

THE SOCIAL ORGANIZATION OF OPIOID USE FOR CHRONIC PAIN

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ABSTRACT

This dissertation is an institutional ethnography of the social organization of opioid use for chronic pain management in Ontario, Canada. Within the context of the contemporary ‘opioid crisis,’ people with chronic pain have found their access to prescription opioids restricted as physicians rapidly taper patients’ doses, adopt ‘no narcotics policies,’ and bar people with chronic pain who use opioids from their practices. These changes in physicians’ work of prescribing opioids have had significant impacts on the lives of people with chronic pain.

To explicate these abrupt changes in patients’ access to opioids, I conducted interviews with people with chronic pain and with health care practitioners, as well as analyses of texts including prescribing guidelines. I found that physicians have changed their opioid prescribing practices since the late aughts as the medical profession has come to be targeted as responsible for increases in opioid-related harms in North America. While previous panics around drug use targeted people who use drugs and attempted to change their behaviour, recent shifts in medico-legal conceptions of opioids have meant that opioid users have emerged in the public imaginary as blameless victims of unscrupulous physicians. Strategies to resolve the ‘epidemic’ of opioid-related harms have focused on changing physicians’ prescribing practices through new forms of opioid pharmacovigilance, surveillance, and punishment.

In response to these modes of surveillance and punishment, physicians have responded by adopting work practices that demonstrate their compliance with and accountability to these regimes of ruling. These include tapering patients’ doses and refusing to prescribe opioids to any patients ‘tainted’ by social determinants of health such as poverty or racialization. While people with chronic pain are not directly targeted by interventions to end the opioid crisis, they are

impacted by these policies as physicians change their opioid prescribing practices in response to heightened surveillance and risk of penalties such as losing their license to practice or public shaming.

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CHAPTER ONE

1.1 INTRODUCTION

This dissertation is an institutional ethnography of the social organization of opioid use for chronic pain in Ontario, Canada. My interest in this topic first emerged in 2018 when online support groups¹ for people with chronic pain were suddenly inundated with posts from worried members, asking if anyone else's prescribing physician had decided to abruptly taper their daily dose of opioids. The sense of alarm grew exponentially as, by the end of 2018, there were reports of patients suffering in pain as their physicians tapered their doses to negligible amounts, refused to fill opioid prescriptions entirely, or 'fired' them as patients. By that point, online support groups saw nearly daily posts as new members flooded in. It seemed as though everyone was trying to understand what had happened, but nobody had the answers.

Prior to this, I had finished my Master's thesis on the topic of chronic pain content within medical curricula in Ontario. In 2016, I joined the doctoral program in Sociology at York University. As I worked through my courses, I was in regular conversation with several other people with chronic pain. Between trading updates on our conditions and any new treatments we might have uncovered, we occasionally discussed the topic of my PhD dissertation. I wrote my Master's thesis on medical curricula because I and other people with chronic pain were curious about what exactly physicians learned in medical school when it came to chronic pain. There was, of course, the option of continuing that investigation for my dissertation. I also toyed with the idea of studying the financial challenges complicating the lives of people with chronic pain. Others in

¹ After much discussion between myself and other members, I have decided not to name these support groups to protect members' privacy. The groups represent a mixture of private and public forums, most of which are hosted on social media platforms.

our circle thought it might be interesting to focus on pain clinics—many of us were curious about who operated these clinics, who funded them, and how they fit into the wider health care system.

As I tried to settle on an area of inquiry, my primary concern was ensuring that whatever topic I chose, it would be relevant to people with chronic pain. As I discuss below, one of the objectives of this dissertation is to produce a sociology *for* people with chronic pain, not about them. As such, in the words of a friend of mine who also lives with chronic pain, I wanted to choose a topic that would give us the most “bang for our buck.” It was at this time that online support groups were suddenly flooded with posts from fearful members trying to understand why their access to opioids for chronic pain management had suddenly been restricted. Those months were a whirlwind of confused video calls, extensive forum posts followed by pages and pages of comments, and harried attempts to try to mobilize a group of people spanning from one side of Canada to the other, most of whom lived with debilitating illnesses that had become much worse once they no longer had access to their usual analgesics.

There were two questions that needed answering: “why has this happened?” and “who did this?” Speculation abounded. We knew that beyond the scope of our everyday lives, there were all kinds of decisions being made that we were not privy to. Those who had been forced to taper their dose of opioids or refused a refill reported that their physician was afraid of prescribing. Afraid of what? we wondered. Afraid of whom? These were patients who had been on the same dose of opioids for ten, twenty, thirty years. Their pain was well-managed and they suffered minimal to no adverse effects. Something had happened, that much was clear. And although people with chronic pain who use opioids were not aware of what had happened, or why, their everyday lives had come to be significantly impacted as a result.

Although at that time I did not use opioids to manage my pain, I was acutely aware of the effects of these abrupt changes, and what the shift in prescribing practices meant for people who use opioids for chronic pain. I was faced, I realized, with a problematic. While I describe below the primary tenets of institutional ethnography as a mode of inquiry, I raise here the question of the problematic because it grounds my orientation to the experiences of people with chronic pain who use opioids. Dorothy Smith (2005), the originator of institutional ethnography, appropriated the term “problematic” from Louis Althusser as a means of identifying a “field of investigation that is larger than a specific question or problem” (Smith, 2005, p. 38). In outlining the possibilities of producing a sociology for women, Smith puts forward a conceptualization of the everyday as problematic, the aim of which is to produce for women descriptions and analyses of their everyday worlds in which we uncover the larger social organization to which that everyday world is articulated (Smith, 1987).

The problematic of this study emerged as I witnessed the everyday lives of the people around me. Activities being performed elsewhere and elsewhen had come to bear on the worlds of people with chronic pain who use opioids. From the standpoint of their lived actualities, they had some glimpses of the extended relations that had precipitated this change: their physicians spoke in a roundabout way of being too afraid to prescribe opioids, while also referencing new policies put forward by the College of Physicians and Surgeons of Ontario (CPSO) to monitor and regulate physicians’ opioid prescribing practices. It was possible to cobble together, then, some elements of what had happened. But it remained unclear to people with chronic pain how it had come to be that they were abruptly denied access to opioid analgesics.

As I attuned myself to this problematic, I organized my study such that I began within the everyday lives of people with chronic pain who use opioids, and, from the standpoint of where

these people *actually* were, addressed the problem of how their everyday worlds were put together through extended social relations that were not entirely discoverable within their lived actualities (Smith, 1987). People were doing all kinds of things and making all sorts of decisions that came to bear on the lives of people with chronic pain, whether or not they had ever met, and whether or not people with chronic pain were aware of these doings or had any sense of how they had unfolded. As one of the participants in this study, Simon², remarked: “These people haven’t met me, I haven’t met them, but, you know...They decide on my fate. Because they have the degree, Leigha.”

Before I continue on to outline the objective of this dissertation, I want to touch briefly on my own experiences of chronic pain. Since 2012, I have been living with an autoimmune condition that results in frequent periods of inflammation and physical discomfort. I also suffered a break in my right jaw joint in 2015, requiring splint therapy, treatment from a neuromuscular dentist, and ongoing physiotherapy. In addition to suffering from daily, intractable pain, I have also struggled to navigate the health care system in search of effective treatments. These experiences sparked my interest in investigating the social organization of health care for chronic pain, and why it is so many of us have faced tremendous obstacles in trying to understand how this system works and how we might best traverse it.

As someone with chronic pain, I undertook this study as a member of a complex, heterogenous community that has been trying to organize itself with the goal of effecting change. I also produced this dissertation as someone pushing through what often has come to feel like a nearly insurmountable level of physical pain. Some of this dissertation will be dictated by voice, as there

² All participants in this dissertation are referred to using pseudonyms. I elaborate on my use of pseudonyms, and other means of ensuring participant confidentiality, on page 35.

are days, weeks, and sometimes months where the inflammation in my fingers is so severe I cannot type. While I have always preferred to write with pen and paper, my hands are often too clumsy, and so my husband and I spend countless hours scanning library books so I can make electronic notations on my laptop or pass the text through text-to-voice software. Because of ongoing pain in my tenuously-healed right jaw joint, I have had to space out interviews as these conversations frequently stretch well beyond an hour and, by the end, the joint is usually throbbing and swollen.

I have tried to bring participants' embodied experiences of chronic pain into this dissertation because the body is so often missing in our sociological investigations. Institutional ethnography situates itself within the everyday lives of women as a refusal of objectification. As Smith (2005) writes: "What has been repugnant, dangerous to the purity of the world of enlightened intellect, has been the presence of the mortal body that women's presence inserts, our breach of the divide that insulates mind's recognition that it has, dwells in, is not separable from, a body" (Smith, 2005, p. 22). This dissertation, while taking as its object of inquiry the institutions and extralocal relations comprising the social organization of health care for chronic pain, embeds itself firmly in the standpoint of people in their material actualities. Thus, the work is ethnographic in that people's experiences, activities, daily lives, and perspectives are investigated as a means of generalizing beyond individuals' particular experiences (Smith 2005).

The participants I interviewed described their physical suffering in painstaking detail, warning me beforehand that they hoped I was not squeamish, that I should stop them if their description was too "gross." Just as Dorothy Smith describes, I too occupy a standpoint that undermines the "dichotomy of mind and discarded body on which universality depends" (Smith, 2005, p. 23). Much of the sociological analyses I have read in producing this dissertation have felt oddly

disconnected from my own lived reality as a person in pain. Taking the standpoint of everyday people, as I strive to do in this dissertation, can have transformative implications for sociology.

1.2 OBJECTIVE

I undertook this dissertation with the goal of investigating how opioid use for chronic pain is socially organized in Ontario, especially within the complicated historical context of the so-called ‘opioid crisis.’ The problematic that inspired and guided this research is the growing disjuncture between the actual lives of people with chronic pain who use opioids for pain relief, and the kinds of policies, guidelines, and institutional actions that have come to bear on their use of opioids. In every interview I conducted with someone with chronic pain, I asked myself: how has this person’s everyday world been put together? What are the extralocal relations—the activities taking place elsewhere, elsewhen, by someone the person I am speaking to may not even know—that have come to shape their ability to relieve their pain with opioid analgesics? Every aspect of this dissertation was guided by this problematic and these research questions.

As I will discuss further in chapter two, a significant amount of the social science and qualitative research on chronic pain has been phenomenological in nature. These in-depth explorations of people’s everyday lives are important: rich accounts have emerged that focus on, for instance, making sense of one’s pain (Bullington, 2003; Ong et al., 2004), negotiating the biographical disruption of living with a chronic illness (Bury, 1982; Wilson, 2007; Williams, 2000), living with the uncertainty of episodic symptoms (Denny, 2009), and reconfiguring relationships as a result of living with a chronic illness (Richardson et al., 2007; McCluskey et al., 2015). Narrative analyses are particularly common and tend to focus on the finer details of peoples’

perspectives and consciousness as they grapple with a life in pain (Dow et al., 2012; Dysvik et al., 2013; Garro, 1994; Steihaug and Malterud, 2008).

In the spirit of a critique that builds on what has already been done, I approached this dissertation as someone familiar with this literature and cognizant of its value. However, in adopting institutional ethnography as a conceptual framework, I study chronic pain in a way that does not take the person in pain as my object of inquiry. Rather, the ruling relations that connect people with chronic pain to others working across time and space, and that organize their everyday lives without being fully visible or plottable to them, are the focus of my investigation. I am interested in what Webster et al. (2019) describe as the “interface” between the individual and the “vast network of institutional relations, discourses, and work processes” that are hooked into the individual’s everyday life and come to bear in some way on their local actuality (Webster et al., 2019, p. 3). While I take the standpoint of people with chronic pain to uncover traces of the ruling relations that shape the social organization of opioid use for chronic pain, the objective of this dissertation is to investigate these ruling relations, not people with chronic pain themselves.

This is significant for two reasons. First, in shifting the focus of my inquiry, I resist objectifying the lived experiences of people with chronic pain. This shift requires, as Lund (2012) describes it, starting from what people actually do and how they do it, rather than taking for granted the institutional language that conceals these standpoints (Lund, 2012). The literature on pharmaceutical use, for instance, is replete with studies of compliance: whether or not a person takes prescribed medication as directed by a health care provider (Donovan and Blake, 1992; Kipping et al., 2014). In chapter two, I use the concept of “health work” as an empirically empty term that can be filled with the sorts of work people with chronic pain do around their medication (Mykhalovskiy and McCoy, 2002). While I will expand on my use of the concept of health work

below and further in the next chapter, I flag it here to draw out some of the implications of shifting the object of inquiry to institutional relations, discourses, technologies, and work processes. As I came to learn, for instance, about how the people I interviewed refused to fill their opioid prescriptions out of fear of being stigmatized in acute care settings such as emergency rooms, I was able to trace how their work of resisting the label of opioid addict hooks into extralocal relations in which the work of many other people is activated once a person who uses opioids enters an acute care setting.

Orienting to the study of opioid use for chronic pain as a question of social organization was also integral to my relationship with the people I interviewed for this dissertation as well as the wider community of people with chronic pain. Several years ago, in the context of a graduate seminar on qualitative methods in which we conducted interviews on a topic of our choice, I approached several groups of people with chronic pain in search of participants. I introduced myself as a PhD student at York University, and I provided proof of my background and qualifications. I naively thought that this would reassure informants that my study was genuine. Instead, I was met with suspicion and hostility. Three leaders of local chronic groups used near-verbatim language as they warned me that they refused to put group members “under a microscope.” Another woman—now a close friend of mine—warned me that it would be pointless to circulate my call for participants because people with chronic pain have learned to be skeptical of people who claim to be “experts” on their conditions.

Realizing my gaffe, I clarified that I, too, lived with chronic pain. I also described the conceptual framework I was working in and my commitment to learning from others with chronic pain as experts of their lived experiences. I made clear that the interviewees would not be the objects of my study, but rather the ruling relations shaping their everyday lives. Having explained

my approach to the study and my standpoint as a person with chronic pain, the change in the informants was immediate and palpable. As one woman said, I had become “one of us,” and she felt a personal responsibility to assist a “fellow pain patient” in pursuing their research. The response from the community to that small project, and again to this dissertation, has been wonderful.

The objective of this dissertation, then, is ultimately to produce a sociology *for* people with chronic pain. My goal has been to engage in an analysis that can be helpful, meaningful, and relevant for people with chronic pain. As George Smith (1990) writes, institutional ethnography allows for “empirical study of how a politico-administrative *régime* actually works” (Smith, 1990, p. 635). In the face of radical changes in their access to opioid prescriptions, people with chronic pain who use opioids create various speculative accounts of why this shift has occurred, who might be behind it, and how these changes are being implemented. For Smith, these speculative accounts preclude understanding how the world actually works and is put together. I view my relationship with the people who participated in this study as a partnership in which they are the experts of their everyday worlds and doings, and I, as the sociologist, ground myself in this standpoint in order to perceive traces of the ruling relations that I can then map to what other people are doing in different times and spaces. This collaboration allowed me to remain mindful of my research problematic.

With that being said, integral to my analysis is an exploration of people’s experiences of chronic pain to situate us within the embodied experience of living in a painful body while navigating the health care system. It is for this reason that the next chapter focuses on the people with chronic pain I interviewed for this study and entails a discussion of their everyday lives as people with chronically painful conditions. However, my objective is not to produce a solely phenomenological account. People with chronic pain do not need to be told how difficult it is to

live in a painful body. However, for those who have not experienced chronic pain, I use this dissertation as an opportunity to invite you into these everyday worlds. In painstakingly working through the difficult, complicated, and often personal details of participants' experiences of chronic pain, I ground this dissertation fully within their standpoint, rather than an academic literature that risks concealing what people actually do and how these activities are coordinated with others'. Likewise, as this ethnographic research proceeded through identification of other people, institutions, and processes that shape the lives of people with chronic pain and their ability to access opioids for pain management, chapters three and four draw on my analysis of ruling relations made visible from the standpoints of physicians, pharmacists, and other health care providers who, as I came to learn in my interviews with people with chronic pain, are integral to the provision of pain care in Ontario and the use of opioids for chronic pain management.

1.3 TERMINOLOGY AND DEFINITIONS

The question of how to refer to people with chronic pain has emerged as an area in which there are ongoing disagreements within the community, between people with different types of pain, and among advocacy groups. Often, activists tend to prefer the term 'pain patient.' From my background in sociology, and particularly within the framework of institutional ethnography, I tend to resist the term 'patient' as it locks us into certain biomedical discourses and relations of ruling that might circumscribe critical analysis. I am concerned, for instance, that describing people as patients emphasizes their relationship with biomedicine and within a patient-doctor dyad. As in the case of the word 'compliant,' the idea of the patient risks concealing what people are actually doing and how they come to seek and use health care for their pain. Referring to the

community collectively as ‘pain patient’ also excludes those who are unable to enrol as a patient in a physician’s practice, or whose physician has ended their patient-physician relationship.

On the other hand, as I interviewed people with chronic pain who refer to themselves as pain patients, I began to uncover the value of this conceptualization. Rooted as it is in the discourses and practices of medicine, the idea of the patient functions to characterize pain patients as one part of a dyad in which the physician is meant to be the expert who provides care, while the patient receives care. In their dealings with patients, physicians are expected to approach the patient-physician relationship in recognition of the traits that are thought to distinguish the medical profession: altruism, expertise, and disinterested public service (Abbott and Meerabeau, 1998). As I explore in chapter two, for people with chronic pain who are faced with discrimination, stigma, and disbelief by physicians, there is an urgency behind their demands that physicians re-enter this dyad.

Chronic pain is often poorly understood, and many of the conditions and diseases that cause chronic pain are contested. These include fibromyalgia (Aamland et al., 2014), myalgic encephalomyelitis or chronic fatigue syndrome (Brown et al., 2017), symptoms attributed to sources such as dental restorative materials and electromagnetic fields (Mårell et al., 2016), and other medically unexplained symptoms (Dwamena et al., 2009; Nettleton, 2006). While I knew that many of the people I interviewed had been diagnosed with contested conditions, it was only as I began to interview them that I recognized the amount of work they put into not only appearing credible to physicians but also attempting to persuade physicians to enter into what they saw as proper patient-physician relationships.

For those who have been diagnosed with a contested illness or have yet to receive a diagnosis, the use of opioids only heightened their need to establish themselves as patients. As I

discuss in chapter three, the shifting medicalization and criminalization of opioid use has meant that physicians are increasingly pressured to correctly distinguish between ‘legitimate pain patients’ and ‘illegitimate drug addicts.’ As such, for people with chronic pain who use opioids it is especially crucial that they convince the physician to recognize them as a legitimate patient whose use of opioids is medicinal. In view of these regimes of ruling, my understanding of the concept of the patient shifted as I came to know how people actually use that term, and how it coordinates their activities with the everyday work of physicians, pharmacists, and other health care providers.

Though I recognize the importance of the concept of the patient for many of the people I interviewed, I use the term ‘people with chronic pain’ as a means of inclusively accounting for as many diverse experiences as possible. And, while I acknowledge the importance for people with chronic pain of negotiating their relationship with physicians and positioning themselves as patients, I maintain that concerns regarding the biomedical discourse in which the concept of the patient is embedded still require unpacking and teasing apart. Rather than brushing aside these tensions in the community, I take up in the concluding chapters the debates that have emerged among chronic pain advocates regarding language and activist strategies.

Similarly, there is considerable debate not only among people with chronic pain, but also in clinical settings, around the use of the word ‘opioid’ versus ‘opiates.’ The Chronic Pain Association of Canada (CPAC), for instance, prefers the terms ‘opiates’ or ‘opiate medications.’ In my early correspondence with a volunteer at CPAC, she e-mailed me some literature by Josh Bloom, who argues that the term opiates should be used over opioids as the term opioids rests on the faulty assumption that synthetic opioids can or should be distinguished from natural opioids (Bloom, 2018). From my conversations with the folks at CPAC, as well as my understanding of

Bloom's work, I suspect that they and others are concerned that the distinction between natural and synthetic opioids will be used to justify the distinction between 'hard' and 'soft' drugs.³ This arbitrary delineation has tended to result in the stigmatization of some types of drugs—and therefore, their users—over others (Palamar et al., 2012). In regard to the categorization of some opioids as synthetic and others as natural, I agree with Sasha Breger Bush (2020), who suggests that:

It is typical in health and medical conversations to categorize some opioids as 'semi-synthetic,' while others are deemed wholly 'synthetic.' This ontological sleight of hand works to separate 'nature' from 'humanity' in a way that forecloses the possibility of research that, as Padovan puts it, "Helps to explain the evolution of the social as deeply dependent on the natural" (2014, p. 15). From the perspective of social-ecological metabolism, it makes no sense to think about 'synthetic' or 'artificial' molecular compounds as somehow different from 'natural' or 'semi-synthetic' ones, for all of these compounds *are* natural in the simple sense that they are derived from some natural things (plants, rocks, animals, etc.) by way of the effort/labor of other natural things (people) (Breger Bush, 2020, p. 5).

It is crucial in studying opioid use for pain relief that we account for opioids' inherent 'thingness,' as Breger Bush proposes, and that we do away with ontologies that separate the human or human-made from the 'natural.' However, I argue that the distinction between opiates and opioids is not

³ I use the word 'drugs' in this dissertation to refer to any substance taken to alter the user's mood, mind, body, or affect in some way (Goode, 2006). Rather than taking 'drugs' to mean illicit or recreational drugs, I intentionally subvert this distinction by using the term to encompass both licit and illicit drugs. In doing so I intend to call attention to the necessity of interrogating practices of deeming some drugs licit and others illicit, and how these practices are rooted in discourses and processes of racism, colonialism, imperialism, sexism, ableism, and so on.

predicated on whether they are synthetic, but rather on the advances in research and production that have resulted in new forms of opioids and ways of using them.

The term ‘opiate’ is an older one that refers to a drug derived from opium—a residue obtained from the poppy plant’s seed capsules (Ogura and Egan, 2018). For millennia, opium has been used as a powerful analgesic (Aragon-Poce et al., 2002). Opiates, which are derived from opium, provide pain relief by interacting with the brain’s opioid receptors (Ogura and Egan, 2018). The word ‘opioid,’ meanwhile, is a contemporary one that refers to any substance that interacts with opioid receptors in some way, whether or not it derives from the opium poppy. The distinction, then, is not between synthetic, semi-synthetic, or natural, but rather what I consider to be an important mode of identifying the origins of the opioid in question.

The significance of using the term opioid, I believe, is twofold. First, it allows us to locate ourselves within the complex political and economic histories in which opioid cultivation, production, and use have emerged. As Breger Bush demonstrates, practices of producing and using opioids are organized along the fault lines of race, gender, socioeconomic status, and geopolitical context (Breger Bush, 2020). We need to interrogate who uses opioids and who produces them; who has access to opioids and who does not; who has access to what kinds of opioids; and where in the world, on an international, national, and local scale, people are using opioids and to what ends. It is meaningful that the location of opium production has shifted over time. It is important that conflicts have erupted over this production, as well as the trade and importation of opium. It is relevant to any discussion of the social organization of opioid use that as opioids have come to be derived from sources other than the poppy, that this has resulted in geopolitical shifts in production and consumption. These processes have significant material consequences.

Finally, in using the term ‘opioids’, I also attempt to call our attention to the material reality of opioids and their mechanisms of action. Opioids produce certain effects in the body because they interact with opioid receptors. Opioids play a generative role in the encounter between the drug and the person who uses them—this use is situated within, and emerges through, the capacities of that particular opioid (Moore, 2004). Much as we need to concern ourselves with the ways in which discourses of opioid use can be used in criminalizing forms of drug use, so too must we resist anthropocentric conceptualizations of drug use that neglect the role of the opioid itself in these relations of ruling.

Part of my analysis of the organization of opioid use for chronic pain hinges on the distinction that has been made medically, politically, and culturally between opioids used for licit or medicinal purposes and opioids used for illicit (typically recreational or intentionally harmful) purposes. In chapter three, I explore historical shifts in conceptions of opioids in Canada and elsewhere and how changes in who is using opioids, for what purposes, and from whom they are obtained have shaped attitudes toward opioids as either licit or illicit. I use the term ‘opioids’ to encompass these fluctuating notions of opioids and the material consequences of conceptions of opioids on those who use them. My aim is not to reify the distinction between licit and illicit opioids but rather to problematize this binary and to account for the ways in which the joint medicalization and hybridization of opioids informs attitudes toward these drugs.

In this dissertation, I study opioid use for chronic pain at a particular historical juncture: the ‘opioid crisis’ declared since the 1990s as increases in opioid-related harms have been witnessed in North America and elsewhere. This public health crisis is unique in that, as opposed to more recent drug scares prompting the War on Drugs, the opioids identified as the catalysts of this ‘epidemic’ of harms are prescription opioids intended for medicinal use. While I occasionally

use the term ‘opioid crisis’ to contextualize abrupt changes in physicians’ prescribing patterns in Ontario, I also want to flag here the implications of describing this context as a crisis. North America has seen a decades-long pattern in which certain drugs are targeted as the source of a new opioid crisis, activating all kinds of public health, medical, and legal responses. Panic around high levels of OxyContin prescribing and use in the mid- to late-1990s has given way to alarm surrounding the use of fentanyl since 2013 (Bruera and Byock, 2002; Fischer et al., 2018). These moral panics have functioned to produce discourses of people who use opioids as undeserving of support (Crabtree and Masuda, 2019) while also drawing distinctions between white opioid users as innocent victims and racialized users as addicts (Johnston, 2019).

As I grapple with the idea of the ‘opioid crisis,’ I take into account these multiple meanings and trajectories that have figured into the production of opioid use as a crisis. In using this term, I draw on calls made by others in the community to reclaim the idea of an ‘opioid crisis’ as one that includes not only harms related to opioid use, but also the devastating harms that have occurred as a result of what some have called the opioid gap—the abrupt lack of access to opioid analgesics that has emerged due to policy responses toward the opioid crisis (Clarke et al., 2019; Steinberg et al., 2019). Eibl et al. (2016) have described this gap as the ‘other epidemic.’ People with chronic pain who use opioids have used the concepts of an ‘opioid crisis’ and ‘other epidemic’ to subvert taken for granted understandings of what constitutes a crisis and to position themselves as victims of the crisis who deserve resources and support.

1.4 CONTEXT AND BACKGROUND

As I noted above, this dissertation focuses on opioid use for chronic pain during a time of heightened panic around prescription opioid-related harms occurring since the late aughts in North America and elsewhere. While I delve into the history of opioid use and addiction in chapter three, I want to take a moment here to outline the context in which this study took place. I have described already the ways in which I came to identify a problematic in the disjuncture between the everyday worlds of people who use opioids for chronic pain and the abrupt moment when they suddenly found that they no longer had access to the opioids they needed for pain management. Much of this shift occurred during, and as a result of, the contemporary opioid crisis. By the time I began interviewing participants in December 2019, the crisis had been a matter of federal and provincial concern for nearly a decade.

While opioid consumption and overdose have been of public health concern in North America since the 1990s, around 2013 reports of sharp increases in opioid-related harms fueled calls to address what was largely perceived as an epidemic resulting from prescription opioid use (Fischer et al., 2014). In 2015, Canada was found to have the second-highest levels of prescription opioid use globally, behind the United States (Murphy et al., 2015). In Ontario, the total number of prescription opioid-related overdose deaths had increased from 175 in 2002 to 540 in 2012 (ibid. E609), and opioid-related mortality rates have more than tripled since the early 1990s (Alam and Juurlink, 2016). Meanwhile, in the United States, opioid-related harms have grown substantially: in 2015 alone, 30,000 people died of opioid overdoses (Vadivelu et al., 2018). Across North America, there has been increased political and public health focus on opioids, and in particular prescription opioid-related mortalities.

On August 24th, 2016, the United States Office of the Surgeon General mailed a letter and a pocket card to over 2.3 million doctors and other clinicians asking for their assistance in addressing what he referred to as an opioid epidemic (Murthy, 2016). This was the first time in the 145-year history of the Office of the Surgeon General that a letter was specifically issued to clinicians as a call for action. As part of the wider Turn the Tide Rx campaign, the letter was a precursor to the Surgeon General's Report on Alcohol, Drugs, and Health, which was released November 17th, 2016. This report described some of the steps that had been taken to address increasing rates of opioid consumption in the United States. Murthy also impressed upon physicians the importance of utilizing prescription monitoring programs, to consider alternatives to opioid analgesics, and to alter prescribing practices (Vadivelu et al., 2018).

Although these events were taking place in the United States, as Vashishtha et al. (2017) note, "The dynamics of the epidemic in the USA are inextricably linked to events and patterns of trafficking and use in Canada and Mexico" (Vashishtha et al., 2017: 1). The opioid crisis has largely emerged as an issue of continental concern. In January 2020, Canada and the United States announced that they would be cooperating on a Joint Action Plan on Opioids, which would include efforts to combat opioid trafficking through public health, law enforcement, and border control (Government of Canada, 2020). Canada has also engaged in discussions with Mexico on the opioid crisis, announcing in 2016 that the federal government would explore aligned approaches to address the shipment of precursor chemicals for opioid production, as well as drug trafficking in North America (House of Commons, 2016).

Shortly after the publication of the Surgeon General's Report, in 2017 Health Canada and the Canadian Centre on Substance Use and Addiction released a Joint Statement of Action to Address the Opioid Crisis. The report resulted from an Opioid Summit held in November 2016

and focused largely on actions taken to address the opioid crisis in Canada (Health Canada and Canadian Centre on Substance Use and Addiction, 2017). Since then, the federal government has continued to provide updates on the actions they have taken, including passage of the Good Samaritan Drug Overdose Act in 2018, and supporting the development of opioid prescribing protocols and national treatment guidelines (Government of Canada, 2021). Many of the resulting federal and provincial actions have focused on border patrol and law enforcement, access to treatment, and altering physicians' prescribing practices.

In general, policy and public health initiatives to counter the opioid crisis do not seem to have been effective in reducing opioid-related harms. For instance, in reviewing Ontario's fentanyl patch return program,⁴ Tadrous et al. (2019) found that although the fentanyl patch return program in Ontario was associated with a lower volume of patches dispensed by pharmacies, there was no measurable impact on opioid-related hospital visits or deaths. Likewise, a report by Belzak and Halverson (2018) found that opioid-related harms have increased since 2016. More recently, from July to September 2020, there were 1705 apparent opioid-related deaths across the country, the highest number of deaths recorded in a single quarter since 2016 (ibid.). Between January and September 2020, there were more than 20,700 emergency medical responses for suspected opioid-related deaths (ibid.). Opioid-related harms have also been greatly aggravated by the COVID-19 pandemic due to isolation, stress, reduced access to treatment, and limited access to harm reduction services (The Ontario Drug Policy Research Network, 2020).

⁴ Patch-for-patch or patch return programs have been implemented in Ontario and elsewhere in an attempt to prevent the diversion of fentanyl from transdermal patches into the illicit market (Tadrous et al., 2019). Pharmacies participating in patch return programs require that patients return their used transdermal patches before receiving new patches. If the patient does not return one or more of their patches, or the pharmacist finds that the patches have been tampered with, the prescription must be altered based on the number of patches incorrectly returned. The pharmacist must also notify the police and the prescribing physician. On October 1st, 2016, the province of Ontario mandated pharmacy participation in the program through the Safeguarding Our Communities Act (Bill 33).

Despite limited evidence of effectiveness, policies to address the opioid crisis continue to focus on physicians' prescribing practices and the regulation of prescription opioids. Opioids occupy a strange, contingent space in which they are both licit and illicit drugs. As I will discuss in chapter three, the history of regulations around opioids has swung back and forth between no regulation at all to strict limitations on physicians' capacity to prescribe. As in the case of panics surrounding heroin use and cocaine use in the early 1900s (Courtwright, 2001), contemporary policy responses to opioid use have proceeded by identifying one opioid in particular to target (OxyContin, fentanyl), and then curtailing physicians' prescribing of this drug. During the contemporary opioid crisis, physicians characterized as overprescribers have been the target of political and regulatory systems designed to reduce their opioid prescribing dramatically (Desveaux et al., 2019; Dhalla et al., 2011; Diaz et al., 2019).

In addition to blaming physicians for the opioid crisis, the media, legislators, and public health officials have also taken to task the pharmaceutical industry for providing false information regarding the safety of opioids such as OxyContin (Haffajee and Mello, 2017), as well as marketing practices aimed at physicians (Hadland et al., 2019; Eisenberg et al., 2020). The net result has been growing panic that physicians either are uneducated in opioid prescribing and easily duped by patients or the pharmaceutical industry, or that they overprescribe opioids with the intention of being paid by industry. It is within this context of panic surrounding the opioid crisis and fentanyl use, and pressure on physicians to reduce opioid prescriptions, that this dissertation examines the social organization of opioid use for chronic pain.

While the opioid crisis has been of increasing concern across Canada, in this dissertation I focus on the use of opioids for chronic pain in Ontario. I limit myself to one province not only for practical reasons of time and resources, but also because I wanted an opportunity to consider in-

depth the extralocal relations shaping opioid use, and these tend to differ significantly between provinces. In Canada, health care is under provincial jurisdiction, and while the federal government has put forward various initiatives addressing the opioid crisis, some of the most impactful legislation targeting opioid prescribing has been introduced at the provincial level. The implementation of supervised injection sites, for instance, has varied widely between the provinces and territories (Kerr et al., 2017). Focusing solely on Ontario has allowed me to investigate the policies being implemented at the provincial level. With that being said, there are important opportunities for future research to map the ways in which the social organization of opioid use in Ontario hooks into extralocal relations in other provinces and territories, as well as ruling relations at the federal level.

Given that much of the policy response to the opioid crisis has targeted physicians and their prescribing patterns, regulatory colleges for physicians and surgeons have been at the forefront of introducing new policies to monitor and decrease the number of opioids being prescribed (Beauchamp, 2014; Vogel and Sibbald, 2017). Federal, provincial, and territorial governments have exerted a significant amount of pressure on the medical profession to reduce opioid prescribing, despite increasing evidence that prescription opioids are not the cause of rising opioid-related harms (Rose, 2018; Brown and Sloan, 2017). Since professional colleges operate at the provincial level, I limited myself to studying Ontario so that I could carefully map the ways in which the College of Physicians and Surgeons of Ontario (CPSO) has responded to the opioid crisis in the form of directives, regulations, surveillance, and disciplinary actions aimed at physicians and surgeons.

1.5 CONCEPTUAL FRAMEWORK AND MODE OF INQUIRY

This dissertation is situated within the fields of critical addiction studies and sociology of health. The sociology of health, in particular, is a vast literature primarily concerned with the social factors, contexts, and processes that shape health and illness (White, 2002). Moreover, this study also contributes to critical addiction studies in prioritizing the social contexts in which addiction takes place, and by thinking critically about what it means to use drugs and to designate some drugs as licit and others as illicit. In addition to pulling from various threads in these literatures, this study also takes up institutional ethnography not only as a methodology, but as a mode of inquiry. In producing this study, I have been guided by the concepts of the ‘medico-legal borderlands’ and ‘health work’ as a means of identifying traces of ruling relations made visible from participants’ everyday worlds.

1.5.1. Institutional Ethnography as Mode of Inquiry

Institutional ethnography, as I have noted, is a mode of inquiry that looks to map and articulate how the world works and is put together, rather than engaging in theory-building. In some ways, I resist this principle of institutional ethnography; to my mind, theories are systems of ideas used to explain something. Newton, for instance, put forward a theory of gravity in an attempt to explain how the world works and how it is put together; an explanation of our observation that when we drop a rock, it falls. Likewise, my objective here is to explain why it is that when people with chronic pain visit their physician, their access to opioids is suddenly interrupted or restricted.

Given that I am interested in the empirical, material realities of people’s everyday lives, my explanations of how ruling relations work to shape these local actualities are testable. Some

people with chronic pain, for example, speculate that their physicians no longer prescribe opioids because they see their patients as addicts. However, by tracing the extralocal relations hooked into these people's everyday lives—by interviewing physicians, by reading prescribing guidelines, by orienting to protocols as texts-in-action that coordinate activities—I came to uncover quite different explanations for abrupt cessations of opioid prescriptions. As such, I see theory-building as an exercise in understanding and explaining how the world is put together, so that others might benefit from this knowledge. Objectivity here is only relevant in the sense that my explanation of the way the world works is factual (Smith, 1987)—that someone with chronic pain could read this dissertation and see how it is that opioid prescribing has changed in Ontario and, as a result of this knowledge, know where to intervene in these ruling relations to effect change.

I do not believe that institutional ethnography needs to do away with theory entirely in order to produce the kind of alternative, critical sociology Dorothy Smith proposed. I do think, however, that we need to question what it is that we mean by theory. In producing institutional ethnography as an alternative sociology, Smith critiqued the ways in which traditional ways of doing sociology objectify people's lived realities through theoretical concepts and discourses that conceal what the person is actually doing (Smith, 2005). This is not to say that institutional ethnography does not engage with theory at all, but rather that Smith positions institutional ethnography as an alternative to other modes of inquiry in which the knower's discursive position is established as one that transcends the everyday world (ibid.).

Where relevant, I use theory to understand and explain what is happening in people's everyday worlds and the ruling relations that constitute them. Rather than approaching my findings from a conceptual framework that will determine how the data is interpreted, I embarked on this study as a process of discovery (Smith, 2005). The making of this dissertation was a continual

process of gathering data, identifying the visible traces of institutional relations within the findings, and then following that track to another level or node in the organization of opioid use for chronic pain. I also turned to the literature as a tool for explicating and understanding what exactly was happening in the data I had discovered.

For instance, in this dissertation, I adopt the concept of ‘medico-legal borderlands’ from Mykhalovskiy (2011) and Timmermans and Gabe (2003) to recognize the importance of critical analyses at the sites in which health care and criminal-legal practices intersect. The concept of medico-legal borderlands has often been used to study the criminalization of HIV, as in the case of non-disclosure (Mykhalovskiy, 2011; Raikhel, 2013; Grace, 2013). In this project, I use the concept of medico-legal borderlands to attune myself to those moments when public health and criminal-legal practices intersect in the social organization of opioid use for chronic pain. The use of legislative mechanisms, public health strategies, and medical approaches to address the opioid crisis produces crucial intersections between these institutional arrangements that require critical analysis.

I did not begin this dissertation with the goal of fitting my findings within the idea of medico-legal borderlands; nor did I take my data and attempt to analyze it through this concept. Instead, the idea of medico-legal borderlands functioned for me as a reminder to trace not only ruling relations within public health and medicine, but also the places where they converge and intersect with criminal-legal practices. The term ‘practices’ is key here—I remain committed to discovering what people are actually doing, and where. In chapter three, for instance, I take up the use of the Ontario Narcotics Monitoring System by the CPSO to examine the ways in which physicians respond to heightened surveillance resulting from the medico-legal use of this database.

Another key concept used in this dissertation is that of ‘work’—and, more specifically, ‘health work.’ While I have already defined the term above, I want to reiterate here that it functions as an empirically empty concept that can be filled with peoples’ activities. Within the scope of institutional ethnography, work is not limited to paid work. Instead, work is used in a ‘generous’ sense to refer to anything done by people that takes time and effort, that they mean to do, that occurs in discrete conditions, and that they may have to think about (Smith, 2005). In this dissertation, I explore many kinds of work, including the work of people with chronic pain to manage their prescribed opioids to adequately relieve their pain, and the work physicians do in responding to the CPSO’s investigations into their opioid prescribing practices. The merit of focusing on people’s work is that it keeps us in touch with what they are actually doing (ibid. 154).

1.5.2 Critical Addiction Studies

This dissertation is situated within the fields of sociology of health and critical addiction studies. As I approach the use of opioids for chronic pain from a critical addiction perspective, I do so cautiously, as I do not want to automatically equate addiction with chronic pain. As part of my Master’s thesis on medical curricula in Ontario, for instance, I found that much of the curriculum on chronic pain tends to be taught within curricula on addiction (Comer, 2017). I further explore this connection between chronic pain care and addiction care in chapter three. As I will suggest, funding processes, medical curricula, the organization of research on chronic pain, and numerous other ruling relations come together to link chronic pain with addiction.

At the same time, it is also important to recognize that the notion of ‘addiction’ has become central to the everyday worlds of the people I have interviewed. This centrality has nothing to do

with whether or not they are dependent on or addicted to opioids. Rather, much of the health work they do on a daily basis revolves around proving to physicians and others that they are not addicts: providing urine samples, signing opioid treatment contracts, returning fentanyl patches to the pharmacy, and so on. Likewise, for physicians, determining whether a patient is an addict is a core part of the work they do in deciding whether or not to write an opioid prescription. Discourses of addiction—who is an addict, what constitutes addiction, what distinguishes an addict from a legitimate patient—circulate endlessly in the interviews I conducted for this study. At its core, the opioid crisis, like so many other panics around drug use, has revolved around fears over addiction. As such, it is crucial to make clear the ways in which I approach drug use and addiction.

Sociological approaches to drug use have undergone several shifts, including Lindesmith's (1938) ground-breaking work on the social and environmental aspects of drug use, functionalist perspectives on drug use and addiction in the mid-twentieth century (Cloward and Ohlin, 1960; Scheerer, 1978), reactions against functionalism beginning in the latter half of the 20th century (Matza, 1969; Denzin, 1993; Johnson, 1980; Rosenbaum, 1981; Waldorf et al., 1991; Williams, 1992; Sutter, 1969), and, by the end of the 20th century, rationalist studies on the 'choice' to use drugs (Becker and Murphy, 1988; Ainslie, 1992; Weinberg, 2011). As sociologists grew to be critical of depictions of drug users as rational, but misled, actors, there came to be a renewed 'appreciative' perspective on drug use, including the work of Acker (2002) and Dennis (2016). Sociologists and historians have also been particularly concerned with the impact of drug policies and other institutional responses to drug use (Boyd et al., 2016; Omori, 2013), including studies of Canadian drug laws and prohibition-oriented policies (Malleck, 2015; Courtwright, 2001).

Much of the sociological literature on drug use and drug-related policies focuses on criminalization, the factors that lead to the criminalization of certain behaviours and people over

others (Coltrane and Hickman, 1992; Galliher and Basilick, 1979; Burstein and Linton, 2002), and the way criminalization acts as a form of social control (Husak, 2003; Seddon et al., 2008). Others have linked criminalization with medicalization and have demonstrated how drug use has come to be simultaneously criminalized and medicalized (Conrad and Schneider 1980; Roy et al., 2012). As sociologists put forward critiques of medical and criminal models of addiction, there has also been an increase in interest in what Reinarman and Granfield (2015) call critical addiction studies. This tradition includes John Seeley (1962), who questioned whether alcoholism is a disease, Howard Becker (1953; 1967), who demonstrated the social nature of drug use, and Nancy Campbell (2010), whose ethnographic work analyzes the laboratory logics of biomedical research that produce ‘truths’ about addiction.

This dissertation is located within the tradition of critical addiction studies. While critical addiction studies challenge moralistic or criminal-legal understandings of addiction, researchers writing from this standpoint have also questioned medical or ‘brain disease’ paradigms of addiction (Reinarman and Granfield, 2015). In chapter three, I draw on critical addiction studies in arguing that although fMRI technology has been used to view the human brain and to identify differences in ‘addicted’ and ‘non-addicted’ brains, the neuromedical paradigm in which these distinctions are made neglects key contextual variables and risks biological determinism (Reinarman and Granfield, 2015). While proponents of the brain disease paradigm have positioned the latter as a means of freeing us from moralistic views of addiction, instead, the neuromedicalization of addiction has tended to further entrench the binary between addicted/not addicted and licit/illicit drug use (ibid. 9).

Critical addiction studies call our attention to the social and cultural factors that shape drug use. Key to this approach is a focus on historical and cultural specificity. Ideas about addiction and

drug use have changed over time, as have the material circumstances of drug users. As such, the contexts in which drug use takes place are key to understanding drug use and addiction. While drugs no doubt have particular effects that operate within the body, the lived experience of these effects is not determined solely by the pharmacological properties of the drug, but rather by complex social factors and contexts (ibid. 16). Given that marginalization and oppression impact experiences and consequences of drug use, critical addiction studies use multi-disciplinary research strategies that tend to prioritize a variety of voices. Particular attention is paid to forms of subjugated knowledge (ibid. 18).

Finally, critical addiction studies take a consequentialist approach to ethics, in which the rightness or wrongness of an act depends on its actual consequences rather than the initial intent. Drug policies, for instance, are evaluated on the basis of their consequences for people who use drugs. Through a consequentialist ethics, the brain disease model of addiction is critiqued on the grounds that it tends to operate alongside punitive and penal approaches to drug use, and the reality that this model is often invoked to mandate treatment or incarceration for the person's "own good" (ibid.). Instead, critical addiction studies seek to imagine more humane and equitable drug policies that might actually serve to reduce harms.

This consequentialist ethics is crucial for me as I investigate the social organization of opioid use. My focus in studying the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain, for instance, is what the text actually does: how it coordinates people's activities, how it is activated in various sites, and what are the consequences of these doings, particularly as they connect to the work other people are doing elsewhere and elsewhen. In this dissertation, approaching addiction critically means not only taking account of the social factors and contexts in which drug use occurs, but also the discourses and practices that have worked throughout history

to produce some opioids as licit, and others as illicit. I also seek to trouble the notion of addiction. I trace how physicians' work produces some people as addicts, and how their work then hooks into what other people in other spaces and times are doing as they provide care to this person who has come to be diagnosed with an opioid use disorder.

1.5.3 Sociology of Health

This dissertation contributes to the sociology of health by adding to the literature on chronic pain, chronic illness, and opioid use. While sociological approaches to chronic illness are replete in the literature—including Charmaz's (1991) study of experiences of chronic illness and time, and Corbin and Strauss' (1988) work on managing chronic illness at home—there has also emerged a sociological literature on chronic pain. This literature is an expanding one that has focused on the embodiment of chronic pain (Jackson, 1994, 2005; Kleinman and Kleinman, 1994; Whelan, 2003, 2007), the impacts of chronic pain on relationships, sense of self, and everyday life (Sindig and Wiernikowski, 2008; Bury, 1982; Osborn and Smith, 2011; Richardson et al., 2006; Nettleton, 2006), autobiographical accounts of living with chronic pain (Crosby, 2016; Frank, 2013), sociological theorizations of suffering (Mehta and Chan, 2008; Leder, 1990; Honkasalo, 2001; Broom et al., 2015), the influence of class, race, gender, sex, and age as they intersect in people's experiences of chronic pain and access to pain management (Kotarba, 1983a,b; Morris, 1991; Monsivais and Engebretson, 2012; Pryma, 2017; Husum et al., 2002; Bates and Rankin-Hill, 1994; Bates et al., 1997), and the ways in which people with chronic pain navigate health care systems (Werner and Malterud, 2003; Eccleston et al., 1997; Csordas and Clark, 1992).

Much of this literature responds to Bendelow and Williams' (1995) call for a sociology of pain as an explicit subdiscipline that could rescue pain from biomedical frameworks that reduce pain to a biological event. Although this dissertation adds to the sociological scholarship on chronic pain, I do not diametrically oppose myself to biomedical frameworks of chronic pain. Nor do I position myself as biomedicine's 'handmaiden,' as Linder (2010) warns in reimagining the role of critically applied anthropology in public health research. Instead, I approach biomedicine much in the same way that Dorothy Smith (1987) understands ideology, as adapted from Marx and Engels in *The German Ideology*. For Smith, ideology refers to those ideas and images through which the ruling class orders, organizes, and sanctions the social relations that ensure its domination (Smith, 1987). Biomedicine, as the dominant ideology organizing health care in Canada, is explored here by examining the organization of the production of ideas, symbols, concepts, vocabularies, and images that constitute biomedicine (ibid.). In chapter four, for instance, I investigate the production of evidence within the 2017 guideline. I discuss the ways in which vocabularies of evidence, objectivity, and neutrality come to be used in producing the guideline, and how the text operates to coordinate physicians' prescribing practices in such a way as to produce forms of social consciousness of physicians as evidence-based practitioners.

This study is not a phenomenological analysis of people's lived experiences of chronic pain. Instead, it contributes to the literature on chronic pain by articulating the organization of people's everyday realities, and how ruling relations come to bear on their daily lives. I do, however, ground myself in the standpoint of people with chronic pain, and in doing so I draw at length from participants' narratives as they describe the experience of living with daily, intractable pain. In this sense, my work aligns with scholarship such as Heshusius' (2009) critical account of

health care organization for chronic pain and Whelan's (2003) analysis of the documentation of pain related to endometriosis.

Finally, I also draw on and place my dissertation within the sociological literature on professions and professionalization. As the study progressed, it became clear to me that the social organization of opioid use for chronic pain is shaped by tensions between health care professions, as well as contestations between the medical profession and federal, provincial, and territorial governments over who has the right to regulate opioid prescribing. Sociological work on professions has traced the ongoing transformations of the medical profession (Timmermans and Oh, 2010; Roy and Miller, 2012), and the ways in which professionalization has involved territorial disputes between professions (Strong, 1979; Abbott and Meerabeau, 1998).

1.6 METHODS

Institutional ethnography differs in some ways from other, more traditional ethnographic projects in that the goal is not to produce an account of a social or cultural group or an aspect of social life but rather to explicate the often-invisible ruling relations organizing peoples' everyday lives (Balcom et al. 2021). While ethnographers have historically relied on observations of people in their local settings, for institutional ethnographers, direct observations in everyday settings may not reveal the ruling relations under study. Therefore, as in this study, interviews and textual analysis have often been preferred as methods for exploring institutional relations as they allow us to see beyond the participants' local realities (ibid.).⁵ Nonetheless, institutional ethnography is

⁵ There are, of course, many institutional ethnographers who have engaged in observation as a means of investigating ruling relations. These include Diamond (1992) in his work on nursing home care, Corman's (2017) institutional ethnography of paramedics, and Lund's (2012) inquiry into gender and the experiences of women academics, among many others.

still, as Smith (2005) describes it, an “ethnographic enterprise” in which the aim is to explicate the social in people’s everyday activities (Smith, 2005, p.56).

This dissertation is based on forty-one interviews I conducted with people with chronic pain, physicians, pharmacists, and other health care professionals. I also analyzed a number of texts that were mentioned throughout the interviews—these include the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain, screening instruments used by physicians to determine the risk of prescribing opioids to a given patient, policy documents and meeting minutes published by the CPSO, and numerous letters between people with chronic pain, their physicians, and the CPSO. I conducted interviews from December 2019 to March 2021. In total, I interviewed twenty people with chronic pain who use opioids, ten physicians, four pharmacists, and seven other health care professionals (two chiropractors, two physiotherapists, an occupational therapist, a massage therapist, and a nurse). I interviewed people with chronic pain who use opioids for pain relief and who live in Ontario, and I interviewed health care providers who practice in Ontario and who work, or have worked in the past, with people with chronic pain. In the case of physicians, I only interviewed those who have at some time prescribed opioids for chronic pain, and I only interviewed pharmacists who have filled an opioid prescription. The project was reviewed and approved by the university’s ethics review board.

I recruited participants largely through word of mouth. Before I began this study, I had received numerous offers from people with chronic pain who were eager to be interviewed and to tell their story. I also produced a call for participants that was circulated by the Chronic Pain Association of Canada, as well as the moderators of three online support groups for people with chronic pain who use opioids. Recruiting physicians also mostly occurred through word of mouth. During the process of researching my Master’s thesis, and over the course of attending several

conferences on chronic pain, I met a number of physicians who were eager to assist me when I reached out to them regarding this dissertation. Three physicians responded to the call for participants published by the Chronic Pain Association of Canada; others I had heard of indirectly through social media or other colleagues, and I reached out to them directly. Two of the pharmacists I interviewed were recruited through colleagues; two responded to a call for participants circulated through social media. The other health care professionals I interviewed were introduced to me by colleagues or were already known to me.

To protect participants' confidentiality, I did not interview physicians, pharmacists, or health care professionals whose patients had participated in the study or vice-versa. I was fearful of compromising provider-patient relationships, and I was worried that participants would read the dissertation and recognize one another. As such, although people with chronic pain frequently offered to introduce me to the physician who had tapered their opioids or otherwise interrupted their access to prescription opioids, I refused on the grounds that I could not ensure their confidentiality. Likewise, when physicians recommended that I speak to a patient whose opioid prescription they had been forced to taper, I declined.

Of the twenty people with chronic pain I interviewed, four live in Western Ontario, nine live in Southern Ontario, two live in Northern Ontario, and five live in Central Ontario. Participants' age spanned from earlier twenties to late seventies. The majority—fifteen—are women. Every person with chronic pain I interviewed is white except one woman who is Indigenous and one woman who is white and West Indian. All participants had received a diagnosis to explain their chronic pain, although, as I discuss in the next chapter, most of these diagnoses had taken several years to determine. Types of pain among participants include autoimmune diseases, arthritis, complex regional pain syndrome, fibromyalgia, migraine, arachnoiditis,

interstitial cystitis, low back pain, and pain persisting after an injury had healed. Dilaudid, oxycodone, hydromorphone, fentanyl, Tramadol, Suboxone, and Percocet were all mentioned as opioids used for pain relief. All participants had experienced a restriction in their access to opioids in some way since the late aughts.

Among the nine physicians I interviewed, four practice in Southern Ontario, one practices in Western Ontario, one practices in Central Ontario, and three practice in Northern Ontario. Of the seven physicians who are general practitioners, three work specifically with chronic pain patients. The others include a rheumatologist, a neurologist, and a resident who has just recently begun her residency in oncology. Furthermore, as I interviewed people with chronic pain, I began to recognize the importance of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain in coordinating health care providers' work. As such, when I interviewed physicians, I asked if they had been involved in the creation of the guideline. Five had not participated, one participated but was not a voting member, and four participated as voting members.

Two of the pharmacists I interviewed practice in Southern Ontario, and two practice in Northern Ontario. Only one pharmacist administered Suboxone treatment in-pharmacy, and two refused to fill opioid prescriptions unless they had a lengthy personal history with the patient. Of the other health care professionals I interviewed, two (an occupational therapist and physiotherapist) practice in Western Ontario, and the other five practice in Southern Ontario. Two participants—a registered nurse and a physiotherapist—work in hospital settings, while the other participants work in private clinics where services are not covered by Ontario's provincial health insurance (OHIP).

Interviews were conducted over the telephone for two reasons. First, in my previous experiences of interviewing people with chronic pain, I have found that interviews are often

tiresome for them. I suspect this is because we either meet in a public place or in my home, in which case they must travel, or we meet in their home, which burdens them with the role of acting as host. Instead, during telephone interviews participants tend to be much more engaged, and they are usually less weary by the end of the interview. Second, as most of the interviews for this dissertation took place from January to March 2021, during the COVID-19 pandemic and at the time of a province-wide lockdown, in-person interviews were not feasible.

All interviews were recorded and transcribed in full. Most of the interviews were an hour in length—the shortest was thirty minutes, and the longest took over three hours. Following the interviews, several people with chronic pain e-mailed or mailed me documents they had mentioned during the interview: forms, medical charts, letters, and assessments. Likewise, upon request some physicians and other health care professionals e-mailed me copies of assessment forms they mentioned during our interviews. In some cases, participants e-mailed me a form during the interview and we worked through the text together as a means of understanding how they translate the document into their everyday work. When participants provided me with documents bearing their names or other identifying information, I first blotted out this information using a photo editing tool, and then I printed off the document and kept it in a locked cabinet before deleting our electronic correspondence.

While people with chronic pain are identified by pseudonyms, I do not reference practitioners with any sort of name or identifier. As many of the clinicians I interviewed hold multiple roles—such as acting as members of their regulatory college or participating in developing the 2017 opioid prescribing guideline—I felt that there was too great a risk that information associated with specific pseudonyms could be gathered across the dissertation to identify specific practitioners. This was particularly worrisome given the comparatively small

number of clinicians who have participated in activities explored in this study. I have also removed any mentions of specific hospitals, clinics, and geographical locations to further protect practitioners' confidentiality.

Interviews did not follow a structured list of questions. Instead, I utilized interviewing methods suited to institutional ethnography in which the interview emerges as a conversation in which the interviewee is recognized as the expert of their everyday life (Devault and McCoy, 2002). In the case of people with chronic pain, I asked them to start wherever they felt their story began, and to bring me through their experience of living with chronic pain. Most of them were familiar with my research at that point, and so they required very little prompting on my part as they brought me through their history. All participants with chronic pain started their narrative from the moment the pain began, and then went on to describe the various health care providers they have seen and the treatments they have tried, the opioids they have been prescribed, and the series of events through which they came to find their access to opioids interrupted.

As opposed to the interviews with people with chronic pain, which usually flowed effortlessly and were filled with rich descriptions of people's everyday doings, interviews with health care providers often presented a challenge. In general, the chiropractors, physiotherapists, nurse, and other allied health professionals I spoke with were quite willing to go through the minute details of their work with me. Once they understood what I was looking for, and how I intended for the interview to proceed, the conversation ran smoothly. On the other hand, my interviews with physicians varied. Some of the physicians, particularly those who had been introduced to me through other colleagues, were willing to patiently answer my questions as I prompted them for detailed accounts of their everyday work. The majority of clinicians, however, were puzzled about why I was interested in these sorts of details. One of the greatest challenges was gently guiding

these interviewees to describe what they actually do as they tended to use institutional language that displaced and concealed their work and the ruling relations hooked into their everyday lives.

Given that the topic of opioid use for chronic pain is a controversial one, my sense is that some physicians grew wary once I began to question the finer details of their prescribing and practices, particularly those who had been investigated by the CPSO. Often, a physician would answer my questions with a brief, vague statement, and then I would work with them to bring out the detailed elements of their work. The following excerpt of my interview with a rheumatologist is an example of how this process occurred. The physician had just explained to me that if he felt a patient might benefit from opioids, he might start them on a trial:

Leigha: And as a clinician, could you bring me through how you would initiate an opioid trial?

Rheumatologist: Yes. Um, yeah. Well, for chronic pain, we're very careful about what we're using. So, we would maybe start working our way through the opioids, so we'll start with one of the milder ones, maybe start Tramadol, before we move on to the hydromorphone.

Rheumatologist: Okay. Right. And when you say "we," who's involved in this process?

Rheumatologist: Well, just me. It's just me prescribing.

Leigha: Right. So, you have a patient, and you decide to start working through the opioids. How do you decide to start that process?

Rheumatologist: Well, if they've got a history of addiction, for sure, they're not a candidate. And if they are mentally, uh, concerning, then we would be cautious.

Leigha: If they're mentally concerning, or history of addiction. Right. And how would you assess that, mentally concerning?

Rheumatologist: Well, I would look at if they're depressed or, you know, mentally not well.

Leigha: And what exactly would that look like?

Rheumatologist: I would talk to them, have a conversation. These patients, most of them come from another doctor. So, I would get some kind of report, something in the referral, maybe saying they aren't well. So, I...there's a lot of discussion with the patient. We keep the same patients, so we get to know them over the years. But with a new patient, I would ask them about what's written in the referral, or any diagnosis. I would ask, well, do they have a history of substance use? Any psychological problems? Any history of abuse?

Over time, as the interview progressed, the rheumatologist caught on to my interest in particular details about how he worked. My experience in interviewing people in this way is that they often worry they are boring the interviewer; in most conversations, people are not necessarily interested in such a thorough description of someone's everyday work. Clarifying this interest at the start of the interview, and gently prompting the interviewee with reminders, proved to be helpful in eliciting rich descriptions. In this way, the interview became a process through which we constructed knowledge together.

Following the interviews, I used NVivo software to organize interview transcripts and to keep track of the participants and any documents they sent me. However, I did not code the data. Instead, I read interview transcripts, and the texts that had been provided to me, for traces of social organization. As Mykhalovskiy and McCoy (2010) note, "The organizing presence of institutional relations is visible in how people spoke about what they do" (Mykhalovskiy and McCoy, 2010, p. 29). Key to this form of data analysis was attending to those moments in the interview transcript where the person's activities coordinate with someone else's, or where their activities are tied to ruling relations that make this activity possible (ibid.). Often, data analysis involved taking extended passages of text in order to work through participants' explanations of what they did so as to identify moments where ruling relations became visible.

Through this mode of data analysis, the research process was an iterative one in which, based on the traces of institutional relations I found in the transcript, I would go on to investigate how these relations were being coordinated and what activities were taking place elsewhere. In a section of the interview where a participant spoke about being prescribed Suboxone, for instance, my next step was to interview physicians and pharmacists on the work involved in prescribing and dispensing Suboxone. I would also analyze texts, including guidance documents from the Ministry of Health and Long-Term Care, to map the ways in which Suboxone prescribing is reimbursed, and who is eligible for reimbursement. While, as in any research project, there is always a point at which the researcher must stop—a limit within which to retain the scope of the study—my hope is that this dissertation traces many of the ruling relations that have come to bear on the lives of people who use opioids for chronic pain.

1.7 CHAPTER OUTLINE

In this chapter, I have provided an overview of the context and objectives of my research, the literatures I draw on and contribute to in my analysis of the social organization of opioids, as well as a description of my use of institutional ethnography as a mode of inquiry. In the next chapter, I ground us in the everyday lives of people with chronic pain who use opioids. I use the concept of ‘health work’ to account for the daily activities people with chronic pain engage in around their health, including sensing and recognizing pain within the body, seeking a diagnosis, and experimenting with different treatment modalities. I also take up the concept of ‘medication practice’ to identify forms of health work performed around using medication and, in particular, opioid analgesics. I argue that people with chronic pain have adopted novel forms of health work in response to changes in physicians’ opioid prescribing practices since the late aughts. Some of

these activities include setting aside opioid tablets to create an emergency stockpile for days when the pain is worse than usual and weaning oneself off opioids with no support from health care providers to prove one's legitimacy as a 'pain patient' rather than an addict. This analysis also makes it possible to begin to identify the ruling relations organizing opioid use made visible from the standpoints of people with chronic pain.

In chapter three, I move on to map these ruling relations. I take up the concept of the 'medico-legal borderland' to account for the hybridized space between medical and criminal-legal regimes of ruling and how relations of neuromedicalization, racialization, and criminalization have resulted in the attribution of blame for the opioid crisis to individual physicians, the medical profession, and the pharmaceutical industry.⁶ In particular, I focus on the introduction of Ontario's Narcotics Monitoring System in 2012 as a form of surveillance used by the state and the medical regulatory college to monitor physicians' opioid prescribing and to penalize physicians identified by the database as overprescribers. I suggest that this intervention into physicians' prescribing patterns employs modes of coercion, surveillance, and punishment that differ from techniques of self-governance typically associated with medical self-regulation. I recount the new work practices physicians have adopted to ensure their work is accountable to these relations of coercion and I highlight the impacts of changes in physicians' opioid prescribing on the patient-physician relationship.

⁶ In chapter three, I identify pharmaceutical industry practices of researching, developing, marketing, and selling opioids that have contributed to the emergence of the present-day crisis of opioid use. However, I do not engage in a sustained analysis of these relations of ruling. For pragmatic reasons requiring that the scope of this dissertation be limited in some way to provide a detailed account of the ruling relations comprising the governance of physicians' opioid prescribing practices that thoroughly examines this social organization, this study does not include investigation of the pharmaceutical industry in any great depth. Nonetheless, as I remark in the concluding chapter, research on the relations comprising this industry is a pivotal next step for expanding our knowledge of the organization of opioid use in Canada.

In chapter four, I extend my analysis of the social organization of opioid use by focusing on the publication of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain. Alongside the introduction of Ontario's Narcotics Monitoring System, the publication of this guideline and its dissemination and mobilization by the CPSO was identified by participants as a catalyst for changes in their opioid prescribing practices. I focus on two aspects of the guideline: first, its development through a complex structure of committees and literature search and evaluation techniques intended to ensure the guideline's defensibility as a neutral, unbiased set of recommendations; and second, physicians' work of translating the guideline into clinical practice. I argue that the process of creating and mobilizing the guideline was organized by concerns of medical authority and professionalization and the need to reaffirm the profession's singular capacity for regulating opioid prescribing and use. The consequent production of a 'neutral,' apolitical text has meant that it is largely irrelevant to the thoroughly political work of prescribing opioids, and that physicians' attempts to translate it into their local settings has resulted in the disqualification of patients 'tainted' by social determinants of health such as poverty or racialization from care.

In the concluding chapter, I review the core arguments and findings of the preceding chapters and I identify contributions and limitations of this study. Finally, I end with suggestions for future research and advocacy efforts, including the importance of collaboration among researchers, clinicians, and people with chronic pain, the importance of dismantling binaries between good/bad patients, good/bad physicians, and good/bad opioid use.

CHAPTER TWO

2.1 INTRODUCTION

In this dissertation, one of my goals has been to investigate how people with chronic pain go about their lives and how their use of opioids for chronic pain figures into their everyday/night worlds. Each interview was an opportunity to explore what the lives of people with chronic pain look like and how they use opioids. Equally important was an orientation to participants as more than merely people with chronic pain. I strove to co-create interviews in which we worked together to narrate, draw upon, and expand accounts of people whose lives are greater than their chronic conditions. Part of the work of interviewing people with chronic pain was the task of encouraging discussions that captured all aspects of the person's life while also accounting for the significance of chronic pain and opioid use to their experiences.

The other challenge I faced was the struggle to achieve a balance in which I grounded myself in the experiences of people with chronic pain while retaining a focus on ruling relations. Each person I interviewed spoke of the importance of research that would amplify the voices of people with chronic pain and make visible the challenges they face, which tend to be poorly understood. As I designed and carried out this study, I grappled with the tension of trying to produce two kinds of knowledge: intimate knowledge of the day-to-day details of people's lives as they were relayed to me during interviews, and knowledge of the ruling relations shaping the lives of people with chronic pain that became visible through our interviews but of which they were not necessarily fully aware. I found myself looking for strategies to draw on people's accounts without slipping into an analytical framework in which they became the object of study.

My concern was that a project centering the lives of people with chronic pain would reproduce phenomenological accounts that have dominated the sociological literature on pain. This is not to say that this approach has no value. On the contrary, phenomenological work on chronic pain has been essential in situating pain as a daily reality of sufferers' lives with which health care providers are often not familiar. For many of us with chronic pain, studies such as Whelan's (2003; 2007) work on women's experiences of endometriosis and Thomas and Johnson's (2000) analysis of people's descriptions of chronic pain have been an important means of conveying our struggles.

My interest in institutional ethnography emerged as I sought other modes of inquiry that might be of value to people with chronic pain. Several years ago, I was part of a discussion among members of a patient support group on the topic of research ethics. One member quipped: "You don't need a whole study to tell me what it feels like to live in my own body—it sucks." That statement has stuck with me and instilled in me a sense of responsibility to share people's stories in ways that will produce knowledge of value to them. I took up institutional ethnography as one possible mode of inquiry for producing knowledge *for* people with chronic pain—the kind of knowledge I and others imagined in our conversations about research on chronically ill people.

In this chapter, I produce an analysis of the health work performed by people with chronic pain as they navigate their everyday lives. I explore their activities around seeking a diagnosis, trialing treatments, managing their medication, and so on. My focus on people's actual doings and foregrounding the work they engage in on a day-to-day basis allows me to centre the experiences of people with chronic pain such that they do not fall from view while also resisting objectification of their lives. As I discuss below, I focus on health work as a point of entry (Devault, 2006) into the ruling relations that organize the use of opioids for chronic pain in Ontario.

As I learned about the many forms of health work performed by people with chronic pain, I came to understand how these activities coordinate with those performed by health care practitioners, policymakers, guideline developers, members of professional regulatory colleges, and others working elsewhere and elsewhen. These activities produce the medical, criminal-legal, and regulatory ruling regimes organizing opioid use for chronic pain in Ontario. On the basis of findings emerging from my research, one of my arguments in this chapter is that many of the forms of health work adopted by people with chronic pain have emerged as responses to shifts in physicians' opioid prescribing practices. Careful examination of new forms of health work adopted by people with chronic pain serves to ground us in their lived experiences as the standpoint from which, in subsequent chapters, I go on to identify the ruling relations made visible from their everyday/night worlds.

My analysis of health work involved repeated close readings of extended passages from interview transcripts to locate people's activities within the wider narratives of their lives. Likewise, in the writing of this and subsequent chapters, I frequently employ a narrative form whereby I draw at length on interview transcripts to convey the richness and complexity of not only participants' lives but also the ruling regimes investigated in this study. To this end, in what follows, I discuss the everyday lives and forms of health work performed by people with chronic pain by introducing several participants and recounting in depth their experiences of becoming a person with chronic pain, seeking pain care, and changing the ways they use opioids in response to interruptions to their access to opioids. My hope is that extensive examination of participants' accounts will also be valuable for communicating to readers not only how it feels to live in a chronically painful body but also the tremendous consequences of shifting patterns of opioid prescribing for people with chronic pain.

2.2 INVESTIGATING HEALTH WORK AND MEDICATION PRACTICES

In chapter one, I introduced the notion of ‘health work’ (Mykhalovskiy and McCoy, 2002) as an empirically empty concept⁷ that allows us to orient ourselves to what people are doing. However, the concept of ‘work’ has been used more generally in health literatures, particularly those that investigate chronic illness and its management. Corbin and Strauss (1988), in their study of the work performed by ill people and their spouses, use the idea of ‘work’ to categorize the activities required to manage illness. Their use of the concept draws on earlier writing by Strauss et al. (1985) on the tasks performed by health care workers. Strauss and colleagues develop an extended conception of work as sequences of activity through which tasks are accomplished (Strauss et al., 1985). Particularly significant is their inclusion of types of work that might be considered ancillary or unrelated to people’s health, such as cleaning and cooking, which are also recognized to require skill, intention, energy, and time despite the fact that they are mostly unpaid forms of labour. This broad understanding of work also subverts the normative force of terms such as ‘self-care,’ which imply self-surveillance in adherence to biomedical standards around health and illness (Mykhalovskiy and McCoy, 2002).

This conceptualization of work has been employed in numerous literatures, including sociological research on health. Seear (2009), for instance, examines how women with endometriosis experience the process of gaining patient expertise as a form of work. Similarly, Ancker et al. (2015) investigate the work required by patients with multiple chronic conditions to

⁷ McCoy (2006) takes up the concept of work as an empirically empty term in that it does not define certain activities as work over others (McCoy, 2006). The concept can be visualized as an empty basket to be filled with the kinds of work described by participants. Using the notion of ‘health work’ oriented my attention to people’s everyday activities without predefining what is meant by ‘health’ or appropriate or correct ways of caring for or managing one’s health.

manage their personal health information. The concept of work has also been used to consider neoliberal shifts in health care and responsabilization whereby patients are expected to transition from passive recipients to actors engaged in the management of their own health (Gorman et al., 2018; Sultan and Swinglehurst, 2021). Feminist analyses in particular have emphasized the importance of expanding the notion of work beyond paid labour to include, as Pritlove et al. (2018) propose, the unpaid work of patienthood among women living with cancer.

My use of the concept of health work draws on this analytical tradition in examining closely the clusters of activities constituting the work involved in chronic pain management and opioid use outside of normative, biomedical discourses of self-care or treatment adherence. However, for institutional ethnographers, the concept of work is also used to direct attention to the ruling relations that shape people's lives. Rather than classifying different types of work or focusing on private spaces taken as the context in which work occurs, health work within this mode of inquiry enables the researcher to look "at and through [...] health work to the practices and discourses of an institutional complex that condition it" (Mykhalovskiy and McCoy, 2002, p. 25).

This use of the concept of health work also extends the more general concept of work commonly used in institutional ethnography as a means of locating the inquiry in the actualities of what people do every day. Here, work comprises "what people do that requires some effort, that they mean to do, and that involves some acquired competence" (Smith, 1987, p. 165). Within research on health and health care, institutional ethnographers have employed the concept of work to study the work employees do to manage their mental health (Malachowski et al., 2016), the social organization of work performed within families to maintain children's health (Nichols et al., 2016), university students' work in attending to their wellbeing and mental health (Nichols and Lewington, 2020), and the numerous forms of invisible work performed by health care providers

including nurses (Dale et al., 2016; Rankin and Campbell, 2006; Rankin, 2015; Diamond, 1992) and physicians (Webster, 2020; Naess and Haland, 2021; Quinlan, 2009; Webster et al., 2019).

This generous conception of work has also informed institutional ethnographic inquiries into the use of medication as a means of managing, treating, or curing illness. In clinical research on prescribed medication use, the focus tends to be on ‘adherence’ or ‘compliance’—whether the person takes a medication as prescribed. There has been much interest in understanding why some people do not comply with their prescribing physician’s directives and what strategies might increase rates of adherence (Ogedegbe et al., 2004; Kumarasamy et al., 2005; Kvarnstrom et al., 2018; Pages-Puigdemont et al., 2016). Compliance among people with chronic pain has been of considerable interest, particularly in relation to opioid use (Liebschutz et al., 2017; Graziottin et al., 2011; Rosser et al., 2011). Research in this area has focused on the overuse and underuse of pain medication (Broekmans et al., 2009) and factors associated with nonadherence (Timmerman et al., 2016). Physicians’ adherence to pain medication prescribing guidelines has also been identified as a focus for research and targeted intervention (Anderson et al., 2015).

In contrast to the terminology of adherence and compliance, McCoy (2009) borrows the term ‘medication practice’ from Conrad (1985) in her institutional ethnography of the everyday work of using highly active antiretroviral therapy among people with HIV. The concept of medication practice was proposed by Conrad as a patient-centered perspective in which patients are seen as active agents rather than passive recipients whose medication use must be solved within the biomedically-defined problem of noncompliance (Conrad, 1985). Conrad investigates the way people interpret the medication regime their physician has prescribed and how they use medication in creative ways that may vary from their physician’s directives. Likewise, in McCoy’s work on antiretroviral therapy, she considers people’s medication practices as a means of challenging

discourses of compliance and adherence. She identifies a wide range of activities people perform to align their individual experiences with prescribed medication regimes.

Mykhalovskiy et al. (2004) also orient to medication practice as a form of health work in their institutional ethnography of the use of highly active antiretroviral therapy for HIV. The authors draw on conceptions of medication practice and health work to avoid prefiguring normative types of health work and to instead account for a wide range of practices. They also develop a critique of sociological research on compliance in suggesting that the biomedical conception of compliance is more than an authoritative mode of social control. Instead, as in the case of the use of antiretroviral therapy for HIV, adherence is a social technology through which multiple forms of power intersect. Their analysis of adherence differs significantly from theoretical framings of compliance as an ideology justifying physician authority (Troster, 1988), as well as research concerned with revealing the meaning-making and identity-forming work people do in relation to adherence and medication use (Reichenpfader et al., 2019; Hawking et al., 2020; McLaughlin and Zeeberg, 1993).

The strategic use of health work and medication practice as empirically empty concepts helped me to realize my goal of grounding my research in participants' everyday lives without objectifying them. In each interview, I drew our attention toward what participants actually do on a day-to-day basis and how these activities coordinate with what others are doing. Taking an approach to opioid use for chronic pain centered on a genuine spirit of discovery allowed me to locate myself in a research process where the goal was not to evaluate participants' health strategies against normative judgments but to learn how they 'do,' for instance, pain management.

A concern with people's work also allowed me to collaborate with participants in subverting stigma associated with chronic pain and the use of opioids for pain management. People

with chronic pain tend to be seen by medical practitioners and the wider public as malingerers seeking ‘secondary gains’ such as disability benefits, despite a lack of empirical evidence that people with chronic pain fake or exaggerate symptoms (Fishbain, 1998; Fishbain et al., 1995; Bokan et al., 1981; Matthias et al., 2010; Pohl et al., 2019). Tied to this perception is the belief that people with chronic pain are lazy and pretend to be ill as a means of avoiding work- and family-related responsibilities. For instance, many of the health care providers I interviewed expressed a belief that people who use opioids for pain relief are lazy. Several of these practitioners framed the use of opioids as an “easy way out” that exempted patients from having to put in the work of managing their conditions. An academic detailer who previously worked as a community pharmacist bemoaned the use of opioids to manage chronic pain:

The mentality today in society is like everyone just wants a magical pill for everything, you know what I mean? Unfortunately, with pain, sometimes people have to accept the fact that they will live with chronic pain, nothing will ever cure it [...] And it’s a tough sell, too, like I said, the mentality today is, “I want a pill that I can take to fix everything.” A lot of people don’t want to put in the work.

Several other clinicians echoed this pharmacist’s views. One general practitioner felt that patients tend to request opioids rather than doing “safe exercise, relaxation, mindfulness...and all those kinds of things.” A neurologist said he only prescribes opioids to patients who have already tried several other therapeutic modalities, including physiotherapy and cognitive behavioural therapy, and who show efforts of “putting in the work” despite their pain. He also expected patients to maintain their sense of humour and to resist “being histrionic about it.” A family physician noted that some patients have unrealistic goals in that they expect opioids to completely cure their pain. He also felt that some patients demand opioids as an easy fix: “Some people’s preference as they walk through the door is to say, ‘I want Percocets.’”

In contrast to views that people with chronic pain use opioids because they are lazy and unwilling to “put in the work,” I found instead that people with chronic pain engage in a tremendous amount of work around opioid use—and, more generally, chronic pain. There is much more that goes into using opioids for chronic pain than opening a pill bottle and swallowing a tablet—although these acts in themselves are also forms of work. A generous conception of health work and medication practice makes visible the disjuncture between clinicians’ perspectives of people who use opioids for pain management and the actual activities people engage in around opioid use. I do not bring forward examples of health work because I want to contradict clinicians’ conceptions of people with chronic pain as ‘bad’ patients and instead prove that they are ‘good’ patients. Instead, I look to broaden our understanding of what we mean by work and how it is that people with chronic pain actually use opioids for pain management.

2.3 BECOMING A PERSON WITH CHRONIC PAIN

When I asked participants how they had developed chronic pain and when their pain first started, nearly everyone recounted a long, winding journey where from the initial injury or sensation of pain it could take weeks, months, years, and even decades to be diagnosed or to receive treatment. Among participants, it took an average of 7.3 years to be diagnosed, with a range of two months to 27 years. This delay in receiving a diagnosis or treatment most frequently occurred due to lengthy waitlists for specialist appointments, including appointments with surgeons; lack of knowledge by general practitioners or specialists regarding the person’s condition; dismissal by physicians, including attribution of pain to psychological factors; and lack of local diagnostic or treatment options.

Participants habitually synthesized the period of time between the first sensation of pain and seeking medical care with a brief summary before skipping ahead chronologically to the diagnosis itself and the ensuing treatment. When I noticed participants engaging in this kind of skimming, I would ask if we could return to the time many people described as a “waiting period.” This language reminded me of Diamond’s (1992) study of health work among residents and staff in a nursing home in which he worked. As he witnessed long stretches of time where residents were waiting—for their meals, for example—Diamond came to see waiting as a form of work.

Similarly, Timmermans and Buchbinder (2010) describe newborns flagged for potential complications during genetic screening as “patients-in-waiting” as they hover for extended periods of time between sickness and health. Parents and health care providers are typically uncertain whether a child flagged through genetic screening will become ill and, if they do, what this disease will be, as markers are imprecise and indicate elevated risk for numerous conditions. The authors argue that all patients-in-waiting—and those who care for them—inhabit a contingent space between health and illness while they navigate a “lengthy trajectory of medical gate keeping” as clinicians determine whether disease is present and attempt to establish a diagnosis (Timmermans and Buchbinder, 2010, p. 418).

Vindrola-Padros et al. (2021) note that the social sciences have experienced a mobility turn since the start of the twenty-first century as conceptions of social life as fixed and sedentary have been supplanted by ontologies and epistemologies that emphasize the dynamic flow of everyday life. Research on health, illness, medicine, and the body has generated concepts such as healthscapes (Llewellyn et al., 2017), the biotech pilgrimage (Song, 2010), and medical travel (Inhorn, 2015; Sobo, 2009; Holliday et al., 2019) to account for the (increasingly rapid) mobility of people, health care provision, and biotechnologies. However, as Vindrola-Padros and colleagues

argue, periods of waiting or immobility are critical in shaping experiences of health and illness. Waiting is also widely experienced by people seeking access to health care, including patients on organ transplant waiting lists (Rehsmann, 2021) and people immobilized by injuries that will heal only through the passage of time (Stott, 2021).

Likewise, periods of time understood as times of waiting have also been taken up as political spaces in which the politics of waiting operate as a mechanism of biopolitics. Ozolina-Fitzgerald (2016), for instance, analyses the post-Soviet context and the experiences of people who are unemployed and seeking access to welfare assistance as they undergo forced waiting. She argues that neoliberalism produces a temporality in which those who are most marginalized—including migrants, asylum seekers, people living in poverty, and Indigenous people—are incapacitated through waiting. Auyero (2012), in his account of the politics of waiting in Argentina, describes forced waiting as a temporal process in and through which “political subordination is reproduced” (Auyero, 2012, p. 2). These and other conceptions of waiting situate periods of extended waiting within wider structural and institutional relations that produce new subjectivities (Haas, 2017; Janeja and Bandak, 2018).

Throughout my interviews with people with chronic pain, I became highly interested in the extensive waiting periods people endure as they seek pain care. Interviewees shared stories of waiting in line at urgent care clinics, waiting for hours in physicians’ offices and emergency departments, waiting in agony as they watched the clock, counting down the seconds until they could take their next dose of analgesics, and waiting weeks, months, and years in the hopes of being diagnosed or finding an effective treatment. These waiting periods were also of interest to me because even when people reach milestones they expect will put an end to their interminable waiting—obtaining a diagnosis, for example—waiting continues to be an incessant part of their

everyday lives. My discussion of the importance of waiting in the everyday lives of people with chronic pain contributes to the growing literature on waiting while emphasizing in particular the fact that waiting is a form of work.

2.3.1 The Onset of Chronic Pain

A recurrent topic I had not expected to emerge during interviews was the health work involved in determining whether one's pain is severe enough to merit seeking medical attention and waiting to see whether pain or injury will increase over time. This was interesting to me because there is a medical and popular conception that people with chronic pain are hypochondriacs or malingerers who take up resources that could be directed toward other patients (Seto and Nakao, 2017; Tuck et al., 2019). In what Franssen (2019) calls a sickscape of neoliberal concerns around efficiency and strains on underfunded health care systems, these accusations have been particularly salient. However, I found that people with chronic pain spend agonizing days, months, and even years trying to decide whether their pain merits "bothering" a clinician. For older participants, it is difficult to differentiate what they perceive to be normal aches and pains associated with aging from chronic pain that warrants further investigation.

Robert has struggled with chronic pain since he hurt his back many years ago as a security guard trying to contain a riot. Years later, the pain worsened through a process through which, as he explained, "Slowly but surely [the pain] started to degrade over the years until finally I started getting medical interventions, because I just couldn't take it anymore." Likewise, Kim managed her migraines without medical help for years until she was diagnosed with thyroid cancer and underwent surgery in her early twenties. Following surgery, the severity of her head and facial

pain increased to such an extent that she finally sought care from a dentist in search of an explanation.

For those whose chronic pain comes on suddenly and unexpectedly, often because of an injury, the decision of whether to seek medical care still presents itself and requires careful consideration. Jessica, for instance, was accused of wasting hospital resources and of drug seeking when she sought care at the emergency department following a botched endometrial ablation.⁸ Although she arrived at the hospital in great pain, once medical staff learned she used Suboxone for pain management, she was held on an involuntary commitment in the hospital's psychiatric department for being 'hysterical.' Jessica had no doubt her identity as an Indigenous woman played an important role in the treatment she received. Some time later, when Jessica experienced chest pain so severe she collapsed on her bathroom floor, she decided not to seek care and risk further discrimination. Shortly after this episode of chest pain, Jessica underwent routine bloodwork that showed significantly elevated cardiac enzymes. The referring physician begged her to go to the hospital out of fear she had had a cardiac event, but she refused.

My conversations with participants revealed that the path from onset of pain to first contact with the health care system is rarely a linear one. Instead, for most people, seeking medical care is a last resort, particularly for those who are marginalized due to race, gender, and socio-economic status, or who have been dismissed by physicians in the past. It is common for people to wait to see whether their pain will pass or to try home remedies. Then, as the pain worsens or does not

⁸ An endometrial ablation is a procedure intended to destroy the endometrium to treat heavy menstrual bleeding (Munro, 2018). Several techniques and devices are used to burn the endometrium. Although Jessica did not qualify for endometrial ablation given the large size of her uterus, the gynecologist went ahead with the procedure. During the ablation, the device was left in Jessica's uterus longer than the time recommended by the manufacturer. As a result, Jessica experienced a transmural uterine thermal injury (Brown and Blank, 2012)—burns to the uterus—that were not recognized by the gynecologist.

resolve, people may begin to engage biomedicine but in spaces they perceive as peripheral to the health care system: pharmacies where they purchase over-the-counter medication, for instance. Eventually, every person I interviewed sought medical care for their pain. Most often, people booked an appointment with their family physician or visited the emergency department for pain care. From this point began a long journey during which it could take weeks, months, or years to be diagnosed. This waiting period is one in which people with chronic pain must learn not only how to manage their pain and get through the day, but also how to navigate a health care system in which their concerns are often dismissed.

2.4 WORKING TO ESTABLISH A PATIENT-PHYSICIAN RELATIONSHIP

Once people with chronic pain decide to seek care, they enter into a set of ruling relations characterized rather generally as the health care system. This entry rarely occurs seamlessly or without hurdles. Instead, people with chronic pain who have an existing relationship with a family physician found that their physician was increasingly unwilling to treat chronic pain or to prescribe opioids. For those who did not have a family physician, the situation was even more dire, as they found that physicians were disinclined to accept them as patients. This is not surprising: physicians are often reluctant to work with “pain patients” who are perceived as “heartsink patients”⁹ (Spilsbury and Barrett, 2018; Cohen et al., 2011). This trend has been attributed to causes including negative beliefs about chronic pain embedded in medical curricula, the difficulty of diagnosing and treating chronic pain, the relatively low prestige of chronically painful conditions, and, as I

⁹ Heartsink patients are described in the literature and by clinicians as patients who cause the physician’s heart to sink whenever they encounter them. These are typically patients for whom the physician cannot find a diagnosis and whose symptoms are not easily controlled, leading to feelings of failure on behalf of the practitioner (Spilsbury and Barrett, 2018). Cohen et al. (2018) have suggested that the concept of the ‘heartsink patient’ has emerged as an orientation physicians take toward patients whose lack of diagnostic certainty leads to distress on behalf of clinicians.

explore in chapters three and four, growing fear among physicians as they find their opioid prescribing practices governed within new medico-legal forms of surveillance on the part of the state, its agents, and professional regulatory colleges (Harding et al., 2005; Upshur et al., 2010; Webster et al., 2017; Morley-Forster et al., 2003). Thus, following the waiting period during which people manage their pain at home and decide whether to seek medical care, there most often follows a second waiting period before diagnosis or treatment in which they either try to find a physician willing to take them on as a patient or try to convince their current physician that they are legitimate patients worthy of a diagnosis and access to opioids.

The costs of this waiting period were made clear in my interview with Ann, who lived with undiagnosed pain and inflammation for over two decades. Ann's account echoes that of many others whose lives have unfolded in what she referred to as a "purgatory" in which people with chronic pain are endlessly shuffled from one waiting room to another as physicians either dismiss their claims or do little to help them—that is, if they can enter the waiting room at all. As Ann struggled to find a physician willing to treat her, her case was taken on by a care access centre, where employees contacted over a hundred physicians in her region to find someone who would accept her as a patient. Of those physicians, only three responded. Ann described the struggles she has faced to access adequate pain care:

Ann: I have had a lifelong problem. And my experience has been pretty much getting incredibly worse when I hit menopause twenty years ago. But it was pretty bad before that, to the point that it interrupted my working life, and prevented me from doing a lot of the things I had planned to do. And necessitating the medication of narcotics, too. I've been on them more or less constantly for twenty-five years, so that gives you an idea of how long I've been dealing with regular and high-level pain. I can only take a few medications. One of my problems, which I didn't know until they finally diagnosed me with lupus in 2014, is that I can't tolerate a lot of pharmaceutical medication, including narcotics.

Leigha: That's a long time to go without a diagnosis.

Ann: Yeah, well because I was always forced to make my own pain management plans. I never had any help with that.

Although Ann suffered from debilitating symptoms including pain and swelling, for years physicians discounted her suffering as psychological. Ann had expected her complaints to be taken seriously given the visibility of the inflammation in her joints. Instead, by her account, the rheumatologist felt she was “a very unhappy woman that very obviously had a lot of non-physical pain.” In other words, the rheumatologist suspected a psychosomatic process through which Ann was causing her own emotional upheaval and translating this unhappiness into physical pain. This pattern of dismissal continued until the early 2000s, when Ann removed herself from her general practitioner's roster in the hopes of finding a new physician. However, in the early 2000s, the region in which Ann lived was hit with acute shortages of physicians that persist today. This gap compounded the difficulties she faced in finding a physician who would accept her as a patient.

In 2005, Ann found a physician who was well-known for working with chronic pain patients. Although she had to drive two hours to his practice, she found he was sympathetic and willing to help. Unfortunately, his support ended when one of his patients was arrested and charged with illegally selling prescription opioids. From that point on, the physician removed all people with chronic pain from his roster. Although this meant Ann was once again without a physician willing to treat her pain, she said she understood the physician's perspective, especially as panic around prescription opioid-related harms mounted in Canada. As she said: “I mean, the fear these doctors have of law enforcement is just tangible. They are really afraid that they're going to have their livelihood taken away.” Ann was forced to find another physician—or, as she said with her characteristic cynical sense of humour: “I had to go out amongst the heathens and find another

doctor.” This was complicated by the fact that in her small community, there was only one rheumatology practice. Since the rheumatologist there had refused to continue treating her when she did not respond well to chemotherapy treatment or biologics, Ann had few other options.

It was around 2009 that Ann finally managed to find a new general practitioner in her region. In contrast to older physicians who, as I discuss in the next chapter, were prescribing opioids in a manner considerably more liberal than patterns of opioid prescribing seen today, Ann’s newest physician had just graduated from a Canadian medical school and held rather dim views of opioids. Although Ann’s condition continued to deteriorate, the physician refused to prescribe the dose of opioids she had been using since the early 2000s. As her pain worsened, Ann had trouble sleeping and eating. After several months of ill health, she was hospitalized, and her condition rapidly progressed to coma. Fortunately, she regained consciousness and recovered. While in hospital, she was seen by a physician who diagnosed her with lupus. When this diagnosis was communicated to Ann’s general practitioner, he agreed to prescribe hydromorphone for pain management. However, Ann’s relief was brief, as shortly after her hospitalization the physician removed her from his patient roster without warning.

Without other options, Ann reached out to another care access centre. After six months, the centre found a physician willing to take on Ann as a patient. This physician puzzled her because he was both eager to help resolve her pain and heavily suspicious of her as a potential drug user. In addition to requiring that Ann undergo frequent urine drug tests, he also demanded that her husband be screened as well. Unable to determine how best to manage Ann’s autoimmune condition, he referred her to a pain clinic at the local hospital. Once she was accepted at this clinic and attended her first appointment, the physician removed her from his roster, and she was once again without a family physician. Ann briefly found another general practitioner, but he left the

country because he felt he could no longer practice in the atmosphere of suspicion toward physicians prescribing opioids for chronic pain in Canada. At the time of our interview, Ann had not yet found another physician willing to take her on as a patient. She also received little support from the pain clinic.

Ann's account brings into focus a lifetime of seeking biomedical care and shuffling from one physician to another. Although her first physician dismissed her pain as psychological, Ann stayed at his practice for several more years because, from her understanding of the Canadian health care system, a person is expected to have an ongoing relationship with a family physician to access care. Much of the health work Ann performed over the years focused on developing or maintaining a patient-physician relationship. The gaps in care she experienced became longer and more disruptive as physicians grew increasingly fearful of prescribing opioids.

Like Ann, other participants recounted the work of finding and keeping a physician as critical to preserving their access to opioids. The work of becoming, and remaining, a patient occupied people's thoughts. When health care constitutes a complex of institutional relations that operate on the basis of coordination between patient-physician dyads, if a person with chronic pain cannot find a physician willing to enter into this dyad with them—either by accepting them onto their roster or by acknowledging that they do, in fact, merit biomedical investigation and intervention—the possibility of accessing biomedical health care is foreclosed. Trying to establish this patient-physician relationship emerged as a significant form of health work among participants.¹⁰

¹⁰ In some ways, my description of the importance people with chronic pain place on being legitimated as a valid patient seems to mirror Parsons' (1951) theory of the sick role. I did find, for instance, that people with chronic pain seek to establish themselves as patients with the goal of having their pain legitimized and to access care. However, I also found that being a patient emerged not so much as a role one adopted, but rather a set of relations initiated and maintained. Furthermore, in Parsons' work the sick role is understood as a transactional process in which the patient

For people whose chronic pain began in childhood, the work of entering a patient-physician relationship is particularly cumbersome as they are often met with lifelong disbelief from caretakers and physicians. Bill, for example, had lived with chronic pain since sustaining a sports injury at six years old. During our interview, Bill recalled the many ways in which his mother and his family physician dismissed his complaints of pain as a child: “I heard that all my life, ‘It’s all in your head, you’re lying, you don’t need any type of medication, you don’t need anything.’ I’ve heard everything.” It was not until eight years ago that Bill’s physician referred him to a pain clinic after he was forced to visit the emergency department for pain relief. At that time, the clinic specialist diagnosed him with arthritis, 27 years after his initial injury. More recently, Bill has been tentatively diagnosed with lupus.

Gendered dimensions of access to pain care also emerged throughout the interviews. This is not surprising, given longstanding evidence of clinicians’ dismissal of chronic pain linked to conditions gendered as ‘women’s diseases’ and the historical trend of associating chronic pain with women’s ‘hysteria’ (Golden, 2020). Many of the women I spoke with found that pain associated with menstruation was perceived as illegitimate, psychological in nature, or exaggerated. Brenda, for example, has lived in pain since she began menstruating at the age of eight. Although she saw several physicians as a teenager, they attributed the pain to her history of sexual trauma and abuse. It was not until her mid-twenties that a physician agreed to perform a

receives treatment, the right to be excused from social obligations, and other entitlements in exchange for meeting social expectations around patienthood, such as complying with physicians’ directives and showing genuine efforts to get better. In contrast, people with chronic pain saw the patient-physician relationship as a rights-based one rather than a transactional or reciprocal relationship. People with chronic pain and patient advocacy groups often draw on discourses of human rights in arguing that they have an innate human right to access biomedical care. They also frame relief of pain as a human right, drawing on language from the International Association for the Study of Pain around pain relief as every person’s right (IASP, 2004). Many participants argued that their status as Canadian citizens is reason enough to warrant access to care, and that physicians have a professional responsibility to provide efficacious care. These conceptions of patienthood signal the highly political nature of opioid prescribing.

laparoscopy and diagnosed Brenda with endometriosis. In total, she lived in pain for 17 years before receiving a diagnosis. Similarly, Elle developed migraines at the age of twelve when she began menstruating. Although the pain was so severe she would sometimes vomit on the walk to school, her parents and family physician assumed she had mild, occasional headaches and that she was exaggerating her symptoms. It was not until she was in her twenties that Elle was able to see a physician who diagnosed her with migraines and began treatment.

For people with chronic pain, and especially those who develop chronic pain in childhood or in relation to feminized illnesses, the health work involved in maintaining a patient-physician relationship never truly ends. There was no endpoint at which any of the participants felt comfortable in their relationship with their physician; they described a guardedness and alertness toward any sign from their physician that the patient-physician relationship might be terminated. Patienthood requires constant work of proving to the physician that one is a responsible, hardworking pain patient as opposed to ‘lazy’ or ‘histrionic’ drug seekers. Similarly, a diagnosis was not seen as a milestone to reach or a final verdict to be received by the patient from the physician. Participants held complex views of diagnosis, and diagnosis emerged in the interviews as a precarious position requiring numerous forms of health work to maintain.

2.5 WORKING TOWARD A DIAGNOSIS

Diagnosis has been of central concern for social scientists studying health, illness, and medicine. Within biomedicine and other medical cultures, a diagnosis is expected to trigger actions and consequences including—but hardly limited to—treatment (Jutel, 2011). As Jutel (2009) notes, diagnoses are also expected to play several roles: they create social order, classify illnesses,

segment and order corporeal states, identify treatment options, predict outcomes, provide an explanatory framework, and enable access to services such as health care and sick leave. Diagnosis guides medical care and defines the medical profession as physicians are set apart from laypeople and other professionals by their authority to construct a diagnosis.

Particularly important to the study of diagnosis has been an orientation to diagnosis as a process of classification and differentiation through which some symptoms and states come to be understood as pathological (Jutel, 2011; Rose, 2013; Brown, 1990). This includes the creation of new illnesses, such as the medicalization of experiences and aspects of life not previously pathologized (Conrad, 2007) and the production of illness states based on potential future risk of disease as in the case of high cholesterol (Jovanovic, 2014) and pre-conception care for non-pregnant women (Conrad and Waggoner, 2017). Medical sociologists and anthropologists have also taken up the use of novel biotechnologies and disease classifications to produce new “diagnostic cultures,” including mental health disorders and forms of neurodivergence (Brinkmann, 2016; Ronberg, 2019; Lane, 2020; Witeska-Młynarczyk, 2018).

Likewise, attention has been paid to the value of a diagnosis for those who receive one; these benefits are perhaps most evident in the case of contested illnesses and medically unexplained symptoms. Nettleton (2006) and others have argued that those who live with symptoms for which there is no diagnosis to act as an explanatory framework are challenged with doubt and uncertainty from those around them including medical professionals and loved ones. For people with medically unexplained symptoms, a diagnosis is expected to not only legitimate the person’s suffering but to also grant access to treatment (Madden and Sim, 2015).

In contrast to the intended biomedical trajectory in which a patient perceives symptoms of illness, seeks medical care, receives a diagnosis, and then comes to be treated until their symptoms

are relieved, for people with chronic pain, the ‘steps’ of receiving a diagnosis followed by treatment are rarely sequential. Diagnosing chronic pain in the Canadian health care system is an onerous task. A frequently cited obstacle to diagnosis for chronic pain is confusion regarding where a person with chronic pain should be seen and cared for. For instance, although several participants developed chronic pain following an injury requiring emergency services, the emergency department, as well as the bulk of services offered in-hospital, are structured for acute care (Hansen, 2005; Wilsey et al., 2008). In terms of outpatient services, general practitioners tend to have a poor knowledge of chronic pain and treatment options (Green et al., 2001).

Furthermore, I found that for people with chronic pain a diagnosis shapes the care they receive in ways that differ markedly from those typically associated with diagnosis in both clinical and social science literatures. While people with chronic pain engage in extensive forms of health work over weeks, months, and years to arrive at a diagnosis that explains the cause of their pain, most of the people I interviewed found that a diagnosis did not meaningfully impact the pain care they received, although the reasons for the irrelevance of a diagnosis have shifted over the last three decades. According to participants, during the 1990s and early 2000s the prevalent medical culture was one of prioritizing pain relief and orienting to opioid analgesics as highly efficacious medicines with minimal adverse effects. Their views echo historical analyses that compare the emphasis placed on pain management and reducing suffering during this period to contemporary attitudes toward pain and opioid use grounded in suspicion and opiophobia in the face of rising concerns around the opioid crisis (Comerci et al., 2018; Van Zee, 2009; DeWeerd, 2019; Alpert et al., 2022; Jiang, 2020).

For people with chronic pain who first sought pain care during the 1990s and early 2000s, the majority of whom were not diagnosed until months, years, or decades following the first

sensation of pain, whether they had a diagnosis or not tended to have little impact on the treatment they received. In nearly all cases, participants were treated with some kind of analgesic—typically an opioid—before their pain was diagnosed. Others received different diagnoses over the years, but their treatment remained unchanged. Most people were treated through trials of pharmaceuticals aligned with the ‘ladder’ still taught in Canadian medical schools;¹¹ these trials were initiated regardless of whether the person had a formal diagnosis.

On the other hand, starting in the late aughts, people with chronic pain came to find that securing a diagnosis had little impact on the pain care they received not because of an emphasis on relieving pain at all costs but rather because physicians have grown reluctant to care for people with chronic pain and to prescribe opioids even in cases with a clear diagnosis. This shift was evident in my interview with Jennifer, who shared with me an account of the hurdles she faced in being diagnosed in the 1990s. When Jennifer was in her early twenties, she felt the first prickles of pain in her chest while away at university. Afraid she was having a heart attack, she rushed to the emergency department. After hospital staff confirmed she was not having any sort of cardiac event, Jennifer went to see an on-campus physician, who referred her to a pulmonologist. Her lungs were found to be healthy, and at that point the physician did not investigate further; as Jennifer explained, “They started throwing up their hands, and saying, ‘Sorry, we don’t know what to do.’” Later, she was referred to a rheumatologist, who was also incapable of identifying the problem.

¹¹ The World Health Organization (WHO) analgesic ladder was first proposed in 1986 to guide the relief of pain in cancer patients. The original ladder consists of three steps: non-opioid analgesics, weak opioids, and potent opioids (Anekar and Cascella, 2021). Since then, the ladder has been expanded to guide physicians’ prescribing practices for other forms of pain including chronic non-cancer pain. The ladder is also taught in medical schools, including Canadian medical curricula (Persaud, 2014). In my interviews with physicians, many of them referenced the ladder as the primary way they were taught to prescribe analgesics.

Frustrated and desperate for relief, Jennifer reached out to a pain clinic in another city. Although the specialist there was unable to arrive at a diagnosis, he began to administer nerve blocks for analgesia. The process of having the blocks done was in itself a tiresome ordeal and demanded a great amount of health work from Jennifer:

So that's injecting four of these god-awful, unbelievably painful spots that if he touches, I'll scream. So, I get four of these needles injected into spots, and the thing I find out, right, is most patients are sedated for this. I'm not. I get no warning. So, I come back, and he asks, 'Well, how did that work?' And I say, 'Well, I got some relief.' And he says, 'Alright! Then let's do the next side.' I did it because I got some relief. And he used to poke around to find the spots, he would say, 'Okay, that spot, is that where it hurts the most?'... It got to the point where I would mark the spots on my chest myself, so I wouldn't have to wait for him or have him poke all the way around. That helped me manage the pain a bit. But I was going to university. So, when I was going back for my second year, that meant every two weeks [...] I would miss an entire day travelling for treatments.

As Jennifer continued to receive nerve blocks, she went back to her physician one last time to see if she could be diagnosed. She was first referred to a physiatrist working in a rehabilitation medicine clinic, who repeated a pulmonary function test and found nothing wrong with her lungs. Next, she was referred to an endocrinologist, who also found nothing. In her third year of university, exhausted from traveling for nerve blocks and for specialist appointments, Jennifer was referred to a rheumatologist who finally diagnosed her with costochondritis—inflammation of the cartilage that connects the rib to the chest bone. The rheumatologist's first recommendation was to stop nerve blocks immediately, as they worsen inflammation. Instead, he prescribed high-dose aspirin, which relieved the pain completely.

The severe pain in Jennifer's chest wall returned in her early thirties when she was involved in a car crash while driving to work. This time, aspirin did not relieve her symptoms. Instead, in 2005 Jennifer was prescribed transdermal fentanyl patches, and these were highly effective at

relieving her pain until, in the early 2010s, her physician demanded she rapidly taper her dose. Although she had been diagnosed for decades and the original diagnosis was confirmed by a physician in 2010, Jennifer found that a diagnosis was not, in her words, “Your ticket to medication and whatever treatment you need.” Instead: “Nobody really cares about the diagnosis anymore, it’s more about my previous history of opioid use, or doctors trying to see if I’m a drug addict or not.” I discuss these shifts in physicians’ orientation to people with chronic pain and changes in the clinical gaze in the next chapter.

Jennifer’s experience was shared among participants. Simon, who has suffered from back pain since the 1990s, was only tentatively diagnosed with arachnoiditis—a painful condition caused by inflammation of the membranes that protect the spinal cord—in 2015. However, even without an explanation for his pain, in the 1990s and early 2000s Simon’s physician prescribed several treatments including a spinal stimulator, lidocaine injections, methadone, and morphine. When he was finally diagnosed in 2015, Simon had felt confident this diagnosis would open doors to new treatments. Instead, he has found that most of the specialists he is referred to are either unaware of his diagnosis or seem to place little value on it. As he explained:

Well, so my family doctor sent me to this new guy. And for him, he’s all, you know, “No opioids, absolutely no opioids.” I mean, the absolute littlest amount I was on—we’re talking 20 mg of morphine sulfate, and then the Suboxone, which does absolutely nothing—but he says, “No, not even that, we need to get you off all opioids.” So, when I first met him, I asked, “Do you even know what I have? Like, what my diagnosis is?” So, he told me, “Oh yeah, I looked at your file, I looked through it.” So, I said, “Oh, good, so you must know what my diagnosis is.” And he goes, “Mechanical back pain.” I looked at him, and I said, “Mechanical back pain, eh?” So, I tell him about the diagnosis [of arachnoiditis], what the radiologist said, the imaging, and it’s all in my file, but anyway, he goes, “Oh okay, right, right.” And then that’s all done, and then he turns to me and is still all about, “Okay, no opioids.” And here I was thinking, stupidly, I guess, but I was thinking like, ‘Okay,

now he knows what it is I have,’ and this is one of the worst pains experienced by man, I mean, just this awful, burning, nasty pain, so I’m thinking, ‘Now he knows what it is, and he’ll change his tune.’ But no, it didn’t matter. Same response.

Like Jennifer, Simon was startled by the insignificance of his diagnosis in determining his access to adequate pain care. He found particularly disorienting the contrast between physicians’ present-day reticence to prescribe opioids compared to their willingness in the 1990s, in his words, to “prescribe whatever I needed and whenever I needed it.”

Similarly, Chris, who has lived with complex regional pain syndrome (CRPS)¹² since the 1990s, described this decade during which he was first prescribed opioids as the “prescribe away period.” After undergoing six surgeries to attempt to repair a leg injury in 2001, he developed CRPS in his legs. When Chris was first injured in 2001 with a torn meniscus and medial collateral ligament, he was prescribed Percocet, but it proved ineffective in relieving his pain. After the first set of surgeries, he was then prescribed 80 mg daily of OxyContin—in those days, he remarked, “Nobody even batted an eye.” Following the surgeries, he tapered off OxyContin completely.

Two years later, Chris’ meniscus began to fray, so he underwent a meniscectomy.¹³ As the other meniscus frayed two years later, he had a second meniscectomy. Following a debridement surgery¹⁴, the surgeon diagnosed Chris with osteochondritis—a condition in which the bone underneath the cartilage of a joint dies due to lack of blood flow—and he performed microfracture

¹² Complex regional pain syndrome (CRPS) is a chronic condition characterized by pain of the extremities (Taylor et al., 2021). These sensations include pain in response to a stimulus that does not normally cause pain, as well as increased sensitivity to feeling pain. CRPS type 1 occurs without confirmed nerve injury, while type 2 is associated with a known nerve injury.

¹³ Meniscectomy is a surgical procedure that involves removal of part or all of a torn meniscus (fibrocartilage that acts as a shock absorber between the femur and tibia) (Jeong et al., 2012).

¹⁴ Debridement involves the removal of dead, damaged, or infected tissue; the most direct form of debridement is surgical excision (Steed, 2004).

surgery¹⁵ to relieve the pain. Chris was prescribed 120 mg of oxycodone daily. Following microfracture surgery, his pain worsened. However, the orthopedic surgeon confirmed that structurally, his leg had healed, and insisted Chris should not have been experiencing such a high level of pain.

Finished with his surgeries and still without a diagnosis, Chris was left without analgesics as the surgeon weaned him off oxycodone entirely. It was not until he was referred to a neurologist at a pain clinic that he was diagnosed with CRPS and, with this diagnosis, able to apply for disability benefits and request prescription analgesics. However, many years had passed since Chris' initial injury and surgeries, and panic around the opioid crisis was in full swing in 2015 when Chris tried to access pain care. Unlike in the past, Chris found that few physicians agreed to take him on as a patient, and even fewer were willing to prescribe opioids. Eventually, Chris found a family physician who agreed to prescribe a third of the daily dose of oxycodone he was previously prescribed. This dose has been inadequate in controlling his pain. In describing his frustration with the situation, Chris said:

That's the part that irks me, they know I'm in this extreme pain, they understand that I'm suffering, but nobody will step up and do anything about it because they're all worried about their [medical practice] license being under scrutiny. Even my general practitioner, who is very aware, we've had several discussions, and I'm still with him because he has a family member that's in chronic pain as well. And he gets it, like, I'm lucky to see him because every other doctor that I've seen up until five years ago, when I moved to [city], I had to go see them every thirty days, and do the piss test every thirty days or I wouldn't get my prescription. [...] And the thing is, I was part of the world where, "Here, take [opioids], take them, take them." I need them now, and it's, "Oh, now we're going to take them away." Huge turnaround.

¹⁵ Microfracture surgery is a surgical technique to repair articular cartilage by creating tiny fractures in the underlying bone. Blood and bone marrow seep out of the fractures and create a blood clot (super-clot) from which new cartilage develops (Patel, 2000; Centeno et al., 2008; Steadman et al., 2003).

For Chris, inadequate pain management has meant he is unable to work and, given the little amount he receives from disability benefits, he lives in poverty and is barely able to afford rent or food. For the past several years, he has used crutches to assist in mobility, and this long-time use has contributed to pain in his back. The significant amount of health work he performs to access an insufficient dose of opioids, including submitting to regular urine analyses and traveling every month to see a physician, must be performed while also trying to accomplish the work required to, in his words, “just barely stay alive,” including regularly moving to cheaper rentals in the face of rising costs of living and trying to manage his hunger on what often amounts to less than a meal a day.

2.6 MEDICATION PRACTICES IN CHRONIC PAIN MANAGEMENT

In this section, I draw on the concept of ‘medication practice’ as a form of health work comprising the activities people engage in around medication use for chronic pain. Medications—including over-the-counter and prescribed drugs—were a central topic of conversation as interviewees brought me through the arduous work involved in using analgesics for chronic pain. I explore some of the medication practices identified by participants with a particular focus on the work of using opioids. Although opioids are by no means the only medication used by participants, medication practices around opioid use were a major focus of conversation as recent changes in people’s ability to access prescription opioids have had significant impacts on their lives. Rapid shifts in public, political, and medical perceptions of opioid use for chronic pain, and resultant changes in physicians’ prescribing practices, have prompted people with chronic pain to alter their medication practices in response.

For these patients, coming to use medication, and especially opioids, for chronic pain typically entails a process many described as “trial and error.” Bill, for instance, had tried several different pharmaceuticals, including opioids, before arriving at a type and dose of medication that effectively relieved his pain with minimal adverse effects. Each time he was prescribed a new medication, Bill was sent home to monitor his pain levels and whether he experienced any adverse effects. This work of determining, in his words, “if [the medication] didn’t work the way I wanted it to work so I could function,” involved paying close attention to pain in different parts of his body and how it fluctuated throughout the day. Given the subjective nature of pain and how difficult it can be to communicate the bodily experience of being in pain, this process of trial and error is not as simple as noting pain levels for two weeks and making an objective assessment. Rather, participants reported a great amount of mental and emotional work as they try to be ‘objective’ in evaluating bodily sensations when, in the face of great pain, they generally prefer to disassociate from their bodies whenever possible.

In my interview with Chris, he also described a similar experience of trying different prescription medications until he achieved adequate pain relief. In addition to the work of monitoring his body and trying to compare different kinds, levels, and locations of pain, Chris also explained that many drugs produce withdrawal upon stopping and require a lengthy weaning period: “Let me tell you that Cymbalta, or Lyrica, or gabapentin were harder to withdraw from than opioids were. I puked for months. For over two weeks I couldn’t carry a glass of water from my counter to my kitchen table without spilling a bunch of it.” Many other participants have faced challenges with weaning off medication throughout the process of experimenting with analgesics. Some gradually taper their doses with the support of a physician, while others are given little

assistance in weaning and must devise their own strategies such as gradually reducing the number of tablets taken each day or consulting information online.

Coming to use opioids, and deciding which opioid to use, was described by participants who had first started using opioids before the early 2000s as a collaborative effort between themselves and their physicians. Robert, for example, had been using Dilaudid with some success, although he suspected he needed a longer-acting opioid for more consistent relief. He proposed a trial of transdermal fentanyl patches to his physician, who agreed. It took several months of trying different doses until Robert found that a combination of a 25 mcg and a 50 mcg patch relieved his pain without adverse effects. In describing this cooperative process, Robert said: “The doctor and I, we worked out what’s appropriate for me. I made the suggestion. Well, because I know just as much as he does.” Similarly, when she first started to use opioids for pain management in the 1990s, Rose had worked closely with her physician in determining an optimal dose of morphine. Although they agreed on a 3 ml dose of injectable morphine daily, Rose eventually returned to her physician and asked him to reduce the dose to 2.5 ml because she felt she could manage well on a lower dose and hoped to avoid possible adverse effects.

Participants who had been using opioids for several years felt that increasingly, this collaboration had given way to a more authoritative dynamic in which the physician decided what to prescribe at which dose. Ron, for instance, had worked well with his physician until things changed in 2018:

I eventually told her I wanted the prescription, I said, “Well, put me on Tylenol 4.” And I tried that, and I said it was no good. And so, she tried me on Percocet and that wasn’t any good. I said, “Well, maybe on hydromorphone it would be good.” So, she gave me that, and basically, I was on that all along right up to 2018. And then things started to get rough for doctors not wanting to prescribe. Because she wanted me to fill out a

contract, and after reading all the things in the contract, I didn't want to sign it because it's kind of making me guilty and making me look like an addict. You know, I don't drink, but you can't have a drink. Any alcohol, you can't buy it. Not any drug, even what you can buy over the counter, you're not allowed to buy it. Tylenol that's got a bit of something in it, you don't need a prescription, but you're not allowed that. There's all these things that it had on there that made me feel like a criminal. I didn't want to sign it, so she took me off my pills.

Cheryl has also faced similar tensions with her physician. When we spoke, although her pain was poorly controlled by the low dose of oxycodone he prescribed each month, she was afraid of admitting this out of fear that the physician would take it to mean opioids were not effective in relieving her pain and use the opportunity to stop prescribing opioids entirely. Given that she had been his patient for some time, and he had helped her in the past with managing her pain, Cheryl felt guilty for lying. However, the risk of losing her prescription was too great to consider being honest. Rather than, in her words, “rocking the boat,” she tried to manage her pain with the little amount she was prescribed while reassuring her physician that she was doing well.

2.6.1 Using Opioids in the Context of the Opioid Crisis

Like Ron, Cheryl, and other participants mentioned above, people with chronic pain have been affected by programs, guidelines, and policies put in place over the last decade as a response to the contemporary prescription opioid crisis in Canada. Fourteen participants were forced to rapidly taper their opioid dose, four people were taken off their physician's roster as the physician either refused to prescribe opioids or refused to treat people with chronic pain, and five people were allowed to remain on their physician's roster but were advised that their physician was no

longer prescribing opioids. Several participants were switched to opioid agonist therapy¹⁶ to provide analgesia without using opioids—five participants had either used Suboxone in the past or were currently using it, and four either previously or presently used methadone. In response to forced tapering, refusal from physicians to prescribe, and difficulty finding a physician, people with chronic pain have developed medication practices intended to preserve their access to opioids.

Holly's experience illustrates the impacts of interrupted access to opioids for one's health and quality of life. At the age of two, Holly began to communicate to her parents that the reason she cried so often was because she found it painful to sit. Her mother took her to nine different physicians until one investigated further and found a tumour in her spine. She was operated on that afternoon, and then treated with chemotherapy once it was discovered that the tumour was malignant and the cancer had spread to the bone. When the cancer kept recurring, a piece of her spine was removed, and she underwent radiation therapy for twenty days. The result was that where most people have a buttock, Holly has a concave dip that makes sitting very painful. Holly was passed between physicians until her mid-twenties, when two surgeons tried to use implants as a means of filling the gap. The surgery went poorly, and in addition to the pain she had been experiencing since early childhood, Holly subsequently developed sciatica.

Unsure how to remedy the results of the failed surgery, Holly's physician referred her to a pain clinic. After waiting over two years for an appointment, in the early 2000s she was accepted as a patient and directed to try aquafit, chiropractic treatment, and anticonvulsant medications. When these therapeutic modalities did nothing to relieve her pain, the physician decided to

¹⁶ Opioid agonist therapy (OAT) utilizes prescribed opioid agonists including methadone and buprenorphine (Suboxone) as a treatment for opioid use disorders (Tenore, 2008; CAMH, 2016). More recently, as opioid agonists have been found to have analgesic properties, OAT has become increasingly popular as an alternative to opioids given findings that may suggest a lower risk of adverse effects associated with OAT in comparison to opioids (Socias and Ahamad, 2016; Davis et al., 2018; Khanna and Pillarisetti, 2015).

prescribe oxycodone and morphine. With these opioids, Holly's life changed completely. She was able to put her energy back into her work as an artist, and she assisted her husband in his business and in caring for their pets. Then, after several years of opioid use with no adverse effects, in 2017 her physician informed her that he needed to drastically reduce her daily dose, as he was under investigation by the CPSO as an opioid 'overprescriber.' At their next appointment, Holly's physician tapered her dose to a quarter of what she had previously been prescribed. After suffering from withdrawal symptoms for a month, Holly's pain returned, and most days she found herself incapable of getting out of bed.

People with chronic pain shared similar experiences of abrupt interruption or restriction to accessing opioids for chronic pain management, typically in 2010 or later after they had been using opioids since the 1990s or 2000s with no complications or concerns. They also had in common shared strategies adopted to mitigate the impacts of changes in their access to opioids. For instance, many people diverged from their prescribed dose and did not use their opioids as directed so that they could set aside one or more tablets each day for an emergency stockpile that could be drawn upon for days when their pain was particularly severe. Ron adopted this strategy in 2019 when he realized that fewer physicians were willing to prescribe opioids: "I didn't have much [of a dose], but I was saving [pills]. I knew it was going to come down to this. So, if I could save a pill, I would save a little bit." Similarly, Robert was prescribed one pill every five hours, but he found he could usually forego his nighttime pills. He put aside most of his nighttime tablets and used them on days when his regular dose was ineffective at relieving his pain.

A few months prior to our interview, Bill, who had been using oxycodone prescribed by a physician at a pain clinic, wanted an extra bottle of pills in case he needed to get through a bad

bout of pain or in case of an emergency. When he asked his family physician for a second prescription of oxycodone, he was accused of double doctoring:

So, what I was trying to do is, I went to the doctor to get some extra medication, so I had a stock of medication. My doctors didn't see it that way. So, my family doctor took me off my pain medication, and so did my pain clinic doctor. So, it wasn't really a conversation where like, "oh, sorry, we're taking it away from you," no gradual wean off of it, no, nothing. [...] The thing is, my family doctor and the pain clinic were in communication. I told my family doctor I was getting pain medication from the pain clinic. So, my family doctor and the pain clinic knew. But when it came down to getting a prescription refill from the same [pharmacy] I'd been going to for years, they denied it, because I was getting two prescriptions all of a sudden. And that's when it came forward. And that's when they said, "Done."

Participants also adopted forms of health work such as modifying their dosing schedule when they were tapered to a dose that no longer adequately relieved their pain. Ron combined his morning and evening doses so he could work on his farm and maintain his rental properties in the first half of the day. Once the analgesic effect wore off, Ron returned home and rested in his chair for the remainder of the day. Robert, who was the sole caretaker for his wife who had end-stage multiple sclerosis, occasionally increased his daily dose if the physical work of moving his wife from her wheelchair or tending to her needs worsened his pain. In doing so, he had to account for each pill to ensure he would not run out before his next refill.

Likewise, Joan, whose pain resulted from repeated back injuries, also strategically managed the number of opioid tablets she was prescribed each month as a means of getting through the day. Since her physician had reduced her daily dose, Joan skipped her nighttime dose and instead took all the opioids she was prescribed in a day first thing in the morning. Although this allowed her to get more done during the day, she found herself incapable of sleeping without opioids. This change also impacted her husband:

For at least the last six months, I've woken up every single night, so much so that my husband is now sleeping across the hall, because I either wake both of us up or I try and hide my pain so much that I'm lying there biting the sheets to not wake him up. So, now he's sleeping across the hall, so that if I want to get up or move around or rearrange the heating pads or things like that, I can.

For those who do not accurately ration their tablets, the results can be disastrous. Simon, for example, was prescribed a very low dose of OxyNeo for breakthrough pain resulting from arachnoiditis. The low dose prescribed was not effective in relieving his pain, so Simon took additional tablets throughout the day. Inevitably, he would run out of pills after two or three weeks, and then he suffered in agony until the next month when his prescription was renewed. On one such occasion, the pain was so unbearable he nearly took his own life until he convinced himself to walk to the emergency department. He received analgesics at the hospital, and he has since used other therapeutic modalities such as Suboxone in an attempt to relieve his pain.

Another common medication practice is the strategic use of opioids to avoid adverse effects including tolerance and addiction. Without telling their physicians, many people halve their doses, take their medication as needed rather than on a schedule as prescribed, or take breaks where they do not use opioids at all. Kayla, for example, was fearful of the addictive potential of opioids. Although she was prescribed tramadol for the severe pain she suffered due to CRPS, she rarely followed the prescribed dosing schedule:

My mother-in-law was staying with us, because she doesn't live in Canada, and she commented, she goes, "So when do you start to take one [pill]?" And I said, "When I start to cry, I take one. Up until then, I just live in pain." Because I'm really trying to be aware of the fact that they are addictive, and so I'm trying, I can take up to two pills every four hours, but I don't follow that. When I need them, that's when I take them.

Similarly, over the twenty-five years Ann used oxycodone, every month she took a "week off" where she did not use any opioids at all. She found that she tolerated oxycodone quite quickly, and

so she maintained this schedule as a means of avoiding tolerance over time. Although Ann informed her physician of this practice, he refused to believe she was capable of not using oxycodone for a week.

Despite careful adoption of medication practices intended to counter the challenges people face in accessing opioids, eventually their stockpiles dwindle, or their doses are tapered to a fraction of their previous prescription. The impacts of losing access to effective analgesia are immense. For example, whenever Simon uses up his prescribed tablets within the first week or two of the month, he spends the remaining weeks in a state of pain so severe he struggled to describe it. Since the terrible month I referenced above when the pain had been so severe he nearly took his own life, Simon has suffered from flashbacks, nightmares, and other symptoms of post-traumatic stress disorder. Without access to effective analgesia, Simon's quality of life is abysmal. As he told me:

The hardest part is not being able to live a normal life. Go to sleep, get a job, that's part of it, but also enjoyment. When I see the beer commercials or boat commercials, and I see someone out there, on the beach, on the dock, I wish I could cry. I look at it and almost go blank. I go, "How do people enjoy these things? And how could I enjoy these things? How was I able to do that?" I can never commit to anything with friends. I've missed funerals because of this pain. The last one, this guy I worked with, two weeks ago I missed his funeral, and I talked to his sister, and she knows, and I said, "Oh, God...I'll try to make it." But I couldn't, I was knocked out, the pain was so bad. But she knows, and I'll call her sometime soon, but it's just embarrassing.

Many others suffer in similar ways. Brenda, who was forced to switch from oxycodone to hydromorphone and then forced to very rapidly taper her dose, found the pain so overwhelming that her blood pressure increased to the point she suffered a stroke that left her legally blind in her left eye.

Likewise, a few years prior to our interview, Jennifer had been admitted to the hospital for mental health concerns. A nurse noticed her lips were blue due to the cold temperature of the room and alerted a physician. The physician suspected she was cyanotic due to her fentanyl patches and abruptly tapered her 75 mcg patch to a 50 mcg patch. The resulting pain was overwhelming, and the rapid taper caused withdrawal and severe adverse effects. Similarly, when Lisa's physician retired and she was switched to a new practice, the physician agreed to prescribe one more refill of oxycodone and then refused to prescribe any other opioids. Two weeks later, she asked Lisa to return to her office, and demanded she pee in a cup in front of her for a drug screening. Once the last refill of oxycodone ended, Lisa went into withdrawal and became violently ill. Until she found another physician willing to prescribe opioids, she lived a life of "absolute terror and horrible pain" and lost nearly all mobility as a result.

In light of changes in opioid-related policies and programs and physicians' reluctance to prescribe as a result, many people compared the social activities they had engaged in while using opioids to the isolation they now experienced. Brenda spoke wistfully of the twenty years she used oxycodone for endometriosis, describing volunteer activities at her son's school, the long walks she took with friends, and the social events she attended. Since her physician had tapered her dose following an investigation by the CPSO, Brenda described her life as a reclusive one: she spent most days on the couch, and she struggled to walk her dogs.

Rose had also been capable of going out for walks using her cane, caring for foster dogs, and leading what she referred to as a "normal life" during the time she was prescribed injectable hydromorphone. When her physician was investigated by the CPSO and shadowed by another practitioner, he refused to continue prescribing opioids, and Rose's quality of life declined. Rose was isolated in her home and saw few friends. As she told me: "I have no quality of life. I'm just

existing, and not very well.” Last we spoke, she had applied for medical assistance in dying (MAID). While writing a final draft of this dissertation, I learned through mutual friends that her application for MAID had been accepted following changes to legislation in Ontario. Rose died at home through medical assistance after what she once described to me as a “long, drawn-out battle” with chronic pain.

2.7 PROVING ONE’S LEGITIMACY AS A ‘PAIN PATIENT’

A final medication practice that emerged in my interviews with people with chronic pain was the work of proving their legitimacy as ‘pain patients’ as opposed to ‘addicts.’ As I have discussed in this chapter, entering a relationship with a physician and being recognized as a patient is vital if people with chronic pain are to access opioids for pain management. To this end, they take up medication practices aimed at proving to health care providers and other people in their lives they are not addicted to opioids and that they use them solely for medicinal purposes.

Across my interviews with people with chronic pain, I found they were insistent on emphasizing their distinction from addicts. The ways in which they drew this distinction, and their descriptions of ‘legitimate pain patients’ versus ‘illegitimate drug addicts,’ were strikingly similar. For people with chronic pain—and, as I later found, for physicians and other health care providers as well—pain patients are understood to be people who use opioids for the ‘legitimate’ purpose of treating pain. From the perspectives of the people with chronic pain and practitioners I interviewed, legitimate pain patients are expected to never experience a ‘high’ or change of consciousness or perception when using opioids. If they do experience any of these effects, these should be

unwanted and distressing to the patient. Furthermore, pain patients are expected to acquire their prescription through licit channels: from a licensed physician and a pharmacist.

Although according to participants, legitimate pain patients do not necessarily have to comply completely with physicians' directives, there are still strict boundaries delineating 'correct' and 'incorrect' forms of opioid use. For instance, while participants believed that drug addicts sell their prescriptions or give them to other people, in contrast, legitimate pain patients are framed as not profiting from their opioid use in any way, and their use of opioids is not considered to put public health at risk. And, while there was some acknowledgment that legitimate pain patients may have to contravene physicians' orders by modifying their daily doses for the purpose of better alleviating their pain, these medication practices were perceived as acceptable only if they were in response to physicians' reluctance to prescribe opioids for chronic pain. Finally, for people with chronic pain and clinicians, legitimate pain patients were distinguished by their ability to stop using opioids at any time. According to their understanding of acceptable opioid use versus addiction, while pain patients may experience symptoms of withdrawal due to physical dependence, they were perceived to be in control of when they start or stop using opioids.

As my research progressed and, in addition to interviewing people with chronic pain, I also interviewed health care providers and analyzed several policy and regulatory texts, I came to find that participants' preoccupation with being designated as legitimate pain patients is well justified in the face of changing medico-legal conceptions of opioid use and forms of clinical governance described in the next chapter. As such, I was not surprised to find that people with chronic pain adopt diverse medication practices intended to prove their legitimacy as pain patients.

Joan, for instance, whose physician refused to increase her dose of opioids because he suspected she had an opioid use disorder, once took less than half of her thirty-day prescription

and brought eighteen days' worth of pills to her next appointment. She insisted the physician count them himself to verify her claim that she could stop using opioids at any time. Jessica, who had been accused of drug addiction by several physicians, also stopped using opioids to prove she was not addicted. After picking up a refill of Dilaudid and Tramadol, she waited until the end of the month before returning the bottles, almost completely unused, to the pharmacy. She asked for a receipt verifying the number of pills returned, which she presented to her physician. Finally, he seemed to believe her: "I presented that receipt to my chronic pain doctor, and I said, 'See, I'm not an addict.' He said, 'Now I know you're not an addict. You were never an addict.'"

Stories of participants weaning themselves off opioids to prove they are not addicted were common. When she was accepted to a ketamine infusion clinic, Cheryl was advised she needed to lower her dose of fentanyl before beginning treatment. Without medical help or supervision, she weaned herself from 225 mcg daily of fentanyl to 0 mcg over the course of four months. Cheryl stopped using fentanyl not only to be accepted as a patient for ketamine infusions, but also to prove to her physicians she was not an addict after they had accused her of such for several years. Unfortunately, Cheryl's feat at weaning herself was met with disbelief, and her medical chart still indicates she has an opioid use disorder.

Another commonly used strategy entails using analgesics that are not as effective as opioids in the hopes physicians will recognize one's willingness to consider non-opioid treatments and, as a result, recognize the person's legitimacy as a pain patient. Participants repeatedly emphasized the importance of presenting themselves, their complaints of pain, and their experiences with opioids such that they do not appear, in their words, as "obsessed with opioids," "addicted," or "drug seeking." Instead, although the majority of interviewees had years of experience trialing different treatments and knew whether an analgesic would be efficacious or cause adverse effects,

nonetheless they deferred to physicians and agreed to try different proposed pharmaceuticals and therapies including massage, physiotherapy, and chiropractic treatment. As Rose explained:

You already know when you get one of those doctors, you walk in the door [to their office] and they're going on about trying these pills you've already tried before. And then I think to myself, 'Oh boy, here we go.' Because you don't want to go in there and start to list every single pill you've ever taken. I know I've tried every single option this doctor is going to recommend and probably some he's never even heard of. And I've been for massage, and maybe sometimes it might help, but I can't afford to go, so that's a bit of a pointless conversation. But to go in there and say, "I've tried all that, and I'm telling you, the only thing that works for me is the hydromorphone injections." As soon as I say that, in their minds, it's, 'Drug seeker, drug addict, opioid addict.' [...] It does get frustrating because this is years of my life I've spent trying every pill out there, but for them, none of that matters. So, every single doctor, we start at step one again. It's hard not to think to yourself, 'What's the point anymore?'

Although Rose saw her years of experience trialing different treatments as a valuable asset for quickly determining what therapies might work and which would likely be ineffective, from repeated instances of being met with suspicion and derision from physicians who accused her of demanding opioids or 'drug seeking,' Rose learned to, in her words, "Sit back, let them talk, and just nod and say, 'Uh huh, uh huh, sure.'"

Patients' work of navigating the patient-physician relationship in this way have typically been understood through Goffman's concept of 'impression management.' Studies of patients' efforts to control the context of social interaction and to shape others' impressions and expectations toward them have included explorations of impression management by people with chronic illnesses (Vickers, 2017; Maxwell, 2016), experiences of adapting to and managing stigmatized diseases (Grytten and Måseide, 2005, 2006; Livneh et al., 2014), and, in the case of chronic pain, the work of presenting oneself as a credible patient (Werner and Malterud, 2003; Frantsve and

Kerns, 2007) and the careful construction of the self and physical sensations of pain so as to avoid accusations of hysteria or malingering (Werner et al., 2004; Malat et al., 2006).

Through my interviews with people with chronic pain, I identified numerous forms of work that can be understood through the concept of impression management. However, my focus on medication practices led me to consider not only the work of managing the patient-physician relationship, but also the work required to sustain this relationship that takes place outside of clinical settings. For people who use opioids for chronic pain management, the work of presenting themselves as legitimate patients as opposed to drug addicts extends beyond the physician's office and into the patient's home. For Rose, convincing the physician she is a legitimate patient has required not only keeping quiet during appointments and deferring to the physician's expertise, but also managing her pain at home when she is prescribed analgesics and referred for treatments she knows in advance will be ineffective but are necessary to trial so as to demonstrate she is not fixated on opioids.

Many other participants engaged in similar forms of health work and medication practices wherein they agreed to try analgesics they knew would be ineffective as a way of gaining their physician's trust and establishing themselves as credible patients. Lisa, who suffers from interstitial cystitis, found OxyContin to be highly effective in relieving her pain until, under pressure from the CPSO, her physician stopped prescribing opioids. As a substitute, the physician prescribed medical cannabis, but Lisa has found cannabis jumbles her thoughts, causes drowsiness, and makes it difficult to care for her two children. Likewise, although her physician suggested as a compromise that she use a low dose of morphine or Percocet, Lisa knew from past experience these opioids do not relieve her pain and cause serious adverse effects. Nonetheless, to demonstrate she is willing to, as she put it, "play the game and not be difficult," Lisa has agreed over the years

to repeated trials of cannabis and other opioids. Each new trial, she suffers from withdrawal and a severe recurrence of pain.

Lisa, Rose, and other participants who reported similar experiences of agreeing to try analgesics they knew in advance would be ineffective engage in various forms of health work as they attempt to manage their pain and sustain their quality of life during these trial periods. In many ways, these weeks or months of experimenting with treatments are ‘waiting periods’ akin to those described above. Lisa, in recounting the work of using analgesics she knows will be ineffective, explained: “For that month, my life is on hold completely, because I can barely get out of bed.” She survives these periods of trialing ineffective treatments by drinking large amounts of water, using heating pads, sleeping most of the day, avoiding tight clothing and acidic foods, and trying in the midst of unbearable pain to relax and avoid stress.

Similarly, Chris has seen several physicians over the years who have insisted he try non-opioid pharmaceuticals including gabapentin and pregabalin, despite his previous experiences of using these analgesics and finding them to be ineffective. He described harrowing days spent building up to the prescribed dose, and then, inevitably, finding that the medication did not adequately relieve his pain and caused adverse effects including nausea, vomiting, and weakness. Each time a physician recommends a trial of a pharmaceutical he knows will be ineffective, Chris prepares himself for the trial by purchasing large quantities of over-the-counter medication, clearing his schedule of all appointments and obligations for four or more weeks, and, in anticipation of being unable to leave his home due to the pain, stocking up on food—a difficult feat given his small income from provincial disability support payments.

For people with chronic pain, medication practices intended to prove their legitimacy as patients can cause extended periods of pain and reduced quality of life. As in the case of many of

the forms of health work described in this chapter, participants oriented to these practices as “trade-offs” or, in Jennifer’s words, “Short-term pain for hopefully long-term gain.” The growing urgency to distinguish themselves from drug addicts has meant people with chronic pain must demonstrate disinterest in opioids, willingness to defer to the physician’s expert knowledge, and readiness to try any proposed non-opioid treatment, even in cases where a medication or therapy has been ineffective or harmful in the past. Practices including weaning off opioids and modifying one’s dose are also common strategies used to prove one’s credibility as a pain patient who is not addicted to or dependent on opioids. As I discuss in chapter three, these activities are coordinated with physicians’ work of adapting to new forms of governance and surveillance in the contemporary era of heightened opioid pharmacovigilance.

2.8 CONCLUSION

In this chapter, I grounded us in the everyday lives of people with chronic pain through careful examination of the health work they perform on a day-to-day basis. Following an overview of the social science literature on conceptions of work, health work, and medication practices, I went on to discuss the work of becoming a person with chronic pain, seeking a diagnosis, waiting, maintaining the patient-physician relationship, and experimenting with different treatments. I also focused on novel forms of health work adopted by people with chronic pain as a means of adapting to shifts in the organization of opioid use for chronic pain in Ontario since the late 2000s. These medication practices include putting aside tablets to build an emergency stockpile, learning to wean oneself off opioids, and choosing not to use opioids or to use ineffective analgesics to prove to physicians and others one’s legitimacy as a pain patient as opposed to a drug addict.

In identifying these forms of health work, one of my analytical strategies has been to take up people's everyday doings within the wider contexts of their daily lives. Rather than isolating individual actions and examining them in a vacuum, I approached my interviews and, subsequently, data analysis with the aim of understanding participants as more than merely people with chronic pain. Ultimately, my goal has been to convey what life in a chronically painful body actually looks like without objectifying people with chronic pain as the object of study. Within the wider arc of this dissertation, this chapter serves to establish the standpoint from which traces of these ruling relations become visible.

In the next chapters, I move on to examine the medico-legal ruling relations made visible from the standpoint described in this chapter. These ruling regimes include neuromedical conceptions of drug use, provincial and federal criminal-legal systems, discourses of racialization around opioids and those who use them, coercive means of monitoring and penalizing physicians' opioid prescribing practices, evidence-based medicine, and medical professionalization. Reproduced through the coordinated activities of a plethora of actors including physicians, other health care providers, members of medical regulatory colleges, policymakers, and people working at institutions including Ontario's Ministry of Health and Long-Term Care and Health Canada, these ruling relations bear on the everyday lives of people with chronic pain and shape their ability to access opioid analgesics for pain management.

CHAPTER THREE

3.1 INTRODUCTION

This chapter focuses on the emergence of medico-legal responses to the contemporary opioid crisis in Ontario and elsewhere and the ways in which physicians have adopted new prescribing practices to protect themselves from heightened surveillance, investigation, and punishment by the state and their regulatory college. I argue that these interventions into physicians' everyday work of prescribing opioids have shaped the organization of opioid prescribing, dispensing, and use such that physicians prescribe opioids for chronic pain with an eye toward not only relieving the patient's pain but also protecting themselves from penalties including losing their license to practice and public shaming. New forms of work adopted to avoid these punitive measures have had significant impacts for people with chronic pain who use opioids who, in contrast to previous drug scares, are not the object of criminalization or regulation but nonetheless endure tremendous suffering as physicians' altered prescribing practices interrupt their access to opioids for pain management.

My analysis of new forms of governance and physicians' work of prescribing opioids proceeds in two parts. First, I begin by mapping the ruling relations that produce hybrid medical and criminal-legal responses to opioid use that have characterized drug regulation in Canada¹⁷ and elsewhere. I examine the contemporary panic around the perceived crisis of opioid-related harms in view of changes in the medicalization and criminalization of opioids. In tracing this historical

¹⁷ It is important to recognize that the history of opioid use that I detail in this chapter is limited to a largely Eurocentric focus on North America, Europe, and some parts of Central and South America. In focusing on opioid use in the nation now known as Canada, I limit this history to the last two centuries and the emergence of opioid use pre- and post-Confederation. Although Indigenous practices of drug production, trade, and consumption are beyond the scope of this dissertation, important work on this history includes Williams and colleagues' (2020) study of Indigenous Hawaiian psychoactive drug use, Henderson and colleagues' (2022) historical analysis of tobacco use on Turtle Island, and Logan and colleagues' (2012) research on the use of fermented beverages in South America.

arc, I contend that contemporary medico-legal governance of the opioid crisis has differed markedly from prior panics around drug use in that it is not opioid users who have been targeted as principally responsible for the crisis but rather the physicians who prescribe opioids, the regulatory colleges that regulate their use, and the pharmaceutical industry that develops and markets them. I examine this shifting of blame away from opioid users in association with emerging neuromedical discourses of addiction, the racialization of the opioid crisis as a ‘white crisis,’ and the resultant conception of prescription opioid users as blameless victims.

Next, I discuss medico-legal responses to the opioid crisis that have emerged as interventions into physicians’ opioid prescribing practices. In particular, I focus on the introduction of Ontario’s Narcotics Monitoring System in 2012 and how data derived from this system has been used by the state and the medical regulatory college to monitor, investigate, and punish physicians. I suggest that unlike techniques of governing-at-a-distance and self-surveillance associated with the medical profession’s right to self-regulation, these interventions have been highly coercive and punitive in nature. I then move on to describe some of the ways physicians have responded to these new forms of surveillance and punishment, including rapidly tapering patients’ opioid prescriptions, refusing to prescribe opioids altogether, and orienting to patients with suspicion and skepticism. I also highlight the impacts of physicians’ changing work practices on the patient-physician relationship and the erosion of trust resulting from these shifts.

3.2 THE ORGANIZATION OF PRESCRIPTION OPIOID USE

Opioids are a unique class of drugs whose status as licit or illicit is highly contentious. In Canada, while opioid use was largely unregulated pre-Confederation, in the late nineteenth century

onwards the status of opioids and their classification as either poison or medicine has been central to the complex of relations organizing medical and pharmaceutical professionalization, drug regulation, the development of the pharmaceutical industry, and international trade (Courtwright, 2001). The status of opioids as prescription or recreational drug and resulting changes in their legality and public perceptions of their use have had significant consequences not only for people who use opioids but also for those who prescribe and dispense them.

The history of opioid use and regulation in Canada has generally followed what many authors have described as a ‘swinging pendulum’ wherein at one end of the pendulum opioids are lauded as essential medicines, while at the other end they are renounced as dangerous poisons that threaten harm not only to the individual but also to public health and to the nation as a whole (Comerci et al., 2018; Rieder, 2018; Von Korff, 2012; Atkinson et al., 2014; Yealy and Green, 2016). The status of opioids as licit or illicit drugs is the culmination of decades of inter-professional debate, changing professional scopes of practice, the introduction and subsequent amendment of legislation, and evolving social, moral, medical, criminal, and political conceptions of opioids that have shifted the pendulum from one end of the spectrum to another (Hoffman, 2014; Murray and Sikora Newsome, 2021; Kilgore, 2017).

My analysis of the history of drug regulation and use in Canada orients to this history through the concept of the medico-legal borderland. This concept was introduced by Timmermans and Gabe (2003) to account for the discourses, professional specializations, institutions, and subjects that emerge from the intersections between medicine and the criminal-legal system (McClelland, 2013). As opposed to attempts to distinguish medicine and the criminal justice system as distinct forms of social control, Timmermans and Gabe call for an approach that recognizes that in many jurisdictions, social control is achieved through the process of defining

actions through a hybrid of medical and legal principles (Timmermans and Gabe, 2003). These hybrids cannot be reduced to their separate parts; rather, it is the interweaving of the medical and the legal that characterizes the activities taking place at this borderland.

The concept of the medico-legal borderland has been taken up to explore how actions once criminalized have come to be seen as medical, actions once medicalized have come under criminal-legal jurisdiction, and hybrid responses have emerged in response to actions that fluctuate at the intersection between disease and criminal behaviour (ibid). Research on HIV criminalization, for instance, has situated responses to HIV within the medico-legal borderland as a means of accounting for hybrid medical and criminal-legal responses to HIV infection. Mykhalovskiy (2011) takes up HIV prevention efforts and considers how this work is performed within a medico-legal borderland in which public health, criminal law, and governance are coordinated by the idea of significant risk. Sanders (2015), in his work on HIV criminalization and resulting changes in patients' and care providers' practices, describes public health nurses' work as they change the way they document post-test counseling sessions.

The constitution of addiction as a disease and/or a criminal behaviour is another space where intersections of medicalization and criminalization are visible. As Bourgois and Schonberg (2009) observe, medical definitions of substance abuse and addiction have long included references to 'maladaptive behaviours' such as recurrent legal problems as a category that combines both medical and criminal-legal concerns around drug use. Research within the space of the medico-legal borderland also draws our attention to questions of gender, sex, race, and other social locations that shape medicalization and criminalization. For instance, in her work on HIV criminalization and racialization, Manning (2019) argues that the medico-legal borderland must be understood not only as a space where medicine and law intersect, but also as a contentious

borderland shaped by racial hierarchies and white supremacy. Likewise, patriarchal relations of sexism and cissexism mediate the interconnecting relations constituting the medico-legal borderland. Knight (2017) discusses opioid-dependent parenting as occurring at the intersection of criminality and clinical care.

Examining the contingent space between medical and criminal conceptions of and responses to drug use has been pivotal to my analysis of the organization of opioid use for chronic pain. Investigating both medicine and the criminal-legal system as ruling relations through which opioid prescribing and use are monitored and organized has made it possible to recognize how it is that people with chronic pain have come to experience interruptions to their access to opioids despite the fact that they are not the object of regulatory responses. Likewise, as Timmermans and Gabe suggest, the medico-legal borderland is also a site of struggle and of third-way solutions (Timmermans and Gabe, 2002). Although conflicts may erupt, these tensions also open the possibility of undermining dualities between medical and criminal conceptions of drug use, and of imagining more equitable and humane responses to increases in opioid-related harms.

3.3 OPIOID USE AND REGULATION IN CANADA

While the first Opium Act in Canada was introduced in 1908, the Canadian regime of drug control began prior to the twentieth century and continues to extend into the present. Generally, in Canada and elsewhere, the legality of a drug has depended on its status as a medicine controlled by legally recognized health care providers such as physicians and pharmacists and used for ‘legitimate’ or medicinal, i.e., non-recreational, purposes (Acker, 2002). The status of a drug as licit or illicit has also depended on social, cultural, and religious understandings of its primary

purpose (Adrian, 2003). Regardless of how a state or regime of ruling makes this distinction, defining any substance as a ‘drug’ as opposed to a licit pharmaceutical has meant that it must be socially controlled through a formal apparatus, whether that apparatus is the medical profession, national and international legal mechanisms, or a hybrid of both (ibid.).

The history of legislation around opioid use in Canada demonstrates how regimes of ruling have come to determine which drugs are medicinal, which are poisonous, and in which contexts (Malleck, 2015). In Canada and elsewhere, the contemporary distinction between legal and medicinal versus illegal and recreational drugs emerged in large part due to physicians’ and pharmacists’ efforts to gain control over access to drugs and the right to determine the medical uses of drugs beginning in the late nineteenth century. At times, these professions competed for the exclusive right to perform restricted activities such as prescribing opioids, while at other times they formed coalitions to challenge government regulation.

One such alliance took shape in the 1870s as physicians and pharmacists challenged government intervention into medicinal drug use. Practitioners argued that medical authority and expertise meant they were uniquely capable of regulating drug use. They further claimed that government meddling in medicine would compromise professionals’ ability to exercise their clinical judgment in caring for patients (ibid.). These arguments were supported by the growing movement in medicine and pharmacy to position these professions as scientific enterprises with access to objective knowledge that sets them apart from other professions.

Despite tensions between the medical and pharmaceutical professions as they attempted to expand and solidify their scopes of practice, between the middle of the nineteenth and beginning of the twentieth centuries the legal status of pharmacists changed as pharmacy established itself as a profession entitled to set criteria for licensure and to self-regulate (ibid.). Provincial pharmacy

acts establishing the legitimacy of pharmacy as a profession introduced lists of substances whose control was restricted to physicians and pharmacists. These poison schedules framed poisons as substances that could cause significant deleterious effects to the body (most concerning of which was ‘poisoning’—acute overdose that could result in death) if dosing and use is not carefully monitored by an expert. Pharmacy acts identified physicians as the experts who held authority to monitor use of poisonous substances and recognized the physician’s prescription as the means through which patients could obtain scheduled substances, although some freedom was given to pharmacists to assess purchasers’ character and to sell certain restricted drugs to individuals with whom they were familiar.

Early pharmacy acts empowered pharmaceutical associations to identify substances that should be added to provincial poison schedules. The Ontario Pharmacy Act of 1871, for instance, put forward a poison schedule that included not only opium, its preparations, and morphine, but also poisonous chemical elements and compounds (*ibid.*). Through these poison schedules, certain drugs were identified as medicinal and therefore licit only when they were prescribed by a physician and dispensed by a pharmacist for medical purposes. What exactly constituted a ‘medical purpose’ was also determined by the professions. The illicit nature of non-medicinal opioid use was further entrenched with the introduction of the Opium Act in 1908, which barred the importation, manufacture, and sale of opium for non-medical purposes. As Malleck (2015) argues, this act was “one of a set of measures, spread out over three years, that ushered in the criminalization of drugs in Canada” (*ibid.* 215).

The rapid implementation of legislation intended to restrict opioid use took place within a larger movement toward prohibition fueled in no small part by concerns regarding the health of the nation. White supremacist ideals of a white, Eurocentric North America shaped growing public

and political concern that forms of drug use such as opium smoking by Chinese labourers risked compromising the nation's integrity (Logan, 1999). Fears that drug use and addiction might erupt into a public health crisis were informed by racist ideologies that supported the maintenance of the 'purity' of North American white nations (Moore, 2007).

Eugenics, a renewed focus on building a healthy, white nation, and growing political and public concern in the face of newer and more potent opioids such as morphine spurred the development of prohibitionary legislation at the beginning of the twentieth century. These regulations attempted to mitigate drug use by limiting internal and external influences tempting white Canadians to use drugs. Once again, conflicts between the professions and the federal, provincial, and territorial governments erupted as policymakers sought to restrict not only recreational drug use but also the harms associated with medicinal drugs. Of particular contention was the introduction of legislation restricting physicians' ability to prescribe opioids for maintenance purposes to people diagnosed as addicts (Boyd, 2021).

The history of opioid use following prohibition-era legislation has been marked by a swinging pendulum of attitudes toward opioids. The next six decades would witness shifts in regimes of drug control as, at times, opioids were medicalized and their use brought under the purview of medicine, while at other times opioids were condemned as poisons. The criminalization of drug use reached its height after Nixon's declaration of the War on Drugs in 1971 as the punitive and racist policies deployed to win this 'war' trickled across the United States and into Canada (Odeh, 2013; Gordon, 2006; Khenti, 2014). Public perception of drug use as concentrated in marginalized non-white communities, and the belief that drug use was a threat to white victims as these habits leaked out of urban areas into white suburban milieus, intensified drug criminalization

through measures such as the mass incarceration of Black young men throughout the 1970s onwards (Moore and Haggerty, 2001; Hansen et al., 2020; Lassiter, 2015).

Beginning in the 1980s, there was a gradual remedicalization of opioid use as opioids were taken up with renewed vigour by physicians concerned with relieving physical suffering in patients (Hastie et al., 2014; Leung et al., 2017). The resulting increase in prescription opioid use, particularly within the context of an emerging paradigm of addiction as a ‘brain disease’ and the concurrent racialization of opioid use as a white phenomenon, sparked new panics around white opioid use and threats to the nation’s health that have been pronounced as a public health crisis requiring urgent government action.

3.4 THE BRAIN DISEASE MODEL OF DRUG USE AND ADDICTION

While the roots of the contemporary opioid crisis stretch back to the nineteenth century, the centre of this drug-related panic hardened in the 1980s and 1990s with the concurrent development and marketing of prescription opioids and the new emphasis placed on ensuring rapid and effective pain treatment. In 1996, the American Pain Society designated pain as a fifth vital sign to be measured and treated alongside other vital signs such as respiratory rate (Jackson, 2002; Campbell, 2016). The urgency placed on attending to pain was reflected in medical curricula and prescribing practices as clinicians were expected to mitigate the risk of leaving pain untreated or undertreated. Within this context of increased concern around pain management and heightened interest in chronic pain and its treatment, the sale and use of novel opioid pharmaceuticals prospered (Scher et al., 2018; Chidgey et al., 2019; Jiang, 2020).

In 1996, Purdue Pharma introduced OxyContin, a sustained-release formulation of oxycodone marketed as a safe opioid with low risk of addiction (Van Zee, 2009). OxyContin was marketed as a means of providing patients with consistent pain relief while avoiding the multiple doses required when using short-acting opioids (Argoff and Silvershein, 2009). Purdue conducted an aggressive marketing campaign to promote OxyContin while also funding pain education programs, including a pain management course at the University of Toronto (Persaud, 2014). These methods of influencing physicians' prescribing habits and encouraging patients to seek OxyContin led to a boom in sales. The huge success of OxyContin, as well as a shift in medical culture toward more liberal prescribing of opioids, resulted in a significant increase in opioid prescriptions in North America and elsewhere (DeWeerd, 2019; Alpert et al., 2022; Jiang, 2020).

At the same time, another important medical development was underway: the introduction of functional magnetic resonance imaging (fMRI), which allows for real-time imaging of neural activity (Reinarman and Granfield, 2014). Studies utilizing fMRI imaging examined the impacts of drugs such as cocaine and heroin on visual activation (Sell et al., 1997), brain reward circuitry (Breiter and Rosen, 1999), the orbitofrontal cortex (London et al., 2000), brain activity and emotion (Breiter et al., 1997), and emotional memory (Cahill et al., 1995). The ability to visualize brain activity and to connect changes in this activity with drug use led to advances in neuroscience including the common pathway hypothesis, which states on the basis of fMRI imaging that the brain's response to psychoactive drugs is similar to its response to other pleasurable activities.

Representations of the brain derived from fMRI imaging have been enormously influential in addiction research and treatment. As Dingel et al. (2014) note, fMRI images have supported understandings of addiction as a brain disease not only because of the power of these images to make 'objective' claims about the brain and the person themselves, but also because these images act

as signifiers that are made meaningful through their interpretation. Campbell (2010) suggests that the value of the fMRI as a tool is “lodged in its potential to change public perceptions—to effectively change the ‘truth’ upon which members of the public proceed on the path to recovery [from addiction]” (Campbell, 2010, p. 92).

The resulting neuroscientific paradigm has defined addiction as a chronic relapsing brain disease. This model aligns with modern strategies of risk governance that Rose (2003) describes as the production of the neurochemical self—a fabrication of the self marked by the molecularization of psychopharmacology as the self comes to be located in the brain’s molecular processes and structures. He argues that one of the implications of this emphasis on the brain has been a focus in addiction research and treatment on identifying whether, at a molecular level, individuals are susceptible to addiction (Rose, 2003; Rose and Abi-Rached, 2013). Katchergin (2017) describes this trend as a process of neuromedicalization whereby personality and consciousness are reduced to the physical-corporeal seat of the brain (Martin, 2004). Just as medicalization subsumes all aspects of the human condition under the purview of medicine (Conrad, 1992), so too does neuromedicalization contribute to the discursive formation of new subjectivities (Ortega, 2009) and animate new forms of social control (Isin, 2004).

In addition to framing an approach to addiction that is thought to be evidence-based and informed by the most cutting-edge advances in neurobiology, the neuroscientific model has also been lauded for its potential to diminish the moralization of addiction by shifting drug use from ‘badness’ to ‘sickness’ (Reinarman and Granfeld, 2014). If some people are neurobiologically and genetically more susceptible to addiction than others, as the argument goes, it stands to reason that addiction should be treated as any other disease (Leshner, 1997). However, as Courtwright (2014) has argued, promises of reduced stigma associated with medicalization have gone unrealized and

instead have produced, at best, a “contested medicalization” (Courtwright, 2014, p. 64). Reinerman and Granfield (2014) go further in contending that political, public, and medical opinions of addiction have continued to combine the definition of addiction as a brain disease with the notion of addiction as immorality and that, as a result, neuromedicalization has yet to counter prohibitive approaches to drug use.¹⁸ These changes in medical conceptualizations of addiction have emerged within the hybridized space of the medico-legal borderland as neurological paradigms of addiction have been informed by, and in turn have reproduced, coeval changes in the criminal-legal regime of drug control.

3.5 CRIMINALIZING DRUG USE IN THE CONTEXT OF A ‘WHITE CRISIS’

The history of drug use and regulation in Canada has been marked by intersecting racist and colonialist anxieties that the non-white Other might sully the ‘purity’ of the white nation (Courtwright, 2014). However, the contemporary opioid crisis is unique in that it has been racialized as a white crisis whose gravity comes from the impact of opioids on groups that are

¹⁸ The brain disease model of addiction has been further challenged on two fronts: concerns that this neuroscientific model is reductionist and that it individualizes addiction, and resistance to the pathologization of everyday experiences. While there is widespread acknowledgment that the brain plays some role in drug use and addiction, the brain disease model engages in biological reductionism by excluding the social and cultural factors that influence a person’s experience of using drugs (Reinerman and Granfeld, 2014). Evidence of brain activity associated with addiction does not imply that addiction can be reduced to neuronal activity. There are concerns that the brain disease model of addiction may lead to oversimplified conceptions of addiction that reduce addiction not just to the individual user but also to their minute neural and physiological makeup. The pathologizing gaze of the brain disease paradigm has also expanded definitions of addiction to include food addiction, sex addiction, and gambling addiction as medical diseases requiring diagnosis and treatment, raising concerns that an increasing number of human experiences and conditions have come to be pathologized as brain diseases (Reith, 2014). Contextual factors, including not only the individual’s psychosocial experiences but also wider political and economic structures that play a role in the distinction between a behaviour that is normal versus one that is dangerous, unhealthy, or incorrect are dismissed when everyday behaviours such as drug use come to be pathologized. The brain disease model of addiction has also had significant impacts on policy responses to drug use including coercive or mandated treatment justified by the perception that addicts suffering from a disease that alters the function and structure of their brains lack the cognitive capacity or autonomy to make decisions (Merikangas and Risch, 2003; Carter and Hall, 2017). Neuromedical models of addiction have also been used to justify invasive and high-risk interventions such as brain surgery (Krack et al., 2010).

typically not associated with drug use or related criminal behaviours in the public imaginary: white mothers, white suburban teenagers, white working-class populations in rural and remote areas, and white patients whose iatrogenic addiction stems from prescription opioid use following injury or surgery (Hansen and Skinner, 2012; Mendoza et al., 2019). Addiction, now neuromedicalized as a brain disease, has been paired with discourses of whiteness and innocence that shift the blame for drug-related harms away from white drug users who are perceived as suffering from a chronic, relapsing disease of the brain through no choice of their own. The re-racialization of opioid addiction through white exceptionalism has shifted blame for the public health crisis of opioid-related harms away from white users, who become legitimate patients deserving of care, and instead toward unscrupulous prescribers and pharmaceutical companies accused of victimizing opioid users (Mendoza et al., 2019).

The depiction of the contemporary increase in opioid-related harms as a white crisis is not entirely inaccurate. Through an ironic turn of events, racist discourses and institutional relations have operated within medicine in ways that restrict racialized non-white people from accessing opioids for pain relief (Mossey, 2011). Research has found, for instance, that physicians hold misconceptions about pain and race, including the belief that Black people do not feel pain at the same intensity as white people, and that certain groups such as Black women and Indigenous people are exceptionally strong and accustomed to physical suffering (Inciawar and Maldonado-Bouchard, 2012). Other misconceptions include the belief that Black people have longer nerve endings and thicker skin than white people and therefore feel less pain (Cerdeña et al., 2020), and that Black people have a greater tolerance for extreme heat (Hoffman et al., 2016).

These beliefs have a long history rooted in slavery and the colonial obsession with identifying physical markers of difference between white and non-white bodies, as well as

arguments that justify slavery on the grounds that Black people are more resistant to physical suffering (Hoffman et al., 2016; Plous and Williams, 1995). The impacts of racist pain beliefs, in addition to other structural forces and forms of organization rooted in racism and colonialism, have produced significant inequities in pain management. For instance, white patients are more likely to be prescribed opioids at emergency departments than Black, Hispanic, Asian, and other non-white patients (Pletcher et al., 2008). Black patients who do receive opioids are more frequently subjected to drug monitoring compared to white patients, are less likely to be referred to a specialist (Hausmann et al., 2013), and are more likely to have restrictions placed on early refills (Becker et al., 2011).

Prescription opioids have also been marketed to the public and to physicians as an analgesic for white patients. Parker and Hansen (2021) argue that in the 1990s industry-sponsored medical education, biomedical opioid research, and opioid marketing drew upon racialized distinctions between ‘pain patients’ and ‘opioid abusers’ that have persisted in shaping medical opinion on opioid safety. Furthermore, given that one of the defining features of whiteness is its absence or invisibility as a racial category, the whiteness of prescription opioids has largely gone unnoticed. Hansen et al. (2020) define whiteness as a ghost variable that has played an invisible role in opioid development, prescription, and use, as well as treatment for opioid-related harms including addiction.

The invisibility of whiteness and the invisible racialization of prescription opioids is deeply interwoven with the brain disease model of addiction. As whiteness is the invisible, default, and assumed norm, neurobiological research on addiction has taken its subject as the white, ‘neutral’ body from which universal truths about the brain and drug use can be derived (ibid.). The neuroscientific medicalization of addiction has thus been centered on a white subject whose drug

use is conceptualized as a disease rather than a moral failing or a criminal act. This notion of addiction diverges widely from historical images of racialized drug users since fMRI brain imaging produces a racially unmarked image of the addict that represents the implicitly white “average human” (Reinarman and Granfield, 2014, p. 6).

While the racial coding of drugs including crack cocaine and cannabis has informed punitive drug policies intended to protect ‘innocent’ white communities from predatory drug use, the blamelessness of white addiction as a disease necessitates medical treatment rather than punishment (McLean, 2017). Whiteness also supports white patients’ privileged access to health care, as in the case of inequitable access to opioids described above. Thus, as Hansen et al. (2020) put it, “whites are ushered into one system of narcotic distribution that is geared toward biomedical individual consumption, whereas nonwhites are ushered into another system of narcotic criminalization and control” (Hansen et al., 2020, p. 852). This segregated system has led to the implicit and explicit perception of the contemporary opioid crisis as a crisis of licit opioids used by white patients.¹⁹

¹⁹ A particularly contentious aspect of public perceptions of and political, legal, and medical responses to the opioid crisis has been debate around whether opioid-related harms are attributable to prescription opioid use or whether these harms are associated with the use of drugs procured through illicit channels and/or used for purposes deemed non-medicinal. In a comprehensive review of public-facing opioid-related surveillance and epidemiological reports in Canada, Belzak et al. (2018) found no national measures of illegal opioid use in comparison to prescription drug use. However, while prescription opioids were identified as an early driver of the contemporary opioid crisis, illicit drug use was suggested to be a likely cause of increased deaths across Canada, due in part to the increase toxicity of drugs on the illegal market resulting from illegally manufactured fentanyl and its analogues (Belzak et al., 2018). Gomes et al. (2018) reviewed all opioid-related deaths in Ontario from January 2013 to December 2016 and found that of the 2833 documented deaths, an active opioid prescription on the date of death was common but declined over time (38.2% in 2013 to 32.5% in 2016). The postmortem toxicologies of 37.8% of people who had an active opioid prescription at the time of death also showed evidence of non-prescribed opioids. The authors suggest that both prescribed and illicit opioids play a role in increases in opioid-related harms. Others including Tadrous et al. (2019) have evaluated the impacts of programs intended to reduce prescription opioid use in Ontario, finding that although Ontario’s fentanyl patch return program was associated with lower volume of fentanyl patches dispensed by pharmacies since its introduction in 2012, there have been no measurable effects on rates of opioid-related hospital visits or deaths.

Conceptions of white drug users as victims of the opioid crisis have produced new clinical modalities for diagnosing and responding to addiction. In 2007, the American Pain Society introduced the term ‘pseudoaddiction’ to describe patient behaviours that may occur if their pain is undertreated (Bell and Salmon, 2009). While addiction is understood as resulting from permanent alterations in the brain’s structure and function, pseudoaddiction is distinguished as a consequence of temporary changes that result from long-term opioid use. Patients suffering from pseudoaddiction may exhibit behaviours that are typically attributed to addiction, such as purposeful deception of physicians. Within the model of pseudoaddiction, these behaviours are not associated with a permanent alteration of the brain but rather undertreatment of the patient’s pain and desperate actions on the patient’s part as they seek relief. The physician is thus burdened with the responsibility of differentiating ‘bad’ addicts from ‘good’ patients in the face of behaviours that are “virtually indistinguishable” (Bell and Salmon, 2009, p. 173).

The introduction and uptake of the concept of pseudoaddiction signals a softer criminal-legal approach to drug use characterized by increased medicalization and less punitive responses. As Bell and Salmon (2009) argue, pseudoaddiction allows for the redefinition of addiction for “nice people”: white, middle-class patients who do not have a history of drug use (Bell and Salmon, 2009, p. 174). Distinctions based on race are particularly concerning given the evidence of endemic undertreatment of pain among non-white racialized people and other marginalized groups. This undertreatment may worsen as racialized people are further distinguished from white opioid users who represent “the right kind of chronic pain patient during an opioid epidemic” (Huang, 2018, p. 239). Responses to prescription opioid-related harms have been informed by what Lassiter (2015) describes as the “reciprocal criminalization of blackness and decriminalization of whiteness,

grounded in the differential policing and discursive framing of pathologized urban spaces and idealized suburban spaces” (Lassiter, 2015, p. 128).

Shifting perceptions of opioids, racialization, and addiction have resulted in a reconfiguration of the boundaries of the medico-legal borderland through which social control over opioid use is organized. As Mendoza et al. (2019) note, surges in opioid overdoses associated with white communities have prompted state and public health responses that differ radically from the interventions that accompanied the War on Drugs. Likewise, highly sympathetic media depictions of the opioid crisis have further informed benevolent medical, political, and public responses to opioid use. Thus, rather than the mass criminalization and incarceration of racialized people that resulted from the War on Drugs, a separate space has been carved out for white opioid users whose addiction is medicalized and treated through both public health and biomedical interventions (Netherland and Hansen, 2017).²⁰ The result has included state and regulatory college efforts to monitor, audit, and punish physicians suspected of inappropriately prescribing opioids, and measures taken to reorganize the medical profession, medical education, and pain management.²¹

²⁰ Although there have been some exceptional cases in which white drug use is criminalized, as in the use of methamphetamine in white rural communities, Murakawa (2011) argues that this difference is due to a class-based segregation in which white methamphetamine users are seen as the “bottom of the white racial-economic spectrum: ‘white trash’” (Murakawa, 2011, p. 223). Within the project of nation building integral to drug policies and drug control in Canada, white methamphetamine users come to represent anxieties around the white social position and fears that white supremacy is declining. Similarly, when OxyContin was first associated with opioid-related harms in rural, low-income settings in Appalachia, it was described as ‘hillbilly heroin’ in an intersection of whiteness and class that, although stigmatizing, ultimately evokes sympathy in comparison to depictions of the use of racialized drugs such as crack cocaine (Netherland and Hansen, 2017).

²¹ Other criminal-legal responses to increases in opioid-related morbidity and mortality put forward by federal, provincial, and territorial governments in Canada have largely targeted foreign drug suppliers and external traders. The federal Drugs and Substances Strategy, for instance, includes six components: prevention, treatment, enforcement, harm reduction, evidence, and funding (Government of Canada, 2019). Enforcement is aimed at increasing the capacity of law enforcement to target organized crime and the making and distribution of illicit opioids, identifying and controlling new substances, and preventing cross-border movement of illicit drugs and the chemicals used to make them. Other legal measures aimed at mitigating the harms associated with opioids incorporate proposed regulatory changes to include information handouts and warning stickers alongside opioid prescriptions and to require opioid manufacturers to institute risk management plans (Government of Canada, 2018). As part of its drug control strategy, the government has also committed to reducing crimes committed as a result of drug use through the Drug Treatment Court Funding Program, which provides court-monitored treatment and community services to non-violent offenders

3.6 MEDICO-LEGAL RESPONSES TO THE CONTEMPORARY OPIOID CRISIS: ONTARIO'S NARCOTICS MONITORING SYSTEM

As part of its strategy to curb the opioid crisis, in 2012 Ontario's Ministry of Health and Long-Term Care developed and introduced the Narcotics Monitoring System (NMS). The NMS is a central database of dispensing records used to monitor the prescription and dispensing of controlled substances. These monitored drugs are listed in Canada's 1996 Controlled Drugs and Substances Act under nine poison schedules; they include opium and opioid analgesics such as morphine, codeine, and hydrocodone. Under the directive of the provincial Narcotics Safety and Awareness Act passed in 2010, all pharmacists practicing in Ontario must submit dispensing records of controlled substances to the database. The system then conducts a Drug Utilization Review (DRU) of these records to detect issues such as double-doctoring or cases where patients have filled a prescription at multiple pharmacies (OPDPD, 2012). In these cases, the NMS issues an alert to the pharmacist in real-time.

For pharmacists, the NMS is not only a software into which they input prescribing records but a program that guides the work of dispensing opioids. A pharmacist practicing in Northern Ontario noted that while the Ontario College of Pharmacists (OCP) had circulated instructions on how to use the database when it was first implemented in his county in 2012, his knowledge of how to use the system has largely derived from the technical components that guide his work. As he explained:

as well as programming for youth (ibid). Policies oriented to abating prescription opioid-related harms have focused on changing physicians' and pharmacists' work practices. Other measures introduced at all levels of government include funding commitments toward harm reduction strategies such as providing free access to naloxone kits.

Pharmacist: So, the thing with the program is, it just tells you what to do. So, you go through, and it asks you for the information and you just put that in. So, for us in [town], we get opioid prescriptions on the electronic medical record, we receive them off the Internet, they're sent to us on their [the local health team's] medical record platform. So, we receive [the prescription], and physicians have a unique signature, so we don't have any problems with forgeries here. We don't have, let's say, a patient coming in with a handwritten prescription. It's all electronic. So, then you're prompted to put in that information and make sure it's accurate. So, you just go through the list. So, I'm looking at it now, and there's client ID number, so the code from whatever ID the patient has given me, and then you have their first name and last name, gender, information about the prescription...so the DIN [drug identification number], the quantity being dispensed, the days supply, the prescriber's license number, my ID number.

Leigha: Okay, right. And then you put that in and submit it?

Pharmacist: Exactly. And then you're going to get a message back. Well, so, one thing that can happen is what's called a data integrity check. So, that just means everything you submitted is valid, you've filled everything out. Which makes it pretty much impossible to make a mistake. So, you might get a response saying it's rejected because of data integrity issues, because you forgot to put the patient's name or something. And then you could also get a warning, so, what's called a drug utilization review warning. There's a couple of different codes you could get. One would be too early of a refill or too late, or double doctoring.

Leigha: And what would happen if you get one of those codes?

Pharmacist: Well, if it's because of a warning, like double doctoring or maybe the patient has gotten the same medication from other pharmacies, my job as the pharmacist is to then figure out what's going on. With the warning I'll get some information like the pharmacy where another prescription was filled, and their phone number, and then I could call that pharmacy to see what's going on. Or I would call the prescribing doctor and tell them I'm getting this warning message. And obviously I would ask the patient, like, "Hey, the system is flagging you because it says this refill is too early, you're not due for a refill for another week." And it might be something like they lost their pills or something.

When pharmacists receive a warning through the NMS that potential use of opioids deemed inappropriate or illicit may be taking place, they are expected to exercise their professional judgment in deciding whether to dispense. When I asked this pharmacist what it might mean to exercise his professional judgment in these circumstances, he hesitated before responding: “It depends.” There have been some cases, for instance, where a patient comes into the pharmacy and explains that they have been ill and therefore are late refilling their prescription. In these cases, he may call the physician to confirm, but typically he will dispense opioids despite the NMS warning. In other instances where the patient does not seem to have a valid excuse, he will refuse to prescribe and alert the physician of suspected inappropriate opioid use.

Overall, the pharmacists I spoke with were highly ambivalent toward the NMS. Their reservations stem in no small part from the additional labour and stress associated with using the database. A pharmacist practicing in Southern Ontario felt that although the program was straightforward and easy enough to use, the wider context in which the software has been implemented and the demands placed upon pharmacists by the government and their regulatory college have meant that prescribing opioids was rarely, in his words, “worth the trouble.” This view was echoed by other pharmacists who have chosen to no longer dispense opioids in their pharmacies due to the heavy workload required to dispense in ways that comply with new legislation and OCP policies. A pharmacist working in Southern Ontario eventually chose to no longer dispense opioids given the heightened requirements around documentation. This was particularly true for dispensing transdermal patches such as fentanyl patches, as pharmacists are required to collect and document receipt of used patches.

Pharmacists were also critical of the NMS and the obligation placed on pharmacists to police patients as well as physicians. An academic detailer noted that the pharmaceutical

profession has a long history of contention with the medical profession, and that in the case of the opioid crisis, pharmacists have been called upon to protect the public by assisting in scrutinizing and monitoring physicians and their opioid prescribing practices. Likewise, a community pharmacist felt that the NMS eroded relationships between practitioners:

When this [the NMS] all came out, they [the OCP] gave us a bunch of information about how to use the program, what's the point of the system, okay? And if you read those papers—and I can give them to you—they use this language where it's all supposed to be this big, happy family coming together to protect the patient. So, they literally call it a “circle of care,” which, I mean, the idea is that you and the prescriber are working together to help keep the patient safe. But it doesn't feel like that, believe me. I've had cases where police are called on doctors because there's this suspicion that they're not prescribing correctly, or their patients are selling their opioids on the street. And I didn't go into this field to keep an eye on doctors or report them. I don't really see that as my place. But that's what we're being asked to do.

This pharmacist was concerned not only with the potential repercussions for physicians whose prescriptions are flagged through the NMS, but also the use of the database for surveillance measures intended to track prescribing patterns across the province. His concerns are not unfounded: in addition to using the database to inform pharmacists' dispensing decisions, Ontario's Ministry of Health and Long-Term Care also uses the data collected through dispensing records to identify drug utilization patterns and to detect “unusual activities” indicating that a physician is an opioid ‘overprescriber,’ in which instances the ministry reports suspected illegal activity or professional misconduct to law enforcement and the CPSO (OPDPD, 2012).

While the database is not accessible to physicians and pharmacists (beyond the interface used by pharmacists to input data and the limited information they receive if the DUR finds evidence of inappropriate use), the ministry sends the CPSO information regarding specific physicians in circumstances where prescribing surpasses certain thresholds. These thresholds

include cases where physicians meet two criteria: prescribing 650 oral morphine equivalent daily and a single dispense of 20,000 oral morphine equivalent daily of one opioid (CPSO, 2016a). Physicians are also identified as overprescribers if they prescribe a greater number of opioids, measured in both prescriptions written and doses prescribed, compared to other physicians in their region.

Data from the NMS is acquired by the CPSO in two ways. In some cases, data is periodically sent to the CPSO's Registrar. After reviewing the data, the Registrar refers the case to the CPSO's Inquiries, Complaints, and Reports Committee for investigation. In other instances, the committee receives a complaint against a physician and may contact the ministry directly to request data from the NMS if the complaint relates to opioid prescribing. The Inquiries, Complaints, and Reports Committee will then investigate the physician's work by auditing patient charts and interviewing the physician to determine whether there is evidence of professional misconduct or incompetence. The committee comprises physician and public members of Council—the governing board of the CPSO—as well as non-Council physicians and a number of physician inspectors who specialize in areas of medicine relevant to the investigation. One physician who has acted as an inspector described the process as follows:

Typically, I got anywhere from three to twenty files from the doctor's practice, so different patients. And then it's like detective work. I review the files for what we call standards. So, do they meet the standard of practice of the profession? What is their knowledge, skills, and judgment, and are there any harms to the patients in their practice? And then we would do an interview with the doctor, and in some cases after the interview we would decide that more charts need to be looked at because there are issues we still need to look at. And in some cases, we were actually doing an assessment to see whether the doctor can practice safely and prescribe controlled substances. And as an inspector, we don't actually ever say, "You should do this, you should do that." We simply talk about the quality of their work and the concerns we have about the quality. And it's up

to the [Inquiries, Complaints, and Reports] committee to decide the punishment and if they're going to be referred for discipline. And then, when it's all over, you just get a note from the College saying, "Please destroy all of the documents, thank you for your help."

Following this review, the panel determines whether misconduct or incompetence has occurred through a majority vote cast at a panel meeting. If a majority vote is reached, depending on the nature of the case the physician is either referred to a panel by the Inquiries, Complaints, and Reports committee for incapacity proceedings or to be cautioned, or, if an allegation is related to a complaint or Registrar report, to the Ontario Physicians and Surgeons Discipline Tribunal. This five-member tribunal panel consists of both physicians and members of the public including at least two public members and one physician who is also a member of the CPSO Council. The tribunal holds a hearing to determine whether the physician has committed an act of professional misconduct or is incompetent (OPSDT, n.d.).

In cases where a majority of the tribunal has found proof on a balance of probabilities—which requires that the CPSO show through its investigation that it is more likely than not that the alleged misconduct happened—the tribunal can order penalties including revoking the physician's license to practice, suspending their license temporarily, imposing terms, limitations, and conditions on the physician's license, reprimanding the physician, and requiring that the physician pay a fine to the Minister of Finance (*ibid.*). The tribunal may also order the physician to pay costs of the hearing and investigation to the CPSO. If the case is not referred for discipline, the Inquiries, Complaints, and Reports Committee may caution the physician. Both committees may also request an undertaking between the CPSO and the physician, wherein the physician agrees to certain activities to address the committees' concerns. Undertakings may include education, supervision,

and monitoring and are also posted on the physician's public register while it is in effect. Undertakings, penalties, and cautions also appear on the physician's public register.

In 2016, the Inquiries, Complaints, and Reports Committee opened an investigation into the first cohort of physicians who were flagged by the NMS as opioid overprescribers and whose information was provided to the Registrar by the ministry. This investigation was led by a specialty panel formerly named the Narcotics Monitoring System Panel and now called the Prescribing Panel (CPSO, 2017a). A total of 84 physicians were flagged by the NMS and investigated. When the investigation concluded in 2017, the CPSO released a report indicating that the college engaged in an undertaking with 44 physicians required to practice under a clinical supervisor and to participate in education activities. Three physicians had their prescribing practices limited, three are no longer practicing, one was referred to the disciplinary tribunal, and three were still under investigation (CPSO, 2018).

As part of my inquiry into the use of NMS data to investigate physicians, I spoke with practitioners who were investigated by the CPSO as opioid overprescribers as well as physicians who sat on the investigations and discipline committees. Physicians who had been investigated by the CPSO depicted the process as a harrowing one that occupied months, and sometimes years, of their lives as investigators demanded access to several patient charts and regularly requested hearings to gather additional information. One physician described the experience as follows:

Physician: Well, when I found out the College was auditing me, the first thing that happened was I stopped taking new patients, because you can't do the paperwork to satisfy the College and then take on new patients. Like, it's not possible.

Leigha: And when you talk about this paperwork to satisfy the College, what kind of paperwork is that?

Physician: Well, you know, I get a notice, and I have very little time to satisfy it, you know, like maybe three weeks or whatever. They want all my notes from whatever time to whatever time, they want it all, I have to photocopy it. Then I send it to my lawyer, and he has to put it in this digital [format] and he has to send it to the College, and they'll come back and say, "Okay, we want stuff from some more days. This day, that day, that day." It takes me hours and hours, where I'm in the office when I should not be in there doing that sort of thing. And copying a chart is an enormous amount of work. And then they want every prescription, every piece of paper you have, and I have to do that sort of thing. And I have a deadline. I deliver it to the lawyer, he sends it on, and then they mull it over.

Leigha: So, you have a lawyer who helps you with all this.

Physician: Definitely. As soon as I got that first letter telling me they were looking into me, I just knew this was going to be a big kerfuffle. So, the lawyer sends it over, and finally, they send it to someone who's going to go over it all. And then I have a meeting with them, and they ask various questions. They come up with a report on me and I have an opportunity to do a rebuttal letter. And I, you know, explain why I did whatever. And in my opinion, everything I've done has been totally appropriate. And the people who are investigating me have fewer years of practice [than me] and way fewer qualifications than I have. And they get to decide, you know, "We don't like the way you did this, wherever, whatever." And I'm under enormous pressure to present all this to the College and explain my side of things.

Other physicians investigated by the CPSO shared similar accounts highlighting the substantial amount of work required to comply with the CPSO's directives and provide evidence as requested. Of the physicians I interviewed who have been investigated as opioid overprescribers, one retired from medicine to avoid the trouble of undergoing investigation, one was cautioned and required to undergo education and clinical supervision, one had their license temporarily suspended, and one had no action taken against them.

My findings related to the use of the NMS to monitor, audit, and investigate physicians' opioid prescribing practices challenge some of the existing literature on the regulation of the

medical profession. Foucauldian analyses of professional regulation, for instance, have used the concept of clinical governance in suggesting that physicians are regulated without direct intervention through the expectation that they will participate in their own self-surveillance and self-governance (Flynn, 2002). Allen (2000) argues that professional regulation is a mode of governing-at-a-distance to promote “responsible autonomy” whereby physicians are expected to exercise clinical judgment while also demonstrating their accountability to performance measures including fiscal responsibility. Clinical governance is thought to align with the authority of professions to self-govern as autonomous professionals while ensuring their compliance with neoliberal state expectations of performance and efficiency (Light and Levine, 1998; McKendry and Langford, 2001).²²

These forms of governance have been centered around medico-administrative forms of accountability where economic rationality and cost-effectiveness are paramount (Timmermans and Almeling, 2009; Timmermans and Epstein, 2010). Studies of evidence-based medicine as a means of increasing economic efficiency have illustrated the way new forms of management shift the work performed by physicians (and other health care providers including nurses) as clinical staff are expected to participate in their own self-surveillance as a means of meeting performance indicators (Flynn, 2002; Allen, 2000). As opposed to these disciplinary methods of governing-at-a-distance, what I have found instead is that medico-legal governance of opioid prescribing in the context of the contemporary opioid crisis has taken on a decidedly more coercive and punitive character.

²² Political economists have also provided critical insights on the relationship between medicine and the state. These have included examinations of health care provision (Coburn, 1983; Coburn, 2006; Armstrong et al., 2001; Armstrong and Armstrong, 2010), health reforms including neoliberal privatization (Medvedyuk, 2015; Coburn, 2001; Drache and Sullivan, 1997; Lee et al., 2002), and the gendered and racialized aspects of health care (Armstrong and Armstrong, 1983; Armstrong et al., 2001; Syed, 2021; Smith et al., 2021; Bailey et al., 2020).

As physicians have come to be targeted as responsible for opioid-related harms, the measures taken by the state and, consequently, medical regulatory colleges have moved beyond merely providing standards and policies to ensure competent practice to instead monitoring minute details of physicians' work and directing all aspects of opioid prescribing. The use of the NMS and medico-legal governance of opioid prescribing as a form of social control was reflected in physicians' contentions that interventions to alter the way they prescribe opioids curtail their ability to exercise clinical judgment in ways that account for patients' individual contexts and yet are invisible in NMS data. There are parallels between these concerns and literature on clinical judgment and autonomy, particularly in the face of evidence-based medicine and standardization (Zeldow, 2009; Fava et al., 2015).

We might understand these new, more direct forms of governance through the concept of 'opioid pharmacovigilance,' proposed by Knight et al. (2017) as an extension of the World Health Organization's conception of pharmacovigilance as a set of practices intended to "enhance patient care and patient safety in relation to the use of medicines, and to support public health programs by providing reliable, balanced information for the effective assessment of the risk-benefit profile of medicines" (WHO, 2006, p.8). Knight and colleagues expand this definition to account for the importance of pharmacovigilance for modern governance of opioid use. They suggest that a new era of opioid pharmacovigilance has shifted the goals of pain medicine away from the framework of the late twentieth century centered around pain relief and social justice toward an emphasis on accountability to public health and the medical profession. I would further propose that opioid pharmacovigilance intended to intervene into opioid-related harms has been deployed in ways that are not intended to merely inform physicians' decision-making and medical practice but rather to

coerce physicians into prescribing opioids in particular ways through surveillance, investigation, and penalties including losing the right to practice and public shaming.

3.7 PHYSICIANS' CHANGING WORK PRACTICES IN THE FACE OF SURVEILLANCE

The CPSO's 2016 investigation into opioid overprescribers marked a fundamental shift as physicians became aware of the extent to which their opioid prescribing practices were being monitored, evaluated, and potentially referred for penalties. While in 2012 physicians were made aware of the introduction of the NMS and how it would be used by pharmacists to coordinate practitioners' prescribing and dispensing activities, they were generally unaware of how the database would be used to monitor and investigate physicians' prescribing practices. One physician said:

When doctors were told about the [NMS], we were told, "This is just to keep patients safe, it's to help you and the pharmacist make sure there's no double-doctoring." Which, I mean, there's a lot I could say about that. There are a lot of stories of patients who are flagged on these systems without knowing the whole context and then that red flag follows them around for life. But anyway, that was supposed to be the whole thing—patient safety. But then we started to hear about the College investigating doctors because of the prescribing information on that system. And, I mean, you would hear just really awful things...Really good doctors being investigated and losing their license for no reason. Nothing bad had ever happened to their patients on opioids. And for a lot of us, myself included, that was a moment of realizing, 'Okay, they're really watching my every move now.'

For the physicians I spoke with, it was not until the CPSO announced its investigation in 2016 that they began to fully grasp how the ministry and the CPSO intended to use the database. Much of their information came from the media, as *The Globe and Mail*, *CBC News*, magazines, and local newspapers covered the CPSO investigation and the results of investigations and hearings

(Taekema, 2018; Popplewell, 2021; Grant, 2016; Pearson, 2018; CBC News, 2016; Delisle, 2019). Details regarding the investigations have also been published in the CPSO journal eDialogue (formerly Dialogue), which many participants cited as one of their primary sources for information regarding the first and subsequent investigations.

Others were unaware of the use of NMS data for investigations until they received a notice that they were being investigated by the CPSO or they heard stories from their colleagues under investigation. One general practitioner recalled a “sinking feeling in [her] stomach” when she received the first letter from the College alerting her to the investigation into her opioid prescribing practices. She said:

The thing is, there’s always some kind of monitoring happening. The medical profession is self-regulating, so that means we regulate ourselves to protect the public. So, the College isn’t there to protect doctors, it’s there to protect the public. But this was different, because never before in my twenty-plus years of practice had I ever had any aspect of my practice tracked to that sort of extent. It just doesn’t happen. If the College is going to audit you, it’s because a complaint has been made by a patient about your practice, or there’s some evidence of poor practice or poor judgment. But in this case, none of my patients using opioids had any problems at all. Almost all of them have been using opioids for years and years and have never had an issue. So, there were two really weird things happening—first of all, the College had never tracked us so closely before, and second, never before could you get in trouble with the College when no harm had been done and there was no complaint or proof of bad practice.

While not all physicians were investigated or disciplined by the CPSO for their opioid prescribing practices, the climate of fear that erupted following these initial investigations spurred even those clinicians who had not been audited to lower the number and dosage of opioids they prescribed for chronic pain. As a general practitioner explained, once the investigations began, news quickly spread across the province and physicians reacted accordingly:

There's a tribal drum that spreads the message very quickly from doctor to doctor, or from doctor to pain clinic, that the College is targeting doctors who prescribe opioids for chronic pain. They're often looking at prescriptions written for specific patients when usually these are patients who have been on the same dose for years and years. Well, word spreads and then doctors are nervous about somebody coming to look over their shoulder and one day coming to do a twenty-chart review that's going to tie them up for years. Now, some doctors did squeak through [the investigations], but some of my colleagues were sanctioned by the College, and especially when these are respected experts in the field, that news spreads.

Alongside the use of the NMS to monitor physicians' opioid prescribing patterns, the state and the CPSO also began to introduce a number of programs, policies, and regulations intended to reduce physician prescribing. For instance, in 2016 the CPSO released an interim opioid strategy, published an opioid position statement, and disseminated new guidelines that urged physicians to adopt significantly more conservative work practices around opioid prescribing. These changes were a signal to practitioners that the medical profession was rapidly shifting its stance of opioid use for chronic pain and that physicians were expected to immediately comply with these changes.

Some physicians responded to these changes in CPSO and state policy by rapidly tapering patients' opioid doses to a threshold they hoped would not alert the NMS. One medical resident described this task as "really finicky" work that requires experimentation with different types and doses of opioids until physicians happen upon the "magic number" on the basis of which the CPSO will "leave [them] alone" while also ensuring some level of pain relief for the patient. Other physicians have chosen not to prescribe opioids at all and have instituted in their practices 'no narcotics' policies. Some have taken early retirements to avoid scrutiny from the CPSO. And, in some cases, physicians have implemented unspoken policies of refusing to accept people with chronic pain onto their rosters and discharging existing patients.

Among the many impacts of physicians' growing reluctance to prescribe opioids for chronic pain, one of the most significant consequences has been the emergence of the 'opioid gap,' a term used to describe the widening gap between the opioids people need to effectively manage their pain and their actual ability to access opioids (Iliades, 2016; Seidel, 2021). The rise and expansion of this gap has been attributed to physicians' fear of prescribing opioids (Clarke et al., 2019; Kaboré et al., 2021). My interviews supported these claims, as I found that people with chronic pain and practitioners shared stories of dwindling access to opioids for people with chronic pain as physicians are coerced by the state and their regulatory college to reduce their prescribing or stop altogether.

The growing gap between opioids needed for adequate pain relief and actual access to opioids has been particularly impactful for legacy patients. The term 'legacy patient' refers to people who, as opposed to 'opioid naïve' patients, have an existing history of opioid use for chronic pain (Rieder, 2018; Kertesz et al., 2019). Typically, legacy patients were first prescribed opioids for chronic pain management in the 1990s and early 2000s, and they have since used opioid doses that, by today's standards, are well beyond the recommended dose threshold or ceiling. Nearly all participants interviewed for this dissertation are legacy patients. Likewise, for opioid naïve patients, the inability to access opioids has meant that they have suffered from significant pain while trying other treatment modalities that are ultimately ineffective.

The impacts of the opioid gap were also illustrated in my conversations with physicians still willing to prescribe opioids despite having been personally investigated by the CPSO or having witnessed colleagues undergo this painful process. Many physicians practice in regions in Ontario where a shrinking number of practitioners are still willing to prescribe opioids for chronic pain. Physicians reluctant to prescribe have referred their patients to the few physicians still willing

to prescribe opioids and, as a result, people with chronic pain using opioids have come to be concentrated in a small number of practices. This shift was spurred by, and consequently fed into, the use of the NMS to identify opioid ‘overprescribers’ (Morin et al., 2017). One physician aptly described the absurdity of the situation:

You now have this ridiculous situation where the College is going to audit every doctor who’s flagged by the [NMS] system as an overprescriber, which means they prescribe more opioids than anyone else in that region. So here, in [city], I can tell you that myself and two other doctors are the only ones willing to even consider prescribing opioids anymore. Everyone else is terrified of either losing their license or being caught up in investigations for years. And you can’t even blame them for that. But now, so there are only a handful of us still prescribing, so let’s just say I’m writing scripts for opioids for thirty patients on my roster, and I’ve already tapered those doses as far as I can—honestly, probably too low for the patient to get any kind of relief from their pain, but I have no choice, according to the College. Well, if I’m writing thirty scripts a month, and no one else in the entire city of [region] is prescribing a single opioid, well, of course I’m going to be flagged as overprescribing. Because I’m the only one prescribing them. So, you can see where this is going. If the few doctors still prescribing opioids are audited and told to stop prescribing...then there’s no one left at all. And it’s the patients who suffer.

Physicians also expressed great concern for the general state of chronic pain care and the impacts of the widening opioid gap on people with chronic pain. One family physician summarized the difficult position she found herself in as follows:

I can tell you that in [city] here, you could go to anybody with a serious chronic pain problem, and they will not give you a single opioid. There are now seven doctors in [city] who are chronic pain specialists and every single one of us has been investigated and had their practice destroyed. So, what happens to me is, I try not to take on new patients because I simply can’t deal with that, but I see people who have been cut off totally without notice by their doctor who’s trying to save their own license. But when I get these stories, I feel sorry for them, so I’ve taken in a number of them because I know if I don’t take them in, they’re going to go into some horrible withdrawal, and nobody will treat their pain. I had planned to decrease my work a bit, but these

new patients have taken up an enormous amount of my time. It's been a huge amount of paperwork and going back and forth between the College because I've taken on these patients and I'm continuing to prescribe opioids and so I have to constantly justify myself to them.

In addition to the increased work associated with a larger patient roster and regularly responding to the CPSO, another general practitioner was also facing significant financial struggles. After paying for legal representation throughout her investigation by the CPSO, over the last year her practice “barely broke even.” At the time of our interview, this physician was trying to decide which outcome would be worse for herself and her patients: continuing to prescribe patients’ regular doses of opioids until the CPSO revoked her license, or responding to audits until she could no longer afford to keep her practice open.

Some clinicians spoke of the difficulties facing practitioners and people with chronic pain in Northern Ontario. The situation in this region is unique on several fronts. Lack of clinical resources including pain clinics, specialists, and physicians providing primary care have meant that it is typical for physicians to practice into their seventies and eighties. Without new physicians available to replace them, many of these clinicians resist closing their practices. As one physician practicing in this region put it, “In Northern Ontario, and especially in [town], physicians work until they fall dead on rounds, so it’s very common for patients to one day have a doctor and the next be without one.” This lack of physicians and adequate resources has meant that people with chronic pain will often go years without a family physician. Instead, many are treated by locums who often refuse to prescribe opioids for chronic pain because they will be leaving shortly and cannot monitor the patient.

Benintendi et al. (2021) use the term ‘orphaning’ to describe the trend wherein growing numbers of people with chronic pain have been unable to find a primary care provider or to access

adequate pain care. The phenomenon of patient orphaning is not limited to Northern Ontario but instead has become a critical factor in the expanding opioid gap. Among the many people with chronic pain who have been orphaned since the late 2000s, legacy patients have experienced some of the greatest impacts as their access to opioids they have been using for years is abruptly cut off. So too have opioid naïve patients been affected as those who developed chronic pain in the contemporary era of opiophobia have been unable to access opioid analgesics at all.

3.8 SUSPICION, SKEPTICISM, AND SHIFTS IN THE PATIENT-PHYSICIAN RELATIONSHIP

The work practices physicians adopted in the face of surveillance and punitive measures by the state and the CPSO have had significant consequences for physicians' work as well as the patient-physician relationship. Practitioners described a growing sense of suspicion and skepticism toward patients that they regretted and yet held as necessary to protect themselves against the risk of being investigated or punished for prescribing opioids. In many ways, this suspicion represents an extension of existing skepticism toward chronic pain and those who suffer from it. Associations of chronic pain with gendered forms of hysteria, the subjective nature of pain, biomedical models dismissing pain as purely psychological, and theories that patients pretend to suffer from chronic pain for secondary benefits such as exemption from paid work contribute to widely held skepticism toward people with chronic pain and particularly those who use opioids (Werner and Malterud, 2003; Buchman et al., 2016; Tosas, 2021).

Earlier in this chapter, I described the concept of pseudoaddiction as it has emerged from a softened neuromedical approach to drug use that distinguishes 'legitimate' pain patients suffering

from inadequate pain management from addicts. I noted that one of the consequences of the use of pseudoaddiction as a medical category has been growing pressure on physicians to correctly distinguish pain patients from addicts in the course of their everyday work. The boundaries between addiction and pseudoaddiction are blurred and ways of classifying legitimate versus illegitimate opioid users are constantly evolving. Tasked with correctly identifying which patients truly suffer from chronic pain and therefore ‘deserve’ opioids has led physicians to orient to patients as potentially duping them into prescribing opioids in ways that might be investigated and penalized by the CPSO as misconduct or incompetence.

One of the ways physicians manage their suspicion toward people with chronic pain who use (or are requesting) opioids is through the use of work practices described as “detective work” or “investigative work.” Using the language of investigation to account for clinicians’ work is a common discursive strategy. Most often, associations between physicians and detectives are drawn to emphasize the work physicians do in solving the mystery of a patient’s illness or symptoms through the discovery of clues (symptoms) (Andrews, 1993). In relation to prescribing opioids for chronic pain, the term “detective work” was used by participants to describe a different set of practices. Detective work here refers to determining the facticity of a patient’s claims to distinguish ‘legitimate patients’ using opioids for medicinal purposes from people using opioids for ‘illegitimate’ means. As opposed to investigations of the body and its symptoms to produce a diagnosis, here the patient and their story are the objects of investigation as clinicians try to establish whether their claims of pain and their accounts of responsibly using opioids are accurate. This includes listening to patients’ stories and comparing their narratives with known facts about their lives and medical history to determine if their story “adds up.”

I first learned about the use of detective work in this manner when I asked physicians to talk about the everyday work of caring for people with chronic pain and describing opioids. Hoping to prompt them to provide detailed descriptions of this work, I asked clinicians to bring me through a typical appointment with a patient who is either using opioids or who may benefit from their use. In my interview with a neurologist, I provided an example of what this work might look like: “Maybe you start by saying hello, asking general questions, then maybe you get into the opioids they’re using and how that’s going.” I found, however, that for physicians the work of prescribing opioids began with an assessment not of the person’s symptoms or pain but rather the credibility of their claims. As the neurologist responded: “Well, before all that, the first thing is...who is this person? If they’ve been using opioids for years now, I want to hear their story and see if it adds up.”

The work of determining whether a person’s story “adds up” was identified as one of the primary purposes of taking the patient’s medical history. As one physician noted, details regarding a patient’s diagnoses and previous treatments were often easily found in the patient’s chart; far more important was the work of assessing the facticity of the patient’s claims. A general practitioner described this work as “reading between the lines” of a patient’s account of their medical history to determine whether their story “makes sense.” This work is particularly important in treating legacy patients who often arrive at the physician’s practice after years of using opioids for complex chronically painful conditions. Patients’ assertions that they have never misused opioids, that they have only ever been prescribed opioids from one physician at a time, or that they have never suffered adverse effects are scrutinized against the patient’s chart and also within the wider context of their life.

Questions about employment, family situation, past and current medical history, drug use, and mental health are important means of gathering information that can be compared to a patient's chart. This information can also be scrutinized to determine whether the patient's responses fit into other details of their lives. A patient's claims must be measured against what is already known to be true about the person's life circumstances and the physician's overall impression of the patient. As a neurologist explained:

Well, the mistake of doctors in the past—not all doctors—is that they didn't ask the right questions or look into [the patient], look into their background...I mean, certainly, patients can lie. If they're looking for opioids and you ask them about their previous history of drug abuse, they can lie about it, because that would be a big contraindication about their lifestyle. But then you need to use your judgment. If somebody comes in and they say that, you know, "I've never abused drugs before, I don't use alcohol, I don't smoke," but they're living at the Salvation Army, with that kind of background, that's not a person you want to put on opioids.

These details about a patient's life are crucial for determining the validity of their statements. Another strategy used for verifying the veracity of patients' claims involves tracing the origins of the person's pain, checking whether their allegations can be verified, and deciding whether their story is sensical. If a person is able to prove the cause of their pain, such as post-surgical pain from a surgery that can be confirmed through the person's chart and in the original referral, there is a greater perceived likelihood that their responses to other questions will be truthful.

For physicians who have been practicing for many years, the ability to discern a patient's motives and the truthfulness of their statements is a form of knowledge honed over time. One physician noted that it was sometimes difficult to explain her reasoning for prescribing opioids to one patient while refusing to prescribe to another. While she suspected that the decision was made based on an unconscious bias toward characteristics such as a person's clothing or their mannerisms, the patients whose stories she investigated further tended to be those who set off her

“alarm bells.” For one physician who cares for people who are precariously housed or unhoused, years of working with this population have provided him with an intuitive sense of whether people are being truthful, as well as crucial knowledge regarding the person’s daily life, their social networks, and their reputation through word on the street.

The work of “reading between the lines” of a patient’s account also requires that physicians carefully consider the patient’s demeanour and disposition. A neurologist described a trustworthy patient and a good candidate for prescription opioids as one who is not overly emotional:

The person I’m going to consider [for prescription opioids] is the person who has a reason for their pain. You know, they’ve got chronic back pain from a surgery that didn’t work, or pain from diabetes, or shingles. They come in and they say, in a very matter-of-fact way, “I’ve got terrible pain. I hope you can help me.” And they maintain their sense of humour, and they say, “I’m doing the best I can, I’m trying to work, but this pain is horrible and I’m really having trouble functioning.” They’re very straight about it. And they’re not histrionic about it. There’s no affective component.

Another physician described the struggle she faces when evaluating the merits of a patient’s story if the patient becomes emotional. She described “big, grown men” who are “coming in crying and saying, ‘I can’t function. I can’t do this.’” In these cases, she felt that she could not prescribe opioids with any certainty that the patient would not misuse them: “Do I know that they’re not selling drugs? Do I know they’re not doing something else with their drugs? I don’t know that.” One of her concerns around emotional patients was the possibility that this sensitivity was the result of opioid withdrawal rather than genuine pain that merited treatment.²³

²³ Physicians’ work of ensuring that patients’ stories are factual often engages stereotypes associated with marginalized people and doubts toward the veracity of their claims. There exists a large literature examining physicians’ beliefs and how these lead to dismissal of patients’ concerns, some of which I addressed in chapter two. The examples provided here echo research on physicians’ perceptions of people who use drugs (or are suspected of using drugs) (Merrill et al. 2002; Buchman et al. 2016), racialized non-white people (Balsa and McGuire, 2003; Naidowski et al., 2020), and women (Norman, 2018) as being untruthful, deceitful, or exaggerating their symptoms.

While physicians generally felt that they had grown quite adept at investigating patients' claims and assessing their truthfulness, there were still some instances in which they doubted their judgment. This was particularly true in the case of legacy patients who were referred to them from another practice, typically after being orphaned within the context of the opioid gap described above. These patients, many of whom have been using high doses of opioids for years, prove challenging to physicians as their behaviours are perceived as indistinguishable from addicts' behaviours. A medical resident provided me with an overview of the "red flag behaviours" that might indicate substance abuse or addiction—early prescription refills, refusals to consider tapering, demanding a particular type or dose of opioid, and becoming upset upon restriction of access to opioids. By the same token, she also acknowledged that people with chronic pain who need opioids for adequate pain relief display the same behaviours. She and her colleagues have noticed with great concern an increase in these difficult-to-discern behaviours as people with chronic pain find their access to opioids restricted.

Physicians also use various medical tools and tests as a means of verifying the facticity of patients' claims. The use of medical tests in this manner presents what one family physician called a "double-edged sword." On the one hand, quantitative data such as blood test results were perceived as objective proof that a patient is a legitimate pain patient, and physicians felt that this evidence could not be criticized, questioned, or reinterpreted by the CPSO. On the other hand, these tests are not infallible. Physicians have found that as patients' access to opioids is restricted, many people have become proficient at 'cheating' tests. Furthermore, physicians have become hesitant to employ these tools out of fear that patients sensing skepticism from their physician might grow fearful and refuse to disclose important information such as adverse effects related to opioid use.

The purpose of gathering evidence is not only to verify a patient's claims, but also to defend oneself against investigation or punishment from the CPSO. Quantitative data from blood tests or urine tests indicating no presence of drugs other than those prescribed were perceived as indisputable evidence that the choice to prescribe opioids is beyond reproach. Similarly, diagnoses supported by imaging or other test results were seen as a more defensible reason for prescribing opioids than prescribing for forms of chronic pain that could not be located in the physical body. Physicians acknowledged that this emphasis on a 'visible' or detectable cause of pain excluded many people from accessing opioids as numerous chronically painful conditions cannot be easily located in the body or proven through testing. Nonetheless, in one practitioner's words, physicians felt that their "hands were tied" as the choice to prescribe opioids to someone with a contestable illness could put them at risk of investigation.

One of the most commonly used tools to verify patients' claims were urine drug screening tests. When I asked a physician if the results of urine drug screening allowed her some peace of mind that the patient was not diverting or misusing opioids, she scoffed and said, "Well, I mean, you can fake anything nowadays. So, I don't know what the College will expect next, if they want me to go in there with the patient and hold the cup." Several other physicians doubted the utility of urine drug screening, including another physician who nonetheless felt pressured to regularly order this test:

There's always that little piece of me that has to check the patient's urine and make sure there's nothing bad in their urine. Even people who have been on opioids for a long time, I'll still screen, because people can present well but may have substance problems, and that falls back on me. But, I mean, there's so many ways to cheat it. I know patients can bring in fake urine, there's devices you can use to have a fake bladder with you, it has a warmer so you can pour the urine into that. There's some where you put a pump under your armpit because

in methadone clinics there might be a camera pointed at you. So, there's this whole world out there and if a patient manages to trick you, it's your head on the line if the College finds you at fault.

While these manners of cheating tests were widely cited by practitioners, very few had ever experienced a patient using these strategies. The goal, as the physician explained, was not necessarily “to catch criminals, but instead to cover all your bases so when the College comes knocking you know you’ve done everything you can to make sure the patient isn’t misusing.” Many clinicians doubted the value of perpetually screening patients and worried that these forms of testing damage the patient-physician relationship.

Imaging tests such as MRI, CT scans, and x-rays were perceived as near guarantees that the CPSO would recognize the legitimacy of a patient’s claims of chronic pain and their need for opioids. However, clinicians also feared tactics that might be used by patients to cheat these tests. As in the case of urine drug screening, very rarely, if ever, had physicians personally encountered these forms of trickery. Rather, knowledge of these tactics has spread by word of mouth. One frequently mentioned strategy was the use of doctored images. Physicians scrutinize MRI, x-ray, and CT scan images for signs that the image has been downloaded from the Internet or borrowed from a friend and then modified with the patient’s name and information. Physicians described zooming into the image and searching for aberrant pixelation or odd blurring, as well as contacting the laboratory where the imaging took place to verify its provenance.

Documenting all aspects of a patient’s care was widely held as one of the most critical aspects of protecting oneself from the state and the CPSO. As in the case of other facets of their work, physicians’ charting practices have shifted over time to prioritize avoiding surveillance, investigation, and punishment by the CPSO, often at the expense of patient care. Physicians drew on various forms of imagery and metaphors to describe the work of documentation—in the “battle”

to defend oneself against the CPSO, documenting was said to be “your last saving grace,” “your last line of defence,” “your best defence against the College,” and “the biggest shield” against auditing.

The importance of properly charting all aspects of a patient’s care came to the fore when the CPSO initiated its investigations of physicians identified as opioid overprescribers in 2016. As one practitioner explained:

This was different from other investigations because usually, if you’re a practicing physician, the only way the CPSO will call you and audit you is if there are complaints. And these audits weren’t educational, they were hand-slapping audits. So, now you have physicians who are beloved by their patients, who were prescribing opioids exactly the way they were told to for decades—and might have been prescribing high doses but, again, were doing that in accordance with what had been best practice at the time—who all of a sudden found that by virtue of their prescribing practices they were being called in for a serious chart review to defend their licenses. And I sat on one of these [committees] and basically, you get the physician’s charts, so if there are maybe five patients in their practice who might be receiving high doses of opioids, you get those charts and you go through them, and you have to decide if the physician met their duty of care. Did they start at a low dose and go up slowly? Have they tried tapering? Did they try things other than opioids? If you don’t have all of that documented, it becomes a big problem.

One physician investigated as an overprescriber found himself explaining and defending every word in his patients’ charts and every decision, no matter how minor, he made in prescribing opioids. He said: “It could be as simple as, ‘Well, you suggested to that patient to taper, and they said “no,” so you said you’d revisit it, but you didn’t bring it up at their next appointment. You brought it up at the appointment after the next, which was six months later.’ Little things like that.” Physicians involved in auditing charts used the same word—“ridiculous”—to describe the level of detail at which physicians’ prescribing practices were scrutinized.

The lengths to which physicians documented every detail of patients' care was attributed to the need to ensure that they could prove that their clinical judgment was faultless and their decisions to prescribe opioids were beyond reproach. Only one clinician felt that this increase in charting resulted in a reduced risk of harm to the patient; the other participants felt that excessive documentation, as well as other changes to their work described in this chapter, have had no bearing on reducing the patient's risk of harm and might in fact increase this risk if patients feel pressured to lie or to hide aspects of their medical history.

In many ways, these shifting practices resonate with those investigated by Sanders (2015) in his examination of public health nurses' changing documentation styles in response to HIV criminalization. Through his interviews with nurses, Sanders came to find that they adopted a "hyper-vigilant inscription style" in which they not only documented additional notes regarding counseling sessions with HIV positive clients but also were attentive to the relevance of these notes for potential future criminalization of the client (Sanders, 2015, p. 402-4). Likewise, physicians have adopted a hyper-vigilant form of charting wherein they consider not only the relevance of their notes for tracking the patient's response to opioids and informing future care but also how these notes might be perceived by CPSO auditors. This charting work hooks physicians' activities into relations of surveillance, coercion, and punishment as they make sure to leave documentary evidence of prescribing practices that will protect them from scrutiny.

Particularly important has been notetaking that emphasizes details of the clinical encounter that physicians felt were routine and hardly worth noting but whose absence the CPSO would seize upon. In reference to the work of explaining to patients the potential adverse effects of opioids, one audited physician said: "As a matter of course, I'm always going to run through those side-effects with patients, and I'll make a note of, you know, 'Discussed potential side-effects related

to x opioid.’ But now I’ll take the time to note every single side-effect I mentioned, any questions the patient had, and how I answered.”

In addition to providing little value to the patients under their care, physicians felt that extensive charting work took away from the time needed to care for their patients and, in many instances, negatively impacted the patient’s ability to access appropriate chronic pain care. One physician whose charts have been audited by the CPSO described the work of documentation as “almost a form of malicious compliance where, if the College wants to know every single little thing I say to the patient and every single step of my thought process, sure, I’ll write that, and they can have fun reading this massive chart.” When I remarked that these extensive notes seemed to be of dubious value for patient care, he agreed, adding that this level of documentation has also made it challenging to refer patients to other physicians or for specialist care: “The truth is pain patients are already a tough sell. So, you send someone with decades of really complicated chronic pain and they’ve used all sorts of opioids over the years, and then on top of that, you send them along with this chart that goes into the hundreds of pages. I mean, you can’t blame doctors, specialists, for taking one look at that and saying, ‘Forget it.’”

3.9 MANAGING THE PATIENT-PHYSICIAN RELATIONSHIP

Growing suspicion and skepticism toward people with chronic pain who use opioids and the perceived need to verify that they are legitimate pain patients was not a mere inconvenience for physicians. Rather, this new responsibility was felt as a fundamental shift in both their sense of self as a medical professional and their relationships with their patients. Physicians felt stuck in a lose-lose situation in which they either satisfied the CPSO but let down their patients, or they

supported their patients in managing their pain but risked sanctions from the CPSO. This was particularly difficult for physicians with decades of experience who had long been upheld as experts in the field of chronic pain management and whose colleagues still continued to refer complex cases to them. Finding that the opioid prescribing practices they had used throughout their careers were suddenly disparaged as the cause of a public health crisis has been a heavy burden for many.

One family physician lamented the paranoia that has seeped into physicians' interactions with patients who use opioids for chronic pain. To his chagrin, he found that medical students and resident physicians have begun to emulate these behaviours and attitudes. Educated in the era of panic around the opioid crisis, many of the students he works with are hypervigilant toward people with chronic pain and especially those who used opioids. A medical resident I interviewed echoed his thoughts: as a resident physician, she felt that the risks of prescribing opioids are typically too great not only for the patient but also for herself as a junior clinician. For students, the experience of witnessing disciplinary action from the CPSO toward senior colleagues and respected clinicians has engrained a deep fear of prescribing opioids lest they too be investigated.

After being audited numerous times by the CPSO, one physician found her understanding of what it means to be a professional, and to be a medical doctor, significantly challenged. As physicians in her geographical region refuse to take on patients with chronic pain who use opioids for fear of reprisal from the CPSO, she has accepted these patients into her practice with the knowledge that otherwise they might not receive any care at all. Her dedication, she said, was first and foremost to her patients with chronic pain:

I could tell you all my patients are suffering terribly now. And I do the best I can, I hang on the best I can, but the College is just destroying me. But believe me, lots of doctors have just said—and I don't blame them—but

really, at the end of the day, they're just done with it. They've given it up, and they won't prescribe opioids ever again. They've just been persecuted too much. And I feel sorry for the patients. And I'll hang on as long as I can and treat them, but I really worry about what's going to happen when I'm gone. Who's going to look after them? If the College ever comes down against me and I can no longer practice, then these patients will have nobody to prescribe for them. So, it's really quite pathetic.

For this physician, her professional responsibility to care for her patients clashes with the pressure she faces from the CPSO to reduce the number of opioids she prescribes. While she is upheld by colleagues and patients as a caring physician who has improved the lives of many people with chronic pain, the CPSO's endless critiques of her opioid prescribing practices are difficult to endure. It is challenging, she explained, to see oneself as a good doctor for years and then suddenly find that you are seen by your regulatory college as a bad doctor.

Similarly, another physician resented the pressure he felt from the CPSO to remain suspicious of his patients as potential sources of malpractice. He said, "I didn't become a doctor to hover over my patients and watch their every move...And I didn't become a doctor, go through medical school, to be a detective." While he recognized that opioids could cause dangerous adverse effects and that physicians need to exercise careful judgment around opioid prescribing, he also argued that there is a substantial difference between "doing one's due diligence versus stalking your patients." His other concern was that although clinical judgment is essential to safe opioid prescribing, the investigations and punishments employed by the CPSO have curtailed physicians' confidence in exercising their clinical judgment.

This skepticism has also impaired physicians' relationships with their patients. Physicians voiced concerns that it is difficult to cultivate trust—a cornerstone of practicing medicine and ensuring patients' safety—while also remaining suspicious of patients' claims. One physician

observed that patients are aware of these changes and, in his experience, have grown increasingly reluctant to talk to their physicians about pain, injuries, or other symptoms out of fear that they will be dismissed or accused of drug seeking. These concerns are not misplaced; as I discussed in chapter two, many people with chronic pain refuse to report opioid-related adverse effects or reduced efficacy of analgesics for fear that their physician will seize the opportunity to stop prescribing opioids altogether.

Caring for people with chronic pain can be challenging due to the vexing nature of intractable pain and the lack of effective treatments. In this already fraught situation, the use of tools such as urine drug screening puts additional strain on the relationship. One family physician described the growing pressure to investigate patients and the veracity of their claims as fundamentally altering the physician-patient relationship:

Now we've been made to be investigators and detectives and to be really suspicious of everybody who's on an opioid all the time. It doesn't make for a very comfortable relationship with your patients. And it's changed. I mean, my relationship with my patients has changed because of this compared to thirty years ago. Where before it was, "How can I help you?" it's now, "Prove to me that you should be helped." That's a terrible, terrible situation, you know, and it doesn't happen in any other part of medicine. If someone says they're depressed, we don't hold their antidepressants because they might be lying to us [...] And it's now, as I said, "Prove to me that you're the right person for this treatment, and I'm still going to be suspicious about you the whole time."

A medical resident I interviewed also worried that patient-physician relationships would become more difficult to navigate over time. Particularly for patients with stigmatized conditions such as fibromyalgia and chronic fatigue syndrome, she has found that the mere suggestion that a physician might doubt their claims or suspect them of malingering is often sufficient to deter patients from seeking care at all.

In the face of these fractures in the physician-patient relationship, physicians engage in various work practices in the hopes of salvaging the relationship as best they can. For many, the most important strategy is to be as transparent with patients as possible. Physicians described showing patients letters they have received from the CPSO indicating that they are being investigated or referred for penalties as an opioid overprescriber. They hold frank conversations with their patients about their fear of losing their license to practice or the right to prescribe opioids. The work of trying to maintain a good relationship with patients while also emphasizing the risk that the CPSO might audit their practice was a source of significant stress.

Physicians have also struggled to maintain a relationship with patients resistant to tapering or ceasing their opioid prescriptions. For these physicians, a new form of everyday work has emerged as they attempt to convince patients to agree to a taper or to stop opioid use altogether without irrevocably damaging their rapport. One strategy to this end is to attribute blame to the CPSO as a means of displacing the patient's frustration from the physician to the College. As one family physician explained:

I do have some bull—I'll call them fibs—that I tell patients. And you can argue with me that that's inappropriate, but I'll say to patients, "The College is very, very strongly looking at doctors prescribing higher doses of opioids. If I keep prescribing for you, I'll probably lose my license, because the College is keeping a close eye on me." Well, that's not true, but the patients don't know that. They just hear me saying, "I don't want to lose my license." And, you know, I'm not being dishonest, I'm not telling a bold-faced lie, because the College *does* monitor high prescriptions now. They just haven't audited *me*.

While this physician felt that her decision to shift blame to the CPSO is justified, she also admitted to a niggling concern that deception and dishonesty will continue to seep into the physician-patient relationship as physicians attempt to placate both the CPSO and their patients.

When I asked physicians how we might move forward to reduce harms to patients and improve the patient-physician relationship, one of the most frequently mentioned suggestions was an urgent need to dismantle the binaries between licit/illicit opioids and good/bad opioid users. Overall, practitioners felt that ensuring patient safety—and, consequently, protecting public health—requires collaboration between physicians and their patients such that clinicians believe patients’ personal experiences of chronic pain and opioid use. One general practitioner summarized the issue concisely when he argued that the goal should not be “holding our patients and ourselves under a microscope” but rather “taking people at face value and not seeing opioids as this carrot we can dangle to make patients comply or force them into honesty.” Practitioners and people with chronic pain agreed that fostering trust was far more urgent than sowing seeds of skepticism.

3.10 CONCLUSION

In this chapter, I suggested that the contemporary panic around opioid-related harms is unique in that blame for this public health crisis in Ontario and elsewhere has been shifted from opioid users to physicians and the medical profession. Medico-legal responses to the perceived harms associated with prescription opioids have included the introduction of Ontario’s Narcotics Monitoring System as a mode of surveillance used by the state and the CPSO to investigate and punish physicians flagged as opioid overprescribers. Unlike modes of governing-at-a-distance or self-governance associated with medical self-regulation, these interventions into physicians’ prescribing practices have been coercive and often punitive in nature. In the face of these new forms of opioid pharmacovigilance, physicians have adopted work practices intended to protect them from investigation and punishment, including rapidly tapering patients’ doses, refusing to

prescribe opioids, verifying the veracity of patients' claims, and altered charting practices. These changed work practices and, more generally, heightened pharmacovigilance around physicians' opioid prescribing practices, have been of significant detriment to the patient-physician relationship.

In the next chapter, I move on to consider a second catalyst identified by participants as the cause of changes in physicians' opioid prescribing practices: the publication of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain. I explore two facets of the guideline: first, its development as a text intended to support the authority of the medical profession in self-regulating opioid prescribing, and second, physicians' attempts to translate the guideline into clinical practice. I will argue that efforts to produce a neutral, defensible text through specific techniques of evaluating evidence as well as the formation of 'balanced' or 'neutral' committees has resulted in a clinical practice guideline that is largely irrelevant to the actual work of prescribing opioids. I also demonstrate the ways in which physicians' attempts to translate the guideline into clinical practice have focused on ensuring their accountability and defensibility by prescribing only to 'neutral' patients untainted by social determinants of health, with disastrous consequences for people with chronic pain disqualified from care.

CHAPTER FOUR

4.1 INTRODUCTION

In this chapter, I examine the development and uptake of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain (hereafter referred to as the guideline). Before beginning this study, I was already familiar with the guideline as it has been the topic of considerable scrutiny and debate among people with chronic pain. Much of the speculation around the cause of physicians' changing opioid prescribing practices has focused on the guideline, giving rise to suspicions that its recommendations have forced physicians to adopt comparatively more conservative forms of opioid prescribing since its publication. Likewise, patient advocacy groups and other commentators have attributed physicians' growing reluctance to prescribe opioids to the guideline (CPAC, 2019; Cukier, 2020; Delisle, 2019; Schatman et al., 2019; Ross, 2017).

Repeated associations made between the guideline and restrictive opioid prescribing practices emerged as a disjuncture as I came to find that the guideline does not recommend these restrictive practices and, in fact, often advises against them. Stranger still, the physicians I interviewed were highly knowledgeable about the guideline and could quote recommendations verbatim. If physicians held considerable knowledge of the guideline and none of the recommendations advise rapid tapering, ceasing opioid prescriptions, or refusing to treat people with chronic pain, I could not understand why practitioners continued to attribute their adoption of these work practices to the guideline. I was also unconvinced by theories put forward by friends and fellow activists with chronic pain that the guideline was being used as a scapegoat for physicians to justify their reluctance to prescribe opioids.

Just as I was confused by this apparent contradiction, it has been immensely baffling to the creators of the guideline (Kahan et al., 2018). In response to growing panic among clinicians and patients that the College of Physicians and Surgeons of Ontario (CPSO) is ushering in a new era of opiophobia based on the text, its creators have been quick to engage in knowledge dissemination activities funded by Health Canada (which also sponsored the development of the guideline). This outreach has included the publication of articles clarifying the recommendations (Busse et al., 2018a; Busse et al., 2018b; Busse, 2021) as well as appearances on podcasts (CEP, 2018) and radio broadcasts (Green, 2017) to educate physicians on the correct interpretation of the guideline.

In this chapter, I argue that the disjuncture at hand is not one of misinterpretation or misunderstanding on behalf of physicians. Instead, through an institutional ethnographic lens, I take up the guideline not as a repository of information but rather as a participant in social relations that comes to be activated as physicians translate the text into their local settings in ways that are relevant to their everyday work. Operating at the juncture between physicians' local actualities and the extended medico-legal ruling relations described in the previous chapter, the guideline coordinates physicians' everyday prescribing practices across these institutional relations. Its use by physicians has been further shaped by the CPSO's mobilization strategies intended to prompt uptake of the recommendations. Physicians' altered prescribing practices are therefore not the result of inattention or misapprehension of the guideline but rather strategic attempts to ensure that their work is accountable to forms of surveillance and coercion that have emerged as interventions into their work of prescribing opioids.

Through my interviews with people involved in the creation of the guideline, I came to find that it was developed in no small part with an eye toward supporting the medical profession's authority in reinstating physicians as experts whose evidence-based knowledge and expertise are

imperative to mitigating increases in opioid-related harms. There is an urgency to this task as physicians have come to be held responsible for the present-day opioid crisis by the provincial and federal governments, public health agencies, some advocacy groups, the mass media, and public opinion (El-Sabawi, 2019; Sun, 2022; Mendoza et al. 2019). As a result, the medical profession has had to demonstrate that physicians are uniquely positioned to resolve the crisis through their use of scientific, evidence-based practices, and that the profession is capable of self-regulating without state intervention. The central concern informing the creation and subsequent mobilization of the guideline by the CPSO has been its defensibility: proven reliance on objective, scientific, and neutral facts such that the guideline and its use by physicians are beyond reproach.

Significant problems related to risk assessment, pain management, and the physician-patient relationship have emerged in physicians' local practices as they attempt to translate these objective 'truths' into clinical contexts that are organized through highly political medico-legal ruling relations. In attempting to render their opioid prescribing practices accountable to the guideline and its organizing concerns of ensuring neutrality in prescribing, physicians have resorted to disqualifying from care any patient who is 'tainted' by social determinants of health such as gender, race, and history of drug use. Central to my argument is the recognition that opioid prescribing by physicians is thoroughly political and that attempts to render this practice apolitical may have consequences for those who find themselves barred from accessing opioids for pain management.

My analysis of the development and use of the guideline proceeds in three parts. First, I provide a brief outline of the literature on clinical guidelines, evidence-based medicine, and institutional ethnographic approaches to textual analysis. Next, I piece together the work practices through which the text was created. I describe the use of techniques including searching and

reviewing the literature according to evaluation models informed by evidence-based medicine as well as practices of forming and directing committees with the goal of achieving unbiased opinions around opioid prescribing and use. I then draw on my interviews with physicians in recounting their work of attempting to translate the guideline into their local clinical settings in ways that render their prescribing practices accountable to the relations of medical professionalization, neutrality, and evidence-based medicine to which their work is coordinated by the text. I focus on physicians' use of screening instruments and risk management questionnaires to ensure that opioids are prescribed only to 'neutral' patients unencumbered and untainted by determinants of health such as a history of trauma or racialization. I also demonstrate how the use of screening instruments in this way has created barriers to care for those who are most marginalized, including two of the people with chronic pain I interviewed for this study.

4.2 TEXTUAL ANALYSIS OF CLINICAL PRACTICE GUIDELINES

Social science research on clinical practice guidelines has taken up questions of standardization, autonomy, and evidence-based medicine in exploring how guidelines come to be produced and implemented, and to what effect. Clinical guidelines are systematically developed statements intended to support physicians and patients in making decisions about health care (Timmermans and Berg, 2003). They are a primary means by which diagnostic and therapeutic knowledge is disseminated to practitioners, and their value has grown exponentially since the rise of evidence-based medicine in the 1990s (Mykhalovskiy and Weir, 2004). Evidence-based medicine elevates certain forms of knowledge over others—placing randomized control trials at the top of the hierarchy of knowledge—and, as a project to reshape biomedical practice, creates a presence for this evidence in clinical practice. Guidelines have come to be positioned as an ideal

medium to disseminate evidence-based knowledge to busy practitioners who cannot keep up with rapid advances in biomedical research (Timmermans and Gabe, 2003).

Berg et al. (1997) provide a comprehensive summary of the benefits and limitations associated with the use of guidelines in clinical practice. In organizing clinicians' actions and the rationale of these activities, guidelines can serve as a foundation for discussion by explicitly describing actions and decisions that were once implicit. However, guidelines also risk reinforcing the tendency in medicine to perceive patients' trajectories through the health care system as a sequence of individual rationalized decisions without accounting for contextual factors and the health care provider's own knowledge and competencies. Berg and colleagues argue that guidelines are so rarely implemented because of the clash between the formal image of health care practices embedded in the guideline and the material realities of practitioners' work.

Adler and Kwon (2013) identify the guideline's "mutation of the medical profession" as a process through which guidelines have been introduced to replace physicians' traditional decision-making autonomy by standardizing and formalizing elements of clinical practice that are implicitly learned through apprenticeship and experience (Adler and Kwon, 2013, p. 933). The authors describe guidelines as carriers of the mutating features of the medical profession that transmit these features into new settings. Similarly, Mykhalovskiy (2003) and others have characterized clinical guidelines as participants in social relations that come to be activated by local readers and users. Others have taken a poststructuralist approach to clinical guidelines in defining them as sites of relational power struggles where, as in the work of Cooper et al. (2021) on Australian maternity care, risks of harm are negotiated.

One topic of considerable concern in social science research has been physicians' adherence to guidelines. A substantial knowledge mobilization and translation literature has

emerged around the task of ameliorating clinicians' understanding of and adherence to guidelines (Ouimet et al., 2006; Wang et al., 2021; Wilson et al., 2014). Researchers and knowledge mobilization experts have experimented with several strategies including publishing guidelines in academic journals and online, presenting guidelines at meetings, eliciting feedback from stakeholders, furthering practitioner education, and improving technological accessibility (Wang et al., 2021; Timmermans, 2005). As adherence comes to be conceived as a problem of a research-to-practice gap, various evaluation instruments and experimental designs have also been developed to identify barriers to implementation and how these might be addressed.

Clinical guidelines have also been taken up by institutional ethnographers interested in evidence-based medicine and medical practice. Rankin and Campbell (2006), in their exploration of new forms of management in nursing care, highlight the way evidence-based managerial strategies have shaped nurses' work. Similarly, Corman (2017) examines the impacts of reforms to paramedic services in Alberta and the role of standardization through evidence-based protocols. Mykhalovskiy (2001) accounts for the implications of evidence-based medicine and standardization through an institutional ethnographic study of care pathways as texts that outline the interventions and activities that are expected to take place over the duration of a hospital stay. Webster (2020) has also highlighted the role of evidence-based medicine in developing best practices for the use of thrombolytic therapy for acute strokes.

Like other institutional ethnographic analyses of clinical guidelines, my examination of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain is not intended to determine whether guidelines are valuable or irrelevant; nor is this a knowledge mobilization project aimed at ascertaining how barriers to guideline implementation might be addressed. Rather, as Mykhalovskiy and Weir (2004) propose in their review of social science research on evidence-

based medicine, I take the guideline as a point of entry into the ruling relations organizing opioid prescribing and use. My analysis of the guideline began from the standpoint of physicians' practices of reading and applying the text as a form of work that made visible how the guideline operates at the juncture between the forms of surveillance and coercion described in chapter three and physicians' work practices described below.

4.3 TEXTUAL ANALYSIS IN INSTITUTIONAL ETHNOGRAPHY

Texts are of great value for institutional ethnographers as they allow us to discover dimensions of ruling relations within local settings (Smith, 2005). Texts are unchanging and replicable: they stay the same across time and space regardless of the reader, and this characteristic gives them the capacity to coordinate extended institutional relations. For instance, ruling relations of health care and chronic pain management are accomplished through everyday activities occurring at different times and in different places and performed by a multitude of people who may have never met. Texts are essential for coordinating the activities through which institutions 'happen'—they standardize and generalize ruling relations at the juncture between ruling relations and local settings. However, texts are not prescriptive; as an agent of the text, the reader brings its forms of organization and its institutional discourse into their local setting.

Smith draws on Veblen (1954) in her account of the use of texts in objectifying ruling relations. These relations expropriate forms of organization that develop among people within their local settings. It is in this way that people come to be accountable to any "master-concern 'higher up' in the hierarchy of business" (Veblen, 1945, p. 155, as cited in Smith, 2005, p. 17). Master concerns are described by Smith as the categories and frames of institutional discourse into which

local practices are hooked up; these interests devised elsewhere and elsewhere become an imperative toward which the individual in their local setting must ensure that their work is accountable (ibid. 216). This notion is helpful in thinking about the concern of the medical profession to ensure its continued authority to self-regulate and how this concern comes to bear on physicians' everyday practices as they are accountable to interests held 'higher up' in the profession and practice of medicine.

Another important facet of texts for Smith is their use of institutional categories such that the subjects of institutional relations are not individuals but rather a class of persons (ibid. 117). Smith suggests that we cannot find within institutional texts the perspective of actual people: "Agency is assigned to institutional categories. Someone who can't be subsumed under the institutional categories assigned agency has no agency" (ibid.). As I explore in this chapter, within the objectifying text of the guideline and medical screening instruments, the individual is located within a class of persons understood as 'patients' and physicians' work of prescribing to these people can be understood only insofar as they can be subsumed within the category of patient.

4.4 PRODUCING THE 2017 CANADIAN GUIDELINE FOR OPIOIDS FOR CHRONIC NON-CANCER PAIN

The 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain spans just over a hundred pages and touches on topics such as starting an opioid trial, optimizing non-opioid therapy, dosing, and tapering (Busse, 2017). Development of a new opioid prescribing guideline was first proposed by a group of practitioners and epidemiologists who sought funding from several sources but were unsuccessful due to political motivations and conflicts of interest

intensified during the opioid crisis.²⁴ A major barrier to funding was hesitancy among institutions that had originally funded or were presently using the 2010 Canadian Guideline for Safe and Effective Use of Opioids for Chronic Non-Cancer Pain. These institutions were reluctant to support the creation of a new guideline that might challenge the recommendations of the previous protocol with implications for insurance coverage, workers' benefits, provincial health coverage, and public-private partnerships in which these institutions have a vested interest.

As opioid-related harms continued to increase in Canada and elsewhere and rose to prominence as an issue of national concern, the Canadian federal government expanded the focus of its National Anti-Drug Strategy in 2007 to address not only illicit opioids but also prescription opioid use (Fischer et al., 2019; Government of Canada, 2007). In relation to this expanded scope, in the mid-2010s Health Canada made available contribution funding for projects responding to drug and substance use issues in Canada. Much of this academic funding has been distributed through the Canadian Institutes of Health Research (CIHR). Funding to develop a new prescribing guideline was successfully secured on the premise that this protocol would update and revise the 2010 guideline through a comprehensive review of the literature.

Motivation for this project came not only from concerns around increasing rates of opioid-related harms but also perceived limitations of the 2010 guideline. Totalling over 160 pages in two parts, the 2010 guideline contains five clusters of recommendations (NOUGG, 2010). All 24 recommendations are accompanied by a statement, a discussion, and a summary of the peer-reviewed evidence. The recommendations and their supporting evidence are graded on a scale of

²⁴ Details in this chapter related to the creation of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain derive from my interviews with practitioners involved in the creation of the text. Given the small number of people involved in this process, I withhold most of the information regarding their specific involvement and roles to protect their confidentiality. Where noted, I also draw on descriptions of committees and the literature review process outlined in the guideline itself.

A to C based on the quality of the evidence, which is determined by factors such as methodology and sample size.

While the 2010 guideline was met with a generally positive response by practitioners, physicians also felt that the guideline was far too lengthy and that the format was suboptimal (Chang et al., 2016). There was also considerable controversy around the grade A recommendation that most patients' pain can be effectively managed at a dosage at or below 200 mg morphine equivalent daily. Previously, consensus statements and guidelines had not specified an upper limit and instead recommended that physicians dose to effect or to the point of intolerable adverse effects (Jovey et al., 2003). The 2010 guideline's definition of a 'watchful dose' at 200 mg morphine equivalent daily contradicted over a decade of opioid prescribing practice and was not supported by high quality evidence (CADTH, 2012). The group of practitioners and epidemiologists who received funding to update this guideline further critiqued the 2010 protocol on two fronts. First, they argued that the process of evidence synthesis did not adhere to high standards of objectivity. Second, they were critical of previous protocols that drew extensively on clinical judgment statements and expert opinion rather than evidence derived from the literature and, ideally, from randomized control trials.

These critiques were grounded in wider concerns among regulatory college committee members and other stakeholders within the medical profession that the 2010 guideline no longer fulfilled the requirements of a core document standardizing opioid prescribing for chronic pain. As panic around opioid-related harms in Canada increased in the late aughts and the medical profession came under fire for their role in the so-called opioid crisis, there was an urgent need for a guideline that could fulfil a newly emerging role of supporting the authority of the profession and its capacity to self-regulate by demonstrating that its members' opioid prescribing practices

were based on the highest quality available evidence. This authority was crucial as the profession sought to demonstrate that it was not an external threat bearing upon innocent patients and making them ill but rather an institution singularly capable of regulating opioid prescribing and of determining, based on the best evidence available, in which instances opioid use is safe.

The medical profession's concerns that public and political animosity toward physicians would result in changes in legislation governing the profession have not been unfounded. The boundaries of medicine and other professions have endured changes during historical periods when federal, provincial, and territorial governments have introduced legislation in the face of opioid-related panics, while the medical profession has long insisted that the government's power to control medical practice should be tightly restricted. A central argument to this end is that only medical professionals have the knowledge and expertise necessary to regulate clinicians; self-regulation is put forward as necessary to protect the public from harm.

The profession's capacity for self-regulation is further defended on the basis that medicine is an evidence-based discipline which guarantees, among other things, that clinical decision-making aligns with the best available evidence, thereby ensuring the public's safety (Timmermans and Kolker, 2004; Timmermans and Oh, 2010). Evidence-based medicine has become a vital means through which the medical profession has continued to argue that it must be allowed to self-regulate with as little interference from government as possible, lest political opinions and agendas result in biased medical practices (Timmermans and Mauck, 2005).

In its negotiations with different levels of government, the CPSO has prioritized the solidification of the medical profession's authority in regulating prescribing practices to safeguard public health. While calls for reform have insisted that physicians' rights and privileges be restricted (Furlan, 2017; Kane, 2016), the CPSO has instead argued for greater extension of

physicians' powers. In August 2016, for instance, the CPSO responded to a draft of the *Safeguarding Our Communities Act* from the Ministry of Health and Long-Term Care. The regulation in question establishes a patch return program through which patients using transdermal opioid patches must return their used patches to the pharmacist before receiving their next dose. The CPSO responded by emphasizing that the proposed regulation would not be sufficient for addressing opioid-related harms (CPSO, 2016b). Rather, they recommended "specific, proactive strategies to promote a more co-ordinated, system-wide approach to mitigating opioid abuse," which should include "giving physicians greater access to provincial narcotics monitoring data [from the NMS] to help them confirm the patient's prescription history" (CPSO, 2016b, p. 53).

The introduction of Ontario's Narcotics Monitoring System in 2012 and its use for surveillance of physicians by the state also gave rise to tensions between the state and the CPSO as the profession attempted to guard against erosion of their right to self-regulate. A physician who participated in the development of the guideline and who has also been involved as a member of the CPSO explained:

Physician: All of a sudden, you have this situation where the provincial government has decided to take things into their own hands. And the College, of course, reacts very strongly to this. Because the role of the College is ultimately to protect the public, but it's also almost in competition with other professions and the government to make sure doctors are the only ones who can do specific protected acts like prescribe opioids. So, now, the College sort of had its hands tied, because if we went ahead and responded strongly to this system [the NMS], that's going to be a problem when doctors are already seen as shady and causing all sorts of problems because of opioid prescriptions.

Leigha: And when you say, like, 'the College,' who would that be exactly?

Physician: So, you can see online on their website that the College has this structure. Every other professional college is going to have a similar structure. At the top, you have Council, and that's the governing board where

they basically set the strategic direction of the College and also make policies and things like that. And then you have other committees, like the [Executive Committee], and you would have the Registrar, and together those committees are making decisions.

Leigha: And I'm assuming not by themselves. Like, the College is part of the medical profession more generally.

Physician: Exactly. So, in Canada, each province has its own college of medicine, but there are other bodies like the [College of Family Physicians of Canada (CFPC)], and they're the ones establishing standards for across Canada. This wasn't really what I did, I can only speak to this so much, but I know the College [of Physicians and Surgeons of Ontario] was always in close contact with people from the [CFPC]. And when this all started in 2012 [the introduction of the NMS], there were a lot of meetings happening where these different colleges are trying to figure out, "Well, what do we do now?" Because as I said, we had to be really cautious because we don't want to anger the public or the government when there was already a lot of concern around opioid prescribing and doctors not prescribing appropriately. But at the same time, this was really a pushback against the College [on behalf of the government] that I don't think we'd seen before.

Tasked with managing this tension between adhering to government regulation and insisting on their right to self-regulations, members of the CPSO and the CFPC tentatively agreed to partner with the provincial government in supporting new policies, legislation, and modes of surveillance intended to reduce opioid-related harms. This move was, in another physician's words, "Probably the most politically expedient because the College isn't saying 'no,' it isn't refusing to comply, but at the same time in the background they're scrambling to try to set limits on how far the government can go [in regulating the medical profession]."

For the medical profession, proposals to update Canada's opioid prescribing protocol were an important opportunity to reinforce medicine's authority in determining best practices for opioid prescribing based on scientific evidence. In contrast to previous guidelines, including not only the 2010 Canadian guideline but also a protocol published by the US Centers for Disease Control and

Prevention in 2016, the new Canadian guideline drew explicitly on evidence-based medicine while limiting the use of clinical knowledge and judgment to inform recommendations. In this way, the CPSO and other regulatory colleges in Canada could demonstrate that they were shifting toward a new future of opioid prescribing based on the best available evidence. While the guideline was not developed specifically by the CPSO or other regulatory colleges, nonetheless there was significant crossover as practitioners involved in the creation of the guideline were also members of these colleges. Likewise, medical colleges such as the CPSO developed policies to disseminate and frame the use of the guideline in specific ways. One of the committee members involved in creating the 2017 guideline explained that within this context the most important goal was ensuring the guideline's defensibility:

We did it so that any recommendation would be defensible, there would be a paper trail where we could say, "This is how we came up with this." And also, to address a real limitation of some other opioid guidelines that had come out and made lots of recommendations in areas where there was no evidence at all, and they had simply said, "Well, the experts we've involved think you should do this." And there were lots of examples of that. So, we set out a process, you know, all these sort of steps that we felt would be really critical to be able to defend the rigour of the product that we ultimately had.

Other participants echoed the importance of ensuring that the recommendations made in the guideline be, in their words, "airtight" and informed solely by "the best available evidence," by which they meant objective, scientific evidence obtained ideally through randomized control trials.

4.5 OBJECTIVITY AND THE WORK OF ENSURING DEFENSIBILITY

The creators of the guideline attempted to ensure defensibility in two ways: first, by organizing the development of the guideline such that there was minimal bias from committee

members, and second, by drawing solely on high quality, rigorous evidence. A four-member Steering Committee was responsible for planning the development of the guideline, oversight, and policy decisions; a fifteen-member Guideline Panel comprising thirteen clinicians and two patient representatives was responsible for developing, presenting, and voting on the recommendations; a thirteen-member Clinical Expert Committee acted in an advisory role to the Guideline Panel on the basis of their expertise in chronic pain and opioid prescribing; and a sixteen-member Patient Advisory Committee also had an advisory role to the Guideline Panel. The work of producing the guideline was organized in such a way that participants were carefully assigned to committees based on their perceived expertise and experiences.

The composition of these panels was also intended to ensure that the guideline recommendations were subject to “minimal influence from financial or intellectual interests” (Busse et al., 2017, p. 16). Objectivity was of primary importance to the guideline developers and served as the foundation for many of their decisions. One practitioner felt that the greatest challenge of this work was balancing the tensions between needing clinicians’ expertise in the development of recommendations while also mitigating the impact of their individual biases on the recommendations. The primary strategy used for ensuring neutrality was to bar from the Guideline Panel any person who had financial or intellectual conflicts of interest that might influence their opinion of opioid prescribing for chronic pain.

Financial conflicts of interest were understood primarily as clinicians’ associations with the pharmaceutical industry and whether their research or teaching activities were funded by industry. Intellectual conflicts of interest included written publications that were either favourable or unfavourable toward opioids, as well as other indications of bias such as positions on various committees or involvement in certain organizations. The ability to prove that the voting members

were neutral was paramount, as was the need to distance the guideline and the profession from the pharmaceutical industry, which has also been castigated in North America and elsewhere for its perceived role in rising rates of opioid-related harms. As one participant explained:

We needed to be able to demonstrate that we've made an effort, yes to reduce bias from the recommendations themselves, but also that we sought out and acquired experts to provide their perspective on the issue from both camps. You know, we don't want something at the end of the day where people can say, "Oh, we're not going to pay attention to it because you didn't have any experts to represent our side of it." And then there's the issue of the pharma companies, which is a whole other set of problems. A lot of people are going to see that as the biggest risk of bias, if a doctor has some sort of link with industry, and that becomes a conflict of interest. Even the slightest hint that we were influenced in any way by pharmaceutical companies will mean the recommendations aren't taken seriously.

Ensuring that the guideline was defensible against accusations of bias meant that the Guideline Panel was primarily composed of clinicians and experts in guideline creation with methodological backgrounds who did not have a particular opinion on opioids. While experts with financial or intellectual conflicts of interest could participate in guideline development, they were limited to a non-voting advisory role. Likewise, the Steering Committee was composed to ensure a balance in perspectives on opioid use, and the Patient Advisory Committee included patients who had both positive and negative experiences of opioid use, as well as the parent of a child who had fatally overdosed through use of prescription opioids.

The composition of 'balanced' committees and the use of various tools to grade the available evidence were designed to reinforce the guideline's objectivity. The participants I spoke with described practitioners' opinions on opioid use as situated across a spectrum that ranged from opiophobia to opiophilia. At the far ends of the spectrum were clinicians who either rejected all uses of opioids for chronic pain or who embraced liberal prescribing practices. Very few clinicians

or experts were perceived to be in the middle of this debate. Instead, the topic of opioid prescribing was recognized as so polarizing that temperate views were thought to be in short supply.

Within the spectrum of opinions on opioid use for chronic pain, the developers of the guideline tried to attain a neutral position by landing somewhere in the centre of this continuum. Discussions between experts and practitioners were organized in the hopes that the two extremes of opiophobia and opiophilia would balance or cancel each other out in a metaphorical conception of discussions as calculations through which the problem of opioid prescribing could be solved and the ‘truth’ could be uncovered. As one participant put it: “You have people from both camps who are either pro-opioid or anti-opioid, and you have a conversation, and then ideally you find the truth somewhere in the middle.” So, too, did the review of the literature proceed by excluding publications that were perceived as skewed by sources of bias and therefore strayed too close to an extreme position.

Much of the work of creating the guideline did not center around reviewing the literature or voting on recommendations but rather on trying to put together balanced committees, and especially on finding ‘unconflicted’ people to sit on the Guideline Panel. Given the polarizing nature of opioid use since the late aughts, it was also difficult to assemble the Clinical Expert Committee as most practitioners held strong opinions regarding prescription opioid use for chronic pain. Heated debates around the use of opioids, especially within the tense, high-pressure context of the opioid crisis, meant that many clinicians were divided into two camps—those who believed that, overall, the use of opioids for chronic pain was beneficial, and those who felt that the use of opioids was harmful. There was considerable animosity between these two camps. As one interviewee put it, “A lot of these people just despised representatives from the other side. I mean, they’d even say, ‘I won’t be in the same room if that person is there.’”

Assembling the Clinical Expert Committee thus required that separate meetings be held with clinicians to convince them to work with physicians who might hold conflicting views. One of the most successful means of doing so drew on physicians' fears that opposing views to theirs would influence the guideline; clinicians were invited to the expert committee on the grounds that there was a need for representation from 'their side' such that the 'other side' could not influence the recommendations to suit their agenda. Another way guideline creators managed to convince physicians to join the expert committee was to bar members of that committee from voting on recommendations. Their role was to be solely advisory and to provide context for the Guideline Panel to understand how opioid prescribing for chronic pain takes place in clinical settings. According to one participant, it was crucial that all committee members understand that "the voting is going to be driven by the evidence."

The exclusion of experts with financial and intellectual conflicts of interest ultimately led to a situation where there were few eligible Canadian experts to sit on the panel and vote. Instead, international experts were invited to vote on these recommendations. As one clinician noted:

We have some tremendous pain specialists in this country, but they weren't considered to be eligible to be on this [panel], because they had conflicts. Because if you're an expert in something, the pharmaceutical companies are going to be looking to you for education. So, as soon as you give a talk for a company, you're considered to be a puppet of the company and that's just not true. I think the principle of declaring conflicts of interest is that you say, "I have these conflicts," and that sometimes will prevent you from voting on certain topics, and that's fine. But the reality is that the people actually working in this [field], the actual experts on chronic pain and opioids, they're the ones who are getting funded to do research and being asked to give talks by pharmaceutical companies. I mean, if someone isn't being asked by companies to speak for them or isn't getting funded or isn't writing in this area, maybe there's a reason for that. And now you also have people involved who don't actually have experience working with people who are in pain, so like epidemiologists,

consultants, and that's fine, I'm sure they're very smart people. But the ones actually on the ground, looking after people suffering from the condition, they're not involved.

Given the lack of 'unbiased' Canadian experts eligible to sit on the Guideline Panel, experts were invited from countries including Lebanon, Switzerland, Norway, and the United States. This decision was controversial as many participants felt that these international experts did not understand the socio-political climate of opioid use for chronic pain in Canada and therefore might orient to the research questions and recommendations on the basis of perspectives on opioids in their own country. For some, this risk of international bias was perceived to be a much greater threat to the neutrality of the discussions and resulting recommendations than the bias that might result from the inclusion of Canadian experts with strong views on opioid use.

4.6 SEARCHING FOR AND EVALUATING EVIDENCE ON OPIOID PRESCRIBING FOR CHRONIC PAIN

The other crucial component to creating defensible recommendations was the use of high quality, rigorous evidence. The work of searching and synthesising the literature was conducted by graduate students and medical students who, from the perspective of guideline developers, were not invested in the outcome of the recommendations and were therefore unbiased. The quality of the evidence was evaluated through the grading of recommendations, assessment, development, and evaluation (GRADE) method (ibid. 17). GRADE has four levels of evidence: very low, low, moderate, and high (Siemieniuk and Guyatt, n.d.). Also known as certainty in evidence or quality of evidence, this rating is a framework through which the risks of bias, imprecision, inconsistency,

indirectness, and publication bias²⁵ are assessed. A high certainty rating is given if the reviewers believe that the true effect of the intervention is similar to the estimated effect derived from the results of the study, while a low certainty rating means the true effect is probably markedly different from the estimated effect. In this hierarchy of certainty, evidence from randomized control trials starts at high quality, while evidence that includes observational data starts at low quality due to the perceived subjectivity of such data and potential confounding factors.

On the basis of the GRADE system, recommendations were made either against or in favour of an intervention, and the recommendation was graded as strong or weak depending on the quality of the evidence. A strong recommendation suggests that all or almost all patients would choose the intervention, while a weak recommendation implies that there are important variations in the decisions patients are likely to make. A weak recommendation indicates that the decision to choose an intervention should be a shared decision-making process, while a strong recommendation signals that it is usually not necessary to present all options to the patient. The 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain makes ten recommendations, of which four are strong recommendations and six are weak.

The research questions guiding the literature review were formulated during meetings between stakeholders including clinicians and patients (Busse et al., 2017, p. 16). Using the PICO format (population, intervention, comparator, and outcome), a total of twenty-four research questions were formulated. In the process of searching the literature, it quickly became apparent that there was a paucity of evidence related to many of the topics and outcomes of concern to stakeholders and members of the committees involved in the creation of the guideline;

²⁵ Publication bias is a phenomenon in which studies published in peer-reviewed journals are much more likely to report statistically significant results than studies that report non-significant results, particularly in the case of smaller studies (Goadsby and Cittadini, 2014).

furthermore, the available evidence was assessed overall to be of low certainty and low quality. Evidence was flagged as potentially suspect due to numerous reasons including commercial funding, relatively small sample size or non-randomized sample, poor study design, conclusions incorrectly drawn from the available evidence, small study effect,²⁶ asymmetrical funnel plot,²⁷ indirectness of effects,²⁸ differences between outcomes of interest and reported outcomes, low response rate, lack of a comparison group, and short study period.

Numerous causes for the lack of high-quality evidence around opioid use for chronic pain were put forward by the clinicians I interviewed, and others have been suggested in the literature. Perhaps the primary barrier is the subjectivity of chronic pain; unlike diabetes, for example, where the dose-response effect of insulin can be measured by taking a person's blood sugar, determining the efficacy of opioids for relieving chronic pain depends on self-reporting by patients. While pain response has been measured using tools such as the Visual Analogue Scale, the results of these studies cannot easily be generalized or validated. Given its subjective nature, chronic pain is therefore not well suited to study through randomized control trials, the gold standard of evidence-based medicine (Smith et al., 2020).

I would also argue that the lack of evidence perceived as high quality may be the result of a model of literature search and evaluation that is not appropriate for understanding aspects of opioid prescribing for chronic pain. The GRADE system relies on an intervention-effect framework that is not suitable for answering all research questions or interpreting all aspects of

²⁶ Small study effect occurs when studies sometimes show different and often larger treatment effects than large ones (Schwarzer et al., 2015).

²⁷ On a funnel plot designed to check for the existence of publication bias, an asymmetric funnel plot emerges when there is a relationship between the treatment effect estimate and study precision. It has been attributed to publication bias, differences between studies of higher and lower precision, and use of an inappropriate effect measure (Sterne, 2011).

²⁸ In attempting to establish treatment effect, there may be evidence for an intermediate process and, therefore, some indirectness in causality (Agler and de Boeck, 2017).

the experience of opioid use and chronic pain. In my interviews with clinicians and people with chronic pain, I found that the reality of prescribing opioids is much messier than a linear sequence of dose and response in which the response can be quantified and evaluated. The complex reality of prescribing opioids and the work of weighing the benefits and risks of harm associated with choosing to use or not to use opioids cannot be evaluated within a dose-response model. In this sense, although the GRADE model is intended to ensure that the evidence used in the creation of the guideline is high quality and unbiased, it is important to note that the model itself is biased toward a particular conception of science, chronic pain treatment, and evidence.

The lack of high-quality evidence identified through the GRADE system meant that most of the research questions put forward by guideline committee members could not be answered through the literature review. Recommendations were not made in cases where there was insufficient high certainty evidence and, as a result, only ten of the original twenty-four research questions were answered and included as recommendations in the guideline. The available evidence pertained mostly to questions around initiating opioids for opioid naïve patients. Only three of the recommendations address care for patients already using opioids, of which two are weak recommendations. Other areas of concern, including the effectiveness of harm reduction strategies, how to discuss tapering with patients, long-term outcomes of opioid use, psychosocial factors determining risk of harm, comparative effectiveness of opioids for various chronic pain conditions, and whether and how to use instruments for predicting risk of opioid-related harms are not addressed in the recommendations, although some of these topics are mentioned in best practice statements and clinical expert guidance documents.

Among the clinicians and other health care professionals I spoke with, the lack of evidence regarding opioid use for chronic pain was widely recognized. Clinicians who participated in

developing the guideline were not surprised that the literature review yielded so few high-quality results and expressed reservations about relying solely on this ‘high certainty’ literature to answer pressing questions. As one physician said:

So, the new guideline is like half the size, if not even less, of the older one, and you get ten recommendations. And that’s it. And there’s no suggestions for tools for follow-up, how to care for these legacy patients who have been on opioids for years, how to have these conversations and make these decisions. Basically, [the creators of the guideline] said, “we’re gonna do everything there’s evidence for,” which, basically, there’s dick all, and so there’s nothing in there about the reality of what we’re actually seeing in pain patients. It was really a guideline about initiation, a guideline for if you’re thinking about starting opioids, not a guideline for what to do if you have someone who’s been well-established on them, because you’re not going to find a lot of evidence for that, and especially not from an RCT [randomized control trial].

Other practitioners suggested alternative study designs and forms of knowledge production that they felt were more appropriate for informing practices around opioid prescribing for chronic pain. During a discussion with a practitioner who sat on one of the guideline committees, we considered the language of ‘best available evidence’ and ‘best practices’ and reflected instead on the possibility of developing recommendations based on ‘promising practices’ (Fazal et al., 2017; Plamondon et al., 2019). Although a protocol based on promising practices might not serve the same authoritative function for the medical profession as a protocol based on best practices, orienting to opioid prescribing in this way might allow for a more collaborative approach as experts and practitioners acknowledge the limitations of research on opioid use for chronic pain while prioritizing the value of knowledge gained from sources other than randomized control trials.

Ultimately, for the developers of the guideline, the defensibility of the recommendations and the necessity to prove that they are evidence-based outweighed the need for guidance on topics for which there is little evidence appraised as high quality through the GRADE model. In their

work of forming committees and directing the review of the literature, experts and practitioners involved in the creation of the guideline hoped to reveal the ‘truth’ of opioid prescribing once all sources of bias and subjectivity were eliminated. In view of the highly political medico-legal ruling relations organizing opioid prescribing, the creation of these recommendations hinged on the ability to find within the spectrum of biased opinions and evidence a neutral, apolitical middle ground where the truth was thought to reside—despite the fact that opioid prescribing, and the work of producing the guideline itself, are thoroughly political.

4.7 TRANSLATING THE 2017 CANADIAN GUIDELINE FOR OPIOIDS FOR CHRONIC NON-CANCER PAIN INTO CLINICAL PRACTICE

From the moment of its publication, the 2017 guideline was highly publicized and disseminated by provincial and territorial regulatory colleges. The CPSO published a commentary on the guideline in its journal *eDialogue* noting that the CPSO’s president at the time “welcomed the new guideline” (CPSO, 2017b, p. 24). He was quoted describing the guideline as “an important part of a long-term strategy to deal with an opioid crisis that has developed over many years” (*ibid.*). While absolute compliance with the guideline was dismissed as neither achievable nor desirable, physicians were urged to “be aware of the guidelines and be able to explain any diversion from them” (*ibid.*). However, the guideline was circulated and promoted to physicians in ways that they felt contradicted these statements and instead coerced them into following the guideline. One physician explained:

So, if I want guidelines on asthma, let’s say, or angina, I as a family physician would go to the relevant journal article in the relevant journal and pull out the newest asthma guidelines. And as far as knowing something new is out there, you’re definitely going to hear it from maybe another physician or at a conference or talk or

something like that. Even just myself, out of interest, I might be seeing a lot of patients with asthma and think to myself, “Hey, it’s been a few years, let me see if there’s something new out there.” And then I read it and it informs how I treat asthma in my patients. These guidelines [the 2017 opioid prescribing guideline] came to us from our College. So, no other guideline has ever come from our College before. And so, our licensing body that’s responsible for all of our income and whether or not we can continue to practice has suddenly taken this vested interest in the new guideline. So [the guideline creators and members of the CPSO] actually did a province-wide tour and talked about it and explained what each of the recommendations means. So, even though I have to go online and search for the guidelines for asthma, these guidelines for opioids are given to me in a nice fancy binder. And the message at the time was, “Oh no, no, they’re just guidelines, you don’t have to follow them.” But that’s not actually how it went. These guidelines were given to us by the College. So compared to the guidelines for asthma, which I use to inform my considerations in the treatment of asthma, these guidelines were presented to us as doctrine. I mean, this is my licensing body, so if they’re presenting me with a guideline, then the subtext to it all is, “You better listen.”

Just as use of the NMS by the state and the CPSO has represented a coercive means of directing physicians’ opioid prescribing through surveillance, investigation, and punishment, so too have physicians perceived the CPSO’s use of the guideline as another instance of coercive intervention into their work practices. Another physician drew parallels between these two interventions when she said: “For the College, the government deciding it’s going to monitor doctors was really a big infringement on [its right to self-regulate], so it’s like the College pushed back against political meddling by saying, ‘No, *we’re* the ones who are going to tell doctors what to do to try to solve this opioid crisis.’” Another physician who was a member of the CPSO during this period summarized the circumstances as “this situation where the College feels like it’s losing control so it’s trying to get that control back, and it does so by really tightly restricting how we can prescribe opioids. I guess to say to the government, ‘Look, we have it under control, so you can go away now.’”

As physicians felt compelled to translate the guideline into their local practices, a fundamental disjuncture emerged between the guideline and its master concerns and the actualities of prescribing opioids. The guideline requires that physician force ‘neutral’ and ‘unbiased’ forms of opioid prescribing into clinical settings that are anything but neutral. This has not meant, however, that physicians do not use the guideline. Despite its irrelevance for much of the everyday work of prescribing opioids, physicians have made efforts to use the guideline as a means of demonstrating their compliance with the CPSO and its new orientation to opioid prescribing. The disjuncture between the content and form of the guideline and what physicians actually do in prescribing opioids has therefore led to practices that are ultimately not accountable to the physician’s local setting or the lived actualities of people with chronic pain who use opioids. These practices have had devastating consequences for people with chronic pain for whom the guideline’s conceptions of ‘neutrality’ and recommendations intended to produce ‘apolitical’ clinical settings are not only irrelevant but harmful. An example of these witnessed harms is the use of screening instruments to identify ‘neutral’ patients to whom opioids may be safely prescribed.

Physicians described widespread use of screening instruments to calculate a person’s susceptibility to addiction and other opioid-related harms. Use of these instruments resonated with my interviews with people with chronic pain, many of whom reported experiences of being screened through these tools. However, although physicians attributed their use of screening tools in this manner to the guideline, in actuality the text has very little to say about screening instruments, besides the following caution: “Despite the availability of various screening instruments, none have been shown to predict patients unsuitable for opioid therapy” (Busse et al., 2007, p. 28). According to clinicians and experts involved in the creation of the guideline, this lack

of information around screening is attributable to the paucity of evidence around screening instruments assessed as high quality or high certainty by the GRADE model. Nonetheless, screening instruments figured prominently in clinicians' and patients' accounts. I argue that this disconnect can be understood as a consequence of physicians' attempts to translate the guideline into clinical practice.

The use of screening instruments discussed in this section diverges from some of the typical ways in which they have been implemented and researched. Generally, screening has been used as a means of identifying risk of disease before symptoms or other indicators emerge. In the case of addiction care, screening has also been used within a harm reduction paradigm whereby those who are most susceptible to addiction are provided with targeted interventions aimed at their individual risk factors (Dimeff et al., 1999). This approach to harm reduction operates within a framework focused on social determinants of health including trauma and marginalization intended to raise consciousness among care providers of the determinants shaping drug use and addiction. Many physicians spoke of the importance of this intersectional, trauma-focused approach to chronic pain care and opioid use and how it once guided their work of prescribing opioids prior to increased surveillance and punishment of physicians since the late aughts.

In contrast, physicians described a shift in their stance toward addiction screening, social determinants of health, and patients' histories of trauma in the face of heightened surveillance by the CPSO and the state. Within this context of coercion, surveillance, and possible punishment, physicians have taken up screening tools as a means of calculating risks associated with opioid use not only for individual patients, but also to the physician and to their license to practice. Patients with high risk scores are perceived as 'tainted' by confounding variables including race, gender, history of trauma, and history of drug use. These patients are perceived to be too complex to be

prescribed opioids in the scientific, step-by-step, evidence-based manner laid out by the guideline. Without specific recommendations to guide the work of prescribing opioids to these “messy” or “complicated” patients, many physicians have erred on the side of caution and refuse to prescribe opioids to people with elevated risk scores.

Two complications arise as physicians translate the guideline into their everyday practices: first, the paucity of high certainty evidence related to the bulk of activities constituting the work of prescribing opioids; and second, the reality that opioid prescribing is a messy, complex, ever-evolving practice and that people with chronic pain using opioids are equally complicated. While in response to panic around the opioid crisis the medical profession has sought to neutralize the space of the clinic and the work of prescribing opioids, it is at this particular moment that opioid use has become highly politicized as the medico-legal ruling relations coordinating opioid use shift and contemporary understandings of opioids as medicinal or poisonous fluctuate.

The two genres of texts analyzed in this chapter—the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain as well as the screening instruments used to assess opioid-related risks—objectify people with chronic pain and erase their perspectives and agency. Within these texts, people with chronic pain are reduced to the category of ‘patient,’ and this category is restricted to neutral, straightforward patients whose pain is easily diagnosed and treated. The lived realities of people with chronic pain—the “messiness” of their lives—are erased despite the importance of these actualities for the provision of care.

In the case of the guideline and screening instruments, people with chronic pain have agency only insofar as they can fit within the narrow confines of a patient as delimited by the texts. This conception of a legitimate pain patient deserving of access to opioids is grounded in aforementioned notions of objectivity such that complicated or messy patients fall outside of the

strictures of the ideal neutral patient. As such, most people with chronic pain cannot be subsumed within the category of ‘patient’ and, as a result, physicians’ work of prescribing opioids cannot be rendered accountable to the guideline or screening instruments. For fear of being flagged as inappropriately prescribing opioids, physicians often choose not to prescribe to these patients.

4.8 MEDICAL SCREENING AND THE PRODUCTION OF NEUTRALITY IN MEDICINE

In response to interventions into physicians’ opioid prescribing practices including surveillance and punishment, physician’s work of prescribing opioids has become more tightly bound to the quantitative scores calculated through screening instruments. In many ways, this approach adheres to the modern orientation to quantification described by Porter (2020) as a technology of distance—a means of minimizing the need for intimate knowledge, locality, and personal trust. Numbers have also become a tool for diminishing or settling conflict. The irrefutable ‘fact’ of quantitative data can be used in highly effective ways for coercion or, at the very least, for persuasion.

Screening and risk assessment tools are valuable for physicians in that they provide a generic, duplicable text that is widely recognized among health and allied professions and from which scores can quickly be calculated as a means of assessing the patient’s risk of harm. The quantifiable nature of risk scores means that they are perceived as objective and, as such, provide an irrefutable justification for prescribing opioids to a patient if the physician is audited by the state or the CPSO. Screening tools with calculable scores also offer physicians a way to refuse to prescribe opioids or to insist that a patient taper; as one physician put it, “It’s difficult to argue with that number, especially when you’re the one who answered the questions.” For physicians

who prefer to rapidly taper patients or refuse to prescribe opioids altogether, the use of screening scores to defend this decision against their patients can be very useful.

According to people with chronic pain and clinicians, prior to the panic around opioid-related harms in the late 2000s screening instruments were primarily used to collaborate with patients in minimizing the patient's risk of harm to the greatest extent possible. Physicians described past experiences of prescribing opioids to patients with histories of trauma or complex social lives and listed a range of strategies used to reduce potential harms associated with opioid use. These strategies included bringing in the patient and their family to talk about safe opioid use, addressing mental health concerns, using blister packs to support patients including those with dementia to avoid overdose, co-managing the patient's pain with specialists, and working with the patient to determine the safest and most efficacious dose of opioids. As one physician explained: "There were definitely patients you saw who had more of a risk of misuse or addiction, but that never meant I wouldn't prescribe at all. It meant I'd be having ongoing conversations with the patient and trialing different opioids to see what works."

A registered nurse explained that prior to state and regulatory pharmacovigilance toward physicians, an elevated risk score obtained through screening instruments did not bar a patient from receiving opioids. However, this approach has since changed:

Let's say someone who's had arthritis in their knee for years, and after screening you find they have a high risk score, which tells us that they might develop a substance use problem. Well, before, you would never just cut them off. So, let's say the patient was taking 100 mg per dose, then we'll try to keep them at that dose until we can start making some changes—but always with the patient. And that doesn't mean cutting them off, but, you know, maybe trying different options. The patient's feelings about it mattered, too. But if we reduce their dose abruptly, they can go into withdrawal. So, that was before. But now, a lot of doctors are stingy when it comes to prescribing opioids. And you learn who those doctors are, and you know that if they get a new patient and

their risk score is a high risk score, you just know it's going to suck. It makes for a really uncomfortable shift. But in the doctors' mind, they have more to lose, they put themselves on the line by prescribing, so now they won't prescribe unless they really have to.

Similarly, an occupational therapist working alongside physicians in an outpatient clinic described physicians' use of screening instruments and how these practices have changed alongside growing reticence to prescribe opioids for chronic pain. She drew an apt comparison to account for the shifting purposes of screening: "You know like a strainer, or a colander, that you use for cooking? That's what this is, [physicians] are using a colander to filter out patients until pretty much the only ones left are the ones who present, I mean, as close to no risk as possible." When I suggested that it seems as though physicians are now willing to prescribe only to no-risk, rather than low-risk patients, she agreed, adding: "The moment you have someone with, let's say, [a] history of substance use, or trauma, then you know there's no way in hell a doctor is ever prescribing opioids to them."

One of the most frequently mentioned screening instruments was the Opioid Risk Tool, a self-report screening form to assess a patient's risk of opioid addiction (Webster and Webster, 2005). The test is divided into two columns: one for 'female' and one for 'male.' A series of factors that may impact susceptibility to addiction are ordered into rows and include the patient's family history of substance abuse, personal history of substance abuse, age, history of preadolescent sexual abuse, and presence of psychological disease. For each applicable indicator, the patient must mark the parallel box in either the 'male' or 'female' column (there are no directions for patients for whom these gender categories do not apply). History of preadolescent abuse, for instance, is worth three points for women, but zero points for men, while family history of alcohol use is worth three points for men and only one point for women. Based on these answers, the

patient's score is tallied: a score of 4 to 7 indicates moderate risk for opioid abuse, and a score of 8 or higher indicates a high risk for opioid abuse. It is not difficult to reach a score of four or higher—for example, a woman with a history of preadolescent sexual abuse (three points) between the ages of 16 to 45 (one point) is assessed to be at moderate risk of opioid abuse.

For patients already using opioids, screening instruments such as the Addiction Behaviours Checklist (ABC) are available to determine whether they demonstrate “inappropriate opioid use.” As in the case of the Opioid Risk Tool, the trouble with the ABC Checklist is its wide applicability to most people with chronic pain who use opioids. The questionnaire includes a list of behaviours that may be observed by the physician, and each behaviour is worth one point; these include hoarding medication, running out of medication early, expressing a strong preference for a specific type of opioid or a specific route of administration, expressing concern about future availability of the medication, indicating a need for the medication, and discussing analgesic medication as the predominant purpose of the appointment, among several others. A score over three indicates “possible inappropriate opioid use” and should flag for “further examination of specific signs of misuse and more careful patient monitoring (i.e., urine screening, pill counts, removal of opioid)” (Wu et al., 2006, p. 1). Of the observed behaviours, the majority pertain to every person with chronic pain I interviewed for this dissertation.

Screening instruments organize physicians' and patients' work practices in ways that differ markedly from the intended use of these scores for early identification of illness, harm reduction, or targeted interventions to improve health. Instead, in this context, scores are used by physicians to calculate the risk of prescribing opioids to a person with chronic pain and to what extent this person diverges from the ‘neutral’ patient whose behaviours and attitudes are not tainted by psychosocial determinants. The higher a person's risk score, the further they stray from the

objectified category of the neutral patient present in texts such as the guideline and who can be prescribed opioids with virtually no risk of scrutiny or punishment by the CPSO. Although for many physicians the bulk of the work involved in prescribing opioids relates to prescribing for legacy patients or people with complex forms of chronic pain, these patients are not addressed in the guideline, and therefore physicians' work of prescribing to these patients cannot be made accountable to the text.

This mismatch between the guideline and the material reality of prescribing opioids was of great consternation to physicians, who identified a distinction between the “guideline that’s been put together by consultants and experts” versus “the reality of doctors on the ground.” They also put forward critiques that the guideline has “very little to do with the reality of caring for people with chronic pain” and “the guideline has done a real disservice to patients because it has absolutely no basis in the reality of these people’s lives or what it actually means to have chronic pain or to use opioids.” Practitioners felt that the guideline is removed from their everyday lives and that it fails to address crucial topics such as caring for people with comorbidities, harm reduction, and how to switch, titrate, and taper opioids. As one general practitioner put it:

If you have someone who’s never used opioids before, and has a super straightforward case—I mean, basically, a situation so simple that it isn’t even really chronic pain, just acute pain that’s gone on a bit longer than the patient would like—but unless that’s the person in front of you, then forget it. For me, most of my patients now are legacy patients, because I’m the only one willing to take these patients on. And that’s fine. But then to put out these guidelines that have nothing to do with caring for legacy patients, giving me no instruction on how exactly they’d like me to keep these patients safe or even protect my practice, then it becomes really frustrating. And if you don’t follow the guideline, that’s basically the end of your career.

The challenge of translating the guideline into their clinical practices has meant that for many physicians, rapidly tapering patients and refusing to prescribe opioids have been some of the only

options available to them to avoid scrutiny by the CPSO. Using screening instruments to identify complex patients whose chronic pain and use of opioids falls beyond the scope of the guideline has been a critical means by which many physicians attempt to reduce their risk of contravening the guideline by ensuring that they prescribe only to the opioid naïve or straightforward cases addressed by the recommendations. Anything beyond this scope, in one clinician's words, "Is the wild west where at any second the College can decide they don't like how you're prescribing [opioids] and there goes your license."

My investigation into physicians' use of screening instruments benefited greatly from working through these forms with clinicians. I was especially interested in how physicians determine that a patient's score is too high to risk prescribing opioids. While many of the answers to my questions about physicians' everyday work tended to begin with the qualification "it depends," in the case of screening instruments, I found that their quantitative nature and straightforward calculation mean that there is very little interpretation or clinical judgment required. One physician explained: "That's the beauty of this sort of test, you just check everything off—so, 'history of substance abuse,' check, 'history of childhood violence,' check—and then whatever number you get when you add everything up, the form will have the cut-offs."

In the case of the Opioid Risk Tool, for instance, a score over eight represents "complete contraindication for opioid use" and can be readily drawn upon in refusing to prescribe opioids. While mid-range scores from three to seven may in the past have merited some interpretation and consideration, clinicians were clear that in the current context of pharmacovigilance, such a score is also, as one physician said, "A complete no-go." Meanwhile, physicians felt relatively confident that a score of two, one, or zero could be used to justify the decision to prescribe to the CPSO. And, most importantly, this low score confirms for the physician that the patient is a simple, neutral

case and that the work of prescribing fits within the scope of the guideline. Typically, these patients have not previously used opioids, are diagnosed with a straightforward disease that accounts for their chronic pain, and match the criteria set out by physicians that I have discussed in the previous chapters: unemotional, non-affective, and disinterested. In the case of opioid prescribing, disinterested patients allow for the physician to take up the role of a disinterested, impartial knower, rendering their work accountable to the guideline.

4.9 THE IMPACTS OF USING THE ADVERSE CHILDHOOD EXPERIENCES SCORE TO DISQUALIFY PATIENTS FROM CARE

Among the many screening instruments used by physicians to assess a patient's risk of susceptibility to addiction or opioid-related harms, one of the most commonly used is the Adverse Childhood Experiences (ACE) score. The ACE score was originally developed as a means of studying population-wide social determinants of health to explore the links between psychosocial determinants and disease. The framework originated from a study conducted by the CDC and Kaiser Permanente, an American consortium of for-profit and non-profit entities offering health care and health insurance (CDC, 2021). The study took place from 1995 to 1997 and gathered data from over 17,000 people on their childhood experiences, current health status, and behaviours. On the basis of these findings, the ACE framework was proposed as a means of understanding how psychosocial determinants might contribute to a person's future wellbeing and health.

The standard ACE test asks about three types of ACEs: abuse (physical, mental, and sexual), neglect (physical and emotional), and household dysfunction (presence of caregivers experiencing mental illness, divorce, incarceration, substance use, and domestic violence). One

point is allocated for each type of trauma the individual has experienced before their eighteenth birthday. According to the original study and ongoing research, the higher a person's score, the greater the likelihood that they have experienced significant trauma and that they are at greater risk of developing conditions, illnesses, and behaviours such as smoking, substance use, obesity, diabetes, suicide attempts, sexually transmitted diseases, and heart disease (Felitti et al., 1998; Boullier and Blair, 2018).

Although the ACE framework was originally developed to study population-wide psychosocial determinants of health, the questionnaire has since been used in clinical settings to assess trauma and to determine how best to provide care (Lacey et al., 2020). As I came to find from my interviews with physicians, people with chronic pain, and other health care providers, the ACE questionnaire has also been used in deciding whether to prescribe opioids for chronic pain, as a high score is perceived as a contraindication to opioid use. In addition to using the ACE framework for this purpose, some physicians and people with chronic pain also reported the use of expanded or altered ACE tests that ask patients about living in foster care, childhood history of bullying, whether they are Indigenous, the types of substances they have used in the past or are presently using, and the types of chronic pain they experience.

While many of the people with chronic pain interviewed for this dissertation have been screened through the ACE score, I focus on two women in particular whose access to opioids and adequate pain care have been compromised by the use of this score to filter out high risk patients: Melissa, a white woman in her fifties living in Central Ontario, and Jessica, an Indigenous woman in her forties living in Eastern Ontario. Their accounts bring to the fore the work required of people with chronic pain as physicians implement novel tools and techniques to resist increased pharmacovigilance. I begin with Melissa's experience of disclosing sexual trauma as a means of

maintaining access to prescription opioids, and then shift to discuss the challenges Jessica has faced in accessing opioids due to a high ACE score.

Melissa suffers from significant chronic pain in her neck. The pain began at a young age: her first recollection of a physical sensation of discomfort stretches back to the age of five years old at her grandfather's funeral, where she experienced unbearable pain in her neck. When Melissa turned eight and the pain worsened, her parents brought her to a chiropractor who suspected that the issue was an odd curvature in her spine. Every week from the age of eight to sixteen, Melissa visited the chiropractor for adjustments to her spine that did little other than aggravate the pain. Since then, the pain has continued to occur in a series of flares or episodes that make it incredibly difficult to go to school or work. In 2009, Melissa experienced an episode so severe that she took an extended leave of absence from paid work.

In an attempt to help Melissa manage her pain through this episode, her physician prescribed a variety of pharmaceuticals including anti-inflammatories, muscle relaxants, and opioids, but they had very little effect. In 2010, when fentanyl patches first came to Canada and were approved for use for chronic pain, her physician suggested a trial to see if they might relieve her pain. To Melissa's surprise, the fentanyl patches were "like a miracle drug." On a dose of 25 mcg, she resumed her paid work, and she could pursue the busy lifestyle she had enjoyed before 2009. Although the patches did not entirely erase the pain—as Melissa put it, "There was always this pressure that felt like my head is a ten-pound bowling ball sitting on a toothpick"—the relief was sufficient to allow a resumption of her previous life.

Nonetheless, Melissa's condition continued to deteriorate, and in 2017 she found that the curvature of her spine had progressed to the point that 25 mcg fentanyl patches were no longer effective at relieving her pain. It was also in 2017 that Melissa's physician was contacted by the

CPSO with a warning that she had been identified by Ontario's NMS for patterns of opioid prescribing that outpaced those of other clinicians in their region. After receiving this warning, Melissa's physician refused to increase her dose of fentanyl. She has also repeatedly attempted to taper Melissa's dose. However, as tapering renders Melissa essentially bedridden, her physician continues to prescribe the 25 mcg fentanyl patches while warning that someday she may be forced to stop prescribing opioids altogether.

A few months prior to our interview, Melissa had been referred to a pain specialist with the goal of assessing whether other non-opioid therapies might relieve her pain. At the appointment, Melissa found herself scrambling to negotiate an uncomfortable conversation as the physician screened her using the ACE framework. As she described:

So, I saw the doctor and she agreed that, you know, I've got pain issues or whatever. She did pinpoint some things I wasn't too thrilled about. Part of her questions asked if I'd ever suffered child abuse. And I have, I was raped when I was ten. And she really wanted to pin my chronic pain on that. All of a sudden, she gets all excited and she goes, "Oh, there's lots of studies out there showing that chronic pain sufferers have been abused as children." And then she asked me, you know, what happened, and what my parents did about it. And she pinned my chronic pain on the fact that my parents really didn't do a whole lot, and that they apparently didn't teach me coping skills. And I'm thinking that this isn't the only time that they needed to teach me coping skills. They taught me things throughout my life. You know? Just because they didn't deal with this that well doesn't mean I didn't learn coping skills.

In response to the physician's fixation on her history of abuse, Melissa tried to explain the relative unimportance of this abuse in relation to her chronic pain without protesting to the extent that the physician would see her as hysterical, in denial, or delusional. She was greatly concerned that the physician would insist she attend some form of psychotherapy as a means of managing her chronic pain. In the past, Melissa has encountered many physicians who have insisted that the pain is "all

in her head” based on her history of trauma and who have consequently refused to prescribe opioids. She feared her physician would seize on this opportunity to taper her dose of opioids or stop prescribing altogether. Melissa was also hesitant to pursue psychotherapy on the grounds that the specialist had misinterpreted her situation and the impacts of her history of sexual assault.

The ACE framework was used in this situation (and others Melissa has experienced in the past) to prioritize the significance of some experiences over others, irrespective of how Melissa actually felt about them. Use of the instrument in this manner also reduced her chronic pain to a psychological symptom. While Melissa had also experienced other difficult circumstances that she felt might actually be associated with her pain, because these experiences are not listed in the ACE questionnaire, it was difficult to mention them during the appointment without, as Melissa put it, “Now looking like you’re actually depressed or you really do have problems.” The appointment was structured by the physician’s use of the ACE form and how the physician translated the text into their local setting—here, as a means of identifying a cause for Melissa’s pain and to determine whether she should be prescribed opioids for pain management. In this way, the ACE score results in disqualification from care.

When I asked Melissa about how she navigated the appointment, she explained that most people with chronic pain have a long history of telling physicians what they want to hear so that the physician will not cause them further harm. Melissa was well aware of the risk factors and signs of potential drug abuse physicians look for in their conversations with people with chronic pain. She knew, for instance, to soften her explanations of the success she has had with opioids in the past, using statements such as “I think they’ve helped” or “I guess they’ve worked.” She also knew to limit discussion of comorbidities or determinants that might impact her use of opioids. As she said:

I mean, to be honest, I had to downplay it. And I wanted to be honest, I want to be open about it and answer her questions. But you sort of learn to downplay it and when not to bring it up. So, I mean, this was full-on rape, and I was ten years old. Like, don't get me wrong, I think about it, and it's horrible, and I've seen him in my adult life and it's not pleasant, I'd like to not speak to him again. But anyway, I downplayed what happened, and then I also downplayed how much the [fentanyl] patches help.

At the time of our interview, Melissa had not yet heard back from her physician about the results of the appointment, and we have since lost touch. Based on prior experiences, Melissa was afraid the physicians would conclude that her neck pain was “all in her head” and determine that she no longer needed opioids; she was equally fearful that her high ACE score and history of sexual trauma would lead her physician to cease prescribing opioids. Melissa also worried that she would be forced to speak with a psychotherapist who would sideline her opinions in favour of their expert medical knowledge. Being coerced to speak about these issues with another stranger risks furthering the harm she experienced.

While Melissa worried about the future impact of her high ACE score on her access to opioids, Jessica has a long history of, in her words, having her ACE score “weaponized against [her].” Jessica is an Indigenous woman who lived in a small, rural community before moving to a larger urban centre in Eastern Ontario. The move, which forced her to leave behind her elderly and ill parents, was necessitated by the discrimination she faced in trying to access pain care in their small town. As I explained in my description of Jessica's life and experiences of chronic pain in chapter two, much of the pain she lives with was caused by an endometrial ablation she underwent when she turned forty in the hopes of ameliorating pain associated with endometriosis. Although her uterus was later found to be too small to ablate, the surgeon proceeded anyway, burning her uterus to such an extent that the pain required her to be catharized. Jessica lost nearly 90 lbs as she was passed from physician to physician, until finally they referred her to a specialist in a larger

city who could assess the post-ablation ultrasound. Many of these physicians, including her gynecologist, attributed the pain to past sexual trauma and, on this basis, refused to perform a hysterectomy to relieve the post-ablation pain.

Prior to 2016, Jessica had effectively managed her pain with fentanyl patches. With her pain better controlled, she was able to engage in physiotherapy, and these exercises allowed her to reduce her dose from a 25 mcg patch to a 12.5 mcg patch. However, when her family physician retired and she was transferred to a new practice in 2017, her new physician refused to prescribe fentanyl and abruptly switched her to one Percocet tablet daily. Eventually, Jessica was referred to a physician who specialized in pain management, and he prescribed opioid agonist treatment (OAT) in the form of Suboxone.

Jessica spoke at length about her intersecting experiences as an Indigenous woman and as an OAT user and how she believed they are interconnected. For instance, when I asked Jessica to bring me through the appointment with the pain specialist that resulted in an OAT prescription, she described the significant amount of work she had to engage in to convince the rheumatologist that she is not an addict. As a means of determining whether she is addicted to opioids, the rheumatologist required that Jessica fill out an ACE questionnaire:

When I went to my rheumatologist, he had me fill out this form. Adverse Childhood Events, ACE. And it asked me questions about, well, are you Indigenous? Check. Do you have any relatives who are addicts? Check. Uh, have you experienced sexual abuse, a bunch of stuff, from before a certain age? And so, I checked all of that off. And everything you check off, it's an increase in your risk. And the higher your score, the rheumatologist thinks you're more at risk that you'll be an addict. And so, mine was high—not from anything I've done, the last time I drank was half a cooler at my high school prom and I didn't like the feeling at all. So, nothing I did, but just, being Indigenous, and yes, having my relatives who are addicts, but not what from I've done. And so based on my high score on the ACE, the rheumatologist decided it was too risky to prescribe me opioids.

In addition to doing very little to relieve Jessica's pain, using Suboxone also led to stigmatization and new barriers to care. When her pain became unbearable, Jessica sought care at the local emergency department in the hopes of receiving some form of analgesia. However, because it was indicated in her medical records that she was using Suboxone, the hospital staff suspected she was seeking drugs and refused to provide opioids:

And [the prescribing rheumatologist] wrote in my medical records, I carried a note saying, "Patient is on Suboxone for chronic pain." Which, I have a copy of this note. Nobody in the ER would look at it. Every time I went to the ER, the minute they saw I was on Suboxone, they wrote, "Patient is a RAM patient. Rapid Addiction Medicine patient." I presented them the note and they wouldn't even look at it. And I'm at the ER, all doubled over, and I'm getting screamed at that I'm wasting time and hospital resources. I was screamed at: "No opioids for you because you're an addict."

As a result of these experiences, Jessica weaned herself off Suboxone without medical assistance. More recently, her physician offered to prescribe OAT again, but she refused out of the fear that she will once again experience discrimination. Although she was prescribed anti-depressants that demonstrate some analgesic properties, she weaned herself off these pharmaceuticals as well because physicians would note her use of anti-depressants and attribute her pain to solely psychological factors. Her use of certain medications, combined with her high ACE score, has meant that Jessica regularly faces obstacles to accessing adequate analgesia.

From the standpoint of Melissa and Jessica's everyday lives, we can see the ways in which their work of managing physicians' perceptions of them and negotiating their access to opioids coordinates with physicians' work of juggling not only risk of opioid-related harms to the individual patient but risk of harms to public health, to the medical profession, and to the physician's license to practice. Jessica described herself as "far from the perfect pain patient," alluding to physicians' refusal to prescribe opioids to anyone who does not conform to the ideal

of the neutral patient free of any confounding psychosocial variables. While Melissa and Jessica suffer greatly from chronic pain and experience substantial impacts to their quality of life due to reduced access to opioids, the use of the ACE screening tool to filter out complex or messy patients has exacerbated the harms they experience.

Ultimately, the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain, as well as the screening instruments surveyed in this chapter, objectify the everyday lives of people with chronic pain and remove them from the materiality of their lives. Subsumed within the category of ‘patient’—and, as I have argued, a particularly restrictive conception of an ideal, neutral patient—few people with chronic pain fit within these narrow strictures. As a result, while physicians attempting to translate the guideline into their clinical settings have taken up screening instruments as a strategy for ensuring that they prescribe only to people who fit this objectified notion of a patient to ensure that their work is accountable to the guideline and its master concern of neutrality, this filtering process has meant that people like Melissa and Jessica cannot be recognized or accounted for and therefore tend to be barred from access to opioids.

4.10 CONCLUSION

In my analysis of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain, I have considered the work practices involved in producing the guideline to map the ruling relations organizing this work. The guideline was developed to play a crucial role in participating in social relations of opioid prescribing, use, and regulation by operating at the juncture between the physician’s local practice and extralocal ruling relations. I have described the work of creating the guideline to demonstrate how these activities orient to the concerns of the medical profession

within the contemporary medico-legal borderland organizing opioid use by producing a set of defensible recommendations that can serve as proof of evidence-based practice.

In critically analyzing conceptions of neutrality and evidence to inform the creation of the guideline, my argument has been twofold. First, I have noted a significant mismatch between the focus of the recommendations and the reality of prescribing opioids over the last decade. As the guideline creators insisted on only using high quality evidence as judged by the GRADE system, they were limited to a small number of studies. The lack of Canadian experts and clinicians on guideline committees further limits the relevance of the recommendations to the current socio-political context in which physicians are prescribing opioids. Ultimately, politics of expertise, knowledge, participation, and decision-making placed in tension competing perspectives on the value of opioids and how they should be used for chronic pain. Attempts to neutralize this political space resulted in a protocol that is largely irrelevant to the local realities of prescribing opioids.

While the guideline and its recommendations have little to say about the actual work of prescribing opioids, this does not mean that physicians have chosen to ignore the guideline. Rather, attempts to translate the guideline into their clinical practice have resulted in shifts in physicians' opioid prescribing practices, including a refusal to prescribe to patients who do not adhere to the neutral, objective ideal set out in the guideline. Among the many implications for clinical practice, in this chapter I highlighted the impacts of this disjuncture between the text and the local setting on physicians' use of screening instruments to avoid surveillance and possible punishment by the CPSO. As I illustrated in my discussion of the experiences of two people with chronic pain, this use of screening instruments has led to disqualification from care with significant repercussions for individuals' health and their quality of life.

I turn now to conclude this dissertation with some thoughts on the findings of my research and connections between these empirical findings. I discuss the contributions of this research and limitations, and I also offer suggestions for future research as well as avenues of advocacy, including an urgent call to dismantle binaries between licit/illicit opioids and opioid users and legitimate/illegitimate opioid use.

CHAPTER FIVE

5.1 CONCLUSION

The objective of this dissertation has been to produce a sociology *for* people with chronic pain. From my own experiences as someone with chronic pain and as a member of support groups for people in pain, since I began my doctoral studies in 2016 I have witnessed abrupt changes in the lives of people with chronic pain as they face interruptions and restrictions to their ability to access opioids for pain management. My goal in pursuing an inquiry into these changes has been to produce knowledge on the basis of which people with chronic pain can effect real changes in the ruling relations shaping their everyday lives. In this way, rather than objectifying the lived realities of people with chronic pain, my aim has been instead to take up the ruling relations organizing opioid use in Ontario as the object of inquiry.

In this concluding chapter, I begin by bringing together connections across the relations under study as a means of mapping the social organization of opioid use for chronic pain. I return to the everyday lives of the people with chronic pain described in chapter two and I look to answer some of their questions about their daily experiences of struggling to access adequate pain care and opioid analgesics by drawing connections between their experiences and the medico-legal relations discussed in chapters three and four. I then move on to detail the contributions of this project and its limitations before closing with thoughts on future avenues of research and activism.

5.2 THE SOCIAL ORGANIZATION OF OPIOID USE FOR CHRONIC PAIN IN ONTARIO

As I noted in chapter one, my investigation into the social organization of opioid use was driven in no small part by two questions facing people with chronic pain as they have found their

access to opioids curtailed, interrupted, and denied—first, why has this happened? And second, who did this? These questions demonstrate the understanding of people with chronic pain that decisions about pain care and opioid prescribing are being made elsewhere and elsewhere by people who may or may not be familiar to them. Curiosity about how activities performed across time and space come to be coordinated in constituting institutional relations is a cornerstone of institutional ethnography and guided all aspects of the interviews I conducted and subsequent analysis.

The institutional ethnographic nature of the study has meant that I pursued avenues of inquiry as they emerged in my interviews. As I glimpsed traces of the ruling relations organizing opioid use throughout my conversations with people with chronic pain, I went on to interview physicians and other practitioners involved in prescribing opioids, dispensing opioids, and otherwise caring for people who use opioids for pain management. I also analyzed guidance, policy, and regulatory texts and drew on diverse literatures to extend my understanding of the ruling relations organizing opioid use for chronic pain in Ontario, how these regimes of ruling are produced by everyday activities performed by people across time and space, and how these relations come to bear on the lives of people with chronic pain by disrupting their access to opioids.

On the basis of this research, I have argued that although people with chronic pain have been significantly impacted by changes in opioid prescribing and shifting attitudes toward opioid use, these consequences have largely emerged as secondary effects of new forms of governance grounded in opioid pharmacovigilance that have emerged in the face of panic around the opioid crisis in North America and elsewhere. As physicians have come to be identified as principally responsible for increased rates of prescription opioid-related harms since the late aughts, the state and its agencies have sought to curb the ‘epidemic’ of harms by altering physicians’ opioid prescribing patterns and, ultimately, to reduce the number of opioids prescribed. The introduction

of Ontario's Narcotics Monitoring System in 2012 marked the expansion of pharmacovigilance and surveillance as the state and the College of Physicians and Surgeons of Ontario (CPSO) have used the data aggregated through this database to identify physicians who 'overprescribe' opioids in comparison to their colleagues in the same region.

Attempts to alter physicians' everyday work of prescribing opioids were further extended through the publication of the Canadian Guideline for Opioids for Chronic Non-Cancer Pain in 2017. Through my analysis of the production of the guideline and its uptake by physicians, I have suggested that the work of producing a defensible, 'neutral,' evidence-based guideline on which to ground the authority of the CPSO to regulate opioid prescribing has meant that the protocol's recommendations are not applicable to the bulk of the actual work of prescribing opioids for people with chronic pain. While physicians' uptake of practices that diverge from these recommendations (including rapidly tapering patients' prescriptions and refusing to prescribe opioids) has been attributed to miscomprehension or misinterpretation by clinicians, I have proposed that it is not misunderstanding that has informed these new practices but rather the impetus for physicians to ensure that their work is accountable to the master concerns that shaped the funding, development, and dissemination of the guideline. Physicians' attempts to translate these concerns into their work of prescribing opioids has informed the uptake of new risk management strategies that disqualify from care people 'tainted' by determinants such as race and history of drug use.

Attempting to map the ruling relations under study proved challenging as interviews and textual analyses made visible an unwieldy number of actors, forms of work, and translocal relations implicated in the organization of opioid use for chronic pain. A helpful strategy for tracing connections between these aspects of opioid prescribing and use has been to return to my interviews with people with chronic pain and their stories, many of which I described in chapter

two. When I approached these experiences with the two questions raised above—why is this happening? Who is doing this?—the social relations organizing opioid use and prescribing became visible in such a way that I was able to explicate their emergence and their impacts on people’s everyday lives.

In chapter two, I used the empirically empty concept of ‘health work’ to account for the activities people with chronic pain perform around their health. I drew at length on several participants’ narratives in describing forms of work including trying to decide whether to seek care, waiting for diagnosis and treatment, using opioids and other medications, and attempting to prove one’s legitimacy as a patient. The work involved in proving legitimacy as a patient is a notable example of how the coordination of people’s work makes visible the ruling relations organizing their everyday lives. In chapter two, I described proving one’s legitimacy as a pain patient as a medication practice through which people with chronic pain attempt to distinguish themselves from addicts. Strategies to this end include weaning themselves off opioids, using analgesics less effective than opioids to prove they are not fixated on opioids, and carefully managing how they describe their pain to and navigate appointments with physicians.

There is ample research on impression management and how people with chronic pain carefully manage how they speak and how they behave to avoid stigma associated with chronic illness, pain, and opioid use. My interest, however, was in starting from the individual’s standpoint to then map the ruling relations their activities hook into and through which this work is coordinated with others’. In my interviews with physicians, I found that they were greatly concerned with distinguishing ‘legitimate patients’ from ‘drug addicts’ to avoid potential punishment from the CPSO for prescribing to a patient who could be accused of addiction. Physicians recounted forms of work including piecing together patients’ stories to see if they “add

up” and scrutinizing test results to verify the veracity of patients’ claims. Their suspicion toward people with chronic pain arose from a need to protect themselves from the intensification of surveillance and coercion from their regulatory college and the government through use of Ontario’s Narcotics Monitoring System. Physicians were highly alert to any sign that patients may be using opioids in ways that would draw the eye of the CPSO and potentially lead to investigation and punitive measures.

In chapter two, I also described participants’ strategic willingness to use medications they know will be ineffective to demonstrate that they are not fixated on opioids. The importance of this health work was underscored by my interviews with physicians, who, as I explained in chapter three, are wary of patients who appear to be overly emotional or whose sole aim is to receive an opioid prescription. Likewise, as I learned about physicians’ work of using screening tools to filter out patients who are not ‘neutral,’ as discussed in chapter four, I noticed that many of the questions raised in these screening tools pertain to fixation with opioids. In chapter four, I described physicians’ use of the Addiction Behaviours Checklist to identify behaviours that might signal “inappropriate opioid use,” including expressing a strong preference for a specific type of opioid, indicating a need for opioids, and discussing opioids as the main purpose of the appointment. These red flags and physicians’ overall concern with distinguishing ‘legitimate’ patients from ‘illegitimate’ addicts have necessitated forms of health work such as those described above as people with chronic pain downplay the importance of opioids for managing their pain.

Mapping the medico-legal ruling relations and relations of professionalization and evidence-based medicine organizing opioid prescribing also provided crucial insights into why physicians have abruptly changed their opioid prescribing practices in ways that harm people with chronic pain. While there is, understandably, endless speculation on behalf of people with chronic

pain around this sudden shift—including suspicions that physicians dislike people with chronic pain, or that they do not care about their suffering—I found instead that the physicians I interviewed were greatly concerned with the impacts of their decisions to rapidly taper patients’ doses or to stop prescribing opioids altogether. Nonetheless, while the consequences for people with chronic pain weighed heavily on them, physicians also felt obligated to continue with these prescribing practices to avoid scrutiny, investigation, and punishment by the CPSO.

Physicians also speculated about the sudden turn by the CPSO toward more conservative forms of opioid prescribing. During our interviews, physicians put forward theories including a widely held belief that the CPSO and the government were collaborating to “improve optics” by giving the impression that they were taking a hard stance against opioids by punishing physicians. Another theory was that the CPSO’s championing of the 2017 prescribing guideline was a result of cooperation between the CPSO and the government to use panic around opioids as an opportunity to more directly control physicians’ prescribing practices. Through my interviews with members of the CPSO and analysis of texts including policy documents and meeting minutes, I came to find instead that the relationships between regulatory colleges and all levels of government have been fraught as legislators attempt to regulate opioid prescribing and professional colleges attempt to instate their authority to self-regulate. Mapping the history of drug regulation in Canada was a vital means of contextualizing these tensions.

Ultimately, while my investigation of opioid use began from the standpoint of people with chronic pain, the object of inquiry has been the ruling relations organizing opioid use in Ontario. A central focus of the study has been to produce intimate knowledge of the everyday lives of people with chronic pain to convey our struggles and triumphs and the impacts of changes in physicians’ opioid prescribing practices, while also producing knowledge of ruling relations of

medicalization, criminalization, professionalization, and evidence-based medicine as they emerged through participants' accounts. Seeking to understand why people with chronic pain abruptly found their access to opioids interrupted and who was behind these changes opened up opportunities to map the translocal relations shaping everyday experiences of opioid prescribing, opioid use, and living with chronic pain.

5.3 CONTRIBUTIONS AND LIMITATIONS

The knowledge gained through institutional ethnographic inquiry into opioid prescribing in Ontario allows us to move beyond speculation and to instead account for the real, concrete activities through which opioids come to be prescribed and used. Understanding how opioid prescribing actually works affords opportunities to directly intervene into these relations. Likewise, this dissertation also provides insights into the everyday lives of people with chronic pain and how people actually go about their daily lives, take opioids, navigate the health care system, and try to sustain some quality of life. Knowledge regarding the work people do in attempting to determine whether their pain merits treatment, the dubious value of a diagnosis for many people with chronic pain, and the work required to use opioids for pain management challenge many pre-existing beliefs around people with chronic pain as lazy, seeking secondary benefits associated with chronic illness, or unwilling to put in efforts to ameliorate their pain.

The study also troubles existing notions of compliance and beliefs that opioid-related harms result from non-compliance on behalf of users (who are charged with not adhering to physicians' directives) and physicians (who are accused of refusing to comply with clinical guidelines). Binary conceptions of people with chronic pain as either 'good patients' who comply

with physicians' directives or 'bad patients' who use opioids 'inappropriately' fail to account for the structural determinants shaping opioid use and the actualities of using opioids for pain management. Notion of physicians as either good, responsible physicians who follow clinical guidelines or bad, irresponsible physicians who misunderstand, refuse to read, or refuse to follow purported best practices also fail to consider how physicians actually translate these protocols into their local settings.

This dissertation offers critical addiction studies and several subdisciplines within the field of sociology (including sociology of health, medical sociology, and sociology of professions) insights into the way prescribing and using opioids for chronic pain actually works. The findings that emerged from my analysis also contribute to our understanding of how policies, programs, and regulations enacted to curb the crisis of increasing opioid-related harms impact the everyday lives of people who use opioids. This information is critical if we are to develop and implement policies that reduce opioid-related harms without unintentionally causing other harms associated with restrictions to critical medications. Likewise, descriptions of the impacts of increased surveillance and punishment and concomitant shifts in practitioners' work of prescribing opioids highlight the consequences of the medico-legal regulation of opioid use for the patient-physician relationship and other aspects of clinical work. These insights also challenge existing notions of professional self-regulation and governing-at-a-distance given the coercive, punitive nature of interventions into physicians' prescribing practices.

In addition to these contributions, it is also worth noting some limitations of the study. While my interviews with people with chronic pain afforded me with opportunities to map, in great detail, the organization of opioid use, the majority of participants were members of patient support and advocacy groups, friends or acquaintances, or people who subscribe to volunteer-run listservs.

It is possible that these individuals differ from other people with chronic pain, perhaps in relation to their access to the internet and digital literacy, their participation in advocacy work, or their connections within networks of people with chronic pain as well as practitioners. I am uncertain whether interviewing people outside these networks would reveal other heretofore invisible aspects of the ruling relations organizing opioid use, but the possibility is worth noting. As noted in chapter three, most of the people with chronic pain interviewed for this study are legacy patients who have been using opioids for many years. It is possible that this focus on legacy patients may have also obscured other aspects of opioid prescribing and use. Likewise, many of the practitioners I interviewed are sympathetic to people with chronic pain and therefore saw and responded to calls for participants circulated through the aforementioned channels. Further understanding of the everyday work of prescribing opioids and the coordination of this work might be revealed from the standpoints of practitioners who are not involved in these networks and communities.

Another limitation relates to the geographical scope of the study. As I quickly came to realize the complexity of the ruling relations coordinating opioid use and prescribing across Ontario, I decided to limit my research to this one province rather than try to make sense of extended translocal relations across Canada. However, as I heard frequently throughout my interviews, the provision of chronic pain care and opioids for pain management differs across the provinces and territories. As health care in Canada is delivered at the provincial level and professions in each province and territory have their own regulatory colleges, responses to the crisis of opioid-related harms and attempts to curb opioid use have varied, sometimes significantly. Examining these relations at a national and international level could reveal additional features of this organization.

The institutional relations organizing opioid use for chronic pain are intricate and potentially countless. In writing this dissertation, my aim has been to explicate, as concisely as possible, the medico-legal ruling relations at the core of changes in opioid pharmacovigilance, clinical guidance, and shifts in physicians' prescribing practices. There are, however, other regimes of ruling beyond those explored in this project that have shaped the way opioids are prescribed and used. Perhaps the most significant of these are the relations of scientific research and development, funding, and marketing constituting the pharmaceutical industry. In chapter three, I noted that while physicians have been targeted as primarily responsible for increases in opioid-related harms, so too has the pharmaceutical industry been heavily criticized for its role in marketing and selling prescription opioids. While it was beyond the scope of the present project, ethnographic inquiries into the organization of the pharmaceutical industry and the coordinated translocal activities through which opioids are researched, developed, marketed, and sold provide important insights into the organization of opioid use in Ontario and elsewhere (see, for example, Petryna et al. 2006). Likewise, while this study focused principally on the use of opioids prescribed within the setting of the clinician's office, other spaces where opioids are prescribed, dispensed, and used, such as hospitals, in-patient clinics, and pharmacies may be equally important sites for further investigation.

5.4 FUTURE DIRECTIONS FOR RESEARCH AND ADVOCACY

Much of this project has focused on trying to understand what has happened in the past to bring us to the present day—what decisions were made, often without the input or awareness of people with chronic pain, to lead to the present moment where access to opioids for pain management is increasingly restricted. In concluding, I want to cast our sights forward in

considering next steps for research on chronic pain and opioid use as well as advocacy efforts. At several points in this dissertation, I have noted questions, problematics, and avenues of inquiry that are beyond the scope of this study but critical to furthering our understanding of opioid prescribing and use. While I have argued that physicians and the medical profession have been held responsible for increases in opioid-related harms, so too has the pharmaceutical industry been targeted as a catalyst for high rates of opioid use and adverse effects. Investigation into the ruling relations constituting this industry, and the coordinated work of researching, developing, producing, marketing, and selling opioids is a vital next step for mapping the organization of opioid use for chronic pain.

Another important line of inquiry concerns the ever-shifting relationships between people with chronic pain, particularly patient advocates, and the pharmaceutical industry. In recent years, patient advocates have taken up the industry as an ally in demanding access to opioids. Research on this trend has included Rose and colleagues' (2017) work on funding received by patient advocacy organizations by for-profit companies and how these relationships might influence activism. In the case of opioids, there is a need for greater understanding of how these allyships are formed and how patient-industry relationships are navigated.

Another facet of the organization of opioid use that I briefly touched upon in this study but did not have the space to further explore are the experiences of other health care providers including pharmacists, physiotherapists, and nurses in the face of shifts in the clinical governance of opioid use. My interviews with these practitioners were rich with descriptions of the impacts of new regulations intended to curb the opioid crisis and physicians' changing prescribing practices on their everyday work of providing care to people with chronic pain. Many participants, for instance, felt that as physicians have grown increasingly reluctant to prescribe opioids, allied and

alternative health professionals have been expected to fill the gap by taking on care for these orphaned patients. These relations of professionalization, division of labour in health care, and the organization of chronic pain care in Ontario are critical to the use of opioids.

One of my aims in this dissertation has been to challenge the binary of licit versus illicit opioid use and legitimate patients versus illegitimate drug addicts. An important step for future research is a continued commitment to exploring the artificiality of these divides. Many people who use drugs for reasons deemed illicit also have chronic pain and, on the basis of their drug use, cannot access opioids for pain management. Likewise, there are also many people with chronic pain who, in the absence of access to opioids through licit channels, have procured opioids through illicit means. There are also countless people who use opioids for medicinal or licit reasons—reducing their pain—while using the same or other opioids for reasons perceived to be illegitimate, such as deriving pleasure from the experience. Further understanding of these and other groups of drug users is pivotal if we are to fully account for experiences of drug use and how they are organized.

Perhaps most vital for future research is a commitment to not only including the voices of people with chronic pain but ensuring that these are at the forefront of research on pain and opioid use. While there have been some endeavours in recent years to invite people with chronic pain to sit at the tables where decisions are made, these ‘patient representatives’ are usually greatly outnumbered by ‘expert’ panelists. They typically play, at most, an advisory role at arm’s length to the actual creation of regulations and recommendations. We also need to acknowledge the reality that many of these committees and working groups tend to feature the same handful of people with chronic pain over and over.

This fact was of considerable concern to many of the people with chronic pain I interviewed, who felt that their perspectives as outsiders of these networks are excluded. For instance, one person with chronic pain I interviewed described past attempts at scheduling meetings where physicians, people with chronic pain who use opioids, and decision- and policymakers could meet and discuss changes in access to opioids. When he finally managed to schedule a meeting, the hall was filled to the brim with people with chronic pain. Many had traveled for hours to attend. However, of the dozens of physicians, members of the CPSO, and government officials who were invited, only one politician joined, as well as a CPSO member who left within half an hour to attend a family barbecue. No physicians were present. These types of working groups organized and led by people with chronic pain are pivotal if we are to develop policies and programs with equitable outcomes.

The highly political nature of opioid use within the context of the opioid crisis has meant that perspectives on their use have tended to be polarized. In my description of the composition of the 2017 guideline committees in chapter four, I remarked on the tendency for most practitioners, researchers, and other experts to position themselves and others as either favourable or unfavourable toward opioid use for chronic pain management. The perception that those on the “other side” hold fundamentally opposing views and that the “two camps” are incompatible have hampered attempts to address challenges related to opioid prescribing and use. As has been evident in the dissemination and implementation of the resulting guideline, attempts to find a place of neutrality somewhere in the middle of these two poles have been ineffective. There is an urgent need to think critically about divisions made between people who use, prescribe, and regulate the use of opioids and how charges of either ‘opiophilia’ or ‘opiophobia’ constitute *ad hominem* attacks that do very little to advance safe and equitable opioid use.

A second division has emerged between people with chronic pain and medical professionals. In many circles, there exists an “us versus them” mentality as people with chronic pain suspect the medical profession of either directly causing or, at best, dismissing their suffering. Members of patient support groups and volunteer organizations often refer to professional academic, scientific, and clinical organizations as “the enemy” or “the other side.” Moreover, people with chronic pain who are associated in some way with the medical profession are often perceived as traitors whose integrity has been tainted. Meanwhile, the literature is replete with examples of stigmatizing, dismissive, and skeptical views held by clinicians regarding people with chronic pain. I heard many of these beliefs expressed throughout my interviews with practitioners: criticisms of people with chronic pain as lazy, hysterical, dramatic, weak, delusional, and difficult to work with. Acknowledgment of and genuine efforts to bridge these divides will be essential to future research and advocacy if we are to effect changes that are relevant to the lived experiences of people with chronic pain and physicians’ everyday work of prescribing opioids.

Finally, in view of my discussion above regarding activist strategies to improve access to opioids for pain management, I urge people with chronic pain and our allies to recognize the importance of collaborating with other marginalized communities. For instance, a number of impactful changes have emerged from the work of people who use drugs, particularly as they have called for harm reduction strategies that prioritize their voices. There are many lessons to be learned from their long histories of activism. Distancing ourselves from marginalized Others will only serve to further entrench immensely harmful binaries between good/bad opioid users and legitimate/illegitimate users. In chapter four, I emphasized the significance of an approach to opioid use that accounts for social determinants of health not as confounding variables but rather as identities and experiences that necessarily shape the everyday lives of people with chronic pain.

I encourage patient advocates, clinicians, researchers, and others involved in this work not to attempt to neutralize these determinants in order to prove that people with chronic pain are the ‘right’ type of drug user, but rather to insist on a recognition of the many structural and historical forces that impact our ability to access adequate pain care.

Of the many changes that will benefit people with chronic pain and ensure greater, more equitable access to adequate pain care, one of the most pressing is a revision of the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain. From my conversations with practitioners and members of the CPSO, I am aware that there are plans in place to update the recommendations. This is a critical opportunity to address the irrelevance of the text to the lived realities of prescribing and using opioids and the protocol’s unintended impacts. Future iterations of the guideline must be prefaced with ongoing discussion of what constitutes evidence, what evidence we deem to be most valuable, and who is an expert on the topics of opioid use and chronic pain management in Canada.

We must also rethink the new and intensified forms of clinical governance and opioid pharmacovigilance that have been deployed in response to panic around the opioid crisis. The use of quantified data through Ontario’s Narcotics Monitoring System erases the everyday lives of people with chronic pain and the impacts of attempts to curb physicians’ opioid prescribing. In many ways, this intensification of surveillance and punishment has created and amplified harms for people with chronic pain rather than reduce harms associated with opioid use. Efforts toward drug decriminalization are an important step in abating these harms, but so too is a commitment to rethinking the patient-physician relationship, the relationship between physicians, the state, and their regulatory college, and how techniques of surveillance erode the trust necessary to promote better health among people with chronic pain. The goal should not be to once again swing the

pendulum from opiophobia toward unrestrained opioid use, but rather to complicate our conception of drugs and those who use them to bring the pendulum to a stop.

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