalgia. In fact, both are needed here. How can we account for the ways in which fibromyalgia *becomes* fibromyalgia and how this becoming shapes those it has touched (as in, how fibromyalgia is constructed) while prioritizing the lived experience and knowledge (as in, standpoint) of those living with its symptoms, who are left out of defining it?

Rather than ask if fibromyalgia is simply a result of the social, political and economic world that has produced it—and thus perhaps imply that it does not truly exist because it has simply been constructed—I wonder if we can consider biology, genes and whatever we have confined to the realm of “nature” as always already having histories of

production (Ahmed 2013). The truth is that a constructionist approach has been applied in an unhelpful way in relation to fibromyalgia. Ironically, social construction has served to individualize fibromyalgia, painting it as a condition that results from a personal failure or inability to adjust or bounce back from the conditions and responsibilities of neoliberal subjecthood (see Chapters 5 and 6). This framework has allowed physicians to dismiss fibromyalgia's existence and people's experience of it entirely, contributing to its stigmatization in Asbring and Narvanen's (2002) sense of calling into question the "veracity, morality, and accuracy of patients' symptom description" (148). This in part emanates from a hierarchical view of disease that posits organic or visually identifiable evidence of pain or illness as more real, more important and more urgent than invisible or unidentified illness. This posits those carrying the invisible illness as less than, and sheds doubt on the veracity of their claims.

The study of an illness that is yet to be known inherently assumes an epistemological inquiry. For, if an illness is unknown, we must ask: How does it come to be known? Which knowledge do we value in attempting to know this illness, in drawing the contours of what it holds, in delimiting what it is and what it is not? Whose knowledge do we trust in making meaning of it? Fibromyalgia's biomedical absence leads to suspicions about its legitimacy (Baker 2002). It raises questions such as: How can we trust what people experience simply because they say they experience it? The emphasis on fibromyalgia as subjective, in much of the literature, confirms this concern. In their feminist work on fibromyalgia, White, Lemkau and Clasen, too, emphasize the importance of the epistemological nature of debates on fibromyalgia:

The distinction between the scientific and feminist epistemologies raises several important questions. If patients complain of pain and fatigue for which physicians

can find no pathophysiological cause or evidence, whose knowledge is authoritative—that of the physician or the patient? In the absence of physical findings, people afflicted with FM have been accused of fabricating pain for secondary gain, or of merely manifesting psychological problems. How aggressively can biomedical aspects of the disorder be pursued if women’s subjective complaints of pain and fatigue are trivialized or assumed to be psychological in origin? (2001: 55)

Investigating medically unidentified illness has brought me to consider the tension between scientific or medical epistemologies and knowledge grounded in the experience of those they marginalize. The concept of objectivity at the heart of medical epistemology is instantly put to scrutiny when there is no medical evidence to work from. Yet, the myth of objectivity persists in medical research and practice, and this even with a plethora of research that proves continuing medical prejudice in healthcare encounters, diagnosis and treatment. As Malterud (1999: 283) writes, “a medical diagnosis is seldom a biological fact.”

Rather than shying away from or joining the debate surrounding fibromyalgia’s legitimacy or visibility, this research is guided by an epistemological framework that centres absence as an entryway into knowing. Across this dissertation, the absence I call upon is that of intangible structures and the hold of power on our lives, as well as the subjugated and invisibilized interventions, theories, knowledges, and experiences of QTBIPOC. An epistemology of absence brings me to interrogate what absences are actually integral to medical “facts” about fibromyalgia. The histories on which the medical system relies to read patients’ bodies are examples of absent presences that shape medical encounters. An epistemology of absence also allows us to ask not only what appears to be absent (e.g., histories, information, evidence, approaches), but also who is absented from our understanding of illness. I intentionally chose to focus on the subjects

involved in this study as part of this overall approach; I argue that disabled and sick QTBIPOC are completely excluded from knowledge production related to fibromyalgia, reflecting a larger trend of their common exclusion from knowledge production in health studies. Our experiences are often deemed irrelevant or too particular, and our lives, too complicated for the medical system. In relation to fibromyalgia, QTBIPOC—as a whole or as individual groups—do not even appear in the realm of knowledge. So far, they have not even been considered worthy of consideration or consultation. Ultimately, an epistemology of absence is oriented towards social justice, as it asks, who is not here and why? As such, an epistemology of absence guides this work, asking us to see and consider what and who are missing.

I am not the first scholar to prioritize absence in my thinking. Apart from Foucauldian and feminist standpoint epistemologies, a plethora of writers in critical studies have adopted what I consider to be an epistemology of absence, without having used this term. These authors have found significance in what is absent, invisible or erased, or have documented and analyzed processes of erasure. The interdisciplinary works of Jin Haritaworn (2012), Lisa Cacho (2012), Avery Gordon (2008), Jacqui Alexander (2005) and Sara Ahmed (2013), for example, call upon ghosts to discuss power, race, disability, gender, and meaning-making. An epistemology of absence also responds to a recent surge of interest in QTBIPOC histories in Toronto (Haritaworn, Moussa and Ware 2018a), including QTBIPOC disability history (Piepzna-Samarasinha 2018). Further, it reflects the central themes of trauma and healing currently being engaged with by QTBIPOC (e.g., Piepzna-Samarasinha 2015) and other feminist and racialized scholars within the academy (e.g., Million 2013). Reading such work has

inspired me to take absence seriously, rather than to ignore the intangible, the felt and the unproven from fear of lacking credibility as a researcher. As scholars, our inclination, if not obsession, to rely on facts and empirical data is no different than the way the medical industry places primordial value on these things. Felt knowledge, embodied knowledge and subjugated knowledge have long been central to Indigenous and other racialized people's understandings of ourselves and of the world (see, for example, Hill Collins 1990; Jaggar and Bordo 1989; Million 2013; Amadahy 2013), and these ways of knowing have been violently discredited by Western empiricism (Amadahy 2013) in clinical encounters and in research. This is particularly true in studies on health. As Weber (2006: 23) states:

Most scholarship on health disparities that is considered mainstream in the social sciences and biomedical science and that receives the lion's share of research funding emerges from the biomedical paradigm and the psychosocial and biobehavioral approaches that emulate it—each of which employs a positivist epistemology.

Positivist epistemology continues to haunt our inquiries into the social, personal, emotional and political. Beyond interrupting our ways of knowing, it limits our imagination. Yet, other ways are possible. The authors I mention above and the marginalized people who lead in certain areas of health-related activism and other critical science work, all begin with an epistemology of absence, meaning an intentional inquiry into and struggle for the invisible or invisibilized. Among these thinkers and activists are those working on reproductive and disability justice activism (Piepzna-Samarasinha 2018), Indigenous science (Amadahy 2013), South and East Asian approaches to healing and health (ahuja, Gibson, Hwang and Smith 2018), and queer- and trans-led AIDS research and activism (Li 2018).

My method-ill-ogy is thus connected to the epistemology of absence I am detailing, particularly as this type of epistemology urges us to turn to the body, the ground on which felt experience and societal hierarchies play out. Centering the body, this ever raced and gendered absent presence in our lives, means valuing felt knowledge. After all, a method-ill-logy is an ode to felt knowledge, an urgent refusal of the rational, and an invitation to be taken over by that which we cannot rationalize away. Felt knowledge challenges Western medical epistemologies, and is also violently discarded from the clinic and from medical knowledge. It includes but is not limited to “gut feelings, experience, preexisting knowledge” (Ross, Lypson and Kumagain 2012: 636) and other ways of knowing that are rarely taken seriously by the medical system, and even profoundly pathologized. The pathologization of felt knowledge in relation to fibromyalgia cannot be understood without considering the long history of the pathologization of racialized people. Feeling (positioned opposite to “thinking”) has, throughout history, been a marker of race, of gender, of mental illness, and of disability, and a sign of inferiority and underdevelopment. Separation from the body and control of the mind are themes central to conquest, patriarchy, and civilizing missions (themes I discuss at greater length in Chapter 5). As Indigenous scholar Million (2013) notes, felt knowledge and experience also troubles the individualism at the heart of Western epistemologies and ways of knowing as, particularly among Indigenous peoples, it is foremost “community knowledge” (57) that is treated by people outside these communities “not as knowledge at all” (57).

Felt knowledge is met with skepticism in the medical system, a central institution in the maintenance of settler-colonialism and other structures of power. It resides in the

body and requires tuning into it. Ironically, the body is a central site of inquiry in medicine; it is largely how the medical system knows. The body is tested, probed and manipulated to obtain observable evidence or information from which to draw conclusions. Yet, when patients listen to their bodies in ways that are not sanctioned by the medical system, when they are attentive to how their body reacts or what it expresses, independently of medical probing and evaluation, this knowledge is often met with skepticism. This is one of the ways that the experience of fibromyalgia is dismissed in medical encounters; particularly when attached to already marginalized bodies, felt knowledge is not real unless confirmed by medical technologies. Mendelson (2009) provides another example of the discrediting of felt knowledge in relation to lupus. She discusses how patients with lupus were challenged when they attempted to explain to their physicians that they *knew* their symptoms were not arising from stress or emotional distress:

The attribution of symptoms to stress and depression was especially vexing because the participants had already considered that possibility. They led busy lives and were well aware that tension headaches and nervous stomachs could be caused by stress (Kirmayer, 1986). Their first inclinations were to dismiss symptoms as stress related, situational (such as exposures to sick children), or due to overworking. It was only after the symptoms progressed, were amplified, or repeatedly reoccurred that the participants realized their symptoms were not embodied stress and that the cause was elsewhere (Mendelson, 2006). By attending to their embodied knowledge, the participants were able to determine which symptoms arose from stress and which represented something more pernicious; however, this type of knowledge was devalued in the medical encounter. (Mendelson, 2009: 398)

We need to critically consider absence because so much of what governs our lives, of what we experience, and of what ails our bodies cannot be shown, touched or proven. What critical studies that privilege absence teach us, most importantly, is that

absence is produced; absence is a product of dispossession, erasure, displacement and violence (Haritaworn 2015; Haritaworn, Moussa and Ware 2018). Equally, absence acts as evidence; absence is a sign that something present has been erased. An epistemology of absence not only privileges absence, but attends to these processes of disappearing. It asks us to attend to the ghosts that continue to haunt our lives; to ask, who was there then and who is here now? Who is called upon and who is left out to make sense of our current moment of knowing? An epistemology of absence is as much about knowing in order to orient our present and future as it is about archiving our past (see also Haritaworn, Moussa and Ware 2018). For QTBIPOC, an epistemology of absence rejects the disappearing of our ancestors, those ghosts who are mobilized to make sense of our bodies in clinical encounters, but who refuse to serve systems of power if we listen closely. An epistemology of absence opens up the possibility to halt their disappearance, and ours, by revealing the trends of medical violence so embedded in our histories. Thus, letting in ghosts, I assure you, is a matter of survival. I venture into the world of absence with the same fear and curiosity that ghosts arouse, and I urge us to take seriously the power of what cannot be seen. Fibromyalgia, through its concrete yet medically invisible effects on my body, has forced me to do so. In other words, my method-ill-ogy fostered this epistemology of absence.

### **A (QT)BIPOC approach to critical disability studies**

It is illness, too, that lead me, in the winter of 2014, to enroll in a graduate course entitled Experience, Identity and Social Theory taught by Professor Rachel Gorman at York University. In the year preceding Gorman's course, I experienced a terrible spike in

my illness—I was in severe pain twenty-four hours a day, my mobility was restricted and my hearing loss intensified, among other things. My health and function were impacted to the point that, while most people with fibromyalgia have been documented as experiencing flare-ups in their illness for days, weeks, or maybe a few months at worst, I am now entering the fifth consecutive year of the flare-up that started in this period. The curriculum proposed by Gorman was my first true entry into the field of critical disability studies. During the course, we read most of the works that influenced and shaped this dissertation. For the first time in my life, I was reading scholarship by (QT)BIPOC that spoke to me as a racialized person and as a person living with chronic illness. Up until that point, fibromyalgia was an embodied and clinical presence in my life. The knowledge that shaped its meaning to me was informed by medical journals, clinical encounters and internet browsing. While I refer to these sites of knowledge throughout this dissertation, my overall critical approach to fibromyalgia, as reflected in these pages, is informed by this course. My worldview shifted during those few months.

Academia can be incredibly alienating to QTBIPOC, and it has been for me. Moving in a world that has not been designed for us, and in which we are constantly reminded of this fact, can and often does affect our health, learning and success. Gorman’s class was a refreshing break from this alienation in more ways than one, but most importantly it had a profound impact on how I understood and approached disability, race, gender and my own experience of these identities. (This course had a similar impact on other marginalized students, as discussed by Ware and Ejiogu (2018).)

The highly interdisciplinary course was offered through the Critical Disability Studies program; its syllabus pulled from various fields of study, including feminist,

critical race, anti-capitalist and critical disability studies, to name a few. The scholars represented in the syllabus who had the most significant impact on this dissertation—largely (QT)BIPOC scholars—used an interdisciplinary approach to theorize how race and disability are co-constituted. The way I approach and analyze fibromyalgia is highly indebted to the authors I read in this course, and others that they led me to, including Erevelles (2011), Gorman (2005; 2010; 2013), Haritaworn (2012), Cacho (2012), Ahmed (2004; 2013), Dossa (2009), Chen (2012), Mollow (2006), Lorde (1997) and Million (2013). I refer to some of these scholars in this dissertation, while others, though not directly quoted or referenced, completely altered my thinking and experience so I credit them here too.

Those who know disability studies might find this set of authors to be an unusual entry point into the field of critical disability studies, a field whose canon is largely composed of white (and often straight and cis) scholars. Yet, for QTBIPOC such as myself, and as Ware and Ejiogu (2018) similarly argue, (QT)BIPOC scholars *are* our critical disability studies; our canon, if you will. And, in this case, they have given me the tools and theoretical frameworks to grapple with my own understanding of illness and build the interventions I make in this dissertation. Whether they use the term “disability” or not, these authors theorize the relationship between disability, race, gender and class in ways that account for structural power, historical analysis and the experience of marginalized peoples. They theorize the co-constitution of identity categories such as race and disability—a co-constitution central to this dissertation—in a way that differentiates them from traditional work in the individual fields they draw from, i.e. disability studies, critical race theory, anti-capitalist theories and feminist theory. Their

work is grounded in history; it evaluates the role of structural power and provides novel ways of understanding the everyday and the overall systems and structures that inform it.

The framework they propose, and the one I adopt in this dissertation, points us to the long history of racialization of disabled people, and the association of racialized people with inferior physical, intellectual, psychological and emotional deficiencies, as well as their systematic disabling, by processes of what Gorman (2010) calls “disablement,” by institutions and structures of power, such as war, neoliberalism, the prison industrial complex and other systems of oppression that disable people everyday (Gorman 2005). As Erevelles has suggested, eugenics are at the heart of (neo)colonial and nationalist projects, thus making disability “mutually constitutive of race, gender, and sexual orientation within the exploitative conditions of transnational capitalism” (2011: 85). Eugenics rely on the association of racial difference to degeneration or disease, and have long been used to deem racialized people as having unfit bodies and minds; this construction furthers oppressive policies and practices, such as those of forced sterilization, miscegenation laws, segregation and genocide. Today, this equation between racial deviance, sexual and gender deviance, and disability is used to further criminalize populations, control their bodies, and legislate their exclusion from citizenship through other state policies. These policies in many ways depend on the representation of racialized people as always already disabled. For example, Dossa (2009) evaluates the discourses of contagion and the subjection of racialized immigrants to medical examinations, illustrating how Canada equates racialized bodies with disabled bodies, while Erevelles (2011) discusses how disability is linked to colonial, neoliberal

and imperial projects through the exploitation of racialized women in a global neoliberal economic structure.

What is more, this scholarship on the co-constitution of race and disability points to the ways that racialized people's responses to structural violence are pathologized and turned into illnesses in order to preserve the status quo. As such, these texts remind us of the integral role of the medical system in sustaining and providing justification for systems of power. For example, Cacho (2012) discusses how theories of "brain dysfunction" have been used to explain inner city violence in an American context, illustrating how the effects of structural violence are scienticized and thus preserved.

The connections this scholarship draws prefigure novel ways to engage with health, illness, identity, healing and fibromyalgia presents that are currently absent from fibromyalgia studies. Its contributions, namely a serious consideration of (QT)BIPOC interventions and histories in relation to disability and illness, and a critical investigation of the workings of power, are invaluable to fibromyalgia studies, which are currently largely devoid of such engagements. While the themes of these authors' works differ, they all look beyond, underneath, through, above and around to understand the centre, the now. This provides a much-needed approach to the fibromyalgia present, which lingers in the unknown and which baffles, hovers around and slices through positivist, medical and empirical attempts at knowing it. For these reasons, this scholarship guides my work and informs my approach to this dissertation. Specifically, for example, in Chapter 4, I draw inspiration from authors such as Sara Ahmed and Jin Haritaworn to evaluate the role of history in constructing fibromyalgia and its subjects by asking which ghosts are invited into the clinical encounters between QTBIPOC and physicians, and which ancestors are

violently erased from the history of chronic medically unidentified illness and why. Chapter 5 and Chapter 6 are, in a big way, inspired by the work of Dian Million (2013) in *Therapeutic Nations*, who was most influential in my idea to question the psychologization of fibromyalgia by asking what systems of power it serves. Overall, this scholarship provided the critical underpinnings for all the theoretical work I do in the following chapters. It inspired the questions I asked, the knowledge I prioritized, and the interventions I make in the pages to come.

### **QTBIPOC knowledges**

QTBIPOC knowledges are rarely considered in the medical community, and this holds especially true in relation to fibromyalgia studies. QTBIPOC knowledges are generated and engaged with in this dissertation through my reference to the scholars mentioned above, as well as through the interviews I conducted. In the following sections, I discuss the decisions I made concerning how I would conduct this project and interpret the information I gathered. The methodological framework I present here explains how I came to the decisions I have made in collecting, producing and analyzing data, which I consider to include the theories I pull from (presented above), the interviews I conducted, and the content analysis I perform in Chapter 6. This methodological framework is tied to my previous discussion of the epistemological framework grounding my work. As such, it is equally interested in broader structures and regimes of knowledge that impact fibromyalgic presents, in the situated knowledge and experience of marginalized communities, and in absence as a worthy site of investigation.

While I was invested in challenging medical knowledge, my project also moved away from the pursuit of replacing a dominant medical understanding of fibromyalgia with a better or “truer” truth. Thus, I did not seek to assemble an objective research sample of people living with fibromyalgia to unearth a universal or partial authentic experience. In other words, I do not project onto the participants in this research a duty to represent all QTBIPOC who live with medically unidentified illnesses. I started from the assumption that knowledge production and the formation of subjectivity are social and relational, as well as grounded in places, trajectories, encounters and histories. I also valued what Browne and Fiske (2001) name “the micropolitics of health care encounters,” a dimension of health research that is often considered less important than others, or that is dissociated from overarching structures when these structures are the focus of studies.

QTBIPOC have a lot to offer here. In this research, they speak about their experiences, and there are many instances where their experiences align with each other. Rather than consider these patterns to be representative, I view them as worthy of considering or, simply put, important—alongside other knowledges from other sources—to our understanding of fibromyalgia, medically unidentified illness, power relations in health care, and health more generally. Particularly because QTBIPOC knowledges are often dismissed and silenced, and because their violent erasure and exclusion is itself part of the story I am telling here, this research emphasizes these knowledges. I argue that it points us to new ways of thinking and knowing, and helps us question how fibromyalgia, and illness more broadly, are currently thought about and known.

Thus, along with a heavily theoretical engagement, a core method for this dissertation has been generating QTBIPOC-specific theoretical interventions by way of the interviews I conducted with a total of ten QTBIPOC. The concepts, theories, experiences and ideas generated by these interviews interject in and shape my analysis throughout this dissertation, though in some chapters more than others. Rather than be included as simply objects of research whose experiences I read through theory, I value their knowledge, contributions and reflections on the themes and questions driving this dissertation in the same way as the critical disability scholars I call upon to intervene in the medical research and fibromyalgia contexts I explore. This distinction is important because I did not start from capital-T theory, or from the interviews, to arrive to the analysis I present in the following chapters. Instead, there was an interplay between the two. For example, in Chapter 6, when I perform my content analyses, the theoretical interventions I make emanate from my readings of theoretical texts, but participants in this study also had the opportunity to comment on the texts I was analyzing and posed their own theoretical interventions to these texts. This is also an important distinction because, unlike purely empirical research, this dissertation does not rely only on interviews to draw conclusions; I employ participant quotes to discuss ideas and theories, not to prove hypotheses or provide examples to support the points I make in the chapters that follow. As well, at times, my analysis is anchored instead in my own theoretical readings. Thus, you will witness this combined, multi-method approach throughout the dissertation.

This type of approach to research is novel in fibromyalgia studies, but it is not new in anti-colonial, anti-racist, feminist and queer research. It is inspired by the

methodologies - such as reflexive and dialogical methodologies - introduced and adopted by many feminist, queer, and racialized researchers and ethnographers in the last thirty years. Reflexive methodologies, for instance, expect researchers to discuss their role, impact, and process in producing knowledge as they recognize that knowledge is always co-produced (see, for e.g., Harding 2004; Hesse-Biber and Yaiser 2004). In general, these types of methodologies all emerged as a way to grapple with the tensions, limits, and problems with empiricism and notions of objectivity (see, for e.g., Ollivier and Tremblay 2000; Winddance Twine 2000), as well as to honestly reflect on and challenge the traditional divide assumed and encouraged in relationships between researcher and research subjects wherein the researcher is the privileged producer of knowledge (see, for e.g., Haraway 2007; Hesse-Biber and Yaiser 2004). I consider the approach I laid out above as part of this critical feminist and anti-racist tradition. In what follows, I focus on the reasons I conducted these interviews.

Long before the rise of Critical Disability Studies in the academy, QTBIPOC movements were theorizing and practicing important engagements with disability justice, despite not always using this exact term. QTBIPOC communities in Toronto were particularly influential in the development of core ideas and practices on the subject; Toronto was a birthplace of disability justice. In Leah Lakshmi Piepzna-Samarasinha's (2018) essay, "Toronto Crip City," in the anthology *Marvellous Grounds: Queer of Colour Histories of Toronto* (Haritaworn, Moussa and Ware 2018a), the author's recollection of the early beginnings of organizing led by people of colour around race, poverty, disability, psychiatric survivorship and illness gives us new access to this rich history. Among others, she discusses the importance of the Toronto neighborhood of

Parkdale, pre-gentrification, and recalls how organizing led by working-class people of colour contributed to the birth of disability justice and mad activism. A community of sick and disabled QTBIPOC continue this legacy today. Disability organizing overlaps with performance and art scenes, and the members of the community I interview are important contributors to this grassroots and social-justice-oriented movement, different from movements that are rights-based and led by institutions or NGOs. I would argue that, in recent years, the enmeshment between queer social justice activism and disability justice activism has become more pronounced in Toronto. QTBIPOC are at the forefront of disability justice organizing and thinking in the city. The increasing significance of disability and illness in QTBIPOC communities is made clear in interview participant mgc's discussion of how shocking it is to navigate spaces outside of this community in Toronto. For mgc, receiving a medical diagnosis of fibromyalgia was not their entry point into talking about disability and illness; rather, they were already quite politicized on these subjects because of the QTBIPOC community they belong to.

When I just got diagnosed or whatever, there was no time between coming out with chronic pain and being politicized around it. There wasn't. It's just the way my communities were happening so I was, like, disability justice right away, and it really shaped how I came to think about access in my own relation to sick stuff.

Disability organizing and theorizing does not happen in a vacuum in Toronto QTBIPOC communities. QTBIPOC have also been connecting disability justice to other movements, and leading the way in social justice activism. The brilliant leadership of Black sick and disabled artists and activists in Black Lives Matter Toronto, chronicled recently by Ware (2016), is a case in point. Another space, now disbanded, that modeled disability justice is Unapologetic Burlesque, an alternative burlesque performance showcase run by

QTBIPOC, which might not be recorded as part of this history by those not accustomed to the integration of disability justice into art spaces in Toronto. Unapologetic Burlesque's organizers (Giles and Tagore 2018) envisioned it as a place of intentional care and access, and engaged in conversations that centered disability justice that are rare in other similar spaces. My connection to and knowledge of some of this history is largely indebted to my work with the Marvellous Grounds archiving project I have been a part of for the last few years (see Haritaworn, Moussa and Ware 2018a and 2018b). I signal this history here because, while disability justice is so enmeshed with QTBIPOC history, the interventions and activisms sparked by these people and in these places are often missed in traditional accounts on disability and health. This is one of the reasons why I found QTBIPOC in Toronto to be important contributors to this research.

As I was navigating the medical system for my own health, I began discussing my symptoms more openly with friends and community members who often shared their own stories, as well as attending QTBIPOC-led events that centred conversations and performances related to disability and illness. I did not see these interventions and experiences reflected in the medical journals I was poring over at the time. These community-based frameworks became integral to my thinking about health, illness, disability, healing and the medical system. Critiques of abuses of power by the medical system, reflections on the effects of colonialism on body and ancestral knowledge, concepts such as "crip labour" (discussed in Chapter 6) that I build on in this dissertation were brought into my life by sick and disabled QTBIPOC in Toronto. In sum, QTBIPOC in Toronto raised me in relation to the themes I explore in this dissertation. Without this theoretical and practical education, not only would I not be who I am, but this dissertation

would not be the same. QTBIPOC in Toronto moulded my methodological approach. For starters, without the Marvellous Grounds QTBIPOC archiving collective that I was part of, I would not have met many of the participants in this research. Above all, my focus on QTBIPOC knowledge, my interest in a historical approach in Chapter 4, and my consideration of the intersections between race and disability throughout this dissertation are informed by the past and present work of QTBIPOC in Toronto.

In addition to my focus on QTBIPOC Torontonians, this dissertation builds on interviews with participants who are part of an online forum for and by QTBIPOC who are sick or disabled of which I am a member. The sheer number of members in this group solidified for me the prevalence of chronic medically unidentified illness among QTBIPOC. Online support groups have become widely used for a variety of purposes, with 36 million people in the United States alone using them (Mendelson 2009). Online communities are very important in the lives of many who have limited mobility and cannot easily leave their house, as they offer a space of connection, support, advice and friendship. They are even at times a primary source of medical information for those who cannot afford, cannot trust or cannot access medical professionals, or many whose physicians have dismissed them, been unable to help them or given them unreliable information. Online communities can also play an important role in shaping how people narrate and make sense of their bodies and their disabilities or illnesses. Researchers such as Mendelson (2009), who conducted interviews with women living with lupus, have recruited participants from online support groups for these reasons, among others. Online groups related to health are also relevant to queer and trans communities specifically due to the ways in which queer and trans communities crowdsource health information and

look beyond formal health system for care and knowledge (Sharman 2016). This practice is particularly relevant for those of us with MUIs who often cannot turn to health professionals for answers. On this, Sexsmith (2016) writes,

I did my own research. The doctors did not help. The information I found was from personal sources telling their own stories and sharing what they found. I don't love the idea of crowdsourcing my own health and wellness, getting solutions to medical problems on Tumblr, but with a body that's an unknown in the medical system, what else was I supposed to do?

Further, the online group that participants in this research belong to is also a prime site of critical thought on the medical-industrial complex, illness, disability and many other related topics. When I asked E what this group meant to them, for instance, they talked about how it introduced them to people in their city who inspired their politicization in relation to what was happening in their body and the medical system more broadly speaking. In this passage, they discuss making a new friend from this group, and the group's impact on their lives.

Yeah, they're so great, and we live in the same city. And just from talking to them, I saw how medical abuse experimentation could be a reasonable explanation for what I am experiencing, and that medical abuse can leave real lasting damages on people's bodies. It sounds funny, but I hadn't even considered that as a possibility before meeting them and talking to them. Like, we're talking about how we're both Mizrahi Jews, so Jews from the Middle East, and realized that the medical abuse and experimentation on Mizrahi, there's a long history of it, and it's an organized structural systemic thing that keeps happening to us. The Israeli government does it *a lot*. It's been really good having online community and getting affirmation from folks who get it when other people don't.

I could identify with both E's sense that this online group often had answers, support and understanding when other people or places do not, as well as how this group can and often does shape how people think and live with their disabilities or illnesses. Including participants from this online group was important for this reason; the group brings

together QTBIPOC from around the world who are directly experiencing and thinking through the subjects at the heart of this dissertation.

These interventions would have been completely inaccessible to me had I chosen to only include published works for the theoretical framing of this dissertation. For example, the QTBIPOC I interviewed were able to provide qualitative confirmation of the immensity of our community's experience of fibromyalgia and other chronic medically unidentified illness, whereas no such qualitative data exists elsewhere. While robust quantitative data on the prevalence of chronic pain and MUIs among QTBIPOC does not exist, the data currently available on fibromyalgia, combined with my experience and the testimonies of participants suggest a high prevalence of MUIs among QTBIPOC communities.

### **Methods and ethical considerations**

In this section, I detail the specific methods I undertook, including one in-person group interview with QTBIPOC in Toronto, one online video-based group interview and two one-on-one interviews with QTBIPOC from an online forum for and by sick and disabled QTBIPOC, and two content analyses which were useful during my interviews (as I explain below) and specifically for the interventions I make in Chapter 6.

### Interviews

The ethics review board of York University approved my application to conduct interviews on June 25, 2015. In total, I interviewed ten QTBIPOC for this dissertation

between July and November of 2015: five in a group interview in Toronto, three in an online group interview, and two in an individual online interview.

The Toronto in-person group interview with QTBIPOC included five participants who identified as QTBIPOC and as having fibromyalgia or as having experience with medical skepticism in the diagnostic process of a chronic illness. We met at the 519 Community Centre in Toronto, where I rented an accessible and low-scent room to ensure that all participants could participate. The participants were found through snowball sampling: I reached out to key people in the community, and circulated a call for participants on Facebook and by email to my networks (see callout in Appendix A). The callout emphasized self-definition, and did not demand a medical diagnosis as criteria for participation, in part because of a recognition that medical diagnoses do not always accurately reflect the experiences of those living with illness and also because often an emphasis on diagnosis contributes to the exclusion of racialized and working-class people from medical research. I did not take note of any further demographic information on participants. This decision was intentional; sick and disabled people are often mined for research and it was important to me to not create further barriers for participation, namely the obligatory disclosure of further, and potentially identifying, personal information. Moreover, as I was viewing participants as theorists rather than as traditional research subjects, I did not judge this information to be relevant for our intended discussions. Overall, though, I can share that participants were generally between the ages of twenty and forty-five and, based on participants' disclosure during the interviews, members of Black, Indigenous, and people of colour communities were included.

My online interviews with QTBIPOC from an online forum by and for sick and disabled QTBIPOC were conducted over Google Hangout, a free video chat service accessible through the Gmail email platform. I chose this platform because it was free and easily accessible to participants. I gave them a choice to use a more secure platform, but they opted for Google Hangout instead due to easy access. I interviewed a total of five participants, three of them together in a group interview, and two one-on-one. While I originally planned to conduct only group interviews, due to the various time zones people lived in, as well as unexpected health-related situations that forced people to cancel, I had to adjust. In the spirit of my method-ology, I chose to still conduct interviews with people who wanted to participate even if the rest of the anticipated participants could not make it. I recruited participants through a callout post to the forum (with the same wording I used on Facebook and email for Toronto-based QTBIPOC); participants thus reached out to me after seeing this post. Like for the Toronto group, I sought out no further demographic information from this group. Nowhere in this dissertation do I use the exact name of this online group, as it is a closed group that relies on the commitment of its members to preserve its privacy and confidentiality.

For all the interviews I conducted, I chose a semi-structured format that allowed me to ask participants questions but also let them guide the direction of our conversation, which I invited them to do at the start of each interview. Interviews lasted between one hour and a half and three hours. I started each interview by asking participants to share with me some of their experiences navigating the medical system with a medically unidentified illness. I had pre-written a set of questions prior to the interview but I did not follow these in strict order, nor did I ask them all, as you would in a structured interview.

Most of these questions were very general questions and reference points, and I pulled from them based on the organic thematic development of the interview. These include:

- What has your experience been with medical professionals in relation to fibromyalgia or another medically unidentified condition?
- How do you explain what is happening in your body?
- Do you think that race, sex, gender or other parts of your identity played a role in your diagnosis and interaction with medical professionals?
- Has the response of medical professionals changed how you see yourself and your condition?

Other, more specific questions dealt with the core trends in research that I had originally identified based on my readings and experience. I used these questions to consult participants and hear their own theoretical interventions on fibromyalgia research, the medical system, medical discrimination, and key texts and documents in fibromyalgia care, to name a few. I shared some of the preliminary results of my readings and research, and gathered participants' thoughts on these themes. In one such question, I asked the group what they thought of the Canadian national guidelines on fibromyalgia. Some had already heard of these guidelines but most had not. In the latter case, I summarized what I knew and upon request, forwarded the link to participants. As such, parts of the interviews operated more like a focus group in which I invited participants' interventions as theorists.

Due to the spontaneous nature of these exchanges, I cannot list all the questions we discussed here, but I provide some examples above and offer a lengthier list in Appendix B. During the interviews, and afterwards as I was engaging with the

transcripts, participants shaped my research thematically and responded to the other work I was engaging with and analyzing, including medical journal readings and the pain management workbook discussed in Chapter 6. I used the material generated in these interviews for all the chapters in this dissertation, though in some more than in others. I engaged with transcripts as theoretical texts, reading them to inspire the core themes of the research but also as commentary on the themes that were developing for me in other readings. Ultimately, as I shared my knowledge and readings with participants, they shaped my dissertation by sharing their experiences and commenting on my work, sometimes affirming it and other times leading it in a new direction. Arti's introduction of the concept of crip labour, for example, completely reframed my reading of the pain management workbook I was analyzing (see Chapter 6). The conversation between billie, Violet and O in Chapter 4 collided with my work with the QTBIPOC archiving collective, *Marvellous Grounds* (see Haritaworn, Moussa, and Ware 2018a and 2018b), to solidify the core theme of that chapter: history and ancestry. It was important to me to let participants define what about fibromyalgia and unidentified illness was worth talking about, what was on their minds, and what seemed most pressing for research like this one to focus on. At the same time, I also made it clear that common trends in fibromyalgia research lacked the perspective their expertise could provide. As such, my analysis of the transcripts was happening on two levels. In one type of reading, I engaged with the transcripts by asking what themes were recurrent in the interviews. In a second type of reading, I asked how the transcripts commented on major themes in fibromyalgia which I had previously noticed and listed. These themes are represented throughout this dissertation: psychologization; racial, gendered and neoliberal regimes of knowledge; and

history and ancestry. Thus, the content of this dissertation was created through a group effort of the multiple sources of literature and theory I consulted, including medical journals, (QT)BIPOC scholars (in text and in interview), and the texts I analyzed (discussed in the next section).

Consent was provided by all participants. For in-person interviews, participants granted consent in writing by signing a consent form I provided (see Appendix C). For online interviews, I used the same consent form, but consent was given verbally after participants had a chance to read the consent form I sent to them prior to the video interview. While consenting (verbally or in writing), participants also shared the names they preferred to use for the aims of this research (some, as you will notice, are one letter only), and their pronouns (such as she, he, ze and hir) to be used in this dissertation. Some opted to use a pseudonym, while others preferred their common name. Due to the high stakes of visibility for many (such as their relationships to family, health care providers and workplaces), and because some were not “out” as sick or disabled for a variety of reasons, this mixed approach allowed everyone to participate based on their comfort levels and diminished the risks involved in participating. It also allowed those who wished to be recognized as theorists or activists in this field to gain credit for their work. As such, each participant dictated their preference, which I promptly adopted.

All interviews were recorded on my iPhone in mp3 format, and then later I transcribed each interview myself using Word. For the online video interviews, I audio recorded the interviews on my iPhone through voice memo (and thus did not capture them on video), and transferred the mp3 audio files into the same password-protected folder as the written transcripts. I sent transcripts to participants to give them the

opportunity to review their own passages and adapt them in hindsight to clarify, edit or add to their contributions (for group interviews, other participants' passages were blocked out). Some took this opportunity, and others chose not to. After this, I edited some of the passages myself in order to best represent the quotes used in the dissertation. I did not alter the content in this process; the extent of the editing was the deletion of “ums” and “likes” in the sentences, and the omission of filler-like sentences to form a quote that conveyed the speaker's meaning succinctly. While these linguistic markers can in and of themselves be used for analysis in some types of research, they were not relevant to this project. Documents containing the transcriptions were preserved in a password-protected folder on my personal computer.

I use the acronym and category of QTBIPOC in this dissertation and in my call for participants because this is the general term used by the community engaged in this research, both in Toronto and online. Using “QTBIPOC” in the call-out for participants thus made sense to reach participants, as it is a commonly used and identifiable umbrella term within these communities. At the same time, even within these communities, some have pointed out how some use this acronym but ultimately excludes trans people, Black people, and Indigenous people, and it is used inappropriately to gain social and critical currency, without actually doing the work of centering those most marginalized and oft-excluded. Further, I recognize that this acronym can be limiting, in that it can lead to the erasure of the specificities of each community signaled in the acronym. This erasure is particularly possible, seen as I did not ask participants to fill a questionnaire to self-identify. I instead relied on the assumption that if participants responded to the call which sought to recruit “QTBIPOC,” then they felt connected to this term. In retrospect, perhaps

this additional questionnaire might have given me more insight into the positionalities of participants in order to better frame their experiences in larger, structural processes and contexts. I had decided not to ask participants to fill out a questionnaire in order to limit barriers for participants, especially for a community that has often been taken advantage of in research. Though I was unable to completely counteract this issue, I do recognize people's self-determination and the specificity of their experience when applicable, such as when participants freely provide more specific identifiers. For example, I discuss the particularities of settler-colonialism and anti-Black racism throughout these pages. I also do not claim that the experience of the people I interviewed represent the experience of their whole communities; as mentioned above, the participants enter this dissertation as theorists of specific communities of interest to me in this dissertation, and like other theorists, they represent their own thoughts and experiences. Still, because these perspectives are grounded in their social positions, their histories, and their involvement in QTBIPOC movements, they are thus potentially indicative of trending thoughts on the subjects discussed.

Another limitation of the acronym is that, though it is widely used among the communities I engaged with, its use in these communities might have presented a barrier for some to join them to begin with. This is true both in Toronto and in the online group. Acronyms such as QTBIPOC themselves, and the identity categories they refer to such as "queer," have been criticized by scholars outside of the Global North as Western terms taken for granted as universal. In my Master's work in Palestine (Moussa 2011), for example, local activists discussed how language differences, and more specifically the universal centrality of English, erases the particularities of local terms used to refer to

gender and sexual identity. In addition, the spread of English outside of Western countries in LGBTQ organizations seeking solidarity partnerships and funding can increase the association of queerness and transness with whiteness and westernization, which can in turn intensify homophobia and the marginalization of queer and trans people in their home communities. Finally, the acronym QTBIPOC has been in wide circulation with younger generations of racialized queer and trans people, and my use of it for this dissertation - for analysis and recruitment - might have skewed the age of participants towards a younger demographic. This may be true of my use of Facebook for recruitment as well. I did not ask for participants' ages, but can estimate that, overall participants were between their late twenties and mid-forties. I wish that my choices did not exclude older community members from participating; at the same time, it differentiated my research from other fibromyalgia research. Participants were generally younger than most interviewed or used as participants on the topic of fibromyalgia based on the current research, as most of it suggests that fibromyalgia is predominantly affecting people over the age of 50. Participants' experiences and testimonies here suggest otherwise among QTBIPOC, as many participants began developing symptoms at a young age (some as young as toddlers).

Despite this being a theoretical project, I decided to conduct interviews for a few reasons, including the access it gave me to underrepresented theorists. Moreover, previous research has seen the benefit of interviewing marginalized groups in relation to health and health care (e.g., Browne and Fiske 2001; Asbring and Narvanen 2002; Ross, Lybson and Kumagai 2012). I chose to conduct group interviews for the Toronto participants and for one of the online interviews due to time constraints, but also because

group interviews offer some benefits. For one, I was able to provide a setting where participants and I could connect and share space, knowledge and experience together. It was a way for me as a community member and researcher to thank people collectively for their contributions, and to validate participants' knowledge given that, as they indicated in their testimonies, their knowledge is so often dismissed or erased.

### Content analysis

In Chapter 6, I present two content analyses. Other health researchers have used content analysis as a method of inquiry in critical analyses on a variety of health topics. Important work has been done in this regard in relation to mental health treatment, for instance (see Blum and Stracuzzi 2004). The two medical documents I analyze represent well the current medical understanding of fibromyalgia, which is why I chose them. I offer a detailed description and analysis of these two documents in Chapter 6, but here I introduce them quickly and discuss how I conducted my analysis.

The first document I analyze are the latest Canadian guidelines on fibromyalgia (Fitzcharles et al. 2013), which aim to guide health care professionals in the “identification, evaluation, and management of persons with FM” (3) by offering forty-six recommendations compiled by medical experts following a review of the last decade of medical findings on fibromyalgia. These guidelines are also presented in other formats, an executive summary and a website, which I use when they provide information that is valuable but is not reflected in the published report. The second is a pain management workbook that I acquired in a pain management course I attended a few years ago on my doctor's recommendation. The course and its workbook, based in cognitive behavioural

therapy, help to concretely illustrate the application of the fibromyalgia guidelines, and I use these course materials in Chapter 6 to discuss the impact of neoliberalism on medical understandings and treatment of fibromyalgia. The workbook I use is standard in pain management, and while it might contain slight differences with others of its kind, it is broadly representative and provides a useful example of how some of the themes discussed in this dissertation are applied in real life.

The analysis of these documents was influenced by their reading. I first read these documents for other purposes (to personally understand the latest on fibromyalgia treatment and research for the guidelines, and as part of the pain management course for the workbook). I read them a second time, and asked myself what systems of power were being supported by this medical discourse. This reading brought me to notice how these medical documents were upholding neoliberal ideas and practices. Thus, I returned to the documents after coming up with the concept of “neoliberalism” (which I discuss at length in Chapter 6), scanning them to track how neuroscience—and particularly the concept of plasticity—was being mobilized to further entrench and promote neoliberal citizenship. After this close reading, I presented these ideas to the interview participants, and later reflected on what QTBIPOC offer in terms of theoretical interventions to the core themes that emerged from my content analysis. In Chapter 6, I give further detail on the process and outcome of both the content analysis and the engagement of QTBIPOC participants in relation to its core themes.

Ethical concerns generally did not arise in relation to my content analysis of these documents. There is only one of note, which pertains to the pain management workbook. I long debated if I should include the name of the rehabilitation clinic that provided the

workbook, as I did not want to single out this institution for criticism, particularly because the workbook in question represents common practice and theory of pain management courses quite well. Ultimately, I decided to properly cite and include the name of the clinic in order to reference it and give it credit for its knowledge production in the workbook. I also wanted future researchers to be able to find the workbook easily in case it is helpful for other studies.

## **Conclusion**

For this dissertation, I chose to use multiple methods that build on the overarching methodological and epistemological approaches I introduced at the beginning of this chapter. I made this choice in order to produce a dissertation that is theoretical, that critically evaluates the current landscape of fibromyalgia research, and that is grounded in the thoughts, experiences and activism of QTBIPOC, a group of people who have thus far contributed so much to disability justice outside of the academy but have been left out of theorizing in relation to fibromyalgia. I believe these approaches are needed in order to shift fibromyalgia studies and practices to better ground them in the analysis of structures and institutions of power. The theoretical texts I used framed my own thinking throughout this research and in the writing of this dissertation. They were also instrumental to the interview process and to my content analysis. For example, my theoretical background and my content analysis allowed me to share knowledge with my interview participants. At the same time, these interviews shaped my understanding of theoretical texts, medical articles and the documents I analyzed.

Together, the method-ill-ogy, epistemology of absence, and QTPOC-centred approach I have adopted to explore fibromyalgia and other MUIs ground these bodily experiences in the body, the felt, and the absented. These approaches force a halt to the empirical and scientific obsession with medical intelligibility, the cornerstone of epistemological violence, and instead ask us to consider the targets of this violence - bodily knowledge and marginalized subjects alike - as guides to new directions that undo rather than uphold gendered, racial, and neoliberal structures of power.

## **CHAPTER TWO: ON RACE AND HEALTH**

In my extensive review of current research on fibromyalgia, I could not find even one research or study that mentioned race or racialized people. Race analysis and racialized communities are completely absent(ed) from fibromyalgia studies. To my knowledge, no study to date has considered QTBIPOC in relation to fibromyalgia, MUIs or chronic pain. QTBIPOC are even excluded from most studies on queer and trans health, despite the fact that race, gender identity and class are major factors in queer and trans health (Sharman 2016). It is known that medical research often employs white cis men as research subjects and that “women’s illnesses” are less of a priority than men’s (Richman et al. 2000), but in regard to fibromyalgia, as is the case in much of the research on mental health (Etowa et al. 2008), research subjects are mostly white cis women (Kratz, Davis, and Zautra 2012).<sup>2</sup>

The absence of racialized people and race analysis is particularly noteworthy given the links between fibromyalgia’s most pivotal symptom—chronic pain—and race. Some research on chronic pain has shown evidence of its high incidence in racialized communities (e.g., Green et al. 2003), although its impact on our lives and its exact prevalence remain understudied. Along with my own observations and research, participants’ testimonies point to a relationship between race and chronic illness.

In this chapter, I present some of the reasons why race has been ignored in research on fibromyalgia by focusing primarily on the Canadian context. I then review the current landscape of QTBIPOC health research, and discuss why QTBIPOC remain absent from fibromyalgia studies. I end by critically intervening in the current medical

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<sup>2</sup> Whether or not these participants are cis is difficult to know, but I have not found any explicit mention of trans people in fibromyalgia studies.

approach to race and health. I propose a different approach that forms the backbone of my dissertation, and that asks us to question the central tenets of the medical system and medical research. Mainly, I suggest that inclusion is not what is desired here; QTBIPOC are at the forefront of disability justice, mad studies, and alternative health studies and movements that call for the dismantling of the medical system, as its values and interventions are at the heart of systems of power, and for a better understanding of the ways in which race and illness are co-constituted.

### **Absenting race analysis from health studies**

In a Canadian context, the absence of race analysis and racialized people from fibromyalgia studies are unsurprising considering that research on race and health in general is relatively rare and inadequate; data on race is often left out of health registries and national surveys (Nestel 2012). Canadians also cling to a tenacious illusion of a generous health care system to which all citizens have access (Johnson et al. 2004). Yet Canada's settler colonial constitution, years of conservative leadership, and the paring down of research funding, combined with many Canadians' denial of the existence of racism (the "nice Canadian" rhetoric) only reinforce racial inequities in health care and Canadians' awareness of this problem. Buzzwords such as "culture" and "diversity" fit neatly into the discourse and system of multicultural governance. This means that, often, considerations of race are left out as analytical categories (Bannerji 2000; Ahmed 2013; Thobani 2007; Dhamoon 2009).

One of the ways this multicultural ideology manifests is through medical literature's common tendency to blame "cultures" for the health disparities found in

certain racialized groups. It comes as no surprise, then, that a substantial amount of research dealing with race and health focuses on cultural explanations rather than other factors such as racialization or racism (Veenstra and Patterson 2016; Viruell-Fuentes, Miranda and Abdulrahim 2012). Johnson et al. (2004: 256) discuss this problem in the Canadian context:

In response to access barriers, there is a tendency to attribute the problem to the cultural beliefs and practices of the underserved group (e.g., shyness, folk beliefs about disease causality) rather than to discriminatory attitudes and practices of health care practitioners that act as barriers to health care. Culturalism, racism, and othering are thereby overlapping processes that reproduce and reinforce positions of domination and subordination, particularly when health care is provided by members of the dominant group to members of a typically subordinated and marginalized group (Razack, 1998). These overlapping processes affect a wide variety of underserved groups, including Aboriginal Canadians, visible minorities, the disabled, and gay men and lesbians (Browne & Fiske, 2001; J. M. Hall et al., 1994).

In addition to reinforcing power dynamics at play in health encounters, the focus on cultural factors in health care contributes to the wider process known as the “culturalization” of racism and racial inequalities, which is quite common in countries that have adopted multiculturalism as a discourse and policy (see Bannerji 2000). Culturalization, which dilutes race (and the power hierarchies and structures it implies) into questions of culture (Bannerji 2000), and which explains away the results of racial projects as being due to cultural factors, allows researchers, in this case, to depoliticize health and omit structural factors from medical analyses. The focus on cultural explanations also serves to justify the exclusion of analyses of racism, and of race as an identity category from health data and research.

These cultural explanations fit into the two paradigms currently dominating medical explanations of the relationship between race and illness. The first relates racial

disparities in health to genetics, drawing the following equation: “genes determining race also determine the number and type of health problems” (Mullings and Schulz 2006: 4). The second moves away from essentialist notions of race but instead individualizes health problems by attributing health disparities to lifestyle, or culture, without considering the structures that inform why and how individuals make the choices they do (Mullings and Schulz 2006). Both paradigms limit medical researchers’ ability to consider structural factors and the medical system itself in understanding the relationship between race and illness, as they individualize illness. In the following section, I review the current literature on QTBIPOC and health, which helps to exemplify these limitations, and also recounts how QTBIPOC are left out of health studies on race and queer and trans communities.

### **QTBIPOC health research**

There is an undocumented prevalence of MUIs in QTBIPOC communities. QTBIPOC meet two of the known sociodemographic factors for fibromyalgia: we are of marginalized genders, and we are overrepresented among people of low socioeconomic status (Vancouver Coastal Health et al. 2016). Yet, we are absent from fibromyalgia research.

The literature on QTBIPOC health is sparse, which is unsurprising considering that research on queer and trans health more generally is in short supply as well, and there is a lack of interest and training on queer and trans health in the medical system starting from medical school (Sharman 2016). Still today, Barron notes, “the Public Health Agency of Canada does not consider sexuality among the determinants of health”

(2016: 154). Not only is there little research on and consideration of QTBIPOC in relation to health, but we also rarely get to represent ourselves. This is true for most racialized communities, as noted by Ross, Lypson and Kumagai (2012), whose research challenges this trend by centring the experience of Black people in the health system. They write, “few studies have attempted to document laypeople’s perspective by placing them in a role of active knower and someone who has been affected by health care disparities, and even fewer have included racially underrepresented populations” (522). This also holds true for people with illnesses or disabilities (Wu and James 2006), which means that sick and disabled QTBIPOC are at the bottom echelon in terms of priority and have little control over what is written about us when research focuses on our health and experiences in the healthcare system.

Much of the literature on the health of queer and trans people that does exist focuses on the impacts of homophobia and transphobia. There is strong evidence that mental and physical health disparities fall along the lines of gender identity and sexual orientation. Most studies on queer and trans health, though, are produced in the fields of social work, psychology and psychiatry, which explains why mental health disparities are better documented. In their study, Sutter and Perrin (2016) recapitulate some of the research on QT mental health, highlighting the high rates of suicide and suicidal ideation among LGBTQ individuals, and their link to histories of mental disorders, which they posit are generally more prevalent among this community than in heterosexual ones.

According to a large-scale Ontario-based study, suicidality is even more common among trans people, with 77% of trans Ontarians over the age of 16 having considered suicide and 45% having attempted suicide (Bauer et al. 2013). Suicidality is also highly

prevalent in Indigenous Two-Spirit communities (Rainbow Health Ontario 2016). Early deaths are common in queer and trans communities. One study has suggested that gay men die, on average, twenty years earlier than the general population (Canadian Rainbow Health Coalition 2004). The Inter-American Commission on Human Rights (2014) released a report that set the life expectancy of trans women in the Americas between the ages of 30 and 35.

Studies on health disparities based on sexual orientation and gender identity dominate queer and trans health research. The main factor considered for disparities based on sexual orientation and gender identity is the discrimination faced by queer and trans people, with a focus on homophobia and transphobia. The link between homophobia and transphobia, and health, is often theorized through minority stress theory, which “examines the ways in which the unique stressors experienced by minority individuals may be related to mental health disparities” (Balsam et al. 2011: 163). Using this model, authors might argue that minority stress can lead to greater risk of illness due to individuals’ stress response activation, including the increase of cortisol levels, a factor in the high rates of depression and suicidality among LGBTQ people (Benibgui 2011). Others consider how minority stress causes emotional and mental distress, and how it can induce the adoption of behaviours that might be detrimental to health or to seeking care from the medical system (Balsam et al. 2011). This last subject can include research on the experience of queer and trans people in the Canadian healthcare system, for example. As discussed by Ristock, Zoccole and Passante (2010: 10), homophobia affects medical encounters by causing patient distrust towards physicians, thus limiting queer and trans

access to healthcare, as well as by affecting how doctors deal with queer and trans patients, whether consciously or not. They write:

GLBT people have to interact with the health care system at one point or another, for reasons that may or may not be connected to their gender identity or sexual orientation. Many GLBT people will postpone using services for fear of prejudice, discrimination or misunderstanding, many will not come out even though this constitutes not sharing important health-related information, and in other cases, health professionals focus their energy on fixing their patient's orientation or identity instead of taking care of the presenting concerns. Although most doctors, nurses, social workers and other health-care providers don't think of themselves as homophobic, most would be able to relate to feelings of unease, inadequacy or awkwardness when working with GLBT people. (CRHC, 2004; CLGRO, 1997).

Regardless of their intentions, physicians still influence the care received by queer and trans patients and their families, who are often misunderstood and underserved in a system steeped in institutionalized homophobia and heterosexism. Rainbow Health Ontario is one organization that has begun documenting how medical discrimination can, in the least, shape experiences of, or worsen illness; their work focuses on cancer in this respect. In their brief (2016), they raise concerns over the relationship between medical discrimination and access to health care and screenings. They also note that QTBIPOC are more often refused care than white queer and trans people. Trans people, too, are more often turned away. As Sharman has noted, "one in five transgender people report having been denied care by a doctor. Trans people of colour are even more likely to report being denied care" (2016: 18).

Moreover, minority stress theory has been used to analyze data related to the social determinants of health of queer and trans people, including high rates of homelessness and unemployment, for example (Canadian Rainbow Health Coalition 2004). The physical impacts of these factors, beyond suicide and mental health, are

poorly documented. While it is indeed alarming that queer and trans people suffer greatly in terms of mental health and are overrepresented in rates of suicide, the centrality of literature on suicidality can often trump attention to and care for queer and trans communities while they are still alive (a case made by many trans people, and particularly Black trans women; see, for example, Mock 2014, and Robinson 2018).

Some research does concern itself with queer and trans physical health beyond mental health. The work done by Vancouver Coastal Health et al. (2006) alerts us to the potential impacts of experiences that are particular to trans people, including hormone use, surgery and chronic stress, on the cardiovascular system and the development of osteoporosis, diabetes and cancer, among other conditions and illnesses. While cancer research on queer and trans communities is difficult to find, a brief prepared by Rainbow Health Ontario (2016) suggests that LGBTQ people are overrepresented in certain types of cancer in comparison to the general population. Among these claims are that queer and trans people who have HIV/AIDS are at a greater risk of developing Kaposi's sarcoma (a cancer specific to blood and lymph vessels), intraepithelial (or cervix-related) and anal cancer, and cancers caused by infectious agents. More generally, bisexual and gay men have the highest incidences of non-Hodgkin's lymphomas (i.e., blood cancers), and their chances of dying from colorectal cancer and lung cancer have been suggested to be higher than the general population. Some preliminary results mentioned in this brief have also suggested the possibility that lesbian, queer, and gay women might be at a higher risk for breast and ovarian cancer and might experience higher cancer mortality rates from breast cancer.

These studies mainly attribute higher risk or prevalence of certain conditions or illness to queer and trans lifestyles and behaviours. While most mention that queer and trans illness often results of experiencing discrimination or living with additional stress (along the lines of minority stress theory), analysis of these factors remains limited and generally superficial. Statements such as the following, taken from the Rainbow Health Ontario brief on cancer mentioned above, are often the extent of the discussion on this matter:

Despite the lack of population level data about cancer in LGBTQ populations, research shows that LGBTQ individuals are more likely to engage in behaviours that are associated with increased cancer risk. These behaviours often stem from experiences of discrimination in their day-to-day lives. (2016: 2)

Further, some have signaled that the prioritization of gay cis men in research on QT health is a problem. As a research by the Canadian Rainbow Health Coalition (2004) reports, existing studies on the subject generally prioritize the experience of gay cis men and their health concerns, including the prevalence of STIs, HIV, addiction, and mental health problems in this community. On the other hand, they write that “health research on lesbians, bisexuals, transgendered and two-spirit [sic] people is relatively invisible with little Canadian data” (Canadian Rainbow Health Coalition 2004: 5).

Moreover, even within queer and trans health literature, QTBIPOC remain largely excluded, as is the case in the general race-specific health literature and in health research more broadly. The marginalization of QTBIPOC becomes perhaps most clear when we consider that, even when health researchers take interest in the lives of queer and trans people, those who are racialized remain left out (Balsam et al. 2011). This explains how difficult it was for me to find any literature on QTBIPOC health. Generally speaking, the

literature that does exist on QTBIPOC, while more difficult to find, reflects the main findings of queer and trans research, but adds in race and racial discrimination as an additional element to consider. The current model employed in much of the queer and trans literature that takes into account QTBIPOC in fact often tokenizes QTBIPOC or reduces this population to a side note—an approach that is insufficient and essentializing. Gender and sexual identity alone cannot be the only basis for drawing generalizing conclusions about these communities. These aspects of identity are not always the primary focus in the lives of QTBIPOC, particularly when we consider the connections between race and health that I mention above. Researchers often categorize QTBIPOC based on their sexual or gender identities when they are included in research at all, and omit their belonging to their racial communities, which makes it difficult to draw connections between race, racism and health for QTBIPOC communities. For instance, rarely are incidences of depression among QTBIPOC connected to the high rates of depression among Black women more broadly (Etowa et al. 2008). Instead, QTBIPOC depression is more likely to be lumped in with high rates of queer and trans depression. Researchers' choice to prioritize sexual orientation and gender identity over race as illness factors, rather than take an intersectional approach to QTBIPOC health, can severely limit our understanding of QTBIPOC health. In fact, the way homophobia is discussed in relation to racialized communities—primarily based on cultural stereotypes and used as a sign of these communities' backwardness (Haritaworn, Tauquir, and Erdem 2008)—has done little to serve QTBIPOC. It has instead increased our difficulty in negotiating our identity with our home communities by strengthening the association of queerness and transness with whiteness, not to mention its role in helping to justify

colonial and imperial projects (see Moussa 2011 for examples of this in the Israeli-Palestinian context).

While some studies adopt an intersectional approach, most are simply additive; the latter might include racialized subjects, for instance, but not consider the interplay of race and sexuality, or the particularities of QTBIPOC lives. These studies offer similar results as those on white queer and trans health, such as a prevalence of psychological distress and high rates of suicide and suicidal ideation among this community. Sutter and Perrin (2016: 99), whose passage on suicide in queer and trans communities I quote above, turn to QTBIPOC on the same subject here, and confirm the additive nature of studies on QTBIPOC health:

The research suggests that LGBTQ POC may be at particular risk for decreased mental health and increased suicidality (Alegría et al., 2007; Kim & Choi, 2010; Williams et al., 2007). The intersectional identities of sexual/gender minority and minority race/ethnicity have been linked to greater susceptibility to psychological consequences of discrimination (Cochran & Mays, 1994; Diaz et al., 2001; Wilson & Yoshikawa, 2004). However, no study to date has directly tested the potential simultaneous effects of both LGBTQ and race/ethnicity-based discrimination on mental health and suicidality among a diverse group of LGBTQ POC.

In light of the lack of studies on QTBIPOC health, most researchers have approached the subject by suggesting that, in addition to homophobia in society at large, QTBIPOC face homophobia within our own communities. In this way, QTBIPOC are said to experience a supplementary dimension of homophobia, for we must negotiate our sexual and gender identities within our home communities, which are likely to be more homophobic than white families and networks (e.g., Bridges, Selvidge and Matthews 2003). A second stream of this research, less common but still dominant, is interested in racism experienced by QTBIPOC in queer and trans communities (e.g., Giwa and

Greensmith 2012 for the Toronto context; Ristock, Zoccole and Passante 2010). The main conclusion we find is that homophobia within ethno-cultural communities and racism within queer and trans communities can have an impact on QTBIPOC health. More often than not, the impacts considered are related to mental health, including depression and stress (e.g., Balsam et al. 2011) and suicidal ideation (e.g., Sutter and Perrin 2016), likely because, as noted earlier, most of the studies I found were carried out in the field of psychology and social work.

While the scarcity of studies on QTBIPOC physical health is evident, some studies have attempted to identify risks, high incidences or trends. A comprehensive review by Fieland et al. (2007) draws conclusions on Indigenous Two-Spirit health by combining existing health research on queer and trans and Indigenous communities in the US and in Alaska. They suggested that suicidality, mental health problems, sexually transmitted infections and substance use were common among both communities.

### **Beyond social determinants of health**

The paradigms that prioritize genetic factors, lifestyle, or culture continue to dominate even the most progressive medical research. Social determinants of health are most researchers' answer to the widespread prevalence of illness among (QT)BIPOC communities. In all cases, there is a continued belief that race just *is* (Ahmed 2013). This leaves little opportunity to question how race, illness, and disability are co-produced, largely through the help of the medical system.

Research that acknowledges structural racism is a good start to making this shift. Nestel's (2012) study suggests that Black, Indigenous and people of colour, are severely

impacted by racial inequalities in terms of health in Canada. Yet, her research goes further by challenging the notion that race leads to health inequities, to instead propose that it is racism that impacts the health of racialized people. As defined by Viruell-Fuentes, Miranda and Abdulrahim (2012: 2102), structural racism encompasses “the ideologies, practices, processes, and institutions that operate at the macro level to produce and reproduce differential access to power and to life opportunities along racial and ethnic lines.” Considering structural racism in relation to health means acknowledging the medical system as an institution that upholds structural racism and through which racism is enacted, regardless of intent or awareness (van Ryn 2011). Better’s (2007: 11) definition specifies that institutional racism “denotes those patterns, procedures, practices, and policies that operate within social institutions so as to consistently penalize, disadvantage, and exploit individuals who are members of nonwhite racial/ethnic groups.” This structural paradigm shifts the focus from the genetics, lifestyle or culture of racialized people towards the consideration of structural factors in understanding the relationships between race and health or illness. According to Nestel (2012: 7), these factors include the following, among others:

the psychological stress of living in a racist environment; unequal economic opportunities; inequitable access to education and other social resources; lack of adequate housing; exposure to environmental toxins; engagement in risky health behaviours; victimization through social trauma such as spousal and sexual abuse, and other forms of violence; mistrust of the health-care system; and under-utilization of screening programs.

Similarly to Nestel and others, my research moves away from genetic or lifestyle explanations when attempting to identify the relationships between race and health. Further, this dissertation does not simply suggest that these theories are wrong, but rather

that they serve a purpose that is to the detriment of marginalized and racialized populations. I argue that these theories fit into larger regimes of knowledge and oppressive structures. As an example of how this theoretical framework guides my work, I explore how lifestyle explanations fit into neoliberal projects of responsabilization and individualization of illness, and thus work to victim-blame those who are sick and to allow the state to retreat from providing and funding health care (see Chapter 6). Further, I work under the understanding that colonialism and settler colonialism are not things of the past, and that they are sustained through medical justifications and interventions. While dominant national narratives attempt to relegate them to history, I, like many other theorists, researchers and activists, grapple with how they continue to operate, in the same and in different ways, still today. I argue that the relationship between race and health cannot be understood outside of this context. Colonial logics still serve as justifications for colonial projects, including the establishment of biological and cultural hierarchies and civilizing missions. As well, the mechanisms used to colonize, such as racialized violence, the establishment of medically sanctioned racial ideologies and hierarchies, cultural and spiritual subjugation, and land theft, are still in operation, and colonialism continues to affect both the bodies and minds of the people it targets.

Studies on Indigenous health are testimony to the impacts of settler colonialism on the colonized. Indigenous people continue to have the worst indices of health in Canada and, despite persistent research that rationalizes this through lifestyle or biological factors, a growing body of literature has proved that Indigenous health is directly related to processes of settler colonialism, including its elements of “wardship, welfare colonialism, displacement of Aboriginal peoples and continued discrimination

and racism” (Poudrier and MacLean 2009: 307). As well, Indigenous communities experience persistent economic and political marginalization, illustrated by high rates of unemployment, poverty and incarceration, all factors well known to be linked to health. These factors contribute to the overrepresentation of Indigenous people among a large range of conditions and illnesses, including “cancer, suicide, chronic illnesses such as tuberculosis and diabetes, respiratory and circulatory diseases” (Poudrier and MacLean 2009: 307). In Manitoba, where one in seven Indigenous people in Canada live, this community has a shorter life expectancy, more chronic disease and complications due to illness, and higher rates of hospitalization in comparison to the non-Indigenous population (Statistics Canada 2016). At the same time, Indigenous people are less likely to be referred to specialists (Ristock, Zoccole and Passante 2010). The relationship of these facts to settler colonial projects cannot be understated; for instance, the residential school system often included experiences of emotional, physical and sexual abuse, forced displacement, and the state-sanctioned and fabricated scarcity of basic necessities and conditions of starvation (for more on this, see, among others, Paradies, 2016; Million 2013; Simpson 2013; Kanani 2011). Further, the lack of access to healthcare in smaller Indigenous communities, among other factors, forces people to leave for bigger cities. This in turn causes loss of community, which can also affect health status, due to the common experience of depression, anxiety, and drug use as a coping mechanism for loneliness, disconnection from culture, grief and experiences of violence (Ristock, Zoccole and Passante 2010). These factors combine with the medical system’s pathologization of the consequences of settler colonialism and other forms of structural violence, as I discuss in the upcoming chapters. In other words, beyond simply

acknowledging that structural violence causes physical illness, we need to question how medical notions of *what illness is* are racialized.

It is with these key interventions that I venture into a critical analysis of the relationship between race and fibromyalgia in the chapters that follow. Indeed, race and QTBIPOC are absent from fibromyalgia studies. What is needed, though, is not more data on QTBIPOC that reproduces the same social determinants of health research currently starting to circulate. Fibromyalgia studies are in need of QTBIPOC not as objects to study, but as leaders in rethinking a medical system that has long been at the centre of justifying and sustaining structural violence that both causes illness, and pathologizes the effects of structural violence. QTBIPOC are not only more sick, but we are differently sick, differently sickened, and different medicalized. Understanding the relationship between race and illness urgently requires the perspective of QTBIPOC for these reasons. It also calls for critical theory that engages with the co-constitution of race and illness.

Such engagements would help unanchor fibromyalgia studies from the pursuit of legitimizing fibromyalgia through medical empiricism, or from the continued psychologization of marginalized subjects who defy medical rationality by way of their unknown illnesses. These perspectives would ask medical researchers to begin from, for example, questioning medical diagnoses for a start. If racialized subjects are diagnosed differently, how can medical research's emphasis on diagnoses tell us much about who is sick and why? Official statistical databases, which only consider diagnoses, can exclude unreported or non-medicalized illness. According to a Statistics Canada publication, for example, visible minority women are less often diagnosed with chronic conditions than

their white counterparts, but their self-reported general and mental health is worse (Ramage-Morin and Gilmour 2014). If diagnosis is the primary criteria for inclusion in medical research, would people such as the women referenced in this study be counted in data on a chronic condition such as fibromyalgia? Critical considerations of diagnostic processes are uncommon in the literature, which renders the sociodemographic representation of fibromyalgia's prevalence inaccurate.

Other factors of note in the exclusion of marginalized, and especially racialized, communities from fibromyalgia research and data, are physicians' own and historically held meaning-makings, as well as racialized patients' distrust of the medical system due to long standing medical violence, themes I return to in the chapters to come. After all, QTBIPOC entry into a relationship with the medical system is often a violent one. The use of psychiatric and biological explanations of queerness and transness has a long history that continues until this day. Despite longstanding debates and many reformulations of the Diagnostic and Statistical Manual of Mental Disorders, for instance, trans identities remain understood as mental disorders; more recently, biological markers for transness have been sought out in the field of neurology (Erlick 2016).

The types of questions we ask about race and health, too, can either expand or limit our ability to know the relationship between race and illness. On this, Brown (2008: 55) writes:

Studies consistently misspecify perceived discrimination and race-related stress. Consider, for example, life events, chronic strains, and daily hassles that are routinely considered in sociological surveys. Depending on how the survey questions are framed, each of these stress indicators has the potential to be racialized. For instance, the respondent's attribution is the only factor that distinguishes "loss of a job" from "loss of a job because my White supervisor is prejudiced." The only factor that distinguishes "problems at work" from

“problems at work because I am the token representative” is the victim’s attribution.

Considering fibromyalgia’s imputed relationship to chronic or intense life stress, abuse, trauma or psychological distress (Fitzcharles et al. 2012), this point must be considered in research design and research questions on this illness. Questions such as, when medical professionals and researchers speak of trauma as a precursor of fibromyalgia, what is considered as trauma? In other words, what types of trauma fit within the medical system’s grid of intelligibility? When it theorizes that fibromyalgia comes from prolonged stress or trauma, does it take into account what participants discuss later in this dissertation, including war, slavery, racism, colonialism, medical violence and experimentation, and various forms of structural oppression and their continued manifestations and effects in the lives of racialized people? If not, how does this impact who is diagnosed with this illness, how it is understood, and how it is intervened on? These questions are important to this dissertation and to the QTBIPOC I interviewed, as subsequent chapters will detail.

QTBIPOC experience “premature death” (Wilson Gilmore 2007) not only when we are underserved by the medical system or do not have access to medical care, but often when we do, or precisely because we do. The involvement of the medical system in our lives, directly or historically, can be at the heart of the pathologization of our bodies and minds. Not to mention that the rationalities of the medical system are, and have often been, at the root of the global targeting and deaths of our communities, sometimes in our name. Our sexual identities have long been used as barometers for pathology or justifications for colonial and imperial projects.

Moreover, as I will argue in later chapters, we are often dismissed or pathologized for the ways in which our bodies challenge medical hierarchies at the heart of social hierarchies. We are not trusted to know ourselves (Bell 2011), and are thus intervened upon despite our resistance. Illness, attached to our bodies, is often rationalized as an effect of our inherent pathology, or as a ploy to abuse of the system of services and benefits that is in fact built to exclude us and deems us undeserving in the first place. We are assumed to be skirting our responsibilities as good neoliberal subjects that should bounce back from our weaknesses, even when the heart of that weakness is, simply put, the colour of our skin (see Chapter 6).

This chapter set the context to understand the complete absence of considerations of race in fibromyalgia studies, framing it as part of a larger issue within Canadian settler-colonialism, multiculturalism discourse, and the culturalization of race and racial disparities. I argued that the current dominant theories explaining the relationship between race and health are inadequate for the ultimate goal of dismantling the medical system, as they ignore the co-constitution of race and disability, and ultimately serve to sustain systems of power.

In the chapters that follow, I employ the approach to race and illness that I have begun to introduce here to interrogate how fibromyalgia becomes known as fibromyalgia, how psychologization is justified when unknown illness is attached to marginalized bodies, and how, ultimately, fibromyalgia is co-constituted in the service of systems of power as gendered bodies of colour further take shape as pathological. In the next chapter, I perform a similar review and critical intervention as the one I undertook here,

but focusing on the current body of literature concerning fibromyalgia and psychologization.

### **CHAPTER THREE: THE PSYCHOLOGIZATION OF FIBROMYALGIA**

In the late nineties and early aughts, medically unidentified illnesses (MUIs), or at least their diagnosis, knew a notable rise (Barker 2011). Fibromyalgia is among these contested conditions, along with others such as Multiple Chemical Sensitivity (MCS) and Chronic Fatigue Syndrome (CFS). The prevalence of fibromyalgia is inconsistent across sources, but some have calculated its incidence in combination with other MUIs. In 2003, Statistics Canada reported that, combined, fibromyalgia, MCS and CFS impact 1.2 million people nationwide (Statistics Canada 2003). In the American context, Barsky and Borus (1999) suggested that, in the year 1999, roughly ten million people were living with contested illnesses sharing symptoms common in fibromyalgia. According to the latest Canadian guidelines on the condition (Fitzcharles et al. 2012), close to one million Canadians are diagnosed with fibromyalgia alone. Many physicians refuse to either diagnose or treat patients with the illness (Annemans, Le Lay and Taieb 2009; Hayes et al. 2010), which has led some organizations to suggest that the number of people affected might be substantially larger than reported (FM-CFS 2007).

Very little statistical research on fibromyalgia has been conducted thus far, making it difficult to determine if there are specific trends in diagnosing. This being said, researchers are in unanimous agreement about its representation along the lines of gender: women are overrepresented among fibromyalgia patients, with a common ratio situated between six and nine to one typically presented in the literature (e.g., Fitzcharles et al. 2012). Fitzcharles et al. (2012) add that people of low socioeconomic status also form a significant part of those diagnosed. Further, many have reported that racialized communities experience higher rates of chronic pain, which is fibromyalgia's pivotal

symptom (Green et al. 2003; Levy, Ansara and Stover 2013; Ramage-Morin and Gilmour 2014).

Despite the relationship between race and chronic pain considerations of race have thus far been completely left out of research specific to fibromyalgia; my searches between 2014 and 2018 for “fibromyalgia” and “race” in medical or scholarly databases, and even on Google, yielded zero relevant results. Similarly, the incidence of fibromyalgia among queer and trans people has yet to be explored in medical literature, though, as mentioned above, gender is an important factor in the prevalence of the condition.

This chapter reviews some of the global medical literature on fibromyalgia, including Canadian-based studies when possible, to introduce the common definitions and themes guiding medical theory and intervention, and to set the context for the psychologization of this condition that I return to throughout this dissertation. I have found that medical literature on fibromyalgia is more often than not generalizable among Western countries.

### **Fibromyalgia: everywhere and nowhere**

The condition we know as fibromyalgia is most commonly understood to be a cluster of symptoms, of which chronic pain is the most central and widespread. Chronic fatigue is a close second, as it is reported in over 90% of people with fibromyalgia (Fitzcharles et al. 2012). In the last two decades, fibromyalgia has evolved, medically speaking, from a pain-focused syndrome (Martínez et al. 2015) to now include a wide array of symptoms, such as morning stiffness, fatigue, headaches, sleep troubles,

digestive disorders, bowel irritability, forgetfulness, and cognitive issues which include “poor working memory, spatial memory alterations, free recall, and verbal fluency” (Fitzcharles et al. 2012: 9) as well as poor concentration, muscle spasms, painful menstruation, chest pain, anxiety, mood disturbances, limb swelling, numbness and depression. I compiled this list by conducting an overview of medical articles; however, after consulting blogs in which people living with fibromyalgia report their symptoms, I quickly noticed that the more extensive list adds up to over fifty symptoms. In cyberspace, people with fibromyalgia mention restless leg syndrome, varied skin sensations, ease of bruising, recurrent sore throat, vertigo, flu-like symptoms, heartbeat and other cardiac abnormalities, and hearing loss, among many more. This inventory demonstrates fibromyalgia’s breadth: it involves all bodily systems, including the sensory, the neurological, the reproductive and the digestive.

Simply put, in the body, fibromyalgia is everywhere. At the same time, it is nowhere to be found. Despite its characterization as a rheumatological disorder in the 1990s and its most recent association to neurological dysfunctions, to this day fibromyalgia remains categorized as an MUI. “Unidentified” is a descriptive categorization that relates to all of fibromyalgia’s components, from its definition and diagnosis to its cause and treatment. It has been consistently argued throughout the literature that one of the key contributing factors to this status is that fibromyalgia is not supported by medical evidence. As White, Lemkau and Clasen note, “the most problematic aspect of this illness is the discrepancy between the patient’s experience of pain and the absence of both objective physical findings and a biomedical explanation” (2001: 52). This absence consumes a large part of what is written on the condition. Most

medical articles on the subject start by stating, front and centre at the beginning of their articles, that fibromyalgia is mysterious and controversial. It is, indeed, deemed to be a “controversial pain disorder” (Barker 2002: 279) among most healthcare professionals and researchers (Hazemeijer and Rasker 2003; Asbring and Narvanen 2003; Barker 2002; Kissel 2002).

We can trace the first diagnosis of fibromyalgia to the mid-1970s, but it was not until the 1990s that the American College of Rheumatology (ACR) classified fibromyalgia as a “true syndrome” (Fitzcharles et al. 2012: 4). This classification led to the emergence of the tender points test, a fibromyalgia diagnostic test in which doctors apply pressure on eighteen potentially tender points (represented on a chart) across the body of patients who report widespread body pain. Generally, if the patient responds by demonstrating above-average pain in eleven or more of the eighteen tender points, the diagnostic criteria are considered to be met and, after ruling out all other illnesses, the patient is diagnosed with fibromyalgia. Still, the guidelines to determine “above-average pain” and the requirement to “rule out all other illnesses” are quite ambiguous, leaving much to the discretion of the probing doctor.

Although in 2010 the American College of Rheumatology (ACR) pronounced the tender points test irrelevant to the diagnosis of fibromyalgia (Wolfe and Hauser 2011), many recent medical research papers still mention this examination as part of the diagnostic process (e.g., Martínez et al. 2015). More importantly, it continues to be a central diagnostic technique performed in the physician’s office; many of my research participants mentioned being subjected to it as part of their diagnosis, as was I multiple times. It is in some ways a dated formality, acting as a filler since now, no test is

officially deemed necessary to identify fibromyalgia. Indeed, the Canadian guidelines on the condition (Fitzcharles et al. 2012) suggest that close to no testing is actually required for diagnosing patients with fibromyalgia. The guidelines recommend “less tests, imaging, medication use, specialist referrals and primary care visits” (32). In fact, no diagnostic criteria currently exist beyond basic blood work to rule out other conditions that might cause pain (such as arthritis and lupus), the patient’s report of three months or more of body pain, and a physical examination. Now that the ACR tender points test has been excluded, the nature of the physical examination recommended is not specified. These recommendations have already transferred into clinical practices, and doctors have begun to grant the diagnosis simply based on a set of symptoms and a general blood test panel (Fitzcharles et al. 2012: 11).

Another element contributing to the debate about fibromyalgia’s ambiguity is the fact that its causes, too, are undetermined. Many have been proposed, but none are universally agreed upon. Some original theories have been around since the beginning of work on fibromyalgia, and much work has focused on finding new ways to confirm them. More recently, several authors have proposed potential causes, including a few that attend to more structural explanations. I provide an overview here.

Firstly, some researchers have proposed biological explanations. Fibromyalgia was first considered to be a rheumatological disorder, as discussed earlier in relation to the tender points test. Since then, a plethora of physiological causes have been suggested, including the possibility of a genetic predisposition justified by research findings that point to a relationship between mothers who have fibromyalgia and their children’s subsequent diagnosis (Fitzcharles et al. 2012). Very recently, a US-based biomedical

company called EpiGenetics Inc. even released a diagnostic blood test called FM/a which challenges the syndrome's previous associations (FM/a 2018). The examination focuses on white blood chemokine and cytokine patterns, which suggests that fibromyalgia is an immunologic disorder. Thus far, the test has not received much attention or clinical application, based on my experience and my literature review. Other biological explanations continue to appear in fibromyalgia research; for example, associations have been made between the condition and the muscular, circulatory and central nervous systems (White, Lemkau and Clasen 2001).

Despite potential biological explanations, psychology has made its mark on fibromyalgia studies. Post-traumatic, childhood and prolonged severe stress or trauma have been widely referenced as possible causes for the condition (e.g., Cohen et al. 2002; Weissbecker et al. 2006). This has made a significant impact on treatment approaches, including the turn toward the psychological interventions that dominate fibromyalgia treatment. Biological explanations have often collided with psychological ones, or served to justify a move toward psychology in medical understandings of fibromyalgia. In other words, counter-intuitively, the focus on the central nervous system has been taken up as providing scientific proof of the need for psychological interventions.

In summary, the literature on psychologization reveals that, firstly, physicians continue to associate fibromyalgia and other MUIs with psychological causes; secondly, patients encounter this psychologization when interacting with physicians; and, thirdly, this is not confined to a few physicians, but rather sanctioned by fibromyalgia experts and well-known organizations and committees. In this chapter, I review the dominant paradigms that explain the psychologization of fibromyalgia and of marginalized people,

which leads me to then propose a new path inspired by the interventions of (QT)BIPOC scholars in Mad Studies.

I wish to note that while I am critical of the psychologization and psychiatrization of marginalized people living with fibromyalgia, I do not intend, throughout this research, to distance fibromyalgia from psychology and psychiatry in a way that further stigmatizes mental illness and emotional distress. Instead, I analyze the psychologization and psychiatrization of fibromyalgia and QTBIPOC who live with medically unidentified illness in order to reveal the racial and gendered histories of psychologization, psychiatrization, and pathologization, which are integral to our understanding of medical, racial, gendered and neoliberal power. Throughout this dissertation, I take up psychologization and psychiatrization as central problems that permeate our lives within and beyond the medical system, asking what gendered, racial, and neoliberal regimes of knowledge have informed the medical system's focus on psy knowledge and interventions as a way to understand and treat fibromyalgia.

### **The medical bias theory on fibromyalgia skepticism**

In the sections that follow, I give an overview of the landscape of research on fibromyalgia skepticism in order to contextualize my own and my participants' calls for new directions. I spend time here discussing the medical bias theory, as it is the approach that dominates fibromyalgia research currently. An evaluation of this approach has a lot to teach us because the bulk of research available adopts it.

Skepticism towards fibromyalgia is now well documented, as is patient psychologization in medical encounters (e.g., Asbring and Narvanen 2003). Thus far,

they have been explained through two interconnected approaches, what I call the “lack of evidence” camp and the “medical bias” camp. These branches have converged to offer the dominant and agreed-upon medical conclusion on the matter: lack of medical evidence serving to diagnose fibromyalgia leads to medical bias, which in turn leads to skepticism and psychologization. Research that adopts this framework argues that bias exists in clinical assessments and treatments because physicians have nothing else to rely on (no blood or imaging tests, for example) except for patients’ “subjective complaints” (Hirsch et al. 2014).

This position relies on previous research that has shown that medical bias increases when medical evidence is low or nonexistent (e.g., Lachapelle et al. 2014). The prevalence of this approach is in a large part due to the overemphasized medical invisibility of fibromyalgia. In fact, fibromyalgia’s “invisibility” is widely emphasized across the literature as *the* factor that haunts both physicians and patients in clinical encounters.

Yet, two main streams of medical bias research trouble the theory that associates lack of medical evidence to medical bias in fibromyalgia research. Firstly, bias has been documented in relation to other illnesses that are diagnosed based on established medical evidence. This bias occurs particularly when these diseases are attached to gendered, working-class or racialized bodies (e.g., Hoberman 2007; Hoffman and Tarzian 2001). This helps us make a case for demystifying the theory that claims that more medical evidence would reduce skepticism and discrimination toward fibromyalgia patients. Numerous authors (e.g., Hoberman 2007; Hoffman and Tarzian 2001; Taylor et al. 2005) argue that regardless of the presence of medical evidence, medical bias continues to occur

in medical assessments, diagnoses and treatments across a range of contexts, from multiple sclerosis to coronary artery disease (Mendelson 2009).

A prime example often emphasized in research on gender bias is the emotionalization of women's symptoms and the pathologization of emotion in medical settings regardless of the results of medical tests or the availability of medical evidence confirming illness (Hoffman and Tarzian 2001; Mendelson 2009; Munch 2004; White, Lemkau and Clasen 2001). Women are characterized as “hysterical or emotional in much of the medical and other literature” (Hoffman and Tarzian 2001: 20). Hoffman and Tarzian (2001) coined the term “Yentl Syndrome” to refer to the widespread belief among health professionals that women are not truly sick until they “prove that they are as sick as male patients” (17). But it remains challenging for women to prove their illness when medical evidence is not sufficient to counteract gender bias. Even people suffering from illness with established diagnostic processes, such as lupus (which was long considered to be an MUI, and is the subject of Mendelson's 2009 study), face skepticism from physicians, are accused of exaggerating, receive insufficient testing, and are given inappropriate care, such as having their emotions intervened upon rather than their physical symptoms.

Regardless of medical evidence that legitimizes them, illnesses attached to gendered and racialized subjects are met with skepticism in the same fashion as fibromyalgia and other MUIs. Medical evidence takes a back seat to race and gender in medical diagnosis and intervention among racialized communities, as mounting evidence suggests. For instance, “thousands of studies have demonstrated that Black adults and children are less likely to receive appropriate, guideline-concordant, and cutting edge

medical care than their White counterparts, independent of disease status and other clinically relevant factors” (van Ryn et al. 2011: 200). Among racialized and gendered groups, misdiagnosis and underdiagnosis (e.g., Lachapelle et al. 2014; Ross, Lypson and Kumagai 2012), and their impact on access to treatment approaches, are common across a wide range of illnesses, regardless of medical evidence (e.g., Burgess et al., 2008; Burgess et al., 2014; Chen et al., 2005; Green and Hart-Johnson, 2010; Hoffman and Tarzian, 2001; Hollingshead, 2015; Rainbow Health Ontario, n.d.). In sum, these studies point us to the fact that medical evidence is not as central to medical bias as is currently argued in fibromyalgia studies. Patient identity factors such as gender and race are as important, if not more.

The second argument that troubles the theory that lack of medical evidence leads to medical bias in fibromyalgia research is as follows. Numerous researchers have made the case that, when medical evidence is absent, physicians’ perceptions of the *who* (the presenting subject) of illness likely plays a significant role in the clinical encounter, affecting diagnosis and treatment options. Importantly, a wealth of studies have emphasized this tendency in relation to chronic pain, the pivotal symptom of fibromyalgia. Some studies have found that certain racialized communities experience worse pain and increased disability when suffering from chronic pain (Green et al. 2003), yet are more often met with scrutiny and skepticism in clinical encounters (Green and Hart-Johnson 2010; Hoffman and Tarzian 2001). Combined, these factors have enormous implications; skepticism affects the decisions taken by physicians, their relationship with racialized patients, and leads to undertreatment and access to care, which in turn leads to an increase in the presence and intensity of chronic pain in these already heavily affected

communities (Green et al. 2003). In comparison to patients accessing medical services for other conditions, people with chronic pain are also more likely to face discrimination or be taken less seriously (Lachapelle et al. 2014) and particularly so if they are racialized or of marginalized genders (e.g., Green and Hart-Johnson 2010; Hoffman and Tarzian 2001).

Research on medical bias has been useful to fibromyalgia studies by providing mounting evidence that physicians' decisions and behaviours (Burgess et al. 2008; van Ryn et al. 2011) and their perception of racialized patients (Johnson et al. 2004; Moskowitz et al. 2011; Nestel 2012) from medical school onwards (Ly and Crowshoe 2015) are influenced by the patients' race and class, and that racialized people and people of marginalized genders commonly face psychologization and skepticism within the medical system, regardless of their symptoms or medical test results (e.g., Brown and Fiske 2001; Burgess et al. 2014; Ross, Lypson and Kumagais 2012; Kim 2014).

This being said, the baseline assumption at the heart of the medical bias theory—ultimately, that there exists a scientific, objective truth, and that bias steers medical professionals away from it—is contrary to the approach I adopt in this chapter and in this dissertation. The medical bias theory, which is adopted by most fibromyalgia theorists, also understands medical bias as a collection of unfortunate individual perceptions leading to altered behaviours or diagnoses. To the contrary, I view the medical system's oppressive approach as structural and *necessary* for it and the systems it upholds to function. Medical bias is not an interjection of error into scientific theory; it is actively produced and has often gained legitimacy *through* scientific justifications. The theory that bias happens due to lack of medical evidence is related to another widely held belief

about medical bias: what Hoberman (2007: 512) calls “the standard medical liberal’s interpretation.” This interpretation supposes that medical biases are harmless, unconscious accidents committed by well-meaning physicians, who cannot be blamed and instead must simply be further educated. What is most surprising about this perspective is that the documentation of racial disparities in medical journals is plentiful and has been available for quite some time. As early as the 1970s, for instance, researchers Ford and Cooper (1995) proved that surgical treatment was provided to white patients at a much higher rate than to Black Americans. According to Hoberman (2007), over 600 studies in the United States alone have reported on racial health disparities, yet “medical authors have developed a rhetoric and a vocabulary that allow them to deplore racial health and treatment disparities without ever taking any real responsibility for them” (508). Pleading ignorance has also been justified by claiming that “the stereotyping of patients originates in external circumstances such as ‘time pressures’ that exacerbate the already formidable challenges of ‘complex thinking and decision-making’” (512). Much research has been invested in actually proving, in this way, that doctors stereotype without knowing that they do (e.g., Hollingshead 2015). Studies that uphold this belief are yet another example of how scientific research often comes to the rescue of science to the detriment of marginalized peoples’ lives.

Thus, in this dissertation, I think through what is often called “bias” beyond the accidental, and instead consider how the scientific approach has produced the very knowledge and subjects it currently uses to pathologize QTBIPOC fibromyalgic bodies. The approach I adopt focuses on how medical encounters open up histories that are recycled and brought back to life in the present moment. These histories not only

influence medical readings, but have been produced by and are integral to systems of power, including the medical system itself.

### **Psychologization of fibromyalgia**

Generally speaking, psychologization is seen as a type of medical bias. The story goes, because some doctors are biased against certain types of patients, they are more likely to read those patients as being mentally ill as opposed to presenting with genuine physical symptoms. In what follows, I give a tour of the way psychologization has been framed.

Because the medical literature often characterizes fibromyalgia as a somatoform (purely psychological) or psychosomatic (largely psychological, or at least not purely physical) condition, the proposition that fibromyalgia is a manifestation of mental distress and unregulated emotionality (Barker 2002) has persisted despite numerous feminist critiques of similar medical approaches to other illnesses. The very few studies that have considered more structural factors in the development of fibromyalgia—for instance, the role of gendered experiences such as gender-based violence, gender roles and gender socialization—still evoke the psychosomatic theory. For example, Astbury (2006) argues that women’s societal position and subjugation can have health repercussions, including fibromyalgia, categorizing these health consequences as “psychosomatic” (52). My goal is not to completely reject this statement, but instead to trouble its narrow outcome of placing fibromyalgia further into the realm of psychologization.

Another stream in the gender-focused literature on fibromyalgia is the “feminist biopsychosocial perspective” taken by authors such as White, Lemkau and Clasen (2001)

and Barker (2002; 2011). These authors use a historically grounded approach to fibromyalgia, locating it in a genealogy of gendered illnesses throughout history, such as hysteria and neurasthenia. Barker (2011) even names fibromyalgia a “modern-day hysteria.” This is a theme I return to and make central to Chapter 4.

The term “psychologization,” which I use throughout this dissertation, is defined by Richman et al. as when “female illness is socially constructed as erroneously or disproportionately embracing psychiatric or sociocultural contributors” (2000: 178). Other authors have used other terms to refer to a similar phenomenon. For instance, in relation to the psychologization of women’s health problems, Munch uses the term “gender-biased diagnosing,” and defines it as “the notion that somatic complaints by female medical patients are more likely to be labeled by physicians as psychosomatic” (101).

Women are a common focus in research on psychologization because women’s symptoms are so often psychologized; women make up 70% of people who take antidepressants (Woodlock 2005). While antidepressants can be useful to treat depression, and were designed for this purpose in the late 1980s, the use of antidepressants, and particularly selective serotonin reuptake inhibitors (SSRIs), has grown considerably to include the treatment of many symptoms not listed under “depression” in the *Diagnostic and Statistical Manual (DSM)*. Metzl and Angel (2004: 578) discuss this shift, noting that “first approved by the US FDA in 1987 for the treatment of depression, SSRI antidepressants were over the next decade found to effectively treat such illnesses as Obsessive Compulsive Disorder (OCD), Post-Traumatic Stress Disorder (PTSD), Generalized Anxiety Disorder (GAD), and Premenopausal

Dysphoric Disorder (PMDD).” Citing multiple researchers, they go on to explain that, by virtue of their “ease of dosing” and low side effects, they became “the best-selling psychotropic drugs in modern record (Healy, 1997)”. Metzl and Angel say that a “widening set of gender-specific criteria” (577) have come to justify the common use of antidepressants. Based on their evaluation of American news and magazine articles from the year 1985 to the year 2000, they argue that the reasons given for prescribing antidepressants now encompass a great majority of women’s life experiences, including motherhood, marriage, menstruation and childbirth, which have become diagnosable conditions such as postpartum depression and premenopausal dysphoric disorder, for example.

Research focusing on physicians’ experience and choices in relation to fibromyalgia have confirmed the strong tendency to psychologize the condition. For example, Asbring and Narvanen (2003) interview several physicians who attributed psychological roots to fibromyalgia when they could not detect physical causes. Also, much of the medical literature on fibromyalgia associates the syndrome with emotional strain or childhood trauma (see, for example, Wentz, Lindberg and Hallberg 2004).

Other studies have taken a different direction by asking participants who have fibromyalgia to expand on their experiences with doctors. Mendelson (2009) touches on this subject; most of the participants in their study say their physicians explained their fibromyalgia as a result of stress or depression, said they were exaggerating their physical symptoms, refused to perform any further testing, and prescribed antidepressants as treatment.

These experiences of psychologization are widespread among people with fibromyalgia; the literature shows that specialists in the field generally endorse psychologization. Interestingly, psychological theories have remained central to mainstream understandings of fibromyalgia despite medical research that points to other possible causes. While the Canadian guidelines on fibromyalgia (Fitzcharles et al., 2012) mention evidence of neurological malfunction in fibromyalgia patients, this report also suggests scaling back testing and recommends treatment focused on psychotherapy, particularly cognitive behavioural therapy (CBT), and the prescription of antidepressants. Further, in these same guidelines, patients' personalities, including their susceptibility to "neuroticism and catastrophizing" (29), are said to be detrimental to the attainment of better outcomes, a theme that I return to in Chapters 5 and 6.

Another way the psychologization focus manifests is in researchers' research interests themselves. Much of the literature on fibromyalgia is composed of medical studies which attempt to explain how mental instability and maladjusted personalities contribute to fibromyalgia, and to provide evidence for the usefulness of antidepressants and cognitive behavioural or other therapies that address maladaptive personality traits. For this paradigm to drive medical research, researchers must begin with the assumption that fibromyalgia and psychological disorders are connected. For instance, in Wentz, Lindberg and Hallberg's (2004) interviews with twenty-one women, the researchers aimed to "elucidate psychological functioning and psychological processes in women with fibromyalgia" (702). In Toussaint et al.'s (2010) work, "forgiveness enhancement training" is suggested as a complementary treatment for fibromyalgia and chronic fatigue syndrome, while Pedersen et al. (2016) recommend cognitive behavioural therapy to

correct maladaptive traits of people living with fibromyalgia and other similar syndromes.

Other studies have been critical of psychologization and its prevalence in fibromyalgia. In a study by White, Lemkay and Clasen (2001), the authors come to the conclusion that even though most studies draw a link between fibromyalgia and psychiatry on the basis that “30% of FM patients have a psychiatric diagnosis, most often depression,” this leaves 70% who do not, making the association between fibromyalgia and psychiatry hypothetical at best. Their results are interesting insofar as they pay attention to this “other 70%,” unlike other studies that ignore the “absence of a consistent psychological profile of persons suffering from FM” (50).

This “psychological explanation” is not proper to fibromyalgia; researchers who study other contested illnesses offer similar models (see Swoboda 2008). Some research has been done on psychologization in relation to chronic fatigue syndrome (CFS) and multiple chemical sensitivity (MCS), among others. In their work on CFS, for example, Richman et al. (2000) explain how the failure of Western medicine to establish a physical cause of the syndrome created an important shift in which physicians turned to psychological explanations, including the attribution of certain personality traits to people with CFS, such as perfectionism and overachievement, thus rendering it “delegitimized as a biomedical phenomenon within medical, academic, governmental, and public arenas” (173). In the same vein, Gibson (1997) writes about the psychologization of MCS, an equally disputed condition that is often met with skepticism. Gibson explains how, rather than being seen as a legitimate physical reaction to toxic chemicals, MCS has been at times dubbed “chemophobia,” placing the onus on the individual’s mind and fear

of chemicals. For context, Gibson notes that the US National Research Council confirms that only a small percentage of chemicals have been tested for neurotoxicity, and where testing does happen, most research subjects are white cis men, making it impossible to anticipate the effect of chemicals in synergy with genetic and life factors that might be particular to marginalized people. In a poignant example, Gibson relates the story of a participant with MCS who “was diagnosed as having ‘olfactory delusions’ simply because she could smell chemicals that others could not” (486). Jones (2016) offers a similar analysis of the psychologization of endometriosis, stating that doctors psychologize the pain felt by patients and view their responses as catastrophizing.

As Munch (2004) documents, in the 1970s, during the rise of second-wave feminism, a notable amount of critical feminist literature examined sexism within medicine. In this context, researchers began to look into this long history of psychologization of women’s symptoms and illnesses. Building on this early work, Munch proposes that three historical factors continue to guide physicians today, namely, the association of women’s reproductive systems with emotionality, the remnants of psychoanalytic theory, and what Munch calls “the myth of ‘female invalidism’” (104). Radical feminists working on health research, in particular, have proposed that the psychiatric system is a product of patriarchy by way of both its design, based on the masculine values of rationality and objectivity, and its practice (Berg 2002). In their research on the representation of antidepressants, particularly in advertisements, Blum and Stracuzzi (2004) apply such a theoretical framework to think through how antidepressants have served as a tool to discipline women into assuming roles that sustain

society's patriarchal structure. In discussing the popularity of Valium in the 1960s as a precursor to later antidepressants, they write:

It was a time when most white, middle-class mothers were still at home full-time. The sleepy, slightly euphoric, "ambition-thwarting" feelings the drug induced (Koerner 1999) both reflected and helped reproduce this normative femininity. With women now ensconced in an increasingly volatile labor force, we examined popular discourse to discover how Prozac reflects and helps reproduce specific feminine traits normative for our era. (271)

Contrasting the Valium of housewives in the 60s and 70s and the Prozac of today's working woman, Blum and Stracuzzi illustrate how psychologization, and its ensuing treatments, are informed by larger structures and regimes of knowledge. In this case, gendered knowledge is used to reinforce gender roles during what they call "Valiumania" (578) and is employed as a strategy toward sustaining these roles as white women's labour increasingly moved outside of the home. While Valium kept women in place in the home, they argue that Prozac fosters "masculine-typed emotional detachment" to produce the ideal citizen for a neoliberal era. The authors evaluate Prozac advertisements in which "women's productivity and work-place success" (273) are emphasized. For example, in the late 90s, there was "a long running Prozac ad touting the drug's ability to restore a women's 'Productive Days'" (578). As the authors explain, "these are precisely the traits that, in an earlier era, Valium sedated" (273). Given that pain and fatigue, two primary symptoms of fibromyalgia, are associated with laziness and lack of productivity, it is no surprise that antidepressants are part of the treatment options for this syndrome. In *Listening to Prozac: A Psychiatrist Explores Antidepressant Drugs and the Remaking of the Self*, Kramer (1994) says that the drug's idyllic function is to give women more energy.

The focus of feminist studies on the psychologization of MUIs is in part due to the important impacts of psychologization, which has been well documented. I review the impacts that I observed in my research in Chapter 5, but here I wish to give a brief description of my literature review on the subject. Redman et al. (1991) have proposed that psychologization, or in other words “telling patients that they are disturbed when in fact they are not,” may actually lead to the *development* of “psychological disturbances” (538). This observation is in line with a popular notion among people with contested illnesses (see, for example, Dennis, Larkin and Derbyshire 2013) that when patients receive a medical diagnosis, it confirms that they are not simply imagining their physical symptoms, and that they are *not* psychologically disturbed. Scheff (1974) calls this phenomenon—the trigger of psychological disturbance caused by the suggestion of psychological disturbance—a self-fulfilling prophecy. Gibson (1997) offers evidence of this happening with people who live with multiple chemical sensitivity, stating that when patients are not believed about MCS, this can itself cause “psychological damage” (487). In addition, the literature points to a self-censoring and doubting process that happens in response to psychologization. Jones’ (2016) work on endometriosis, for instance, discusses how the normalization of menstrual pain by physicians and society in general often has the effect of making people who suffer from endometriosis symptoms “overlook, downplay, or dismiss them outright” (560). On a larger scale, psychologization has a detrimental impact on the health care system as a whole (Redman et al. 1991; Spitzer 2005) by, among other things, increasing the costs incurred by misdiagnosis, inadequate treatment, and lost opportunities to educate patients on how to

mitigate the symptoms of their actual medical condition and to treat these conditions in their early stages.

### **Rethinking psychologization through Mad Studies**

Various paradigms have been proposed to explain the psychologization and psychiatrization of marginalized people. Biological explanations, and feminist variations on these biological explanations dominate the field. In this section, I review these approaches, to then present a Mad Studies approach lead by (QT)BIPOC to ground the perspective I adopt in this research.

Biological theories of psychiatric conditions are quite common. One of the ways that stigma surrounding mental health has been tamed is, after all, by revealing scientific and research-based evidence that psychiatric conditions are in effect related to biology. Biological models have left the confines of medical research and gained mainstream acceptance, including often among patients with mental health diagnoses (Fallugar and O'Brien 2012).

Given that women are diagnosed with psychological and psychiatric conditions at a much higher rate than men (Fallugar and O'Brien 2012), the causes of this gender disparity have inevitably been explained by emphasizing biological differences between the sexes. Researchers have proposed multiple variances saying, for instance, that women respond differently to stress on a physiological level, that they have higher serotonin levels, or that their ovaries play a role in their emotional dysregulation or endocrine system (see, for example, Astbury 2006).

Traditionally, biological theories on sex differences propose that women and men are simply born with different physiologies, and that women's physiologies make them more susceptible to psychiatric conditions. Researchers who explain fibromyalgia as a physical manifestation of psychological disturbance have thus focused their studies on determining the biological and neurological vulnerabilities that make women more prone to feel depressive emotions and pain. Spitzer (2005: 88) provides a reasoning for this theoretical approach:

Some conditions, such as multiple sclerosis and fibromyalgia, can be difficult to diagnose. This can contribute to health professionals' perceptions that women are neurotic clients. Women with disabilities are more likely to have their conditions attributed to psychiatric causes than men and physicians are more inclined to provide a diagnosis of depression to female patients. Depression has also been cited as a reason why women report more symptoms and functional decline than men. Differential patterns of symptoms and disparate responses to pain may be grounded in physiology as the result of hormonal influences on opiate receptors.

These theories consider psychologization a simple medical response to the fact that women are more often psychologically disturbed due to the differences in their bodies. They situate the problem inside the individual, essentialize biological sex differences, and approve the medicalization of these differences without further analysis.

Some of the arguments key to medical biological theories have been recycled by liberal feminists in resistance to the pathologization of responses to trauma (Berg 2002). Liberal feminist interpretations move away from the idea that these physiological differences are innate and static, but continue to explore how they are biological. Their goal is not to challenge the overdiagnosis of women with psychiatric disorders, but rather to explain *why* women experience these psychological challenges. The main change they bring to traditional medical understandings of these differences is to assert that women

have different physiologies because they are more likely to have survived trauma. They argue that trauma, in turn, leads to physiological and neurological changes that take the shape of what we know as mood disorders, such as depression and anxiety, and personality disorders, such as borderline personality disorder (BDP) or dependent personality (Berg 2002). Thus, gendered differences in immunology, physiology and stress responses are seen as *consequences* of trauma or gender-based violence, rather than simple *causes* of psychological disturbances (Astbury 2006). In many cases, liberal feminists have lobbied for doctors to diagnose these trauma reactions as post-traumatic stress disorder, “which would describe all mental health symptoms as gradations of behavioral, cognitive, and affective sequelae of trauma and abuse” (Berg 2002: 57). This theory locates the cause of mental illness outside of the individual, but their analysis does not go so far as to question the diagnoses themselves, nor do they trouble the authority of scientific knowledge. Instead, liberal feminist critics of psychologization mobilize scientific knowledge to their advantage, leaving the medical system intact, and stop short of exploring how sexist, racist and neoliberal regimes of knowledge contribute to the pathologization of certain ways of thinking, acting and being. For example, they take for granted that stress response systems function in a certain static and universal way, in order to propose that trauma changes how they function. They also accept the medical notion that there are only two types of bodies and physiologies separated along the lines of a rigid binary between sexes, and they minimize the medical system’s role in causing or reinforcing trauma.

Critical theory has rarely guided fibromyalgia research, but some authors have used feminist frameworks, and most of those have employed the biological model

described here. Moreover, some researchers who have investigated the links between race and mental illness do make the case that social injustice is a contributing factor to mental illness and critique the individualism at the heart of psychiatry and psychology, but, similarly, they fail to question the authority of these disciplines and the legitimacy of their diagnoses. This approach is, as Howell and Voronka (2012: 3) suggest, an addendum to biological models that consider social factors. As these authors explain:

It fails, however, to account for how marginalized people (such as the poor, colonial subjects, racialized people, queers and gender variant people, the disabled) tend to get disproportionately diagnosed or pathologized by the psychiatric profession, and how the psychiatric profession has been implicated in processes of colonialism, racism, sexism and heterosexism, as well as in disability and war-making.

Mad Studies and organizing, spearheaded in a big way by marginalized people, interrupt and challenge this approach, namely through the anti-institutionalization and psychiatric survivor movements (see Piepzna-Samarasinha 2018a and 2018b). Emerging from grassroots organizing, and as a new field in its own right, Mad Studies is not engaged with/in fibromyalgia research, despite its serious critique of processes of psychologization and psychiatrization. While white lead renditions of Mad interventions focus on Mad Pride, (QT)BIPOC scholars contribute a critical perspective that questions how “psy” knowledge and techniques permeate our social world, from the clinic to educational institutions to prisons, and are central in justifying and upholding settler-colonial, colonial, and racial violence globally.

These scholars critically examine the role of medical and psychiatric systems and psy knowledge and interventions in pathologizing marginalized people and reinforcing heterosexist and racist structures of power. At the heart of this field is a deep,

historically-justified skepticism towards the role of medical and psychiatric systems. Their origin is traced to their central role in establishing and maintaining social hierarchies needed to justify violence. Thus, this approach moves away from the individualizing answers to psychologization and psychiatrization promoted by other theoretical perspectives, and instead locates a structural problem explained through an analysis of the workings of power. White Mad Studies might employ a similar approach, but generally its goal is to argue that cognitive differences, for example, are not deficits, but instead pathologized features to celebrate. While similar themes might exist in (QT)BIPOC Mad Studies, their goal is not to turn negatives into positives, but instead to inquire about the roots, functionings, and systemic purposes of psy knowledge and interventions. Similarly, in this dissertation, I veer away from the conversation concerning what fibromyalgia is, to instead ask what it does; in other words, how it is created and mobilized in service of systems of power.

I thus recognize the medical industrial complex as a source of violence and illness, not simply a misguided and rectifiable institution. I also propose that a psychiatric response to fibromyalgia is grounded in the needs of the racialized socio-political and economic systems of our times. As such, for (QT)BIPOC, fibromyalgia is not our first entry into the world of psychiatry. It is, in fact, a continuation of the permeation of psy knowledge and interventions that shape our lives and bodies.

Due to its emphasis on white cis women, much of the critical literature on the psychologization of fibromyalgia misses how the concepts of madness (even when gendered), along with psy knowledge and techniques, always work in service of racial projects. According to Tam (2013: 283), “There remains a gap in mapping relations of

race *to* and *in* madness. It is this epistemic gap that fails to account for how race-thinking inherently constitutes psy knowledge.” Indeed, constructions of madness and psychiatric interventions are enmeshed with constructions of race, as they are jointly produced through medically established hierarchies and rationalities. Psy interventions not only serve to pathologize bodies and minds, but also to repair, re-incorporate, and assimilate them into settler-colonial and national projects of racial violence (Tam, 2013). For example, Tam’s work (2013) discusses how psy knowledge and interventions, such as those incorporated into processes of settlement for newcomers, are techniques of settler-colonial belonging, marking the assimilation of immigrant bodies into nationhood, and at the same time, denying Indigenous sovereignty. Tam (2013), along with other racialized scholars in Mad Studies, such as Rachel Gorman and Nadia Kanani, have lead the way in theorizing how racialized people are never just psychiatrized; they are always psychiatrized, as race and madness are co-constituted throughout history. As Kanani (2011: 2) writes,

Psychiatric labelling, treatment, institutionalization, and the lived experiences of racialized psychiatric survivors have been significantly shaped by the political project of colonization; political institutions such as slavery, scientific racism, and eugenicist discourses; and exclusionary immigration policies. Furthermore, these socio-political contexts have shaped the social construction of the racialized “Other”. As a result, madness and race cannot be considered separately from these factors.

It is this key intervention, which is currently overlooked in fibromyalgia studies, that offers a different starting point for theorizing the understanding and intervention into fibromyalgia otherwise, from a (QT)BIPOC perspective.

This chapter allowed us to pause on the literature demonstrating the psychologization of fibromyalgia in medical research, to contextualize it as part of a long

history of the association of marginalized people with madness, and to understand how psychologization can serve to support social hierarchies. I offered insights from Mad studies scholars, and the historical connections they map out, to orient us towards new ways of engaging with the psychologization of fibromyalgia. In the next chapter, this historical approach is central to my intervention into a new stream of fibromyalgia studies that seeks to understand the condition by drawing its genealogy, which currently does not include racialized people.

## CHAPTER FOUR: A NEW GENEALOGY OF FIBROMYALGIA

Syrus: I can't tell you how many times I've been tested for sickle cell. And, if you don't have sickle cell, you don't get sickle cell. 'Cause that's science!

In room: [laughter]

Syrus: I've said repeatedly that I don't have sickle cell. It's in my records! But doctors see a Black person, and they get so excited! Like, "Oh, have you been tested for sickle cell? I should test again!" In a similar way, to some extent, that was the problem with this lupus diagnosis too. A positive ANA blood test isn't enough to say that you have lupus, but my doctor was like "You're Black! It's probably lupus," you know? This idea of who gets what already influences what they're saying. I mean, I don't need to be tested ten times for sickle cell. Once is enough, right?

In room: [laughter]

Syrus: That's all. I just find that so bizarre; "You're Black, so, you probably have it..."

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Syrus, one of the participants in the Toronto group interview I conducted, has had a long and fraught relationship with the medical system dating back to his youth. While he has not been diagnosed with fibromyalgia, the combination of his lifetime of medically unidentified symptoms, the diagnostic process he endured for lupus and celiac disease (both at one point considered to be, like fibromyalgia, medically unidentified illnesses), as well as his decades-long leadership role in Toronto-based disability justice arts and organizing made his contributions to this research invaluable. In the above passage, Syrus discusses the potential impact of race on his diagnostic process. By his account, his body and symptoms were pre-marked, "already," in his words, as he entered the clinic, filtered through alignments of race with illness or "this idea of who gets what." In his case, this translated into health professionals' persistent interest in testing him for

sickle cell (despite a panoply of medical evidence confirming otherwise), and in another case, their reading of his symptoms as lupus, due to these illnesses' prevalence among Black communities.

Here, illness itself becomes Black, and the medical conviction that equates sickle cell to Blackness comes to take epistemological power over the immediate, present, located facts about Syrus, the patient before the physician in these specific encounters. Here, the meaning medical authorities have assigned to race becomes how the body is read, and hence a powerful form of evidence for diagnosis. Yet, illness and race do not exist in a vacuum, as I argue throughout this dissertation; they are jointly and actively produced in time and place, but also, as I explore in this chapter, *beyond* any given present time and place. The physician's impulsive reach backward (to a data set of past research that determined which illnesses are Black illnesses) and forward (to the ambition and hope of discovering more data to confirm and sustain the veracity of past research findings) exemplifies the collapse of time and space in the clinical encounter. What, then, would looking beyond and behind present clinical encounters contribute to our understanding of how, when coupled together, sick QTBIPOC people and medically unidentified illnesses come to be known by the medical system?

Syrus's intervention also points us to the complicated nature of the medical system's reverence of medical evidence (such as blood tests), revealing how tenacious the pursuit of evidence can be, but also how fragile medical evidence is. Medical professionals repeatedly tested Syrus, trying to prove illness through medical evidence. Yet, at the same time, negative results did not override or halt the overshadowing role of race—here, Blackness—in this pursuit. Even when blood tests repeatedly revealed

negative results, race motivated multiple efforts to retest. Race was *the* evidence that formed the backbone of medical reasoning behind all subsequent searches for medical evidence. This example asks us to reconsider the belief that medical empiricism relies on test results to identify, explain and treat illness. Physicians did, of course, try to prove illness through testing, but the *absence* of evidence triggered a diagnostic path that evokes other absent presences<sup>3</sup>, namely the long produced and repeated meanings made about race in the history of the medical system and thought.

This tension is relevant to our discussion of fibromyalgia because this condition is haunted by the medical system's firm belief in empirical evidence. Skepticism towards fibromyalgia patients has thus far been explained as a result of the absence of traditional medical evidence to confirm its existence and cause. Yet, in the experience of the QTBIPOC I interviewed, when X-rays and MRIs revealed negative results, race, gender and other "evidence" was mobilized to make meaning of illness. Thus, the current theory that lack of medical evidence explains skepticism toward fibromyalgia is of limited use to the experiences of QTBIPOC and at times entirely inapplicable.

In light of this, in what follows I consider the ways that medical subjects, particularly those who are racialized and of marginalized genders and sexualities, become medical evidence of illness in their own right. This approach moves away from the medical bias perspective I introduced and critiqued in Chapter 3, and it challenges the historical model, which I will discuss further in this chapter. Both these streams of fibromyalgia studies have a limited capacity to challenge medical empiricism, and are steeped in a white-centric account of the history of illness. With the help of the

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<sup>3</sup> Though used in many authors' writings, I first came upon the concept of absent presence in the title of Mahmoud Darwish's (2006) book "In the Presence of Absence."

QTBIPOC participants I interviewed, I argue that the insides of fibromyalgic bodies (traditionally read through medical technologies) are of less importance than their surfaces (appearance) and their depths (history) when doctors make meaning in present fibromyalgia medical encounters. Starting from the “invisibility problem” of fibromyalgia (i.e. the medical system’s inability to see or find it), I seek to offer a new path to answer the following questions: How is medical knowledge produced in the absence of medical knowledge? How are subjects of illness—the QTBIPOC participants we hear from here—themselves read, as research participant Nora puts it, “before we even get there”? Mostly, in this chapter, I ponder the role of history in the making of fibromyalgic presents.

The methodology of absence I presented in Chapter 1 paves the way for these inquiries. Particularly, the underlying approach I adopt in this chapter calls upon QTBIPOC scholarship that revisits how the past and present become known through violent dismissals, revisions and erasures. Specifically, I was inspired by my work as a collective member of Marvellous Grounds, a Toronto-based QTBIPOC archiving project; by the work of queer of colour scholar Sara Ahmed in *Strange Encounters* (2013) and her concept of “stranger danger”; and by the interviews I conducted with QTBIPOC. In the spirit of my methodology of absence, I turn to these three to propose a new path towards better understanding the fibromyalgic presents of QTBIPOC. First, my work with the Marvellous Grounds archiving project, described above, encouraged me to reevaluate the absence of QTBIPOC in historical considerations of medically unidentified illness. Further, I drew from Sara Ahmed’s (2000) methodology of encounters, in which she starts from her own encounters to discuss larger racial and gendered processes and

structures of power. Similarly, my encounter with the QTBIPOC I interviewed, who discuss their own encounters with medical professionals, guide my analysis and theoretical interventions in this chapter. As Ahmed writes, “the encounters that shape this work are not simply about how and where the stranger is produced as a figure (stranger fetishism), but also *how that figure is put to work, and made to work*, in particular times and places” (15). Ahmed’s central concept of “stranger fetishism” was integral to the questions I pose in this chapter. In many ways, I considered fibromyalgia to be a version of the stranger in my own work; a stranger that is “produced through knowledge rather than as a failure of knowledge” (14). This led me to ask, if not medical evidence, what knowledge is being used to *know* fibromyalgia? Moreover, Ahmed’s concept of “stranger danger” comes into play later in this chapter, where I employ it to reflect on how the ancestry of fibromyalgia can be understood as part of a legacy of medical violence against threatening bodies. I also credit Jin Haritworn’s *Biopolitics of Mixing: Thai Multiracialities and Haunted Ascendancies* (2012) for inspiring my approach of reading the mobilization and claiming of ghosts and ancestors as a way to interrogate who and what they serve and what their return tells us about systems of power.

What all of these interventions have in common is their awareness of the inevitable mark the past has left on the present - or “palimpsest” in Jacqui Alexander’s (2005) terms -, a mark that reappears suddenly and, more often than not, was never truly gone to begin with. At the same time, they all explore the deep burying of other pasts that interfere with the objectives of sustaining the power structures of the present. By engaging with their work and contributions, I explore the histories that are broken open in present-day fibromyalgic encounters—the histories that doctors call upon in order to

know what, supposedly, cannot be known. I propose that QTBIPOC lead us to acknowledge the gendered and racialized ghosts of the past who are involved in shaping present-day fibromyalgic encounters with the medical system, including both the ghosts that are conveniently invited back into the room and those who are violently silenced despite their attempts to be remembered.

Researchers in fibromyalgia studies have begun to trace the lineage of this condition in an effort to better explain the skepticism it is faced with in medical encounters. They have looked particularly at “hysterical” Victorian women as predecessors to today’s fibromyalgia patients. I build on this approach but find it to be insufficient, if not outright violent, because it traces history by skipping over those of us who are racialized, as though the only subject of history is white (Haritaworn, Moussa and Ware 2018a). In this chapter, I instead centre QTBIPOC (and particularly participants Bille, O, and Violet) to lead us to a “different set of ancestors” (Ramirez 2017; Haritaworn, Moussa and Ware 2018a) and to a different genealogy for fibromyalgia. In keeping with these changes, I argue that the current direction of fibromyalgia studies needs to dramatically shift.

### **Historical subjects of fibromyalgia**

In relation to fibromyalgia, very few authors have begun to look past the medical bias perspective I presented in Chapter 3. While some attention has been paid to the gendering and ensuing psychologization of fibromyalgia, medical bias remains the primary lens employed in these studies. A few scholars have broken off from the pack and adopted a historical approach, looking specifically at historical antecedents of

medically unidentified illnesses to explain how we understand fibromyalgia today. Authors White, Lemkau and Clasen (2001) and Barker (2011) have led this approach, situating fibromyalgia in a long line of gendered illnesses throughout history, such as hysteria and neurasthenia; Barker even names fibromyalgia a “modern-day hysteria.” She notes that “The fact that nearly all those diagnosed with FMS are women results in predictable claims that FMS is the new clinical presentation of hypochondriacity and/or hysteria” (Bohr 1995, 1996; Showalter 1997)” (281). While Shorter’s (1992) *From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era* had traced this lineage previously, his approach was far from feminist, and served instead to simply recount how women had imagined or fabricated illness since the Victorian age. Instead, White, Lemkau and Clasen interrogate the impact of gendered regimes of thought on the medical system’s understanding of the condition. They are critical of scientific epistemologies and of the psychologization of women’s illnesses for which science cannot provide explanations. They report, for instance, that MUIs have been explained as resulting from women’s desire to flee their traditional gender roles. While they do not exclude psychological factors, they blend this theory with biological and social paradigms. They advance that the gendered character of MUIs might be explained in part by attending to structural factors, such as the effects of a patriarchal society, including “women’s disadvantaged social position, the prevalence of physical and psychological trauma in women’s lives, and the different social and cultural expectations and pressures faced by women and men” (56).

This historical approach to fibromyalgia has thus far identified hysteria as the starting point of this condition. When I came upon this new history-focused branch of

fibromyalgia studies, I was a collective member of Marvellous Grounds (see Haritaworn, Moussa and Ware 2018a and 2018b). The print and online projects of Marvellous Grounds emphasize and document the whitewashing of queer and trans histories in Toronto through violent processes of displacement, gentrification, colonization and erasure of QTBIPOC. They question who is “worthy of remembering” (Haritaworn, Moussa and Ware 2018a: 4), and how QTBIPOC exclusions from genealogies and archives are “inherent to racial and colonial capitalism. Our absence from the archive, as well as from the spaces and times that it covers, directly intersects with racist border, welfare, policing, and military regimes” (ibid: 5). My immersion into the analysis and theoretical interventions we posed as editors and those of contributors largely influenced my critical reading of this dominant genealogy within fibromyalgia studies.

This lineage presupposes that Victorian women with hysteria are the ancestors of modern day fibromyalgic people, placing white women as the first and only possible historical subjects of medically unidentified chronic conditions. This history dismisses the existence of racialized people and limits our reading of the fibromyalgic present of QTBIPOC by imposing a lens that denies their existence and constructs them as new subjects of their kind (Haritaworn, Moussa, and Ware 2018a). Our absence is not merely an omission, but rather a project of absencing and violent erasures serving to uphold whiteness and its violent structures through a whitening of history. If we instead centre QTBIPOC as subjects throughout the history of medically unidentified illnesses and in the present, it forces us to rethink the lineage of fibromyalgia. We must then ask: if the Victorian hysteric was read as hysterical due to her behavioural opposition to traditional gender roles, what do the irrational QTBIPOC of our medical times threaten today? What

violent processes, knowledges and interventions are hidden through the telling of this story, the subjects it highlights and those it omits?

Further, what does a focus on white women serve in this instance? Tam (2013) argues that madness is to be known in relation to race and racial projects. What systems are upheld through the telling of the story of fibromyalgia as a story of white hysteric women? The current literature in historical fibromyalgia studies argues that these women might challenge gender roles, but is there more to this story? *Marvellous Grounds* argues that omissions are rarely just that; they are active concealments, violently ripping out stories that disturb the celebrations and fanfare surrounding the heroism of historical subjects. What does the story of white hysteric women celebrate? Perhaps the focus on white women in today's research on fibromyalgia can point us to the answer. The traction of fibromyalgia and women's illnesses, the demands for the urgency of health care reform in relation to chronic pain, and the rise of calls for legitimacy of the condition are all wrapped in a cloak of white, middle class victimhood. Medical recognition becomes an entryway into white privilege and nationalism, whereas medical rights are a hall pass for the incorporation of white, sick women into a nation that continues to, jointly, medically abuse and pathologize, and turn away from the pain of, Indigenous, Black, and people of colour.

Thus, the white history of fibromyalgia is indeed one of celebration. Its beginnings justify a neat move towards progress. Its incompleteness (the continued pathologization of white fibromyalgia patients) is but a sign of hopeful arrival. Yet, in a similar way that the authors of *Queering Urban Justice* (Haritaworn, Moussa and Ware 2018b) adopt a framework that “foregrounds visions of urban justice that are disloyal to

racial and colonial capitalism” (13), I wonder where it would lead us to rethinking the history of fibromyalgia and disability, madness, and illness justice in ways that similarly interrupt “racial and colonialism capitalism”, and white and medical heroism? These celebrations can only be interrupted by the arrival of ghosts (see, also, Robinson 2018). Which ghosts, in the story of fibromyalgia, re-emerge in the clinical encounter? What stories do they hold, and why are they so threatening as to be made to disappear?

The QTBIPOC theorists interviewed for this dissertation reveal the proximity of the past in present medical encounters, and the ways in which race and gender themselves have long been used as medical evidence. Specifically, the QTBIPOC I interview point us towards the critical role of the body’s surface (appearance) and depth (histories) in the making of illness, in the diagnostic process and in treatment approaches. Particularly because fibromyalgia poses a challenge to the medical readings of the *inside* of bodies upon which doctors have traditionally relied, this condition offers an interesting vantage point from which to consider the mobilization of the body’s surface and depth as medical evidence to understand bodies that defy medical knowledge.

Finally, and perhaps most importantly, QTBIPOC offer new ancestors and new starting points for thinking through fibromyalgia. They allow us to see how the pathologization of and medical skepticism toward QTBIPOC patients are often created and justified through medical knowledge, and are mobilized to regulate bodies that threaten systems of power. In the next section, I turn to the conversation among participants billie, O and Violet during our online group interview, which intervenes in the medical emphasis on the Victorian hysterical woman as the main ancestor of today’s fibromyalgic patients.

## A ghostly conversation

billie: Some people see me as a hypochondriac, spoiled, white housewife, and they think I'm just making [my illness] up because I'm bored and I have nothing to do. And others see me as a drug-seeking poor person of colour who is just trying to get one over on the system. I deal with those stereotypes a lot, and they are definitely gendered, even though I identify as non-binary. Like, sometimes I'm read as the poor woman of colour who's just trying to get drugs, and other times I'm read as the rich woman who's just trying to get sympathy.

O: I have almost the exact same thing where people most frequently label me as the sort of attention-seeking white girl, or the overdramatic Hispanic girl, and neither of those have anything to do with my lived experience.

Violet: Yeah, um, Aboriginal people can tell I am Aboriginal but I have really, really pale skin. My mother is a redhead. I've got a dark-haired parent and a redhead parent, so the result is dark hair, weird face, very light skin. In Australia, every form you fill out asks you if you are Aboriginal for statistics and blah blah blah. So I go in to doctors and they know immediately that I'm Aboriginal, and I get a lot of doctors telling me that I'm surprisingly articulate and whatnot. But, I know Aboriginal community members who can't go to the doctor for anything, because the doctor just basically writes "junkie" on their form and bans them from ever going to the doctor again. And I've actually been lucky interacting with people for pain management partially because I present as white to white people.

In *Strange Encounters*, Ahmed (2013) writes, "The meeting is singular—it is with 'this other'—and yet also collective—'this other' brings with her other others" (179). This conversation between billie, O and Violet is telling of the way present encounters open up previous ones, or of how othering, in medical encounters today, involves the reappearance of historical others that help shape the experience of present others. The participants' discussion above allows us to witness how Ahmed's work can concretely play out in a clinical setting. In the passage above, billie reports that "some people" (i.e., doctors) view hir "as a hypochondriac, spoiled, white housewife" and assume that hir symptoms are exaggerated or that ze is "making it up" out of boredom. Similarly, O

shares how they are read “as the sort of attention-seeking white girl.” These testimonies are reminiscent of the literature on fibromyalgia that situates this illness in a historical continuum, as the latest instance in a long line of gendered illness that are met with skepticism by the medical system.

Past research positions the beginnings of such readings in the Victorian age, starting with hysteria then and moving forward in time to fibromyalgia now. This literature positions the white, upper- or upper-middle-class Victorian housewife as the model figure, or ancestor, of unidentified illness as it has been understood as fabricated or psychosomatic illness. This lineage is one of white bodies, of white women, of white rich women. While this lineage does lurk in Billie, O, and Violet’s clinical encounters, I am interested here in looking further, or elsewhere, and recognizing the limited application of these studies in the lives of QTBIPOC. The exclusion of QTBIPOC, and racialized people in general, from fibromyalgia studies and thus, inevitably, from these historical perspectives, masks their presence in the story of fibromyalgia and psychologization, as well as the processes a history that includes them might reveal. The interventions of the QTBIPOC participants quoted above shift the conversation in a new direction from where it has focused so far in fibromyalgia studies. They signal other histories and ancestors that are called upon and opened once again (Ahmed 2000) in the current fibromyalgic encounters of QTBIPOC. Their testimonies announce that this shift changes which ghostly figures are involved in the construction of the fibromyalgic body, and in bringing this body into becoming *as fibromyalgic*. Is the Victorian “hysteric,” the fauteuil-lounging white cis woman, the only imaginable ancestor to this story? No, these participants answer.

If the Victorian “hysteric” allowed us to examine the role of sexism in medical understandings, what can other ancestors add to this conversation? In the current “historical perspective” literature on fibromyalgia, the sick, hysterical white Victorian housewife is chosen as ancestor because of the psychologization of her symptoms which, at the time, were unidentified and denied legitimacy by the medical system. By way of the reading of their gender and race, at times, Billie, O, and Violet were read as descendants of this figure. Yet, when their race pierced through this reading, other ghosts interrupted this connection. The participants themselves identify this divide along lines of race. In their conversation, they note that, when “passing” as white women, they are read as “bored,” “attention-seeking” and “spoiled”—all popular markers used to refer to the Victorian “hysteric.” On the other hand, when the participants are seen as being “people of colour,” “Hispanic” or “Aboriginal,” those categories invoke “drug-seeking,” “poor,” “trying to get one over the system,” “overdramatic,” and “junkie.” In another interview, E talks about how being read as a “brown girl” means also being read as “crazy”:

The medical industrial complex sees me as this brown girl and very much treats me worse as a result. Just in the way that I’ve been trying to figure out what’s going on with my body, and the way that that’s consistently ignored as not a real problem. I suspect that it’s related to that and the way that my body is already read as crazy, like, not just my experiences or my brain or whatever, but my literal, physical body.

The reading of the surface of the participants’ bodies assumes a “depth,” a history of ghostly figures that are called upon to support physicians’ decisions. In the process of being known for the first time in the clinical encounter, they are first known again; ancestors penetrate the visual field, and this encounter becomes the latest of many.

billie, O and Violet point us to a different set of ancestors than the Victorian hysteric; in their discussion, we can spot the figures of the “Native junkie” (Violet), the “welfare queen” (billie), the immigrant “jumping the line” (billie), the “overdramatic” woman of colour (O) and the racialized drug user (billie). In a different interview, another participant, E, names familial ancestors who have been subject to medical experimentation due to their ethnicity. E also discusses the impacts of first generation anti-psychotics on Mad people, who are now left deadling with unpredicted symptoms and having to prove their emanence from medical intervention. In yet another interview, Syrus discusses enslaved ancestors and the toll of slavery on their bodies, which brings to mind the medicalization of desire for freedom from slavery (Gilroy 1993). Other ancestors are not named in my conversations with participants, but come to mind when we think of medical skepticism towards QTBIPOC. We can easily recall the AIDS crisis, gay conversion therapy and trans psychiatrization to conjure up queer, trans and QTBIPOC ancestors of medical skepticism. These have been discussed in detail by other scholars elsewhere, but here I bring them up as they point us to ghostly figures that the medical system intervened upon as they threatened systems of power. Leah Lakshmi Piepzna-Samarasinha, a long-time leader in disability justice activism in Toronto, in “Toronto Crip City,” (2018) calls in other, forgotten ancestors that she includes in her history of disability justice activism, including Edmund Yu, a psychiatric survivor who was murdered by police for “acting abnormally” (140) on a Toronto streetcar in 1997. His inclusion by Piepzna-Samarasinha, and his common mention by other sick and disabled QTBIPOC in speeches and rallies across the city, marks our collective integration of his memory into our history, and thus mark him as an ancestor; he who was

misread by armed power, who got tangled in the webs of race and disability, who, in the moment, was himself but also so many others, and who was seen as dangerous when he, in fact, was in danger.

Violet, O and billie identify the symbiotic meaning made about their bodies and themselves in the clinical encounter—their bodies were read as problems, which made *them* into problems too, through being read as haunting figures, “overdramatic,” “junkie,” “poor.” The reverse process also occurred simultaneously; their surface and depth contributed to their bodies being read as problems. As well, the participants also imply that their doctors read these ancestral figures as dangerous. As billie says, hir illness made hir out to be one that is “trying to get one over on the system.” Later, ze explains what ze meant, specifying that “it’s just this weird thing where poor people just want to get on disability because they don’t want to work or something, you know?” As Ahmed (2000) writes, “One knows again those whom one does not know by assuming they are the origin of danger” (32). How is the unknown fibromyalgic body, when racialized and gendered, recognized as dangerous to an institution that upholds ableism, racism and heteropatriarchy as structures of power?

We might look to the integral role of the medical system in disciplining queer and trans racialized bodies throughout history for an answer to this question. Settler colonialism and anti-black racism, for instance, have been established in part through the power of the medical system to define and pathologize racialized bodies. The medical system has been integral to establishing and sustaining conquest and genocidal violence (Browne and Fiske 2001). Throughout history, this system has provided scientific justifications for conquest and the continued oppression of these communities. The

construction of race inferiority and even race itself was a highly scientific and medical process. For instance, Desai (2003: 97) expands on the relationship between science and anti-Blackness here:

Human reasoning had concluded that not only were there physical differences between human beings but that white people were permanently superior to black people (Husband, 1986). Such scientific explanations of “race” did not evolve within a vacuum, they appealed to the mass population. Anthropologists, scientists, and others focused on particular types of evidence gathering such as measuring of head and skull sizes so that they could definitely state that the differences in capacity for civilisation were a result of differences in brain size and that this was evidence of black people’s inferiority (Banton, 1988).

If we were to think QTBIPOC fibromyalgic bodies through Ahmed’s concept of “stranger danger,” as untrustworthy strangers to fear, we must question what they threaten. Ahmed posits that fearing strangers requires that we place them in opposition to a community or home that is already assumed to be safe. They become strange and dangerous by being recognized as other than the familiar and safe. What community or home is threatened by strange and dangerous sick QTBIPOC? Perhaps billie’s observation that ze is read as “trying to get one over on the system” can help point us to the answer. What systems are threatened by QTBIPOC fibromyalgic bodies? Based on the literature on fibromyalgia thus far, we can assume that medical rationality is at stake when faced with an illness it cannot rationalize away or explain. This much seems obvious. But, when we consider the interconnections between the medical system and other oppressive systems, including heteropatriarchy, neoliberalism, ableism and racism, the threat becomes bigger. The demise of Western, white supremacist, heteropatriarchal, and settler-colonial medical and scientific rationality is threatening to all of these systems. What the discourse of stranger danger does in relation to fibromyalgia is hide

how the construction of the medical system—and the larger systems it co-constitutes—as safe, fair and objective is always violent. And this despite the set of ancestors that reveal this violence, as the conversation between O, Violet and billie actually points out.

Perhaps this is the new genealogy that these participants offer: one that includes racialized and gendered ghosts whose illnesses and disabilities were the result of violent medical readings and processes; subjects who were *made sick* through systemic violence and then pathologized by the same system that provided scientific legitimacy for this systemic violence in the first place.

The perspectives of QTBIPOC participants here show us the interference of racial regimes of knowledge in the understanding and treatment of fibromyalgia. Their interventions interject new ancestors into the genealogy researchers have tried to establish for fibromyalgia. To the Victorian “hysterical” are added racialized ancestors who threaten the systems that have produced them. I am arguing that fibromyalgic QTBIPOC belong to this history due to the very real threat that they pose to the medical system, a system that both defines them and utterly crumbles in the face of bodies it cannot rationalize. Next, I examine how a threat to the medical system and medical knowledge ultimately signifies a threat to systems of power, thus placing fibromyalgic QTBIPOC along the continuum of dangerous subjects to be managed through medical interventions.

Numerous studies have revealed the medical system’s complicity in systems and structures of power, including racism, colonialism, settler colonialism, neoliberalism, sexism, state violence and ableism. They point to the medical system’s interest in pathologizing racialized communities’ responses to injustice in order to justify and preserve structural oppression.

The discourse of eugenics has been a defining starting point from which some authors have evaluated this connection. For Taylor, “eugenics discourse developed out of ideas about human standards and normalcy rooted in—and justified by—scientific theory and investigation” (2015: 184). Authors such as Erevelles (2011) have further suggested that this discourse is also grounded in racial hierarchies. This scholarship demonstrates how scientific and medical knowledge has commonly been central to the emergence and maintenance of oppressive and genocidal projects.

Further, some studies have explored how consequences of structural violence, such as urban violence or the desire to flee from slavery, have been pathologized throughout history (Gilroy 1993; Erevelles 2011; Cacho 2012; Bell 2011). Others have argued that medical and psychological interventions can be more violent than mental or physical illness itself (see Bell 2011). They can also be highly coercive, and their power is not confined to the clinic alone. For Gorman, their reach is illustrated by the ways in which “psychiatric profiling and drugging occur in prisons and detention centres, and psy-technologies are expansive through education, social services, policing, and immigration and settlement services” (2013: n.p.).

In Canada and in other settler-colonial nations, such as the United States and Australia, this history is deeply interconnected with the settler-colonial project. Smith’s (2005) *Conquest* is useful in outlining how the medical system has been a mechanism of state violence through, for example, the forced sterilization of Indigenous women and forced medical experimentation. The conditions resulting from these interventions are then used, she argues, to justify further state intervention, more land theft and the denial of rights to self-determination. Million’s (2013) recent work in *Therapeutic Nations* adds

to this by considering the state's and medical system's use of the discourse of trauma and the turn to "'psy' techniques"<sup>4</sup> (102) to justify violent settler-colonial policies, all the while placing the responsibility on Indigenous people to change their conditions by self-managing, healing, and controlling their affective response to structural oppression. "Psy" techniques emerge as an answer to illness and trauma when these kinds of suffering under oppression are reframed as individual or cultural inability to attain health.

Scholarship that explores the co-constitution of race, gender, class and disability can help us understand how fibromyalgic QTBIPOC pose a threat to these systems. The association of irrationality with racialized, gendered and classed bodies has a long history that dates back to colonialism, and that continues until this day through neocolonial, imperial and settler-colonial structures, as well as development-focused projects and justifications for wars and invasions. Science, and particularly psychiatry, has played a central role in creating racist racial hierarchies that have been integral to racist projects and structures. The scientific "evidence" at the basis of racial inferiority related in a large part to the construction of the minds of racialized people as being inferior. Desai (2003) contextualizes the beginnings of the construction of racial categories as happening in

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<sup>4</sup> The concepts of "psy" technique or technologies are now commonly used among scholars working in the field of Mad Studies. For example, Gorman (2013) uses the term "psy-technologies" in a passage I quoted on page 118. Million (2013) uses the term "'psy' techniques" throughout *Therapeutic Nations*. In many cases, authors refer to the work of Nikolas Rose (1996) as a source for the concept of the "psy." As Million (2013) writes, "Rose poses the 'psy' - the psychiatric disciplines and the now verdant self-help therapies as neoliberal technique..." (149). Further, she writes, "Nikolas Rose clarifies the role and growth of psychology as a science and as a human technique for bringing forth more pronounced individuality... Psychology is a complex of knowledges, of theory and practice, actually the site of many practices, that Rose conceives of as *techniques*, or technologies... As such these technologies have been allied with many different projects, most notoriously with disciplinary institutions (including residential and reform schools), prisons, and, of course, mental hospitals." (151) Though I cannot confirm that Rose's work is the origin of this concept for all Mad Studies scholars, it, along with Gorman's, Million's, and the authors' featured in the anthology *Mad Matters: A Critical Reader in Canadian Mad Studies* edited by Le François, Menzies, and Reaume (2013) are recommended for further reading.

tandem with the rise of psychiatry. As an example, Desai writes the following about the co-constitution of Blackness and madness:

The ideology of “race” developed at the same time as psychiatry and hence psychiatric discourse is also influenced by how black people are represented. Samuel Cartwright writing in the *New Orleans Medical and Surgical Journal* (1851) associates blackness and madness by identifying psychopathologies which only black people are prone to. (97)

These psychopathologies included, for instance, “drapetomania, or the disease causing slaves to run away” (97). Resistance to slavery was, at this time, medically qualified as a form of insanity, thus keeping this system in place and providing further evidence that Black people need to be controlled, and that they cannot be trusted to care for themselves.

I suggest here that this history, among others, which equate madness with racialized identity, lives on in the fibromyalgic medical encounter, inspiring an association between “irrational bodies” —in this case, fibromyalgic ones—and marginalized subjects who are already believed to be inherently irrational. Taylor (2015: 182) remarks that

the idea of the able mind has been produced and continues to operate as a racialized and gendered social organizing concept that marks some bodies as mentally incompetent and maintains societal divisions and inequalities along not only lines of ability, but equally along lines of race.

Marked bodies, in this author’s view, are often those that oppose normative structures and come to be known as mentally unstable for this reason. It is crazy to resist oppression, to love against the norm, to desire otherwise. This is what Taylor calls “pathological resistance” or “embodying a lack of self-control, an unwillingness to cooperate, or an inability to be reasonable” (186).

I borrow this concept of “pathological resistance” for its usefulness in thinking through and bringing home the idea that fibromyalgia is an irrational illness—one that challenges scientific rationality—that can only be conceived as attached to irrational subjects. The irrationality of fibromyalgia is accentuated when it intersects with the identities of the bodies it is attached to: for example, to have an irrational illness like fibromyalgia while being a woman is to be irrational, because scientific knowledge is more valued than women’s knowledge, and scientific knowledge says nothing is wrong with you. This is further intensified when we consider how fibromyalgia threatens other structures by way of thwarting the productive abilities of those affected. Taylor writes, “the attribution of irrationality and craziness is often used against those who take an oppositional stance to dominant norms and activities” (186). Taylor continues,

the specter of the disabled mind is deployed against those who fail to conform to dominant gendered and racialized roles and behaviors, and used as a way to bring dissenters back in line. (188)

Ferraro’s (2016) work on cognitive behavioural therapy (CBT) is one illustration of how psychological techniques are used to force conformity, with its goal of moulding “subjects who conform to the alienated individualism of austerity capitalism” (19). Thus, CBT becomes a medically and scientifically backed endorsement for self-managing citizen-producers. I discuss this relationship in relation to fibromyalgia in Chapter 4.

Perhaps more useful is Teghtsoonian’s (2009) reflection on CBT as a corrective technique for faulty personalities. This author writes:

It frames depression as a problem of faulty thinking processes that those experiencing it can learn to correct by replacing “negative self talk” with more positive and “realistic” views of the world in which they live. While many people report significant benefits from CBT, it arguably involves—at least in part—the adjustment of people to the circumstances in which they find themselves rather

than fostering a critical or change-oriented engagement with the inequitable and marginalizing features of their environment. (34)

In light of what I have argued thus far, we can see how Taylor's "oppositional stance" could be not one of simple dissident thought or behaviour but, of dissident (irrational) illness and, thus, identity. If we start from this premise, how do psychological technologies discipline irrational bodies and the subjects attached to them? This is the question I turn to in the next two chapters. In the next chapter, I move on to discuss the strategies of intervention devised by the medical system to quiet this threat by constructing irrational bodies (i.e., bodies that defy medical rationality) as containing irrational minds that need psychological intervention.

## **CHAPTER FIVE: INSTITUTIONAL GASLIGHTING**

In September of 2014, I was nervously sitting in the waiting room of a massage therapist I was about to see for the first time. Having a diagnosis of fibromyalgia, or more generally experiencing medically unidentified symptoms, opens the door for a lot of unsolicited advice and recommendations for cures. I had tried massages in search of pain relief many times but, because few strategies have helped, I had the habit of re-trying them when people recommended them, just in case they might work that time. More often than not, when someone made a recommendation, a sense of guilt would overcome me, in the sense of “maybe I am still sick because I didn’t give this a fair shot” or “if only I tried this one more time, maybe I would get better.” So here I was giving massage therapy a twentieth chance.

When I was finally seated in the office, the massage therapist asked me what the purpose of my visit was. I explained to him that a friend recommended I come for a massage, and let him know that I had fibromyalgia to alert him to the pain I experience when pressure is applied to certain parts of my body.

In that instant, our encounter shifted. He was overcome by something I can only describe as over-eagerness. He must have read about fibromyalgia in some medical article or attended a seminar in the past because in response to my diagnosis, he brought up a number of ideas about fibromyalgia that have been dispelled, as noted in the national guidelines on fibromyalgia (Fitzcharles et al., 2013).

He began to ask me questions that were far too invasive for a first massage appointment. He inquired about my mental health, emphasizing the connection between emotions and body pain. I agreed with him that these could be connected but stressed

that, at this point in my life at least, I was not struggling with depression or other mental health challenges. In his series of questions, most uncomfortable were his questions regarding my childhood: “Did your mom have a Caesarean when she gave birth to you?”; “Was there any trauma in your childhood?”; “Did your parents discipline you by using violence?” After I answered “no” to all of these, he kept pushing and challenging my answers. He insisted that these things must have happened because fibromyalgia results from such experiences.

What ensued were a series of events (patronizing breathing exercises, more irrelevant theories about the why of my condition and so forth) that led me to interrupt him and say, “I really do not feel comfortable with our meeting. This is not why I am here.”

He responded with, “You are angry, are you not?”

“Yes,” I said, “I need this to stop.”

He smirked. My anger was no surprise to him but he took issue with *how* I was angry. “That’s not how you should express anger,” he said, “You should get up, hit something.”

I responded by telling him that it was not his job to explain to me how to express anger, especially since he was the one causing it to begin with. He then told me that he meant to make me angry—*he was doing it on purpose*—to see how I would react, to justify a theory he had.

At this point, every part of me was itching to leave, but he suggested that we start the treatment and I was so confused by what was happening that I agreed. So I lay down on the massage table and he began to work for what felt like hours but was more likely

thirty minutes. When he was done, he said, “I have never seen anyone who breathes so little. You don’t breathe. You barely breathed the whole time I was working on you.”

I left this appointment shaken up, alarmed, finally understanding that my fibromyalgia symptoms *must* be caused by my lack of breathing and my inability to express anger. A professional told me so! Thoughts raced: I have fibromyalgia because I do not breathe! No oxygen is going through me! I do not know how to express anger!

Immediately after, I got to my parents’ house and I began telling them that I figured out what is wrong with me. Then, it hit me: the pain has nothing to do with my breathing. I actually did express my anger. Yes, everyone could stand to breathe more. Yes, maybe punching the chair might have relieved more tension. Breathing and expressing emotions are generally good for the body, yes. But, my lack of breathing, in that moment, was not indicative of anything except the fact that a massage therapist, who was in a position of power and who was entrusted with my care, had instead argued with me about childhood trauma, poked into my life and history without my consent, delegitimized the answers I gave to his invasive questions, purposefully (and admittedly) made me angry just to see how I would react, told me that my way of expressing anger was wrong, and laid me down on a flat surface with my eyes closed for half an hour while he worked on my body. In that moment, it probably never crossed his mind that he had impacted my breathing. In our encounter, he believed I had come in already carrying the problem, remained static in his office, acting like I would in any situation, unaffected by his strategies, and I left the same way, taking the problem with me.

This story is reflective of many of my other encounters with the medical system. For instance, family physicians have questioned the role of depression in my illness after

telling me that there was no way to find relief or treat it, and pain specialists have pushed me to prove that I was in pain in order to receive care, but then accused me of exaggerating if my symptom reporting did not align with how I looked to them. I start with this story because it is a telling example of the strategies used by the medical system and medical professionals to achieve what I call “institutional gaslighting.” Institutional gaslighting is the concept I use to refer to the ways in which institutions use their institutional and epistemological power to make marginalized subjects doubt their experiences, thoughts, and lives, in the service of establishing or sustaining systems and structures of power. Due to the medical system’s epistemological supremacy, and its enmeshment with other institutions of power, and because of the central role it plays in the experience of subjects with fibromyalgia or other MUIs, I use it in this chapter as a powerful example to demonstrate the workings of institutional gaslighting. The medical system participates in institutional gaslighting by pathologizing symptoms it has an active role in producing, and by dismissing illnesses or symptoms that threaten systems of power. It ultimately leverages its epistemological power to transform the consequences of institutional violence into medical or individual pathologies. Institutional gaslighting is a form of epistemological violence; medical knowledge claims superiority over, dismisses, and pathologizes bodily knowledge and lived experience, thus scientifically producing irrationality or madness as all experiences or knowledges that resist or challenge it.

Fibromyalgia hangs so clearly in a space that challenges medical knowledge by way of fibromyalgia’s unidentified status, and is prevalent among communities who have both long suffered at the hands of the medical system and been greatly medicalized throughout history. For these reasons, this chapter is dedicated to the much needed (and

long ignored) institutional violence the medical system wreaks upon marginalized fibromyalgic subjects and bodies. QTBIPOC with fibromyalgia pose a threat to medical rationality. In this chapter, I think through fibromyalgia as an illness against science, or as an illness of irrational bodies, afflicting undisciplined subjects who do not obey scientific knowledge in two ways: first, by not remaining in the confines of what science can know, and second, through their disbelief in the authority of science, expressed by continuing to believe that “something is wrong” even when science, its representatives and its technologies say otherwise. What is the medical system to do with such bodies? I propose that one of the ways in which it manages these dissident bodies is by intervening through institutional gaslighting, and ultimately by using its epistemological power to create a connection between irrational bodies (bodies that defy medical rationality) and irrational minds (minds that need psychological intervention because, ultimately, their very thinking challenges structural power).

### **The institutional gaslighting of irrational bodies**

When I asked the Toronto-based group I interviewed what their priorities were in our discussion, Syrus said the following:

I’m very interested in what happens in the space between knowing yourself that something is going on in your body, and the doctor saying “Yes, there is something going on in your body.” This idea of not knowing but kind of in-your-body knowing, but then the doctors tell you either that you’re ridiculous or that it’s nothing, and then being like, “actually, it’s something very serious.” That is so common.

What Syrus discusses is an experience that is characteristic of navigating the medical system with fibromyalgia or other MUIs. As this research proves, Syrus’s experience is

also typical of most of QTBIPOC participants' interactions with the medical and psychiatric systems more broadly. It raises epistemological questions, and illustrates how medical encounters are reflective of societal hierarchies. The "hierarchy of knowledge" (Nestel 2012) that exists between medical truth and patients' beliefs reflects the hierarchy of knowledge between that of white, hetero, cis male subjects (who are heavily represented among the gatekeepers of scientific and medical authority) and racialized, gendered and working-class subjects, including QTBIPOC. The manifestation of this hierarchy of knowledge does not begin in the medical office, nor does it end there, but it has been legitimized through its anchoring in scientific and diagnostic epistemology. Put differently, to be against Western science—a revered way of knowing in the West and increasingly around the world—is to be irrational. This equation's power is so strong that it is easily internalized, particularly for those of us who suffer from medical conditions that are rarely confirmed or validated by our doctors. As Nora explains,

All I wanted was to hear somebody else say, "You know what, this is what it is." I needed a name for it, is what I needed. I needed to know that this wasn't in my head, which is what it sometimes felt like. Am I actually feeling this? Am I crazy? Is this my anxiety telling me I feel like crap every morning?

Here, Nora's need for a "name for it"—a name for her symptoms—is a call for scientific and medical legitimacy. Reality and truth depend on this legitimacy, to the point where she doubts actually feeling what is going on in her body due to the medical system's inability to confirm it. This need does not emerge out of nowhere; it is fostered and sustained by the medical system itself, which historically and routinely exerts its epistemological power to define, know and remedy bodies that it deems to be pathological. Yet, the inherent pathology of fibromyalgia is its inability to be known. It is

precisely fibromyalgia's escape from the holds of medical knowledge that makes it pathological, or rather, that makes its subjects pathological.

The medical system responds to irrational bodies that it cannot know (i.e., fibromyalgic bodies) through psychologization and institutional gaslighting, thus exerting its epistemological power to equate irrational bodies to irrational minds. As I noted in the introduction to this dissertation, QTBIPOC are particularly targeted for this intervention, due to their existing over-psychologization and the rates of trauma prevalent in this community. As some of the conversations I quote below demonstrate, the psychiatric system's effect on QTBIPOC sets the groundwork for further institutional gaslighting when QTBIPOC encounter the medical system for physical symptoms. Thus, similar psychological interventions both contribute to causing the medical system's perception of certain bodies as irrational and function as the consequences of having such irrational bodies.

The psychiatric system and the medical system, operating hand in hand, collude in a pervasive form of violence—institutional gaslighting—insofar as it involves the violent suppression of QTBIPOC body- and self-knowledge. While participants did not name what they experience “institutional gaslighting,” they did point to the repercussions of their psychiatric and medical experiences on their ability to trust what they felt or knew about themselves, which is one of the typical outcomes of gaslighting. Let us consider a passage where Syrus speaks to this in his conversation with me and the other participants in Toronto:

I have a hard time telling if I'm experiencing a lot of pain or a little bit of pain, and then there are moments where it suggests maybe what you would call a high pain threshold. Like, I walked around on a broken foot for about two weeks before going to the doctor, and she was like, “Didn't you notice that it was

painful?,” and I was like “I guess, but I’m always kind of in pain.” I had MRSA—this drug-resistant staph infection—and I was sooo sick, and I got a sepsis because I went to a conference with it. It was boring into my back. It was very serious. It was so painful that my t-shirt touching my back felt like I was being stabbed. But I was like, “Well, maybe you’re exaggerating. You know, maybe you’re not...” Like, “People are tired all the time. People are in pain all the time, Syrus.” And then, when I finally went to the hospital, I had sepsis. That’s it. That’s 11 o’clock, 12 o’clock is you’re done, right? And the doctor was like, “Didn’t you...? Why did you go to the conference, though?” And I was like “I figured I was just exaggerating.” [Others in the room laugh.] Because I actually can’t tell. And maybe it’s also the history of psychiatric stuff and being in the hospital and blah blah blah, but A) I don’t trust my own assessment, and B) I actually just genuinely don’t know.

Syrus’s experience was shared by many of the participants consulted; the laughter noted in the passages featured in this research was often followed by many heads nodding. This raises the following question: If medical or scientific authority is the stamp needed to legitimize people’s experiences, what happens when QTBIPOC are repeatedly told that they cannot trust what they feel, experience or know? When Syrus says, talking to himself in the voice of a doctor, “People are tired all the time. People are in pain all the time, Syrus,” he is in fact referring to previous conversations the group had about doctors banalizing our symptoms, saying things like “Just take an Advil” or “Everyone’s tired.” When people are told repeatedly that what they feel is not real, a distrust of self-knowledge and of our bodies’ signals settles in and creates a blanket of doubt over the veracity of not just physical symptoms, but our sense of self and our ability to trust ourselves more generally as well.

In my one-on-one interview with E, we discussed the impact of our experiences in the medical and psychiatric systems on our sense of self and our ability to trust what we are feeling.

Ghaida: I think you really hit it on the head when you were talking about it always being assumed that whatever you say is happening isn't actually happening, in terms of physical symptoms or in terms of actual brain reality. Over the years that's made me doubt myself so much in terms of what I know or don't know. I will sometimes feel ridiculous amounts of pain, and then be skeptical that I'm feeling pain, which is such a weird, intense experience. Just recently I've started to realize that that damage of not actually feeling comfortable in my vision of what's happening has permeated in so many areas of my life without me realizing it.

E: I absolutely feel that feel. I've also been diagnosed with borderline and stuff. There are so many days where I'm just like, "I'm making this stuff up," which seems ridiculous but is a theory I have a lot. I'm never really sure. I hear a lot of disabled people feel like, "Oh my god, am I making up my disability?" And I think it's one thing when we internalize messages, but it adds another layer when we have medical professionals literally telling us that our experiences are not real. It reinforces everything we've already been told, and just makes a really big mess.

This conversation, as well as Syrus's suggestion in the earlier passage that "maybe it's also the history of psychiatric stuff," points us to the interplay between psychiatric and medical systems as joint institutions that collaborate in the gaslighting process. First, the potential effects of histories of psychiatrization cannot be ignored; they generally imply that we have been read and interacted with as though we are out of touch with reality, irrational, or making things up. As E says, this also happens in relation to our physical symptoms. Together, these systems work to make many wonder if we are making up our disabilities or truly feeling the pain in our bodies, such as when Syrus doubted the pain that turned out to be sepsis, a serious infection that often leads to death (Mayo Clinic 2016).

Interestingly, catastrophization (a concept I return to below and in Chapter 6) is widely cited as one of the characteristics associated to people with fibromyalgia, or even seen as a cause of it. In contrast, in my research, QTBIPOC often downplayed their symptoms, as shown in the examples above. After lifetimes of having been dismissed,

participants come to doubt what they feel and avoid seeking help from the medical system. As Kumari, one of the participants in the Toronto focus group, says, “Oh yeah, there were so many times where I’ve sprained things or been in pain, and it’s just like, ‘that’s just what happens’...” What follows helps us understand this contrast by clarifying the connection between irrational bodies and irrational minds in regard to QTBIPOC and psychiatric diagnoses. Chapter 2 also helps us understand this experiential dissonance by reminding us that *who* patients are plays a major role in how they are read in the clinical encounter. In other words, the assumption of catastrophization at times overrides its actual practice depending on the medical system’s understanding of who is prone to catastrophization.

### **Psychiatric histories and institutional gaslighting**

Most of the participants in this study, including myself, have struggled with their mental health, and in most cases since a very young age. Our contact with the psychiatric system has played a notable role in our life experiences and in shaping how we understand ourselves, our thoughts and our behaviours. My critical reflection on the psychologization of fibromyalgia throughout this dissertation is not meant to dismiss these experiences. It is possible to both hold space for the emotional and psychological factors that might impact illness (if nothing else because they impact the subjects of illness) and, at the same time, to question why certain people and certain illnesses are quickly explained as psychological and treated by means of psychological interventions. In fact, precisely when subjects experience mental illness, trauma or other forms of mental health challenges, it is necessary to question the impact of their diagnoses, and of how these patients are subsequently read by the medical system, on the care they receive

for physical ailments. In other words, the medical system sees irrational bodies as the result of irrational minds, and irrational minds—those of us with mental health diagnoses or histories of psychiatrization, or even those of us who are read as crazy by way of our gender, sexuality, class or race—as the potential cause of irrational bodies. Due to the medical system’s reluctance to take seriously our claims, our symptoms are read with skepticism, or appropriate testing is not conducted, and symptoms are thus quickly attributed to unidentified conditions.

Karen Cocq, one of the participants in this research, offers an important intervention regarding the ways in which medical legitimacy is granted, or psychological interpretation of illness is conjured, based on the patient’s social location. She also discusses the dangers of discussing emotional factors when navigating the medical system with an unidentified illness.

I was thinking about how the pathology around pain and feeling, or the belief in the legitimacy of the experience of pain, is without a doubt affected by a person’s age, race, and gender. It’s kind of a double bind, where you’re like, “Pain is real pain. It actually hurts.” And, at the same time, yes, absolutely, pain is emotional. And the fact is that you can’t really legitimately talk about those two things at the same time without throwing one out the window. You can’t talk about how pain is emotional and has an emotional impact and sometimes has emotional roots in addition to other things that could be going on without being written off as, like, hysterical or whatever. Talking about these emotional factors makes your pain illegitimate in the eyes of people who consider themselves authorities on explaining what is really happening to you.

Karen’s frustration was echoed by many other participants, who felt that mentioning negative emotions to medical professionals, whether as factors contributing to their illness or simply as being relevant to their life more generally, meant inviting purely psychological explanations to their symptoms and referrals to psychologists. The participants also described being barred access to other types of treatments reserved for

physical (read: legitimate) illness. For many QTBIPOC, these types of medical encounters are similar to walking on a tightrope. Previous mental health diagnoses, often clearly indicated on the charts consulted by their physicians, could turn a casual mention of emotional struggles into a reason to deny adequate health care or even attempt institutionalization. At the least, when colliding with our already compromised status as rational individuals due to our unidentified symptoms, mental health diagnoses—not in and of themselves, but because of what they imply and the stigma attached to them—reaffirm that we are unable to know ourselves (Bell 2011) and are thus unfit to know our bodily experiences and needs.

Another participant, named E, who has had “a lot of experience with psychiatry” (in their own words), told me their physical symptoms had been repeatedly attributed to their mental and emotional state without any testing or further investigation. One of the doctors they consulted attempted to convince them that “antipsychotics will fix everything.” The danger here is that patients’ response to antipsychotics—say, if it does take away some physical pain—can be used to reaffirm the medical system’s stance towards medically unidentified illnesses. The epistemological power of pharmaceutical and medical intervention is so strong that it can dictate our perception of reality. In fact, pharmaceutical companies are being increasingly given a role in the diagnostic process. Patients’ response to medications, rather than testing or further investigation into the cause of symptoms, has become a way to lessen the burden that patients with medically unidentified illnesses impose on the medical system. At times, a positive response to antidepressants is used to gaslight fibromyalgic patients into believing their symptoms are purely psychological. Barker (2011) coined the term “pharmaceutical determinism” to

describe the biomedicalization of any symptom for which there is a medication, as well as the diagnosis of that symptom based on the medication to which it responds. To give a fictional example of how pharmaceutical determinism works: if a sore throat responds to antidepressants, pharmaceutical determinism implies that the sore throat is a symptom of depression. If the sore throat responds to an anti-inflammatory medication instead, then the assumption is that the sore throat is a result of an inflammatory disease. In relation to fibromyalgia, some patients' response to antidepressants is serving to fuel the psychologization of the condition, as well as to support psychotherapeutic interventions which ultimately serve neoliberal goals and reinforce the institutional gaslighting of those with fibromyalgia (as I am arguing in this chapter).

Mental health diagnoses do not only interfere in the types of medical treatments patients receive, but can also bar access to medical support completely. Participant Violet experienced this when the rheumatologist who diagnosed her with fibromyalgia refused to keep her on as a patient because of her bipolar diagnosis, which he said he was “uncomfortable with.” She says that “once you’ve got that out in public, people interpret everything you do as a product of that diagnosis.” As such, not only were her fibromyalgia symptoms attributed to her bipolar diagnosis, but her bipolar diagnosis restricted her access to health care. In Nora’s case, her panic disorder diagnosis haunted every medical encounter. I quote her account in its full length here because the intervention she makes truly captures the experience of institutional gaslighting, which has interfered in her access to care for many health conditions, including fibromyalgia:

I was diagnosed with panic disorder and it’s in my records, so any symptoms that I come in with, doctors automatically assume that they’re my anxiety. I’ve become an expert on my own anxiety so I know what it looks like, and so if something is out of the ordinary, I know the difference.

Like, once, I was getting this numbness; half my face was numb. The fact that I couldn't feel half my face is not normal. So, I go to the hospital, and they say, "So I see you've been having anxiety, you've been diagnosed with panic disorder," and I'm, like, "Oh, great! Here we go again." And so now I brace myself every visit. Every trip to the doctor, I will ask myself a hundred times, "Are you sure you want to see a doctor? Maybe you can fix this on your own," because I don't want to have to go through that again. I don't want to have all of my symptoms questioned, boxed into these symptoms of anxiety. I'm sick of it. Every symptom I've had since my panic disorder diagnosis has been interpreted as a symptom of anxiety. Like, they ask: "Are you stressed out at work? Have you been anxious? Are you taking your anxiety meds?"

Once I even went in with an allergic reaction. My throat was closing up. I told them, "I'm allergic to the cold and I break out in hives." And they say, "It's just your anxiety. What happens is your body is trying to fight an external threat, so it's your anxiety. Your body is attacking itself." So I'm like, "I cannot breathe. My throat is closing. It's not in my chest. Anxiety, I feel in my chest. This is my throat," and they rolled their eyes like "okay, whatever," gave me a shot of Benadryl and they let me stay there for a little bit and sent me home. I felt like absolute crap. I cried the whole time. I'm, like, "I feel these things. Don't tell me I'm not feeling them, and don't blame them on my anxiety."

I still get very upset about it because every time I go to the doctor, I'm going to have to hear this first. This is going to be the intro to anything: "Your anxiety, how's your anxiety?" It shapes all my interactions and also discourages me from seeking help.

Considering the prevalence of mental illness diagnoses in QTBIPOC communities, the implications of the problems that Nora is raising are alarming. In sum, the medical system mobilizes participants' mental health histories or diagnoses to disqualify their physical experience. This interferes with access to care, as well as excluding QTBIPOC from self-determination and decision-making in relation to their bodies and health. Further, one of the most pervasive effects of institutional gaslighting is its ability to make QTBIPOC doubt their own experience and knowledge. If we acknowledge the limited support for people diagnosed with fibromyalgia and other unidentified illnesses, we must open the possibility that a fibromyalgia diagnosis may sometimes be given simply as a

result of the medical system's overall delegitimizing of the experiences of marginalized people, and worse, potentially as a way to perpetuate it. This delegitimization can also be used to block further testing when new symptoms arise that might point to the existence of another condition. In my own experience, after over a decade of being dismissed, and then another five years with a fibromyalgia diagnosis, I recently consulted a rheumatologist who conducted further testing and found evidence of inflammatory disease. In another case, Billie, a participant who had long had a diagnosis of fibromyalgia, was told to "take an Advil" to deal with symptoms of what actually ended up being an eight-pound tumour in her abdomen. As I have explained so far, QTBIPOC point us to the medical system's belief in a symbiotic relationship between irrational bodies and irrational minds. They also signal the threat these bodies and minds pose to a medical system whose legitimacy is anchored in its ability to explain and treat illness. Institutional gaslighting is a defense mechanism against this threat, which it neutralizes by deeming the illness to be elusive only due to its existence outside of the realm of rationality. In other words, what cannot be captured or understood through the use of rational (read: scientific or medical) thought is categorized as irrational.

### **The pathologization of the consequences of structural and medical power**

Institutional gaslighting is most successful in its ability to frame the shortcomings and effects of structural power and state institutions as individual deficiencies. Individual responsabilization for health, a tenet of neoliberal health care, opens way for the medical system to pathologize patients' personalities and behaviours and to put the blame on them for the failures of medical intervention and, ultimately, for the illness itself.

The identification of personality traits as potential factors in the development and intensity of fibromyalgia is common to medical fibromyalgia research, and it affects clinical practice as well. This framework places the onus on patients to better cope with illness, try harder to heal, exercise more, rest more, be less dependent and so forth in order to heal or avoid illness. This convenient frame of thought not only coincides with neoliberal goals of unburdening a medical system that cannot afford to keep failing and thus continually treat untreatable subjects, but also manages to make those of us who live with the condition question what it is about *us* that makes us sick and untreatable, ultimately gaslighting us.

For instance, physicians see fibromyalgic patients as “illness fixated” and, across the literature, these patients are deemed to exaggerate, over-focus on their symptoms, or underplay their role in being sick (Asbring and Narvanen 2003: 715). Such claims are so common that most studies refer to them using the same terms—terms borrowed from psychology, in fact. A closer reading of two of these personality-related terms clearly reveals their use for purposes of institutional gaslighting and to preserve structures of power.

The first, “catastrophization” refers to patients’ irrational perception that their condition or symptoms are far worse than they actually are. The second, “poor internal locus of control,” means a patient’s belief that they do not have control over their own life. Taken together, these characteristics demonstrate the power of medical epistemology over individual experience; it is assumed that the medical system has a more rational understanding of how bad a symptom is, for example. These concepts work to minimize the role of systems of power; if being ill is a result of “poor internal locus of control,”

then patients are resistant to recognizing and applying the control they have over their own lives in order to fight illness. This logic leaves out the multiple factors that are indeed out of patients' control, including the consequences of institutional power, such as poverty, unemployment and trauma.

To these commonly pathologized traits, the QTBIPOC I interviewed for this dissertation added characteristics that they view as responses to power, but that are ultimately used to further pathologize them. They argue that QTBIPOC self-knowledge is not an accidental casualty of a lack of medical evidence; self-doubt is violently produced. They discuss medical professionals' responses to them when they express confidence in their own experience and when they challenge medical authority. When participants prioritized their own knowledge and bodily sensations over doctors' understandings of their bodies, this challenge to scientific authority was often pathologized in and of itself. To trust what is not real by medical standards, or what QTBIPOC patients believed to be real instead of what was scientifically factual, was further evidence of their irrationality. As a result, they were deemed even more untrustworthy and denied the right to make decisions about their health on this basis. Even though there are numerous reasons why marginalized communities might resist, contradict or distrust the medical system, this distrust is often used as another confirmation for irrationality, rather than as a response to institutional violence. An example of this was provided by E, as reflected in our conversation:

Ghaida: I often think about moments where I'm in the doctor's office and we're talking as though my pain is something either inside of me or something that exists outside of their office, but not, like, actually being produced while we're talking to each other. You know what I mean?

E: Yeah... oh man, I feel that. Like, just in the way distrust or fear around doctors is also, like, pathologized. In the States, if you want to forcibly institutionalize someone, you have to prove and collect evidence to prove that they're a "threat to yourself, threat to others." And, on my evidence sheet, some have cited my mistrust of doctors as evidence that I need to be institutionalized.

E's experience of being pathologized for their mistrust of doctors was so impactful that it landed them in a psychiatric ward. This illustrates the power and sanctity of the medical system as the only bearer of truth. This power is so strong that trusting oneself is the only requirement for being considered an opponent of the system. Rationality is assumed to be an orientation toward rather than away from doctors. When the doctor is constructed as all-knowing, doubt is pathologized to a point that it can fulfill the requirement of being "a threat to yourself, threat to others" required for institutional and psychiatric confinement.

This construction leaves out the myriad reasons why QTBIPOC or other subjects would resist the medical system and medical professionals. From the start, if the medical system frames itself as never potentially being the source of violence—as the actual threat—then the subjects opposing it will always be framed as the problem. Yet, marginalized communities' relationship with the medical system is largely not one of trust. Logically, confining someone against their will because they fear you—or simply having the power to do so—is not the best way to get them not to fear you. In this example, the medical system is always already considered to be good and trustworthy (think of the "do no harm" oath at the heart of the medical profession). Thus, the source of illness or pain is always placed outside of the clinic doors or the physician's office, as I say to E in the passage above, or within the subjects themselves, in their bodies or minds. The interviewees in this research resisted these assumptions, instead raising potential links between their illness and their encounters with medical professionals, and arguing

that these encounters might have been contributing factors in their illness. They position the medical system itself as a source of violence, pain and illness, and question the impacts of medical intervention—supposedly aimed towards healing—on their bodies.

In this passage, E draws their own conclusions about what could have caused their current bodily symptoms:

Um, when I was 14 or 15, I was part of non-consensual psych medication experimentation done by some psychiatrist working with the government. I have no medical knowledge to back this up, but I suspect physical symptoms that are happening are probably from damage done to me by like the drug experimentation stuff.

This reasoning helps us understand why E might have been distrustful of medical professionals. Here, through institutional gaslighting, the medical system perceives the results of institutional power as an individual irrational fear that requires psychological intervention. While telling their story, E was hesitant, but not simply due to internal self-doubt. When E approached their doctors to ask if this medication history might explain their symptoms, their doctors used this to further pathologize them and discredit their experience of illness by interpreting their suspicion as another sign of their mental instability. As E recalls, the doctors' response was "them thinking that this stuff that happened to me with medical trials is something that my brain made up and not a real thing that happened." While E asserts there is "no medical knowledge to back up" their theory that medical experimentation might play a role in their current physical experience, the psychiatric survivor movement has been built around denouncing and resisting such non-consensual violence and its impacts. This movement has paved the path to consider how medical interventions can be acts of abuse that have long-lasting effects on those subjected to them. While medical studies on fibromyalgia have thus far

ignored both the impact of the medical system itself on the condition and the teachings of the psychiatric survivor movement in general, the institutional gaslighting framework I discuss here invites us to consider E's discussion of medical experimentation seriously.

My conversation with E, and the fact that we both shared a diagnosis of Borderline Personality Disorder (BPD), made me reflect on my own relationship with psychiatry. Because I received a BPD diagnosis at a very young age, its impact permeated throughout my life. In this passage, I am talking to E about these repercussions:

For me, too, for a big chunk of my early adolescence up to my mid-20s, I was more in contact with the psychiatric system. I've been thinking a lot about how borderline is diagnosed with a certain understanding of how people are supposed to act or not act, or think or not think, and... I think that having that diagnosis at a really young age kind of made me distrust what I was thinking and feeling. It also made me feel that certain ways that I thought or was were wrong, period.

I've also been thinking a lot about how the "good" ways of being pushed by the medical professionals treating me are Western, and developed by white people, and so different than those valued in the environment that I grew up in and in my family and in my culture. All the medical professionals I was in contact with were white. So, how much of how we understand good or bad ways of being or thinking is informed by racism?

This seriously affected everything about me, and I carried these assessments into all kinds of areas in my life. I ended up trying to change myself or felt like things that I did or believed in were wrong. I could never tell, or trust myself to figure out what was what. Honestly, I am still trying to wrap my head around it most days.

My experience in navigating the health care system with BPD has been eerily and strikingly similar to doing so with a fibromyalgia diagnosis. BPD, too, is attributed to "difficult" patients who are assumed to catastrophize their experience in search of attention. I remember experiencing the same denial of care, the refusal to explore or test or overindulge, the skepticism, the change in doctors' attitudes toward me as soon as I

revealed my diagnosis, the assumption that I was making things up and catastrophizing, the moral judgements of my character and my willingness to get better. I remember hearing that my needs were too much, that I was asking for too much, that BPD patients take and take but never get better, that I was a waste of resources, and that this waste of resources in and of itself was something to fix or was part of the problem. I was told that BDP was about feeling too much, not being able to control my responses to difficult feelings, not being able to turn my mind to things other than my emotional state. More than anything, I remember feeling that something about me was fundamentally wrong, that how I process thought, emotion and pain is flawed, and that if I could rewire my brain to process these differently, then I would be cured. Every time I encounter medical professionals for fibromyalgia, these moments come back. Because they never left. Because they are the same. It is haunting. In these moments, every part of me knows: I have been here before. Nothing has changed; I am still here.

About the relationship between BPD patients and medical professionals, Ferraro (2016: 23) writes:

Like the moral treatments of old, to assist those in weakness is to aid and abet weakness. This is a recurring theme of neoliberal psychology: be on your guard against excess help, excess solidarity, excess thought.

Medical professionals deem it a kind of weakness for people with fibromyalgia and BPD to turn toward the medical system for help, particularly “excessive help.” Yet, the medical system’s association of these conditions with an overuse of medical services suggests that for people so diagnosed, the bar is much lower than average for what constitutes “excessive.” Moreover, society’s fear that racialized people and people of low socioeconomic status want to “get one over the system,” as billie posits in Chapter 4,

means that QTBIPOC are often read as burdens, as “difficult.” The bar is likely lower for us too. An assumption of the medical system’s benevolence undergirds its power to determine what counts as “excessive.” QTBIPOC patients diagnosed with BPD or fibromyalgia are excessive; we overstay our welcome, we take more than is kindly offered, we abuse generosity. But, as I have argued here, this framework in itself is a form of gaslighting. When the consequences of structural and medical power contribute to creating the very conditions that we need attention from the medical system to manage, the discourse of excessiveness washes over the debt owed and the reparations needed. The discourse of excessiveness once again explains away our neediness as an individual deficiency rather than as a result of structural power.

Ferraro’s insights on BPD come from within a movement pioneered by feminist trauma therapists who have critiqued the legitimacy of BPD as a diagnosis mainly given to women who are thought to be “difficult” (Tseris 2013). Tseris summarizes the main points of criticism offered by this movement here:

The diagnosis of borderline personality disorder represents a stereotypical woman at her most extreme—emotionally labile, relationally dependent, and self-destructive. There are significant uncertainties regarding the effectiveness of psychoactive drugs in the treatment of borderline personality disorder. A consequence of the failure of the disorder to respond to medication is the labeling of the disorder by professionals as “attention seeking,” as opposed to a genuine psychiatric illness. As a result, women with this diagnosis have often been described as manipulative and undeserving clients by mental health professionals who want to treat “real” biological problems and who believe their time is being wasted on these clients.

I found this passage near the end of my research, and its resemblance to some of my work here is striking. Apart from its discussions of some of the issues I have presented thus far, it also leads us to examine how fibromyalgia patients, too, are deemed

to be “extreme” in their accounts of their experience and in their demands of the medical system.

Emotionality has signified racial and gendered inferiority throughout history. It has formed the basis and justification for many oppressive systems of racial and gender subjugation, including heteropatriarchy, settler colonialism and colonialism, as well as slavery. Emotionality is used to affirm the superiority of some humans over other humans, including able-bodied people over those with disabilities or illnesses, men over women, heterosexuals over those of other sexual orientations (for instance, conversion programs teach gay people not to follow their desires), and white people over those who are racialized (think of the association between Indigenous spirituality and irrationality, representations of Black people as soulful, or imperial invasions of the Arab world based on the stereotype that Arab men are uncontrollably aggressive). The primitivity associated with emotionality renders uncivilized and irrational those deemed too emotional. In the current historical context, civilization is read through the values of a neoliberal society, and thus becomes attached to able-bodiedness. Martin (2006) explains, for example, how the association between primitivity and emotionality later defined the widely circulated 1960s social theory (and basis for U.S. policy) of “culture of poverty,” premised on an understanding that poverty (among racialized communities especially) is people’s dysfunctional inability to control their emotions, and thus their destiny. Dian Million, in *Therapeutic Nations: Healing in an Age of Indigenous Human Rights* (2013), discusses the medicalization and racialization of emotionality, and the impact of these framings on social policy and the rights to self-determination of racialized people, and specifically Indigenous peoples. Million discusses how trauma was a helpful framework

from intimate partner violence activism that is used to explain the impacts of such violence on women's minds and lives, but has become "a central feature" of modernity, mobilized by settler-colonial states to justify state intervention and deny Indigenous self-determination. She explains how "Aboriginal 'wounded' subjectivity" (6), or Indigenous declarations of being affected by settler-colonial violence, was initially necessary to expose the impacts of settler-colonial violence on Indigenous peoples and to claim rights. However, she argues, trauma has become appropriated by neoliberal settler-colonial states, who now deem Indigenous communities too traumatized to govern themselves. As such, state trauma discourse, in the neoliberal settler-colonial era, has made healing from trauma a prerequisite for Indigenous self-determination. In other words, medicalized notions of trauma and healing have become an effective technique of sustaining settler-colonial violence. Medical knowledge thus works to prove that Indigenous communities are too affected by state power to escape it. This development is but one in a long history of ways in which genocide and settler-colonial violence are legitimized by medical power and knowledge. The medical system has played an integral role in authorizing the medical knowledge that has in turn served to subjugate Indigenous people. Further, the medical system has been central to dismissing the symptomatology of oppression. While it has been established that Indigenous mental and physical health have been and remain deeply affected by settler-colonial violence (see, for example, Abdelhadi 2013; Paradies 2016), the medical system continues to dismiss the experiences of Indigenous people, particularly in the clinical encounter. This is an important part of the institutional gaslighting I am discussing. Browne and Fiske (2001: 134) offer an example that illustrates the commingling of medical institutional gaslighting and the manipulation of

emotionality and race. They discuss how, in addition to not being believed when they discuss being in pain, the Indigenous women they interviewed explained that their relationship to pain had been altered by settler-colonialism:

The risk of being dismissed was compounded by some of the women's reluctance to admit to pain or to outwardly express suffering, which they explain is what they had been taught by their Catholic teachers in residential school.

The suppression of Indigenous peoples' right to feel pain began in earlier stages of settler-colonialism, such as in residential schools, and continues today in the clinic.

While I wish to acknowledge the specificity of Indigenous peoples' experiences under settler-colonialism, and do believe that the story I am telling here cannot be understood outside of the story of settler-colonialism, the pathologization of emotionality is also common to racialized people and to many people of marginalized genders, and especially those who share both identities, although its impacts differ between various communities. Emotionality is a target of settler-colonial, racial, gendered, and neoliberal projects, imbued with meaning by a medical system that sustains these projects. When emotionality is medicalized, gendered and racialized, it becomes synonymous with irrationality and illness and, as I have argued thus far, it serves as proof that we are incapable of defining our lives, based on a medical understanding that "an ill mind cannot, by definition, know itself" (Bell 2011: 25).

This essence of this quote plays loudly in my mind when I must face the inevitable medical encounters that fill up my calendar. I find myself tensing up during the intake with my new doctor, anticipating questions about my medical history—a history that includes institutionalization, mental illness diagnoses, medications that stopped me from feeling. My history with the psychiatric system means that, instantly, I lose some

credibility when I explain what is going on in my body. If I have lost touch with reality before, why not now? If I say that my arm hurts, why should my doctor trust me? Me, who has mental health diagnoses that render me untrustable, too emotional, a catastrophizer? Recall Nora's haunting anxiety. In our encounters with the medical system, our medical charts bump up against this notion that an ill mind cannot know itself.

In addition to the pathologization of emotionality, as E, a participant I interviewed pointed out, the medical system also pathologizes gendered and racialized people's dependence on the medical system, even though the medical system's role in sustaining the systems of violence that impact our health creates these conditions of dependence in the first place. Dependence, or lack of self-sufficiency, too, is viewed as an irrational individual deficiency, as E explains:

Anything that I do that could be interpreted as me not being able to take care of myself can be used as evidence as soon as they have it to throw me back in the psych ward. So, I can't—I have to like not give them any more material... I was recently having really, really bad nausea episodes, and as a result having a really hard time feeding myself and that kind of thing, and lost weight because of it. And, for this, amongst other reasons, my therapist freaked out and called the cops and was trying to send me to the psych ward. And that didn't happen, which is really good, but like, that kind of shit... My friend was on the phone with the therapist being like "No, no they're literally like nauseous and they can't eat, like that's totally why this is happening, not because they're incapable of caring for themselves." And, also, like, even if I wasn't capable, that's not a reason to want to institutionalize someone.

The reverence of self-sufficiency and the pathologization of dependence is at play here. Interestingly, as I noted before, catastrophization is considered a dominant personality trait of people with fibromyalgia, and even at times a cause of it. In some of the literature on this topic, catastrophization, "a common intervention target in cognitive-behavior

therapy,” is explained as an over-reliance on others to deal with pain (Kratz, Davis and Zautra 2012: 283). In other words, catastrophization is the word used to refer to people’s maladaptive attachment to others and their tendency to deal with pain and emotions communally rather than on their own. What Kratz, Davis and Zautra call a “communal coping model” is considered among “maladaptive responses to pain”; they write that “evidence from survey and experimental research suggests that high catastrophizers appear to be ‘sounding the alarm’ about their pain, eliciting a reaction from the social environment” (279). The framing of communal coping models as maladaptive is steeped in Western neoliberal individualism, and the proponents of this view completely ignore its ethnocentric basis. This anti-communal line of thinking stands in direct contrast with models of healing that are centred around community healing, such as, among many others, that proposed by queer Latinx Estrella, who writes that “healing is not my own, because health and healing occur beyond just that which is held within a single body” (2016: 234). Further, the pathologization of communal coping does not consider the conditions that generate a need to reach towards others; many of these conditions are created by the same systems that look down on this need. For example, as we have established, people with contested chronic illnesses are commonly left to advocate for themselves loudly and often, as the medical system turns them away and delegitimizes their experiences. Paradies (2016) makes a similar point in regard to the pathologization of personality traits that emerge as consequences of structures and institutions of power, arguing that some of the personality traits associated with people with contested illnesses can actually be caused by violence or oppressive structures such as racism. In short, in many cases, the medical system causes a reaction, and then pathologizes that reaction and

uses it to confirm preconceived ideas about patients' mental state. Recall my example of gaslighting in the context of my encounter with the massage therapist who tricked me into anger to then analyze my response, or how doctors' refusal to take Nora seriously for her allergic reaction due to her history of anxiety increased her anxiety and made her cry, thus confirming their judgements and justifying their refusal of care.

To be affected by systems and institutions of power is seen as maladaptive, rather than an appropriate response. For instance, the medical system's understanding of itself as a structure of care rather than of violence becomes in and of itself a form of institutional gaslighting. Even when emotions are seen as acceptable, the medical system has the authority to dictate how they should be expressed, how intense they should be, and whether and how they should be managed. As an example, forgiveness enhancement training, which Toussaint et al. (2010: 127) have suggested as a beneficial treatment for people with fibromyalgia, assumes that "anger is normal and can sometimes temporarily distract individuals from various symptoms such as pain" but "is, ultimately, unhealthy and self-defeating." The qualification of anger as "unhealthy" is made in a matter-of-fact way, even though many other authors, particularly racialized ones, have proposed other interpretations of anger (for example, see Lorde 1981). Further, forgiveness enhancement training is a strong example of how institutional gaslighting involves the use of medical techniques to manage and erase the voices that dismantle its own self-image: the main goal of such training is to help patients cope with the failure of the medical system.

Toussaint et al. write,

Patients with these disorders often feel they have been treated unfairly and hold anger towards themselves or others, including health care providers (Falvo, 2005; Hanson, 2000). As a result, we believe that forgiveness enhancement training may

be an ideal means to empower patients to cope more effectively with negative emotions that may be contributing to exacerbated symptomatology. (133)

While this training's effectiveness is "speculative" (133), it succeeds in once again placing the onus on the victims of the medical system to better manage their emotions. In the same manner as most other treatments for fibromyalgia, it also focuses on the emotions and mental stability of those experiencing this contested illness. As well, if the goal is to "empower patients to cope more effectively with negative emotions," it is an insulting and arguably patronizing use of resources given that these emotions are often a direct result of patients' mistreatment by medical professionals. These gaslighting tactics, far from benefiting patients, only serve to preserve medical power.

## **Conclusion**

In this chapter, I have explored the ways in which psychological interventions serve as one of the medical system's tools in its effort to manage, dismiss and discipline irrational bodies through institutional gaslighting. Institutional gaslighting works by creating self-doubt and minimizing the role of the medical system and the systems of power it upholds in the production and sustainment of illness. By using medical epistemology to discredit irrational bodies, it also works to minimize these bodies' threat to systems of power. Thus, this chapter practically explores the medical system's central role and complicity in sustaining systems of power, specifically by exploring institutional gaslighting in relation to fibromyalgia, a condition that boldly defies the core logics of medical rationality. In the following chapter, I look further into the purpose of institutional gaslighting and the medical system's role in upholding neoliberalism. I

evaluate how medical paradigms come to serve an economic system that depends on able bodies.

## **CHAPTER SIX: NEUROLIBERALISM AND SELF-MANAGEMENT: MEDICAL INTERVENTIONS INTO FAILED NEOLIBERAL BODIES**

It is a long bus ride and a few transfers to arrive to the rehabilitation centre to which my doctor has sent me to join a pain management group. The closer we get, the bigger the houses appear; the building is nestled in an upper-class neighborhood more than an hour away from my house and, in the dead of winter, my body aches from the journey before I even arrive. The cold, the vibrations from the bus, the rush and shove of Toronto commutes—all of this feels like the opposite of what I need right now, but my doctor seemed adamant that pain management courses are part of the treatment plan for fibromyalgia. It is ironic, in fact, to do things that make my body throb with pain in order to access a pain management clinic, but with few other options in view, I make it to my intake meeting.

This meeting, which I thought would be a basic overview of what the course entails, does cover the course outline briefly, but is more focused on me. Its objective is to determine if I am “ready” to join the course. I fill out questionnaires asking me to rate my attitude and perspective on pain, and my openness to positive, pragmatic outlooks. It is uncomfortable, but not unfamiliar. It is not the first time that I am screened for signs of good patienthood. It is not the first time that medical professionals have given me the impression that the success of medical interventions is a matter of the patient’s willingness and obedience.

Flipping through the course workbook after the intake meeting, I am taken aback. It is suddenly clear that this course is geared towards the adaptation of intrusive thoughts and the molding of actions and attitudes towards pain. It screams cognitive behavioral

therapy (CBT). My doctor just sent me to therapy without my knowledge or consent; here, pain management means self-management.

In this chapter, I read this medical approach to fibromyalgia through what I call “neoliberalism,” making the case that this approach is founded on institutionalized psychological interventions made to mould the brains, thoughts and behaviours of the sick to match neoliberal interests. In other words, I argue that CBT-based pain management courses are a way in which the medical system directly intervenes to transform ill bodies into good neoliberal subjects by extrapolating the science behind CBT. After my content analysis of the course workbook I was given, I present queer-of-colour interventions into the medical system’s pursuit of neoliberal goals. More specifically, participants in this research raise the concept of “crip labour” as a form of direct resistance to neoliberal objectives of productivity, arguing that fibromyalgia and other chronic illnesses force the body to slow down, but also create a principled desire to live and relate otherwise.

### **Individual responsibility and the rise of cognitive behavioral therapy in pain management**

As early as the mid-1970s, healthcare—in Canada specifically, but also around the world—became a pioneering sector of neoliberalization.<sup>5</sup> Nowhere was the state’s retreat from service provision felt more strongly than in this sector. The health sector has increasingly become solidified as a business, with “financial managers,” i.e. physicians, whose clinical decisions came to be governed by a calculated balance of “assessments of

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<sup>5</sup> In this chapter, I focus on the Canadian context, but the neoliberalization and privatization of healthcare is felt worldwide though to varying degrees.

economic costs and benefits” (Teghtsoonian 2009: 30). This bureaucratic shift was both rooted in and aided by ideological policy changes that would push neoliberal tenets on a mass scale. The lasting impact of these shifts, and the intensification and diversification of their pursuit, currently shape how the medical system understands and treats chronic illness. A critical alteration in health-related language, policy and practice that I explore in this chapter is that of individual responsibility.

In Canada, the notorious Lalonde Report formally introduced the interpretation of health as an “individual responsibility” in 1974 (Galvin 2002), and the same notion was current in the United States and United Kingdom at the time. Placing the onus on individuals to care for themselves, the state moved away from an earlier “ethic of state care” (Pitts-Taylor 2010: 639). As such, health was transformed from a “right” upheld by a government accountable to its citizens (at least in theory) into a responsibility or a “duty to be well” (Greco 1993).

We continue to see this shift towards individual responsabilization through federal and provincial initiatives throughout the country. In 2004, for example, the creation of a committee in charge of developing health promotion initiatives to entice British Columbia’s population to adopt healthier choices and reduce their burden on the healthcare system was an integral part of the province’s plan to cap governmental expenses in the province (Teghtsoonian 2009). More widely, the discourse of individual responsibility has concretized in the rise of state-sanctioned self-management programs and cognitive behavioral therapy (henceforth, CBT). CBT, along with interpersonal psychotherapy, has been physicians’ preferred treatment for depression, even over other therapies (and, for some, even over antidepressants) in the last twenty years (Parker and

Fletcher 2007). CBT originally began as a therapy to treat eating disorders but, in addition to its extensive use for depression, has become a treatment of choice for conditions as varied as personality disorders, anxiety disorders, schizophrenia, prejudice intervention, gambling addiction and fibromyalgia, to name a few. CBT-driven self-management programs (group, targeted, and often goal-focused applications of CBT), too, have become preferred state-sanctioned medical treatments for addressing everything from depression to chronic illness (see, for instance, Kendall and Rogers 2007 on the UK's and Australia's self-management national health initiatives). In a particularly jaw-dropping application in the United Kingdom, CBT was made mandatory for people who are unemployed, an intervention that equated unemployment with negative attitudes and in this way made a positive disposition a prerequisite for governmental unemployment support (Friedli and Stearn 2015).

This newer brand of psychotherapy has been the subject of a new thrust of research that argues for the evidence-based effectiveness of CBT. Meanwhile, many authors have shown skepticism towards its widespread approval, arguing that the sample sizes used in studies have often been too small, the studies not rigorous enough and the evidence not strong enough to draw broad general conclusions that CBT is universally effective.<sup>6</sup> In light of debates surrounding its effectiveness, critics have explained the popularity of CBT as part of a neoliberal project for reducing health costs through “short-term, standardized treatments” that push a “system of protocols for thought (whether in the form of ‘acceptance,’ ‘critical positivity ratios,’ correction of ‘distorted cognitions,’ etc.)” (Ferraro 2016: 18).

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<sup>6</sup> For a critique of CBT for depression, see Parker and Fletcher (2007).

Despite these criticisms, CBT is at the root of the design of most state-sanctioned pain and disease management programs, and particularly those targeting chronic pain and chronic illnesses. Its implementation has been driven by the “imperative to contain the rapidly rising cost of the ‘burden’ of chronic conditions created by ageing populations, high levels of hospital utilization among those with chronic conditions and primary health care systems that are unable to respond to this demand” (Kendall and Rogers 2007: 133). Fibromyalgia, as a chronic condition, has not been left untouched by this strategy. Yet, scholars have not yet critically interrogated the motivations behind the use of CBT as an intervention in fibromyalgia. Individual responsibility, self-management and psychotherapeutic CBT approaches dominate fibromyalgia research and practice; lately, neurological explanations for the illness are increasingly being used to justify them. In this chapter, I critically read the presence and implications of these strategies in both the Canadian guidelines on fibromyalgia (Fitzcharles et al. 2013) and the pain management workbook I introduced earlier, through the lens of neoliberalism. Rather than presenting neoliberalism as something that causes medical violence, I consider it to be an important analytical tool for grasping the current medical understanding and treatment of fibromyalgia and its relationship to systems of power.

### **Neoliberalism**

Illness is given meaning through medical models grounded in the socioeconomic and political values and knowledges of a specific time and place. As such, the lens through which medicine reads illness, or even what it considers to count as illness, shifts as certain medical fields rise and fall with new technological discoveries. Shifts also

occur due to other factors, such as the influence of other major health trends, prevailing economic systems, political priorities, social hierarchies, and the demographics of the people affected or diagnosed. As an example, in the late nineteenth century, neurasthenia—a popularly diagnosed condition in America that included symptoms of exhaustion and fainting, among others—was medically understood through electricity-based theories. These theories attributed neurasthenia to the exhaustion of the nerves due to increased urbanization and its pressure on the upper class; the disease was treated through electrotherapy (White, Lemkau, and Clasen 2001). When the field of immunology rose to prominence thanks to its role in the AIDS crisis, an immunological lens was applied to neurasthenia, leading this same condition to be newly attributed to allergens (ibid).

Currently, neuroscience is one of the most powerful medical fields of our time. It is a principal mode of thinking and understanding illness, human personality and human behaviour both in medicine and in mainstream society. In this chapter, I think through the rise of neuroscience in parallel with the dominance of neoliberalism in order to argue that the brain, as well as what we do with it, has become an indicator of neoliberal subjecthood. While this might seem like a break from the concept of psychologization that I have explored in previous chapters, I argue that neuroscience and psychology go hand in hand when it comes to fibromyalgia. The recent (and still ambiguous and limited) neuroscientific explanations for fibromyalgia that are emerging slowly in the literature have, at face value, been mobilized to legitimize fibromyalgia and reduce the psychologization of those diagnosed with it. Yet, in practice, they have more often than not accomplished the opposite by providing organic justifications for the pursuit of

psychological interventions. In other words, while we might imagine that neuroscientific explanations for the condition would diminish psychologization, the two have joined forces to reinforce it.

The modern conflation of “brain” with “identity” makes it difficult to imagine a world without neuroscience. Today, “neurocentrism,” or the view of the brain as “foundational of many aspects of human nature and social life” (Pitts-Taylor 2010: 635) is so powerful that it is common to think of the brain as *who we are*, and to believe we can change ourselves by changing the workings of our brain. Yet, the emergence of neuroscience in the 1960s was a true epistemological shift (Abi-Rached and Rose 2010). To understand the concept of neoliberalism that I am introducing here, we must battle our tendency to see the brain and neuroscience as sources of unassailable truth, and instead consider “neuroscience as an event” or “as a question or a problem” (Abi-Rached and Rose 2010: 16), and question its inevitability and primordality. We must first understand that neuroscience has a history, that it has been constructed over time, so that we can open up the possibility of asking about the *why* of its making. The theory of neoliberalism that guides the analysis I undertake in this chapter thinks through neuroscience in neoliberal times, and neoliberalism in neuroscientific terms. There is a history behind the story we tell about the brain, and it is shaped by neoliberalism and thus also by race and gender. According to Victoria Pitts-Taylor (2010: 648),

We now have to think about this ontology’s historicity. We now have to think not only about how neoliberalism knows and presents the brain, but what kinds of brains are *produced* in neoliberal societies. The brain has joined the rest of the body in becoming integral to self-identity, opened to self-styling and modification. The brain not only *appears* to us (through neuroscientific revelations) to be ontologically open to shaping, but (if the theory is right) it is always already actively shaped and shaping.

Pitts-Taylor argues that one of the most popular neuroscientific concepts of our time—brain plasticity—came to dominate our understanding of the brain’s functioning in the late 1970s and 80s, coinciding with the advent of neoliberalism. She posits that brain plasticity, while opposite in some ways to essentializing or deterministic understandings of the brain, did not replace these models that prevailed before it, but instead complemented them. To make this point, she points us towards the continued circulation of essentializing and deterministic models in popular culture, such as in the “brain type” (left or right brain) quizzes we have all taken at one point or another. I would add that the legacies of racist and colonial deterministic theories of the brain remain too, and continue to be mobilized to justify racist policies within North America and imperialist interventions abroad. As an example, in *Social Death*, Lisa Cacho (2012) argues that the criminalization and poverty of racialized and working class people has at times been justified through essentializing notions of brain rigidity; in a US context, for example, she discusses the adoption of state discourses that associate poverty with limited brain ability to overcome poverty. In *Therapeutic Nations*, Dian Million (2013) provides the example of how intergenerational trauma has been reinterpreted as a neurological deficiency that limits Indigenous people from being able to govern themselves. These uses of neuroscience for the purposes of structural violence target poor people, disabled people and communities of colour, and they rely on conceptions of the brain as unchangeable. The “scientific” notion that the brains of people in these communities are simply incongruent with productive neoliberal subjecthood contributes heavily to their political, social and economic marginalization, ultimately sustaining systems of power such as settler colonialism and racism. Yet, while Pitts-Taylor (2010) views the tension between

plasticity and determinism as an indication of the limited success of neoliberalism (which is associated with plasticity) in shaping how we understand the brain, I argue that these models work together to uphold neoliberal structures and interests; they are simply used together or selectively to sustain the status quo depending on the point being made. Take, for instance, two hypothetical studies, one arguing that difference in emotionality between genders is due to brain structure, and the other arguing that emotions can be managed through brain “rewiring.” The first can dissuade companies from hiring overly emotional women, while the second can convince women to purchase self-help products to defy their “natural” emotionality. I am arguing that neoliberal subjecthood reaches its epitome when we work hard to transform *the static brain we have been dealt*. The tension between rigidity and plasticity does not limit the effect of neoliberalism; rather, the neoliberal system incorporates it. In neoliberal times, where the individual’s ultimate goal is to conquer and take control of nature, rigidity sets the ground for an interest in plasticity. Racist measurements of the brain, long used to justify colonialism by signaling white superiority (Desai 2003), now find their equivalent in the notion that these rigid brains can change, but only if one is willing enough to change them. That willingness and the hard work it entails are qualities also attributed to superior bodies, often determined along the lines of gender, race, ability and class.

For neoliberal subjecthood, adapting the brain is not only a possibility but a requirement, and a coercive one at that. This adaptation is not based in genuine agency; it has its neoliberal purpose. In fact, good neoliberal subjecthood depends on it. Friedli and Stearn’s (2015: 42) examination of the use of cognitive behavioural therapy as a treatment for unemployment is a helpful illustration of this. They write:

The psychological attributes and dispositions of individuals and communities (the ostensible presence or absence of optimism, aspiration, self-efficacy, conscientiousness, sense of coherence) are being used to account for unemployment (and for a range of other social outcomes, notably health inequalities) and are promoted via psychological interventions that aim to modify cognitive function or emotional disposition/affect. Signing up for these interventions is an explicit or implicit condition for receiving support. These trends intersect with and are reinforced by the parallel rise in brain science—“reading social problems through understanding the brain”—which correlates outcomes (crime, addiction, health behaviour, educational attainment) with brain structure. (...) A cheerful disposition, in combination with a thankful heart and highly developed “executive control,” is so widely celebrated in the policy literature that the politics of this reification are rarely questioned.

What this example demonstrates, and what I will argue in this chapter using the pain management workbook in a later section, is how neoliberalism works through the assumptions that we are free to change our brains to achieve the best version of ourselves, as long as this version aligns with neoliberal interests, including not costing the state any money, individually bearing responsibility for results of structural oppression, achieving hyper-flexible productivity, not wallowing or getting stuck in stagnancy (including physical immobility and negative emotions), and adjusting to neoliberal economic and social precarities regardless of their impacts on our health, employment, and lives. This “liberal”—as in liberated—ability to choose how to shape our brains is illusory, for in celebrating our brain’s capacity to do anything, neoliberalism is actually prescribing which things we should get our brains to do. Thus, the freedom to change inherent in brain plasticity quickly becomes a necessity to be “open to *being* changed” (Pitts-Taylor 2010: 639). Our lives (our work, our health) depend on this openness. As such, brain plasticity is a demand of neoliberalism that has been anchored in scientific legitimacy. Resilience, individual responsibility, and control over nature are neoliberal moral values that must withstand the precarity of the very system that demands them.

## **Fibromyalgia and neoliberalism: The Canadian Guidelines**

Fibromyalgia is governed by a neoliberal ethos. In other words, as I explore below, the neuroscientific explanations for the roles of individual personality traits and emotional processing, flaws in central sensitization (the brain's heightened processing of pain), and the individualization of treatment through CBT-based pain management courses underpin the neoliberal medical approach to fibromyalgia, which addresses them together under the umbrella of pain management. What is currently passed off as pain management in fibromyalgia intervention is in fact *self* management, or, because the self equals the brain, *brain* management. Brain determinism (the idea that fibromyalgic brains process pain differently) and brain plasticity (the use of CBT to intervene in rewiring attitudes and actions related to pain processing and management) conspire to tie good patienthood to an overcoming of the brain through a medically guided process of behavioural, emotional and cognitive alteration demanding the cooperation and obedience of a hyper-flexible subject.

Thinking through fibromyalgia as a phenomenon of neoliberalism means being attentive to how we make sense of fibromyalgia in neoliberal and neuroscientific terms, and to how both the rise of neuroscience and the context of neoliberalism shape what fibromyalgia is, who has it, and which interventions are used in managing those people. This project also requires us to recognize and expose the ways in which scientific evidence is used to frame the concept of health based on neoliberal interests. To contextualize my reading of the pain management workbook which I undertake later in this chapter, here I use the "Canadian Guidelines for the Diagnosis and Management of

Fibromyalgia Syndrome in Adults” (Fitzcharles et al. 2013) to concretize the relationship between fibromyalgia and neoliberalism.

This document (and the web reference found at [fmguidelines.ca](http://fmguidelines.ca)), which aims to guide Canadian healthcare professionals in the “identification, evaluation, and management of persons with FM” (3), provides forty-six recommendations compiled by medical experts following a review of the last twenty years of medical findings on fibromyalgia. This comprehensive report and guide is endorsed by the Canadian Pain Society and the Canadian Rheumatology Association. I chose to analyze the document’s advocacy of individual responsibility discourse and self-management intervention because it reflects the current medical perspective on fibromyalgia, at least nationally. (My interviews have also suggested that this overall perspective and its main themes are applicable across borders, namely in the United States and Australia.) These guidelines highlight how medical professionals should view, assess and respond to fibromyalgia, and the document summarizes the background knowledge they rely on to educate and guide their patients. It is also an accurate summary of the current medical literature on fibromyalgia, as it reflects the findings of most of the medical articles I have consulted for this research, thus offering a synthesis well suited to analysis. In addition to this report, below I also use the “Executive Summary” version with the same title (Fitzcharles et al. 2012), in order to zone in on what the authors deemed most important within the longer publication.

A key component of the national guidelines is their recommendations at the end of each section, which set the medical standard for fibromyalgia intervention. Throughout these recommendations, a trend clearly takes shape: the document insists on less testing

and a retreat from provision of care. The guidelines advocate for “less tests, imaging, medication use, specialist referrals and primary care visits” (2013: 32). As mentioned in Chapter 3, the ACR Tender Point Test was in theory made obsolete when fibromyalgia left its original home in the field of rheumatology. The guidelines thus acknowledge that the Tender Point Test is no longer a diagnostic tool, but they have not replaced it with an alternate test. (In practice, some physicians—if not most, according to the interviews I conducted—still use the TPT in the absence of other options.) In fact, the guidelines do not specify any diagnostic criteria. After directing doctors to rule out other illnesses (without providing much direction on this front), they suggest only that the patient must report three months or more of body pain and should undergo a physical examination. Now that the ACR tender point examination is not recommended, the nature of this suggested physical examination is unspecified.

This minimalist approach impacts not only diagnosis, but also treatment. To replace or minimize the use of medication (except for when antidepressants are prescribed) and of the medical system overall, the recommendations champion patient-led approaches, notably lifestyle changes (such as diet and exercise) and maintenance of function (particularly the ability to work). In tow with these individualized approaches is a clear turn towards psychological approaches, including self-management, cognitive behavioral therapy and the prescription of antidepressants when medication is considered appropriate (2013: 16). On the latter point, the authors note that “as the term antidepressant may induce bias and stigma, the term pain modulator has been proposed” (2013: 24). Though ultimately this linguistic sleight-of-hand was rejected in the final

draft of the guidelines, the authors suggest that physicians can use the proposed language modification if they wish.

In connection to the psychological approaches the guidelines advocate, personality factors are given room here too (as I laid out in Chapter 5), and they are treated as targets of self-management programs. According to the authors, “factors that may affect outcome include personality traits such as neuroticism and catastrophizing, poor internal locus of control, uncontrolled depression, and extreme obesity” (2013: 29). The peppering of this document with words such as “self-efficacy,” “catastrophizing,” and “locus of control” ultimately draws a link between patients’ health and their ability to control their bodies and their reactions to their symptoms. Notably, physicians are motivated to encourage patients to be “self-sufficient” and learn “good coping skills” (2012: 121). In an effort to reduce patients’ use of healthcare services, these guidelines discourage dependence on medical professionals for healthcare by attributing poorer health to such dependence. This is but one example of the ways in which the consequences of illness are pathologized and transformed into its causes. In other words, the pathologization of dependence flips the story: instead of acknowledging that people need healthcare because they are sick, the new logic says that people become and stay sick because they rely too heavily on healthcare. These manipulations more often than not serve to orient patients towards fulfilling neoliberal goals (in this case, using the healthcare system less) by using “scientific evidence” that aligns these goals with better health. The concept of self-efficacy further illustrates this, and also points us to the colonial and racist undertones of neoliberal approaches to healthcare. According to Kendall and Rogers (2007: 135–6), self-efficacy is

a psychological construct that refers to the strength of a person's belief in their capability to initiate a specific task to achieve a certain result. Self-efficacy is thought to be enhanced through a number of mechanisms, the most effective of which is performance attainment (i.e. mastery or the experience of success following one's actions). The capacity for change is, therefore, seen to lie within the individual, who presumably becomes more capable as a result of exposure to the conditions which make up the self-management programme.

Kendall and Rogers observe how self-management approaches are couched in developmental discourse, with pre-set stages prescribing a path to “maturation” (136) in which one exhibits certain characteristics, including self-efficacy. Maturation is thus synonymous with neoliberal subjecthood, in this case the ability to perform, to reach set goals regardless of external factors, and to achieve mastery of one's actions, understood as a direct result of one's belief in one's own capabilities. To this, I add that this form of maturation calls to mind imperialist and colonial ideologies. In particular, the reverence of self-efficacy—the assumption that its achievement reflects mental health, and thus leads to physical health—is a prime example of this. It recalls the equation of mastery of nature (e.g., exploitation of land), of the body (e.g., the rejection of homosexuality and non-binary genders), and of one's destiny with racial superiority, an ideology integral to colonial conquest (Smith 2005). This narrative has been used time and time again, forming the theoretical backbone of countless invasions and settlements, and accounting for the denial of Indigenous and racialized peoples' rights to self-determination.<sup>7</sup> In this way, neoliberalism, and neoliberalism more generally, have deep ties to their root systems of racism and colonialism, a lens of analysis to which I return throughout this project.

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<sup>7</sup> For more on this in the United States context, see Smith (2005), and in the Israeli-Palestinian context see Hochberg (2010).

The guidelines' recommendations with regard to the personality components of fibromyalgia are not abstract; they are put into practice in some of the top pain management clinics of the country. My intake appointment for Mount Sinai's pain management clinic in Toronto in 2016, for example, required me to fill out a "Pain Catastrophizing Scale" form developed by Sullivan, Bishop and Pivik (1995). This form involved rating statements—such as "It's awful and I feel that it overwhelms me," "I anxiously want the pain to go away," "There's nothing I can do to reduce the intensity of the pain," and "I keep thinking about how much it hurts"—on a scale ranging from "not at all" to "all the time." These "catastrophizing" thoughts are directly targeted by the pain management group workbook that I discuss in the following section. In the guidelines, the authors encourage physicians to target "catastrophization"—which they define as "viewing situations or symptoms as being much worse than they truly are" (Fitzcharles et al. 2013: 16)—by way of psychological intervention. CBT is the chief psychological self-management intervention pushed by the authors, and they recommend it "even in the absence of overt psychopathology" (18).

The guidelines' advocacy of CBT approaches targeting patients' personality factors helps illustrate how individual responsibility discourses call into question individual *morality*: to be healthy is to have "good moral character," and to be chronically ill is "equated with moral failure" (Caplan 1993: 234). In truth, this theory is not particular to this neoliberal era if we consider how illness was, and sometimes still is, viewed as a form of spiritual or supernatural punishment. What *is* new is the emphasis on "behavioral culpability," which is based on the "belief that people can choose to avoid illness by engaging in healthy thoughts and behaviors" (Galvin 2000: 12). Further, what

is deemed healthy has largely been determined by neoliberal interests, as I have discussed in relation to the idea of dependence on the medical system. Thus, to self-manage is, essentially, to make choices about ourselves that sustain neoliberal structures.

Teghtsoonian (2009: 31) discusses this idea in a study on mental health self-management:

In prescribing the tasks of active self-management for persons who are diagnosed as, or “at risk” of becoming, mentally ill so that they may lead more rewarding and fulfilling lives, such discussions also construct good citizens who take responsibility for making choices that do not burden the health care system with inappropriate requests for costly and unnecessary services. The choices we are urged to make while engaged in the personal projects of ourselves thus come to be aligned with wider neoliberal goals.

Individual responsibility and personal choice come together as guiding principles for neoliberal healthcare. Moreover, these perspectives help reassign the failures of the state and the outcomes of structural injustice to, simply put, wrong choices made by irresponsible consumer-citizens (Galvin 2002). It is thus considered irrational or lazy (Pitts-Taylor 2010) to be ill. To be *chronically* ill, especially, is a direct failure to assume the roles and responsibilities assigned to individuals in neoliberal societies, which include participating in the marketplace and, above all, making good choices.

Another noteworthy element that stands out in the guidelines is the transparent attempt to appease medical professionals’ anxieties about fibromyalgia. Here, neoliberalism takes shape quite clearly. Two main areas seem to be triggering anxious reactions in physicians and specialists. First, the guidelines address the invisibility of fibromyalgia and the fact that it does not appear on X-rays or through the use of other medical technologies. The guidelines reassure physicians by using very preliminary research results that indicate that fibromyalgia has been located in brain scans (Fitzcharles et al. 2013). According to this report, the way to address physicians’

skepticism is to give fibromyalgia legitimacy by providing evidence that “FM is grounded in neurophysiological mechanisms” because of “physician comfort in biomedical paradigms which prioritizes diagnostics” (2013: 14). Yet, this has little impact on the patient experience, as the document specifies that neurophysiological testing is not needed to diagnose fibromyalgia. Second, the overwhelming panic about the cost of fibromyalgia patients to the medical system fuels many of the recommendations made. Case in point: a whole section of the official guidelines is entitled, “How can healthcare costs be contained when treating patients with FM?” (31). Fibromyalgia is referred to as an “economic burden” (2012: 120). Its economic stress is, further, linked to patients’ health care habits, which are considered to be “passive” (121), and personalities, namely their dependence.

The emphasis on physicians’ panic about patients’ levels of productivity and use of other state services, such as work disability benefits, in the national guidelines (Fitzcharles et al. 2012) is a case in point. The guidelines tell doctors to make “every effort” (121) to keep patients in the active workforce. The document links better health with employment (2013: 31), yet fails to account for the wide range of symptom severity in fibromyalgia patients, thus ignoring that fewer or less severe symptoms might be what *enable* certain patients to work. The admittedly inconclusive finding that working leads to better health is made into a recommendation, thus justifying the guidelines’ overall goal to return patients to function and encourage them to decrease their service access. Further, to keep costs low, doctors are encouraged to diagnose the condition early and in the clinic in order to limit specialist consultations and further laboratory investigation.

Taken together, these recommendations work to meet the goal of reducing costs by reducing access to healthcare, and this is achieved by championing neuroscientific and psychological explanations for fibromyalgia, namely brain-centred theories, as well as self-management and CBT interventions. They also point us to the neoliberal roots of medical anxiety surrounding this condition: less testing and early diagnosis go hand in hand, as do neurological and psychological theories, to further appease medical worry about fibromyalgia's "burden" on the medical system and, ultimately, on the economy. Interestingly, while preliminary neurological studies could have the potential to shift the experience of patients, they are used only to appease physicians' skepticism by providing neuroscientific legitimacy. These findings do not impact the emphasis on individualized psychological and therapeutic approaches; they are interpreted in a way that further legitimizes such approaches. Critically reading the Canadian Guidelines through the concept of neoliberalism helps us understand the influence of neoliberalism on the medical standard of fibromyalgia intervention.

### **Pain management workbook analysis**

In 2015, my health took a new turn for the worse and I was diagnosed with fibromyalgia. My doctor, like most doctors, knew very little about fibromyalgia beyond what she found and printed for me from UpToDate, a secondary, edited medical information and resource site that is accessible to anyone (although physicians can have a doctor profile that gives them more extensive access to information). This type of online source is increasingly used by physicians (De Leo et al. 2006). Similar sources include sites such as WebMD and Mayo Clinic, which patients themselves often use; some of the

participants in this research mentioned these as places where they get information. The printout my doctor provided me with contained information that is readily available through a basic Google search, and it reflected much of the national guidelines' point of views and recommendations. We discussed antidepressants; she pushed me to take them, even though I reiterated that it was something I had tried in the past and was not interested to try again at the moment. After we hit a wall in this discussion, she signed me up for a pain management course.

In what follows, I use a printed and bound workbook I received at this course (the Pain Management group at the Toronto Rehab Rumsey Centre in Toronto) to demonstrate how the national guidelines analyzed above are applied in real life. The workbook is entitled *Pain Management Booklet* (Chronic Pain Service of Toronto Rehab Rumsey Centre 2014). Other pain management workbooks, such as the infamous *Managing Chronic Pain: A Cognitive-Behavioral Therapy Approach Workbook* by John Otis (2007), are very similar in content. With that in mind, I conduct a close analysis of *Pain Management Booklet* as a typical example of its genre in order to capture the regime of knowledge that guides these workbooks. *Pain Management Booklet* provides a concrete example of neoliberal health care strategies and serves to demonstrate how they are not simply policy-based or theoretical.

It is worth mentioning that this pain management group was not specific to fibromyalgia, but instead to chronic pain, as is common. Regardless of the specificity of chronic pain in fibromyalgia—which often is very different than chronic pain that comes from an injury, for example, which was the case for many of the other participants in this course—patients are lumped together in these courses and the information is generalized

to all who experience any type of chronic pain. The format of the course was very structured, and most of the talking was done by the facilitators, who presented slides with information that replicated almost exactly the information in the workbook provided to participants. Participation was encouraged but was generally minimal. The participants in this instalment of the course had no part in designing its objectives or foci and, if the group veered off the topic of the day in class discussions, facilitators would guide us back to the plan. Other than to respond to facilitators' questions or ask our own for clarification, our role was generally passive.<sup>8</sup>

The pain management course I participated in used a CBT-based approach. As I have explained above, in this course and in the literature on fibromyalgia, pain management is more focused on self-management than on pain specifically. The CBT approach and the course content illustrate this. The workbook was divided into various modules, namely: Week 1: Understanding Pain; Week 2: Relaxation and Breathing; Week 3: Stress Management; Week 4: Sleep; Week 5: Energy Conservation; Week 6: Back Care and Posture; Week 7: Staying Active; Week 8: Communication; Week 9: Thoughts and Feelings; and Week 10: Expressive Techniques. While there were tips and information on how to manage pain specifically (for instance, I learned how to better use pillows to minimize pain), most of the modules discussed typical CBT approaches to controlling our *response* to pain and to life more generally. Indeed, the first page of the manual makes clear that the objectives of the course are to “create and maintain change in your life through setting realistic goals” (3).

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<sup>8</sup> While I do not focus on these here, it is worth mentioning that some ethical issues arose during the beginning of the first class, in which we were told that the course would be filmed (for a project that I do not recall now). We were not warned of this beforehand and, although we were given the option of opting out, doing so meant dropping out of the class. Thus, giving up privacy was a criterion for accessing the course.

The first module, “Understanding Pain” (11), is dedicated to explaining medical understandings of pain, with a focus on neurological factors such as the nervous system’s role in transmitting pain signals, and the role of neurotransmitters in the body’s stress response system. The flight or fight response is emphasized; pain is considered a survival response that is healthy when attached to a specific event (i.e., what is known as acute pain) and unhealthy when it stays beyond its time of usefulness (i.e., chronic pain). This first module also draws a distinction between pain and suffering, explaining that pain is a “physical sensation” and suffering is our response to pain or “what the mind does with pain sensations” (16). According to the workbook, “while pain may be a constant reality, suffering can be optional”; in light of this, it proposes that people can change their nervous system to “decrease pain perception” (16). This is based on the notion that bodies are activated when faced with danger, stress or trauma, and then readjust when the event has passed. In the workbook, this healthy mechanism differs from “unhealthy stress” (24), explained as a “perceived threat” (45) in which “problems start to occur” and “the brain never quite manages to make the switch from action to rest” (24). The workbook posits that “the stress response is automatic, but the relaxation response must be learned and nurtured throughout our lifetimes” (25). In this course, the stress that our brains must learn to manage, and from which it must switch to relaxation mode, is unclear. On one hand, the stress in question appears to be chronic pain itself. On the other, it seems to refer to life stress in general, believed to contribute to further bodily pain (or suffering). A page dedicated to “what is stress?” (41) explains that modern-day stressors are primarily mental or emotional rather than physical, even though our body interprets them as physical danger like that provoked by a predator. Some ways that are

proposed to change our nervous system are “self-hypnosis” (27), relaxation techniques, and “breathing away stress” (29).

Further, module 3, “Stress Management” is another example of the self-management approach guiding the course. According to this section, the success of stress management depends on a person’s image of themselves and the world, their skillset, and their “feelings and beliefs” (41). Thus, factors such as “attitude towards change” and “self-efficacy” (41) are seen as important determinants of successful stress management. This section also emphasizes the importance of productivity, thus clarifying the course’s neoliberal objectives. In it, we find a page dedicated to “tips to avoid procrastination” (47), for example, which does not seem related unless the course assumes that people who experience chronic pain do not know how to manage their workload and this causes them stress. The book’s patronizing advice includes tips such as “stop worrying,” “start small,” “confront negative beliefs,” “take responsibility for the delay,” and “reward yourself for doing activities you find unpleasant” (47)—all typical of productivity courses and self-help books. Another list is provided on how to stay organized, and a page is dedicated to goal setting and includes fill-it-in “personal action plan” sheets (53). In true CBT fashion, the book targets negative emotions and thoughts for adjustment; they are to be noted, evaluated through “reality checks” (169) and modified. A whole table is available to redirect thought processes towards better ones that help “view the event more rationally” (169). For example, “emotional reasoning,” in which one assumes that one’s feelings match reality, is said to lead to decisions that “may not be rational”; the way to combat this is by reminding yourself that “emotions come and go” and to “try to find evidence for and against your belief and make a logical choice” (165).

“Catastrophizing” can be changed by being “realistic” and asking ourselves “how bad is it really?” as well as trying to “find evidence that the opposite is also true” (164). The workbook reminds us that “thoughts are not facts!” and that “we feel the way we think” (163). Not only do these methods recall the institutional gaslighting I speak of in Chapter 3, but they are also an example of the ways in which people of colour’s spiritualities, such as Buddhism, are recycled within psychology to serve neoliberal goals (I discuss this further below).

The course is designed to shift patients’ focus away from their pain towards productive projects of self-management. At the same time, patients are encouraged to manage their stress, practice self-care and conserve energy—yet all of these tips are framed as useful to increase productivity and efficiency. Thus, caring for our bodies has an end goal. CBT teaches those whose bodies are in direct violation of their responsibilities as neoliberal citizens to lessen the impact of this failure. It teaches us how to make choices that are in line with neoliberal interests: how to remain “functional” (another word for productive), control emotions, plan and bounce back when those plans fail. I am not arguing that people cannot be responsible for aggravating their symptoms. But these self-management approaches underplay the role of structures in what is called “stress” or even illness and assume that if people cannot control their symptoms or their emotions then they are crazy, lazy, careless or not trying hard enough.

Self-efficacy is a target of pain management programs, and these programs aim to make individuals who attend them more capable or successful in this area if they are willing to follow the expertise of the professionals teaching them. In self-management approaches, the failure of the medical system is attributed to bad patienthood, a view that

can be internalized by patients themselves. The intake interview meant to assess if I was “ready” to benefit from the pain management course, which I refer to in the opening story of this chapter, the patronizing tone of the course, and its repeated assumption that being in pain meant not managing pain effectively, together demonstrate the discourse of bad patienthood. This course assumed that patients either do not choose to make better lifestyle choices or lack certain skills that would make them have less pain. This perspective downplays the role of the state and the medical system in contributing to or being the cause of illness.

Teghtsoonian’s (2009) analysis of these “discourses of responsabilization” in relation to depression and mental health highlights how they “direct individuals to become ‘enterprising selves’ who work on, or invest in, themselves in various ways” (29) and to avoid risks—even when those risks are their genetics or their socioeconomic status. Ultimately this approach transforms structural problems, like illness or poverty, “into problems of self-care” (29). Risk thus becomes an individual matter instead of a social one, a transition that further empowers the medical system with authority to determine the steps or methods patients must take to avoid risk (Galvin 2002; Pitts-Taylor 2010). These steps or methods are often in line with neoliberal interests as they orient patients towards “the marketplace” or “expert discourses” (Pitts-Taylor 2010: 644). They also uphold medical authority, framing illness as a result of dissidence, of not obeying medical directives. As Galvin writes, “if we can choose to be healthy by acting in accordance with the lessons given us by epidemiology and behavioral research, then surely we are culpable if we do become ill” (2002: 119). A form of “if only you had

listened” or “I told you so,” this logic is, at its most basic level, “‘victim-blaming’ of people who are chronically ill” (Pitts-Taylor 2010: 644).

Indeed, the targets of neoliberal messages of blame, failure and unworthiness very often internalize these messages, as revealed in studies which have investigated their impacts (e.g., Peacock, Bissell and Owen 2012). Neoliberal interventions depend on common concepts and values to operate, and as I discuss through the concept of institutional gaslighting in Chapter 5, the medical system’s scientific legitimization of these concepts and values makes it difficult not to incorporate neoliberalism’s core tenets into our own narrations of ourselves and our illness.

### **Crip labour and living otherwise**

In this section, I explore QTBIPOC interventions into neoliberal approaches to health and fibromyalgia. I argue that these theoretical interventions refuse the basic assumptions at the heart of the medical approach I have explored thus far in this chapter. They rethink the breakdown of the body beyond individual failing and instead propose that it is the result of a system that has long pushed marginalized bodies to their limit. Interestingly, rather than seeing healing as moulding the body to once again meet the demands of neoliberalism, the participants in this research propose a way out through desire. As such, they lead us to the possibility of living otherwise.

I came into this research knowing from experience how difficult and enraging it is to navigate the medical system. As this dissertation shows, I found that my research participants felt similarly, and this is a point that connects me to communities of QTBIPOC people who are disabled or live with an illness. I also came into this research

feeling disconnected from and hesitant to engage with some in these communities who embraced and saw value in illness. To me, illness is pain upon pain upon pain. I long resented others' pride in their impairments, disabilities or illnesses, and I felt that, for myself, pain was all there was; I could not see any value in it at all. mgc shared a similar aversion:

It really, really sucks. There are so many things that aren't pretty and aren't, like, cute, and aren't movable and aren't easy to have radical pride about. (...) It's just actually so hard and isolating. I couldn't and didn't leave my house for the last ten days because I was so fucking tired. Like, so fucking tired that I couldn't stand for more than two minutes without support. How do we have pride about that?

So, when Arti, one of the participants I interviewed, mentioned that there were parts of illness that were truly revolutionary, I asked about what she meant and listened.

Arti: I really like how crips have a culture of moving slow, which is really apparently anti-capitalist. It's not just talking about anti-capitalism, but our day-to-day realities are anti-capitalist. And, for me, as someone who doesn't organize—in that capitalist organizing way—living my politics is really important to me. And, you know, I do the best I can, and I still fuck up every day but I do the best that I can. And, something else I like is how we create new norms for what's an acceptable level of work. It's probably my favourite thing. (...) And, just hanging out with people who want to do less, and less, and less. People who really value their body as a source of knowledge. Super important. (...) I've had to learn to release intense emotions because I have chronic pain, whereas people who don't have chronic pain don't do that emotional work. That means that I have to take time out of my life from doing things that other people do to do that work because I have to, otherwise I don't function. And that's fucking beautiful. Like, that's the work I want to do in the world. I don't want to be out there producing stuff all the time.

When Arti said “I don't want to be out there producing stuff all the time,” even though I travel in anti-capitalist activist circles, it hit me right in the chest. The hold of internalized neoliberalism is so strong that, even while I critique it at length here, the possibility of not producing being a worthy way of living still escapes me, especially in relation to

myself. The underpinnings of “crip labour” in Arti’s terms—moving slowly, creating new norms for acceptable levels of work, valuing our bodies as sources of knowledge, valuing emotional labour, and thinking life and contribution beyond an obsession with production—completely shake up the values at the basis of neoliberalism, as well as the driving objectives of fibromyalgia intervention. Here, Arti proposes that healing could be a spectrum of opting out of the systems that wear the body down, rather than as a rehabilitative project of forcing the body back in. The emotional work she discusses shows up in self-management and pain management theories as well, but here the intention is not to deal with emotions in order to work more. This work is not a lesser than or a path to; the work of emotions and body care are an end in and of themselves, and beautiful work at that.

Viewing the body as a source of knowledge also troubles the medical approach, as it resists the superiority of medical knowledge and, at the same time, reclaims ways of knowing that were and are threatened by colonial and racial violence. Much of this knowledge was dismissed by the medical system during projects of settler colonialism, colonialism and imperialism. The medical system has acted as a key institution in these projects, providing scientific reasonings for these dismissals. Interestingly, Amadahy (2013) writes about how these same knowledges are now being advanced as “new” scientific discoveries—suffice to look at the appropriation of Buddhism and mindfulness practices in the CBT-based workbook analyzed above! The popularity of yoga, meditation and acupuncture as well as the immense number of studies now dedicated to proving their healing properties are great examples of scientific appropriation. The fact

that the acceptance of yoga or meditation as valid treatments for health problems has aligned with their marketization is not coincidental.

Rather than being a top-down, often coercive and professionalized undertaking like self-management, the work proposed by Arti emerges from individual and collective resistance to systems of power. Arti discusses how our bodies force us to rethink neoliberal structures. Yet, medical authority pushes us to rethink our bodies instead. For example, when a medication fails to alleviate symptoms, the medication itself is not questioned; rather, the problem is attributed to the individuals who do not complete the trajectory of healing expected by the medical industry. Once again, the intake appointment meant to evaluate “readiness” is an example of this. A similar shift in attribution happens often in regard to exercise and fibromyalgia, as Violet, an interview participant, discusses:

Part of the stuff they go through in the pain management group makes me a little bit crazy. So, I totally recognize that a good amount of exercise and eating well will make me feel better. I totally get that. But when I go in and I’m, like, “Yeah, before, three years ago I was going to the gym three, four times a week and then I stopped because of the fatigue” and they’re, like, “Maybe you should exercise more,” I’m like “You’re not listening.” Like, the rheumatologist said, “You could have stopped going for any reason,” and I said, “I just told you why I stopped going: I developed fibromyalgia and it made it impossible for me to exercise.” Like, when I stop doing something because of my symptoms, I don’t need to be told that that thing I’m not doing anymore will help my symptoms.

These are some of the ways that the medical system builds in bad patienthood as a medicalized avoidance of its own limitations.

More importantly, the alignment of medical knowledge with neoliberal interests masks the ways in which illness can be an indicator and result of sickness-making structures. For many of us, this resistance also lies in a long history of the overworking of

our families' bodies by versions of the same systems we must resist now. For instance, Syrus brings up the relationship between slavery and illness:

My dad's family is from Memphis and all the women had to work as the help in the houses, and then in my great-grandparents' generation, they were in on-site labour camps. They had to work fucking hard. And so, of course they were all in pain and tired, and my grandmother and her sisters, they had diabetes, and they had heart problems, and all of these things, and were literally one generation from being enslaved. That expectation of what they can do with their bodies in a 12-hour day or 14-hour day is unbelievable.

For mgc, there's both a feeling of guilt and freedom or resistance in not being able to work:

I just feel shitty that my family works so hard and I'm, like, "Sorry, I can't do that. I can't carry on any of those things because I can't do any of the work that you did. I don't want do all the work that you did.

I, too, relate to this perspective, coming from an immigrant racialized family, and witnessing those around me working to the bone with no complaints, and all the unspoken, unidentified chronic illness they deal with. But, over the course of the interviews and our conversation, I felt a shift. What appeared was an acknowledgment that the breakdown of the body—the forced “can't”—becomes a desired “won't” in our lives, as mgc's intervention above illustrates. In other words, the limitations our bodies also force a reevaluation of, and ultimately a resistance to, neoliberal structures and their demands on our bodies. This resistance takes a different form than the disability pride touted by white disability studies and activism that made me so uncomfortable when I entered this research. It is murkier, tainted by the legacies of slavery, racism, colonialism. It is also coupled with a recognition of all the work done by generations that have come before us, in order to survive. This awareness helps us situate ourselves as the last

incarnation of overworked bodies of colour, and articulate our current resistance to state power as a strong halting of this history. Through our conversations, I see us collectively holding the stories of our ancestors' survival, of their work and their suffering. As I explored in Chapters 4 and 5, we also understand how our own bodies have been shaped through that history. As well, I notice a need, in us, to survive and live differently. In all their specificities, these histories might have created the particular limitations and refusals that we are currently witnessing in sick and disabled QTBIPOC communities. The resulting illnesses and the knowledge of these stories are opening up a desire to survive and live differently. Arti equates "moving slow" with concretely living the politics of anti-capitalism: "to do less, and less," to create "new norms for what's an acceptable level of work"; to, ultimately, live differently. mgc expresses it as "making everything else fit" into their "fibro-bodied" life. Resistance, and shaping "everything else" to accommodate it, involve living from the body out, both a refusal of that which overextends the body and an extension of the body's limits to the world outside of it. This type of living is born out of necessity; "otherwise I don't function," Arti says. At the same time, a desire grows from this need: "...that's fucking beautiful. Like, that's the work I want to do in the world. I don't want to be out there producing stuff all the time." These words and their revolutionary vision continue to echo for me.

These physical and theoretical interventions stand in direct opposition to medical paradigms of healing that model health on the achievement of neoliberal subjecthood. What QTBIPOC in this research bring to light are the possibilities of the body to lead the way in living and healing otherwise. They thus not only expose the joint efforts of the medical and neoliberal systems in moulding good neoliberal subjects through

neoliberal interventions, but also bring up the devastating impacts of overextending and overworking racialized bodies in the past. Further, and perhaps most poignantly, their desire to live in ways that directly oppose structures of power wholly interrupts the values at the heart of such projects. Healing thus becomes not a project of rehabilitation, or of moulding bodies in service of systems of power, but rather, of resistance.

## CONCLUSION

I began this dissertation by reflecting about the deep-rooted resilience around which I had designed my identity. A resilience that I believed, once thought to be crumbled by illness, generated an unparalleled grief. Who am I if I am unable to do? At the end of this six-year long project, I find myself revisiting this grief brought on by a haunted body – a body that is unknown yet continues to interject and shape my daily experience; a body without shape that shapes. Sitting with what I have written, with the texts I reflected on, with the words of the QTBIPOC I interviewed is allowing me to trace the unspoken hold that neoliberal tenets and institutional gaslighting have had on my own life. Particularly, I believe this dissertation forces us to question how resilience, in its medical iteration, is a neoliberal one, shaped by racial and gendered histories that have long involved surpassing pain in the service of systems of power.

The refusal of this service is one that signalled the limits of my imagination and of possibility until I engaged in this work. Pride existed in the destruction of my body. In fact, this destruction was a form of belonging to my ethnicity, to racialized identity, to society. Working, whether it wears the body down or not, was a moral imperative deeply ingrained in my roots and sense of self; it is a tie that binds. And, recalling my conversations with other QTBIPOC in this dissertation, I have witnessed other, in many ways different, but also similar stories, from mge's refusal to work as hard as their parents to Syrus' discussion of the weight of ancestral overworking (see Chapter 6).

Beyond all, though, in the pages of this dissertation, I also see an invitation by QTBIPOC to shift the way we live—a shift that is needed to ensure our survival. Through the conversations I undertook in my research, grief took on a new meaning for me. These

conversations urged me to see fibromyalgia as a continuity rather than a rupture in my life. Drawing the history of fibromyalgia, through critical analysis and in conversation with the QTBIPOC I interviewed, allowed me to realize that my grief was not in response to the loss of my past self, but instead to the weight of the repeating history in my own life, over decades of psychological and physical interventions by medical institutions, and across generations who have suffered oppressive measures and practices of control, erasure and overworking. My awareness of this continuity erases the possibility of the recovery model of medical intervention; we cannot be brought out of suffering by becoming neoliberal citizens. Our only option for healing is to break free of the use of our bodies to sustain the very structures that oppress us and make us ill in the first place.

I hope that this dissertation has begun to connect these dots, and to offer a new history and framework through which to read medically unidentified chronic illness, one which honours ancestors I hope that we can come to claim, as a necessity to healing. I have also posited that the medical system has been a necessary instrument in producing and preserving the systems of power necessary for the erasure of this history, as well as for the production of what I have called irrational subjects. In the following section, I lay out the key interventions I have made in each chapter. I also discuss what they have to contribute to medical research, critical disability and race studies, and to QTBIPOC, when taken together.

## **Contributions**

In the first few pages of this dissertation I asked how fibromyalgia - a medically unidentified chronic illness that is apparently unknown and unknowable - is known. My

premise was that, though medical tests, theories, and technologies have failed to explain what fibromyalgia is and how to treat it, a host of medical theories and interventions continue to explain it. I asked, if it is unknown by the medical system, what knowledges are being mobilized to give it shape? In each chapter, I proposed that gendered, racial, and neoliberal knowledges form the backbone of medical knowledge on fibromyalgia.

I argued that racialized people and people of marginalized genders have historically been treated as pathological, even if—or particularly when—this pathologization is in response to the outcomes of oppression, which I call “the symptomatology of oppression” (see Chapter 5). This has not only served to keep systems of power in place, but also to discredit and bar us from determining our fate. The medical system has been instrumental in preserving systems of power, offering up the scientific language and rationalities necessary to deem us irrational. Yet, at the same time as we are cast outside of the realm of medical logic, it is this very logic that is used to explain our irrationality. In relation to fibromyalgia, this includes the medical system’s use of psychologization and neoliberal interventions, which are sanctioned through medical authority and the state. The institution of, and power given to, the medical system to intervene in the management of irrational bodies has, in the case of fibromyalgia and other medically unidentified illnesses, served to forcibly produce subjects whose thoughts and behaviours align with the objectives of economic and political structures of power.

My interventions came forth in response to the increased state-sanctioned and medically-backed psychologization of fibromyalgia, which, according to the current literature, emerged from the fact that fibromyalgia is unknown and unidentifiable through

medical technologies. This affront to medical rationality—the impossibility of detecting and explaining fibromyalgia using medical rationality and its technologies—is, as I argue in Chapter 4, a main reason for which its subjects are treated as irrational in medical contexts. Taking inspiration from fibromyalgia’s apparent absence, I was guided in this dissertation by what I call an epistemology of absence. As I explain in Chapter 1, an epistemology of absence asks us to take absence seriously as a site of knowledge. It also led me to prioritize the absent theories and subjects in fibromyalgia research. This meant centring critical theory from interdisciplinary scholars who have recently established a new critical race and disability field that interrogates the connections and co-constitutions of race, gender, class and ability. It also meant taking QTBIPOC, from the disability justice movement ground of Toronto and from an active online community, as theorists in their own right.

Prioritizing critical theory and the interventions of QTBIPOC as theorists in their own right in this dissertation has shifted not only my own understanding of fibromyalgia and illness, but also challenged the current themes, priorities and directions of fibromyalgia studies. This approach forces us to acknowledge the role systems of power and their institutions play in shaping our lives, and the toll they take. It asks us to consider who and what profits from the representation of our bodies and minds as sick and crazy and from interventions into these bodies and minds once they are so constructed. This knowledge has thus far been on the margins of medical research, a field in which scientists and medical professionals hold a revered power to know, diagnose, probe and intervene in discussions of health and illness. Yet, I believe it takes those of us visiting the clinics, organizing in the streets and in our living rooms, and living in these

bodies to understand the key question guiding this dissertation: If medical knowledge is not the tool that is used to understand a medically unidentified illness, then what is?

I proposed that we must turn to history to answer this question. I argued that the medical system's historical role in mobilizing medical knowledge in the service of racial, colonial and settler-colonial projects urges us to ask how it is doing the same in fibromyalgic presents. Revisionist histories that exclude and erase racialized people serve to steer us away from this line of questioning. Calling upon conversations with the QTBIPOC I interviewed, I showed how these ancestors are present in current fibromyalgic encounters; I argue that their return plays a role in the meanings medical practitioners make of QTBIPOC in the clinic today. At the same time, QTBIPOC carry these ancestors with us, claiming them as our own in a long history of disability justice resistance and living. As such, ancestors return in each following chapter, such as in Chapter 3 when Syrus discusses slavery and E discusses histories of medical experimentation on their people. These ancestors are integral to the stories QTBIPOC are telling and using to make sense of fibromyalgic presents. Yet, these ancestors and the histories they conjure are "desirable amnesias" (Hodgkin and Radstone 2003) that obscure and erase the effects of power on the lives and bodies of marginalized people.

I have also made the case that there exists an interplay between irrational bodies and irrational minds that underpins the medical system's intervention into marginalized people, and that rests on the revered epistemological superiority of medical and scientific knowledge. I explain that "irrational," in this case, refers to two things: first, bodies that are unintelligible via the lens of medical rationality (including fibromyalgic bodies, but

also the bodies of women, queer people and racialized people), and second, subjects that are always already read as crazy.

In fact, I have argued that the psychologization of fibromyalgic bodies feeds off the long history of psychiatrization of QTBIPOC to disrupt our sense of reality, our sense of self, and our bodily knowledge and experience. More specifically, I have made the case that the medical industry is complicit in structural violence—a case made elsewhere but thus far never in relation to fibromyalgia. I argue that this complicity operates through a practice that I theorize as “institutional gaslighting.” By turning to the bodily realities and medical experiences of QTBIPOC, I critically engaged with the notion that medical knowledge is true knowledge and that bodies that threaten this knowledge are “irrational.” Institutional gaslighting, I argued, helps sustain structures of power by individualizing illness and minimizing the role of sociopolitical and economic structures in producing illness in the first place.

One example of institutional gaslighting that I explored further was the use of cognitive behavioural therapy for pain management, which I argued is a medical tool used to mould failed neoliberal subjects. I offered the concept of “neoliberalism” as a tool to help us understand the medical use of neuroscience in establishing and protecting neoliberalism. Yet, as the final chapter in the dissertation explores, sick and disabled QTBIPOC have begun rethinking how our physical bodies demonstrate the limits of the very structures that might have played a role in producing them. They also urge us to reclaim colonized and subjugated knowledges, as well as build interdependent communities, thus troubling the very survival of oppressive structures. Overall,

QTBIPOC interviewed here point us to the possibility of viewing the very illnesses produced by structures of power as their potential demise.

Taken together, the chapters that form this dissertation urge us to define illness, health and trauma otherwise. They call for definitions that move away from the scientific celebration of white cis abled bodies as the only bodies worth emulating and reaching for. They argue that we need a shift in worldview that offer concepts of illness, health and trauma that break apart and critically engage with neoliberal concepts of health that are at the service of profit-making, the preservation of societal hierarchies, and the justification of local and global violence. These chapters also offer up fibromyalgia as a case study of the interconnected and interwoven interests of medical epistemologies and systems of power. Fibromyalgia, in this case, is taken as a jumping-off point because of its impact on marginalized people and the way its existence hovers between organic and psychological illness; its “absence” in the grid of intelligibility of medical sciences and technologies has allowed me to ask, what, and how, then, does fibromyalgia come to be? And what can this tell us about medical power and the hold that gendered, racial and neoliberal regimes of knowledge have on our lives? In these chapters, I propose a shift from the long-held conversation about what fibromyalgia is to a more pressing one that asks, what does fibromyalgia do? What does it generate? What does it sustain or feed? How is it acted upon by interventions that demonstrate the interests and approaches of our medical system as a whole in our current time and place? So much funding has been spent on chasing down ways to legitimize medically unidentified illnesses, but this does not always serve the needs of those of us who live with them. As O, one of the participants in this research, pointed out, this quest for legitimacy consumes a large part

of the funding and research resources allocated to unidentified illnesses, which is very frustrating to many who live with these conditions. In our interview, O said:

So much of this medical stuff is focused on legitimizing the illness or whatever, and that really bothers me because they just spent millions of dollars renaming chronic fatigue syndrome instead of finding out how to help.

My framework asks us to backtrack; I argue that we cannot know what fibromyalgia is before breaking down the knowledges and interventions currently being used to know it and intervene in it. This means we must ask, for example, what is psychologization, and what and who does it serve? Where did it emerge from, and how has it appeared in our history? Who benefits from the use of this concept and its set of interventions? Who is targeted by it, and why? Fibromyalgia opens up important conversations about established hierarchies of illness in the medical world, consistent stigma attached to mental illness and perceptions of pain, and the role of racialized, gendered and neoliberal regimes of knowledge in creating and attributing significance to the distinctions between mental and physical, between organic and non-organic, and more.

These chapters also demonstrate an urgent need for us to turn to QTBIPOC as theorists on these topics because, ultimately, we need the experience and knowledge they hold, which has been formed by a long history of theorizing and living in resistance and in relationship to systems of power. As QTBIPOC, not only have our bodily experiences been challenged in medical contexts, but our very existence has been and continues to be doubted and challenged (take the case of the debate around the existence of trans people currently happening in American policy today). Further, our self-determination often relies on our abdication of sanity, as the process for trans healthcare access (which involves deeming oneself “mentally unfit”) currently requires (Mock 2014: 214). All of

us, and particularly medical professionals who truly have a desire to offer new ways of knowing and new paths to healing, need the models of care offered and developed by QTBIPOC, their knowledge and their experience in community-building and survival, particularly as communities and interdependencies continue to be torn apart by the very systems upheld by the medical institutions that aim to heal us.

### **Suggestions for future research**

This dissertation is the first on fibromyalgia and race, the first to centre QTBIPOC knowledge and experience on the topic, and one of few that engages with the condition by using a critical theory approach. I hope it has laid a foundation for future researchers and scholar-activists to explore these themes further, and join me in an attempt to change the medically dominated conversation on fibromyalgia in scholarly research.

This theoretical project was inspired by qualitative evidence and my own observation of high rates of medically unidentified chronic illnesses (including of fibromyalgia) in QTBIPOC communities that was, thus far, unattended to in medical research. Quantitative analyses are not generally how I approach research, but I encourage others who have the appropriate skill sets to document quantitative data on the impact of these illnesses in our communities. I have made the case throughout this dissertation that QTBIPOC stories and experiences are rarely believed and often challenged. Quantitative studies can help substantiate the claims my participants and I make. While I do not think that quantitative data should be seen as more legitimate, I do think that it is often more respected in medical communities, given that empirical and quantifiable data is at the basis of medical epistemologies. Thus, quantitative data might not lead to transformative and radical changes to the medical approach to fibromyalgia,

but it could ensure better access and less skepticism, within medical encounters, towards QTBIPOC who live with medically unidentified chronic illnesses. We might need numbers even though they might be “numbers to prove what many of us already know in our bodies, our blood, our bones, our hearts, our spirits, our memories” (Sharman 2016: 15), particularly because our bodies, blood, bones, hearts, spirits and memories are rarely believed.

In addition, at many turns in this dissertation I encountered the topic of genetics as a factor in fibromyalgia, but its scope and implications were too much for me to explore here. Nonetheless, the stories participants share in relation to the intergenerational impacts of slavery, medical experimentation, immigration and overworking point us to an unexplored direction in the genetics conversation. Particularly, one could ask, are we biologizing the impacts of structural violence to determine genetic links of illness? Another question of interest is, how are misdiagnosis, and under-diagnosis and the symptomalogization of structural violence impacting our concept of genetics? A genetic approach asks us to believe in medical epistemology and in the sanctity of diagnoses. The approach I take in this dissertation troubles this; how can we determine genetic factors if we fundamentally understand that medical diagnosing has been informed by gendered, racial and neoliberal regimes of knowledge again and again throughout history? Can genetics, then, in some cases be nothing more than the repetitive pathologization, diagnosing and moulding of bodies, rather than (or in addition to) the passing down of biology?

On a related note, as I mention in Chapter 2, my health limited my ability to properly document and engage with the wealth of online writing about unidentified

medical illness by QTBIPOC. Blogs such as Leah Lakshmi Piepzna-Samarasinha's *brownstargirl.org* and Mia Mingus' *leavingevidence.wordpress.com* are key to understanding QTBIPOC thought on illness and disability justice. My focus here was on generating new conversations through interviews and on engaging with the critical theory that I believed to be important for this project. Originally, these blogs were among the long list of critical theory I planned to engage with, but my health got in the way of my ability to do that. I encourage other scholars to read this work and credit its creators. Better yet, I hope work by QTBIPOC outside of the academy becomes increasingly recognized and funded as theoretical work. Even within the academy, our work is often dismissed or we are pushed out, or become too sick to able to continue our studies (this is a recurring narrative for many disabled and sick QTBIPOC particularly). While academic and scientific research is patented, protected and privatized, community or grassroots knowledge is not treated with similar care. Even when this knowledge is gladly offered up to the public (without desire to be privatized), producers of knowledge who do not hold power have their knowledge stolen and appropriated. Yet, community-produced theory and experience, and activist-scholarship are the origin and the lifeblood of transformative thinking and living. This is true for many subjects but we need to recognize it urgently in relation to health. The issues of "premature deaths" (Wilson Gilmore 2007) in QTBIPOC communities is a pressing one, and conversations and solutions need to come from within our communities rather than being imposed on us. I argue in Chapter 5 that institutional gaslighting is rampant in our interactions with the medical system, but this is a continuation of the gaslighting QTBIPOC experience both in other institutions (such as the academy) and in their everyday life. The difference is that

the medical system has the power to medically justify why our experience and knowledge are not valid by drawing on scientific rationales.

Thus, more than anything, we need research that challenges the claim that the medical system and medical techniques of knowing and intervening in our bodies and lives are all-knowing. And, we need the medical system to shift how and who it sees, or what is permitted in its grid of intelligibility. Interdisciplinary and collaborative research can help shift the empirical approaches that dominate medical research. In particular, building on past research, we need research that further traces the central involvement of the medical system and medical epistemologies in upholding systems of power, in medicalizing the outcomes of structural power, and in symptomologizing the effects of said power. QTBIPOC, who often from a young age enter a relationship with psychiatric and other medical institutions, are impacted by these processes. Institutional gaslighting is pervasive, but most importantly, it is a barrier to liberation. The impact of our self-doubt on our health is immeasurable.

In QTBIPOC communities, at 40 years old, people are already regarded as elders or seniors. The fact that so many of us die so young, combined with the high rates of suicide among both QTBIPOC communities and people with fibromyalgia, is cause for alarm. At the same time, I worry about the quality of our lives, the pain we carry, and our ability to break free from a long standing relationship with the medical system. It pains me to see so many of us sick that intense pain is now normalized between us. I hope that we can turn to those who have come before us to understand our history, and the role of the medical system and systems of power in defining, intervening in, and molding our bodies and minds. There is a rise of critical studies on disability and illness currently

occupying the time of young scholars in the academy, and there is a wealth of transformative work being done by QTBIPOC activists in revolutionizing how we understand ourselves, support each other, and relate to our bodies. I hope this dissertation can be part of this cohort of important work, as it was, in a large part, generated by it.

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## APPENDICES

### APPENDIX A: CALL FOR PARTICIPATION

#### Call for Participants

**Research Study:** Interrogating Pain That is Not There: An Anti-Racist Feminist Approach to Fibromyalgia (working title)

**Researcher:** Ghaida Moussa, PhD Candidate, Graduate Program in Social and Political Thought, York University

I am seeking participants for interviews for my PhD work on fibromyalgia, and race and chronic illness more generally. I am using an anti-racist feminist approach to these questions. I will be conducting focus groups /interviews with people who are members of online communities for and by racialized and/or Indigenous people living with chronic illnesses, and members of queer and trans racialized and/or Indigenous communities in Toronto who are producing critical discourse on race, racism, chronic illness, and disability. In focus groups, we will be discussing questions relating to

- how an ‘unknown’ condition like fibromyalgia comes to be *know as* fibromyalgia;
- how medical understandings of pain might impact those who experience pain that cannot be seen by way of medical technologies;
- the role sex, gender, class, or ability might play in determining which bodies fibromyalgia sticks to;
- the impacts of the turn to mental health, individual lifestyle choices, trauma, and personality characteristics to understand and treat fibromyalgia;
- concerns related to the individualization and pathologization of structural oppression;
- how interactions with the medical system might shift the self-accounts, self-definition, and actions of those living with fibromyalgia;
- and, the role of neoliberal ideology and policy in determining value of life and worthiness of care.

If you are part of these communities, and you are interested in participating, or want more information, please get in touch with me by email.

## APPENDIX B: SAMPLE QUESTIONS

Below is a sample list of questions I asked participants during the interviews. As I mentioned in the Introduction, interviews were not structured and questions emerged based on the content generated by participants. At the same time, I had a list to orient me when needed. This is the list I used:

- How did you come to know about fibromyalgia? What people, spaces, sites, books, or communities have been involved in this process?
- Where have you sought information about fibromyalgia? Has it helped you understand it? Does it align with your experience?
- What has your experience been with medical professionals in relation to fibromyalgia or another medically unidentified condition?
- What kind of testing, treatment, or options for management did doctors provide?
- How do you explain what is happening in your body?
- Do you think that race, sex, gender or other parts of your identity played a role in your diagnosis and interaction with medical professionals?
- Do you feel like your knowledge about your own condition is considered when interacting with medical professionals?
- Has the response of medical professionals changed how you see yourself and your condition?
- What has been your involvement in disability justice organizing, or in any other illness or disability-focused organizing, in your city or online?
- What are your biggest struggles living with fibromyalgia?
- Has fibromyalgia contributed anything positive to your life?

## APPENDIX C: INTERVIEW CONSENT FORM

### **Informed Consent Form and Verbal Consent Script**

**Research Study:** Interrogating Pain That is Not There: An Anti-Racist Feminist Approach to Fibromyalgia (working title)

**Researcher:** Ghaida Moussa, PhD Candidate, Graduate Program in Social and Political Thought

**Purpose of the study:** This research seeks to offer a critical approach to the understanding of fibromyalgia using three sites of inquiry: medical reports and documents on fibromyalgia, online communities of racialized and/or Indigenous people with chronic illnesses, and queer and trans racialized and/or Indigenous communities in Toronto producing critical discourses on race and chronic illness. I mobilize the social knowledges produced in these sites as entry points to a larger examination of neoliberal, gendered and racialized implications of knowledge produced on trauma and pain. This research is, in parallel, guided by critical theories on race and racialization, feminist thought, affect theory, and critical disability studies, to determine how the intersection of these lenses might contribute to a shift in how fibromyalgia is understood and approached. Guiding this research are questions relating to how an ‘unknown’ condition like fibromyalgia comes to be *know as* fibromyalgia; how medical understandings of pain might impact those who experience pain that cannot be seen by way of medical technologies; the role sex, gender, class, or ability might play in determining which bodies fibromyalgia sticks to; the impacts of the turn to mental health, individual lifestyle choices, trauma, and personality characteristics to understand and treat fibromyalgia; concerns related to the individualization and pathologization of structural oppression; how interactions with the medical system might shift the self-accounts, self-definition, and actions of those living with fibromyalgia; and, the role of neoliberal ideology and policy in determining value of life and worthiness of care.

**What will you be asked to do in this focus group:** This focus group is in part an open discussion on the themes outlined above, although guiding questions reflecting the goal of the research will be asked to the group. You are welcome to join the discussion verbally or to express yourself in ways that feel more comfortable (drawing, writing, etc.). This focus group will last up to 3 hours.

**Risks and discomforts:** Some of the questions in the study may provoke feelings of emotional discomfort. Speaking of your experiences with the medical system and of living with fibromyalgia might bring up bad memories or negative feelings. You are free to decline to answer any questions in whole or in part, or to end your participation in this focus group at

any time, with no need for explanation if you do not wish to provide one. Your agreement to participate in this focus group involves your presence amongst others. While I will ask that all participants keep information shared during the focus group confidential, I cannot guarantee this.

**Benefits of the research:** This study provides an opportunity for you to speak about your experiences and knowledge about fibromyalgia, and to contribute to the production of knowledge about it. It is meant to centre often-disregarded voices that could lead to a better understanding of fibromyalgia.

**Voluntary Participation and Withdrawal from the Study:** Your participation in this focus group is completely voluntary. You may skip any questions in part or in full, decide the length and depth of your responses to each question, and stop the interview at any point. Your decision to stop participating or your refusal to answer questions will not affect your relationship with me. In the event of your withdrawal, your contributions to the focus group will not be used for research.

**Confidentiality:** Below, you are asked to state if you wish to remain anonymous, have your first name used, or your first and last name used at the writing stage of this research, and for all other presentations or publications resulting from this research. Please provide the name you would like to use in the section provided below. If you wish to remain anonymous, all identifying information (date of birth, address, unique personal characteristics, etc.) will be removed in the written research. All interview documents (audio recordings, transcripts, etc.) will be encrypted and password-protected after this focus group. They will be safely destroyed three years after the submission of the dissertation.

**Accuracy:** The transcript of your contributions to this research will be provided to you for accuracy review before it is incorporated into the written research. If you wish to make any clarifications or changes, please contact me by email.

**This research has been reviewed and approved for compliance to research ethics protocols by the Human Participants Review Subcommittee (HPRC) of York University.**

**Questions about the research?** If you have any questions about the research or your participation, you may contact me using the email written above. For further questions about the research or ethics process, you may also contact York University.

**Signature:**

I, \_\_\_\_\_, consent to participate in the study 'Interrogating Pain That is Not There: An Anti-Racist Feminist Approach to Fibromyalgia'. I understand the nature of this project and I wish to participate.

**Please chose one of the following options:**

I, \_\_\_\_\_,

\_\_\_\_\_ consent to having my first name published in the dissertation and used in any conference presentation or journal publication that result from this study.

\_\_\_\_\_ consent to having my first and last name published in the dissertation and used in any conference presentation or journal publication that result from this study.

\_\_\_\_\_ wish to remain anonymous in the written and/or oral communications based on this research. I wish to use the following pseudonym: \_\_\_\_\_.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of researcher

\_\_\_\_\_  
Date