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AN INTERPRETATIVE PHENOMENOLOGICAL STUDY
OF CHRONIC PAIN EXPERIENCES AMID THE OPIOID CRISIS

BY
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Approval of Thesis

The undersigned certify that they have read the thesis entitled

**AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS STUDY OF THE LIVED
EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS**

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In partial fulfillment of the requirements for the degree of

Master of Counselling

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Dedication

I would like to dedicate this thesis to my husband who encouraged me to chase my dreams. Despite my repeated desires to quit, you provided unwavering support so that I could finish my education. Thank you for always seeing my potential and inspiring me to overcome obstacles. Without you, this thesis would have never been possible.

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Abstract

For many individuals with chronic pain, opioid therapy is the only safe, effective, and affordable option for pain management. This study used interpretative phenomenological analysis to explore the experiences of four Canadian females managing chronic non-cancer pain to better understand how opioid-related systems-level initiatives impact chronic pain management. Participants provided insight into how the opioid crisis impacted their access to chronic pain treatment, relationships and interactions with medical providers, and their physical and mental health. The results of this study indicate that the physical, mental, and social wellbeing of individuals using opioid therapy to manage chronic pain is significantly impacted by systems-level initiatives such as prescribing guidelines and prescription drug monitoring programs. Further, this study found that systems-level initiatives further exacerbate the institutionalized stigma commonly experienced by individuals with chronic pain. Lastly, this study supports the necessity of further research on how health policy impacts the chronic pain community.

Keywords: Opioid crisis, Chronic pain, Pain management, Opioid use, Systems-level initiatives, Institutionalized stigma

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Chapter 1. Introduction

Background of the Problem

The limited literature available on the impact of systems-level responses to the opioid crisis has demonstrated the overarching and immediate outcomes of systems-level interventions on those using chronic opioid therapy. The few studies that exist have shown that policy adjustments intended to reduce opioid availability have been successful in deterring physician prescribing; however, the reduction in opioid prescribing has affected access to chronic opioid therapy for legitimate pain sufferers. Although these studies are qualitative in nature, they have only foregrounded the immediate effects of systems-level responses such as increased stigma, reduced access to non-pharmaceutical and opioid treatments, and the challenges individuals have experienced with obtaining opioid prescriptions. Additionally, the extant literature has focused on the immediate medical effects of reduced access to opioid therapy. In short, these studies have shown that systems-level responses have been successful in reducing access to chronic opioid therapy, which has left some individuals with undertreated and unmanaged chronic pain. While the literature supports the conclusion that systems-level responses have affected those requiring opioid prescriptions to manage chronic pain, there is limited literature available to understand the psychological and social outcomes as a result of limited access to pain management. There is also insufficient data to draw conclusions regarding the overall impact of the opioid crisis initiatives on the quality of life of individuals with chronic non-cancer pain (CNCP).

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Problem Statement

The rates of opioid prescribing have increased over the past twenty years resulting in a public health emergency termed the opioid crisis. In response to the opioid crisis, government agencies and health authorities have created systems-level initiatives such as guidelines for prescribing opioids, prescription drug monitoring programs, and legal and professional sanctions on prescribers. While initiatives to reduce the impacts of the opioid crisis have been effective at reducing prescribing rates and opioid-related mortality, more research is needed to explore the effects of these initiatives on individuals using opioid therapy for chronic pain. Additionally, valuable information would result from understanding how systems-level responses to the opioid crisis have affected the psychological and social components of individuals using opioids to manage chronic pain. Moreover, this study would foreground the psychological health needs of those with chronic pain, thus highlighting ways to improve pain-related health initiatives.

Purpose of Inquiry

The purpose of this study was to explore how systems-level responses to the opioid crisis in Canada have influenced the psychological health and quality of life of individuals who rely on chronic opioid therapy for pain management.

Research Question

The research question that guided this research was: How have systems-level responses to the opioid crisis impacted the lived experiences of individuals using chronic opioid therapy to manage CNCP?

Importance of the Inquiry

Unmanaged chronic pain may result in a wide variety of negative pain outcomes and lower health-related quality of life (Brennen et al., 2007; Doane et al., 2018). Although many

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pain treatment protocols exist, many individuals may have limited access to health resources to manage CNCP resulting in more significant negative pain outcomes. Within the past three years, the use of chronic opioid therapy has declined because of systems-level interventions intended to reduce opioid prescribing and diversion. Consequently, individuals who once had access to affordable and effective chronic pain treatment may be experiencing difficulties accessing existing prescriptions, physicians willing to prescribe opioids, or alternative pain treatments. That said, there is limited literature available to understand how the opioid crisis has affected the access to opioid pain treatments and quality of life of those with CNCP. Consequently, this study explored the subjective experiences of managing CNCP amid the opioid crisis.

Scope of the Inquiry

The existing literature on the impact of the opioid crisis on individuals with CNCP is limited and focused on the macro-level outcomes of systems-level initiatives. As a result, there is insufficient evidence of how systems-level interventions have affected individuals who rely on chronic opioid therapy to manage pain. Given that the limited studies available on the outcomes of the opioid crisis explore only high-level impacts of opioid pharmacovigilance, this study explored the micro-level impacts from the perspective of the individual with CNCP. More specifically, this study utilized semi-structured interviews with a focus on the above research question to access the chronic pain management experiences of a small sample of four individuals following the opioid crisis. By using interpretative phenomenological analysis, a qualitative methodological framework intended to explore the meaning individuals make of their experience (Pietkiewicz & Smith, 2014), this study collected first-hand accounts of chronic pain management prior to and following the initialization of systems-level interventions for the opioid

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crisis. With the addition of member checking, the data analysis procedures followed those proposed by Smith & Osborn (2007).

Initially used as a methodology in health-psychology research (Smith et al., 2009), IPA is uniquely suited to explore the subjective experiences of chronic pain management from the perspective of the sufferer (Biggerstaff & Thompson, 2008). Although the experiences of CNCP are contextually bound and unique to the individual, experiences pertaining to treatment access following the opioid crisis may inspire future researchers to study the impact of health initiatives on those with chronic pain as well as encourage policymakers to consider the needs of those impacted by health policy. In addition to the implications for future research and policy creation, this study serves to validate the experiences of those impacted by the systems-level interventions and amplify the silenced voices of those who rely on chronic opioid therapy to manage their pain. Although the outcomes of this study are not theoretically generalizable due to the sample size, the shared experiences of managing chronic pain and navigating the medical system may resonate with others, providing the language and validation necessary to discuss chronic pain treatments with their physicians.

Definition of Terms

Biopsychosocial Model of Pain

The biopsychosocial model of pain is a pain framework for assessment, treatment, and management (Gatchel & Howard, 2018). This model considers both the disease (biological component) and illness (psychological and social components) components of pain (Gatchel et al., 2007).

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Chronic Non-Cancer Pain

Literature on the topic of pain management delineates between cancer and non-cancer pain as the symptoms and outcomes are different. Unlike cancer pain that is short lasting, CNCP is persistent or recurrent pain lasting three months or longer and impacted by internal and external factors, affects large amount of population world-wide (Rodiditi & Robinson, 2011).

Chronic Opioid Therapy

Originally used for the treatment of acute injury and cancer pain, the medical community used opioids as a quick and effective solution to minimize excruciating pain. In the mid-1990s following a significant rise in diagnosis of CNCP, doctors and pharmaceutical companies recognized that opioids would also benefit CNCP management over extended periods (Vallerand & Nowak, 2016). Additionally, coverage for existing CNCP treatments such as cognitive behavioral therapy began to decline around the same time resulting in opportunity for pharmaceutical companies to encourage opioid use for CNCP treatment (Dasgupta et al., 2018). Consequently, chronic opioid therapy is the utilization of opioid pain treatments for CNCP management (Vallerand & Nowak, 2016).

Institutionalized Stigma

Following systems-level interventions for the opioid crisis, individuals reported that their relationships with their healthcare providers changed leaving them feeling as if their healthcare providers treated them suspiciously, viewed them as addicts, or refused treatment (Antoniou et al., 2019). Consequently, some individuals with CNCP have reported that the opioid crisis has encouraged institutionalized stigma or stigma stemming from healthcare professionals (Antoniou et al., 2019).

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Interdisciplinary Treatment

Interdisciplinary treatment is a pain management protocol closely aligned with the biopsychosocial model of pain and characterized by interconnected treatment teams from a variety of disciplines (Gatchel et al., 2007). Interdisciplinary pain management differs from multidisciplinary pain management in that interdisciplinary teams are located in one building and foster thorough patient communication by working as one team to deliver a variety of treatments according to the patient's needs and integrated treatment goals. According to Gatchel et al. (2014), multidisciplinary teams may be located in the same geographical location but provide treatments with little integration and communication and often with different treatment goals.

Health-Related Quality of Life

The United States Office of Disease Prevention and Health Promotion defines health-related quality of life as a concept focused on health and wellbeing that encompasses the physical, psychological, and social functioning as well as the impact that health has on the overall quality of life of the individual and society. In addition to the general definition, health-related quality of life has also led to the development of measures to assess the global functioning of patients (Office of Disease Prevention and Health Promotion, 2014).

Social Determinants of Health

Social determinants of health are environmental factors, specifically social and economic conditions, that influence a person's health and general wellbeing (Raphael, 2009). Social determinants of health also play a significant role in the experience of chronic pain and access to chronic pain management resources.

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Systems-Level Responses or Initiatives

Following an increase in opioid overdose and death, government and medical authorities developed initiatives to stem the prescribing and diversion of legitimate opioid prescriptions. Systems-level responses to the opioid crisis included prescription guidelines, prescription drug monitoring programs, legal and professional sanctions, and upscheduling of opioids (Volkow & McLellan, 2016).

Reflexivity Statement

In the tradition of interpretative phenomenological analysis (IPA), I am encouraged to bracket my own experiences pertaining to the study at hand. Although my experience is limited in terms of chronic opioid therapy, I do have extensive experience with chronic non-cancer pain and alternative treatments. I have provided below the reasons why this study has special significance to me.

- (a) As an individual with CNCP, I have struggled to gain access to effective alternative treatments such as specialized psychotherapy for CNCP. Additionally, I have struggled to afford other non-pharmaceutical treatments such as psychotherapy, physiotherapy, and massage.
- (b) I understand the difficulty of managing stigma associated with an invisible illness and the importance of having my pain acknowledged and understood.
- (c) I have experienced a breadth of negative pain outcomes and attest to their encompassing influence on my quality of life.
- (d) I firmly believe that research should influence practice and practice should influence research. My hope is that this research will empower those who have experienced barriers to CNCP management, provide mental health workers an understanding of the

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experience of CNCP, and inform policy makers and health authorities of the implications of their healthcare-related initiatives.

Chapter 2. Review of the Literature

Introduction to the Literature Review

Understanding the ubiquitous nature of CNCP and its outcomes is necessary to fully comprehend the impact of the opioid crisis on individuals managing CNCP. In the literature review that follows, I first provide an overview of CNCP including the following: (a) prevalence, diagnostic criteria, and types of CNCP; (b) CNCP negative outcomes; (c) social determinants of CNCP; and (d) biopsychosocial model of pain experience and interdisciplinary CNCP management. Second, I detail how institutional forces positioned opioids as the gold standard of treatment, thus creating an overreliance on chronic opioid therapy and contributing to the opioid crisis. Third, I provide an overview of the systems-level responses to the opioid crisis. Fourth, I describe the existing literature on the impacts and unintended consequences of systems-level responses to the opioid crisis on individuals with chronic non-cancer pain. Lastly, I summarize the literature discussed and provide the research significance, recommendations, and guiding research question for a qualitative study on the lived experiences of individuals using chronic opioid pain management.

Overview of CNCP in Canada and the United States

CNCP affects approximately 20% of individuals in Canada (Shupler et al., 2019) and the United States (Dahlhamer et al., 2018). Defined as persistent or recurrent pain lasting three months or longer, CNCP differs from acute pain in that it involves different biological mechanisms and is impacted by a variety of internal and external factors (Canadian Pain Taskforce, 2019; Roditi & Robinson, 2011; Schopflocher et al., 2011). Unlike acute pain that stems from an injury or medical intervention, clinicians diagnose CNCP as chronic primary pain or secondary pain. According to the Canadian Pain Taskforce (2019), chronic primary pain is a

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condition within itself. Chronic secondary pain is a symptom of a separate, underlying diagnosis and may result in individuals managing both CNCP and comorbid illnesses (Canadian Pain Taskforce, 2019). Although it is critical to recognize the complicating factors of comorbidity with CNCP, for this research study, all forms of CNCP regardless of their origin are referred to as “chronic non-cancer pain” or CNCP.

The high prevalence of CNCP in Canada and the United States represents the widespread suffering of a large number of people. Schopflocher et al. (2011) stated that more than half of Canadians with CNCP have lived with pain ten years or longer, and nearly half of those with CNCP rate their pain as moderate to severe. Similarly, Dahlhamer et al. (2018) estimated the prevalence of CNCP in the United States included 50 million individuals or approximately 20% of Americans, with 8% experiencing severe or high-impact pain. Both studies contended that advancing age increased both the prevalence and severity of CNCP resulting in one-third to half of those 65 years or older experiencing severe CNCP (Dalhamer et al., 2018; Schopflocher et al., 2011). The sheer number of individuals experiencing CNCP in North America requires significant resources to assess and treat CNCP appropriately in order to avoid the impact of negative pain outcomes on society as a whole.

Impact of Chronic Non-Cancer Pain on Quality of Life

Chronic non-cancer pain is the most common cause of the utilization of physical and mental health resources in Canada and the United States (Institute of Medicine, 2011; Finley et al. 2018). Despite the number of individuals with chronic pain seeking healthcare, many healthcare professionals in Canada self-reported a lack of training and knowledge in the area of chronic pain management (Makary, et al., 2017; Thompson et al, 2018; Volkow & McLellan, 2016). Given the lack of chronic pain training and other barriers to treatment, individuals with

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CNCP may not receive adequate pain treatment resulting in unmanaged pain and negative pain outcomes (Brennen et al., 2007). Continued negative pain outcomes frequently results in significant deficits in the physical, psychological, and social health of an individual.

Individuals with CNCP face a variety of maladaptive physiological, social, and economic outcomes (Brennen et al., 2007). The adverse physiological and social outcomes associated with CNCP include: (a) sleep disturbances; (b) decreased socialization, energy levels, and physical activity; (c) increased functional disability and impairment (Doane et al., 2018; Duenas et al., 2016); and immune impairment (Brennen et al., 2007). Further, individuals with CNCP face occupational and economic challenges due to disability and lower workforce participation; therefore, they are more likely to experience economic suffering that impacts access to treatment (Brennen et al., 2007; Roditi & Robinson, 2011).

In addition to the physical, social, and economic outcomes, Linton and Shaw (2011) asserted that individuals with CNCP are more likely to experience negative cognitive, affective, and behavioural problems than those without CNCP. More specifically, chronic pain sufferers experience frustration, negative affect, increased stress (Linton & Shaw, 2011), pain catastrophizing, perceived hopelessness, and fear-avoidance behaviour (Hooten, 2016; Linton & Shaw, 2011). Moreover, the psychological outcomes of chronic pain include increased prevalence of depression, anxiety (Brennen et al., 2007; D'Arcy, 2010; Linton & Shaw, 2011), and substance abuse (Hooten, 2016). Lastly, existing literature found that individuals with CNCP are more likely to commit suicide than individuals without chronic pain (Tang & Crane, 2006; Darnall et al., 2019).

Although the implications of chronic pain pose a considerable risk of reduced functioning and quality of life for those with CNCP, those in marginalized populations may experience these

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effects at a higher magnitude (Institute of Medicine, 2011). Chronic pain may occur in anyone; however, chronic pain is not evenly distributed across all individuals in a society (Schopflocher et al., 2011). The next section will describe the social determinants of chronic pain and the corresponding marginalized groups at higher risk for negative pain outcomes.

Social Determinants and Health Disparities Related to Chronic Non-Cancer Pain

As previously mentioned, CNCP research has consistently demonstrated that certain groups experience a greater prevalence of chronic pain (Canadian Pain Task Force, 2019; Institute of Medicine (IOM), 2011). The extant literature has also highlighted the specific social determinants that create inequalities in the experience of CNCP. The social determinants underpinning chronic pain create disparities in the severity of the pain experiences and access to pain management resources (IOM, 2011). The population at more risk for CNCP include women, Indigenous Peoples, homeless and low-income individuals, and the elderly (Canadian Pain Task Force, 2019). Additionally, factors such as obesity, sedentary lifestyle, and manual labour also result in a higher prevalence of chronic pain (D'Arcy, 2010). Lastly, individuals residing further from urban centres may also experience poorer pain outcomes due to decreased treatment access (Day & Thorn, 2010).

Chronic pain presents a considerable economic burden to an individual (Phillips, 2009), further exacerbating the challenges of obtaining treatment for those without financial means. Additionally, individuals experiencing negative pain outcomes may have increased absenteeism, presentism, and functional disability, which can impact consistent employment (Goldberg & McGee, 2011). The stress resulting from negative pain outcomes, occupational challenges, poverty, and marginalization presents a cumulative effect on the quality of health, thus supporting the disparities in the experience of chronic pain (Goldberg & McGee, 2011). Given

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the social factors connected to the experience of chronic pain, effective CNCP treatments must consider the surrounding context of those with chronic pain as well as the physiological causes.

Biopsychosocial Model of Chronic Non-Cancer Pain

The frameworks used to explain, assess, and treat chronic pain have evolved to fit the respective political and social zeitgeists (Wailoo, 2015). Although there are several pain frameworks, the biopsychosocial model of pain is the most widely accepted. The biopsychosocial model is a departure from the reductionist view of medicine's biomedical model of pain (Gatchel & Howard, 2018). Further, the biopsychosocial model considers both disease and illness in the experience of chronic pain. While a biological event characterizes "disease", "illness" is shaped by the interplay of biological, psychological, and social forces that affect the subjective experience and outcomes of chronic pain (Gatchel et al., 2007; Turk et al. 2010). Biological forces contribute to the initial physical aspect of chronic pain while psychosocial factors determine the perception and behavioural responses to their physical experiences (Turk & Monarch, 2018). These forces significantly impact the initial development of chronic pain as well as its progression and outcomes.

The biopsychosocial model provides a basis for the assessment and treatment of chronic pain. This model requires healthcare providers to use a multidisciplinary approach to understanding a patient's pain experience, which requires a variety of treatments through an individualized pain management approach (Gatchel & Howard, 2018). The biopsychosocial model is also important in understanding the fulsome impacts of the opioid crisis on chronic pain management and signifies a gap within the extant literature. To date, research pertaining to the opioid crisis has focused on the physiological components of addiction and overdose. Little

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research has explored the impact of the opioid crisis outcomes on the psychological and social aspects of chronic pain.

Psychological and social factors play an integral role within the biopsychosocial framework. Psychological factors such as emotions, behaviours, and cognitions enhance and reduce the experience of chronic pain (Brennan et al., 2007). Consequently, psychological treatments for chronic pain target self-management, behavioural approaches, and cognitive change (Roditi & Robinson, 2011). Multiple studies have demonstrated a correlation between increased pain and disability and fear-avoidance behaviours, negative thoughts, catastrophizing, and poor pain self-efficacy (Main et al., 2010; Richard et al., 2011; Söderlund et al., 2017).

Other psychological factors such as comorbid mental illness may also affect the experience of pain and stigma as well as treatment outcomes (Roditi & Robinson, 2011). Individuals with CNCP are more likely to develop mental health issues such as depression, anxiety, and substance use disorders (Brennan et al., 2007, Tunks, Crook, & Weir, 2008). Importantly, individuals with CNCP and comorbid mental disorders are often referred to as difficult patients, and thus go untreated or have poorer treatment outcomes (Roditi & Robinson, 2011). Given the connection between psychological factors and chronic pain, CNCP treatments should include a psychological component to target specific emotional, cognitive, and behavioural concomitants that accompany pain.

In the same vein as the psychological factors of CNCP, an individual's sociocultural context determines his or her experience, interpretation, and response to chronic pain (Wailoo, 2015). Brennan et al. (2007) stated that myths, irrational beliefs, and a lack of knowledge created barriers to the understanding of pain and its treatment protocols for both medical staff and members of the public. More specially, social learning and cultural norms play a significant role

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in pain-related attitudes and beliefs (Turk & Wilson, 2010), which affects one's willingness to seek and engage in treatment. Access to support, cultural beliefs regarding pain and illness, and learned responses to pain must be considered in order to understand an individual's unique pain experience. When combined with psychological treatments, effective pain management strategies targeting the social concomitants of the chronic pain experience are ideal.

In summary, the biopsychosocial model is critical to understanding chronic pain and its corresponding treatments. Additionally, the biopsychosocial framework is useful for understanding how chronic opioid treatment may exacerbate the psychological and social components of chronic pain, potentially resulting in increased substance abuse and overdose. As previously mentioned, there is a significant literature gap on the topic of chronic pain experiences amid the opioid crisis. To date, little research has explored how systems-level responses to the opioid crisis influenced the psychological and social components of CNCP. The literature that does exist supports the efficacy of interdisciplinary pain treatments, which specifically targets all three components of the biopsychosocial model of chronic pain.

Interdisciplinary Treatment for Chronic Non-Cancer Pain

The consideration of biological, psychological, and social aspects of the biopsychosocial model of pain paved the way to interdisciplinary pain management (Gatchel et al., 2007; Hulla et al., 2019). Although one aspect may be more influential than another, the complex interaction of internal and external factors determines pain outcomes and is unique to each individual (Gatchel et al., 2007). As the physiological status of the individual declines, the interconnected psychological and social statuses follow suit (Gatchel & Howard, 2018; Turk & Wilson, 2010). Interdisciplinary pain management programs (IPMPs) target all three components of the

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biopsychosocial framework, thus maximizing rehabilitation and improving pain outcomes (Turk & Wilson, 2010).

Interdisciplinary pain management programs (IPMP) are patient-oriented approaches using an integration of doctors, medical specialists, psychologists or psychiatrists, physiotherapists, vocational rehabilitation, massage and relaxation training, and patient self-management to treat CNCP (Gatchel et al., 2014; Stanos, 2012). Distinct from multidisciplinary pain treatment where several providers aim to reduce pain, interdisciplinary programs focus on rehabilitation and require coordinated services from various disciplines, communication between service providers, and active patient involvement (Gatchel et al., 2014). Overwhelming evidence supports the short and long-term success of interdisciplinary pain management programs. More specifically, research has shown that IPMPs demonstrate notable improvement in (a) functional ability, (b) psychological conditions such as depression and anxiety, (c) self-reported pain and disability severity, (d) socioeconomic outcomes, and (e) decreased reliance on medication (Gatchel et al., 2014; Oslund et al., 2009; Stanos, 2012). In addition to the treatment effectiveness, IPMP patients tend to have less emergency and primary care visits compared to other approaches, which reduces the economic burden of CNCP (Gatchel & Howard, 2018; Gatchel et al., 2014; Turk & Swanson, 2007).

Despite the evidence supporting the efficacy and cost-effectiveness of IPMPs, the number of IPMPs have declined (Gatchel et al., 2014). Gatchel et al. (2014) asserted that IPMPs are disappearing as the result of decreased funding and resources for pain research and practice, an inconsistent development of interdisciplinary teams, and a lack of insurance coverage. More specifically, third-party insurers may mistakenly view the up-front cost of IPMPs as too high and opt for cheaper, quicker alternatives or outsource services to more affordable providers resulting

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in fragmented care (Gatchel et al., 2014). Consequently, IPMPs are becoming less available, resulting in untreated chronic pain and an overreliance on pharmaceutical pain treatment.

In conclusion, the first section of this literature review provided an overview of chronic pain, CNCP outcomes and social determinants, and the biopsychosocial model and corresponding interdisciplinary pain management. Understanding the negative outcomes and social determinants of CNCP are critical to assessing the toll of the opioid crisis responses on individuals with CNCP. Additionally, the biopsychosocial model is necessary to create a framework from which to understand the comprehensive impacts of the responses to the opioid crisis on those with CNCP. Further, the success of interdisciplinary pain management programs challenges the current practice of single pain management approaches such as opioids. Consequently, the existing gap within opioid crisis research has likely influenced the consideration of psychological and social factors during policy creation for opioid treatment access. With this in mind, the following section will elaborate on how institutional forces created an overreliance on opioid pain management and their initiatives to stagnate the opioid crisis.

Systems-Level Forces in the Treatment of Chronic Non-Cancer Pain

Over the past three decades, chronic pain has represented a battleground wrought with political, economic, and social agendas that determined the type of treatments available and who gets access (Wailoo, 2015). The mid-twentieth century ushered in an era of new pain research, pain management frameworks, and newly discovered medical and alternative treatments (Wailoo, 2015). Despite the growing field of pain management, the number of individuals experiencing chronic pain continued to grow at alarming rates (Wailoo, 2015). Using existing research on chronic pain in the United States, the IOM (2011) attributed the growing rates of pain to aging populations with health challenges, obesity, medical interventions following

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accidents and surgeries, and advancing knowledge and treatments encouraging individuals to seek treatment. As the rates of chronic pain increased, the economic burden on social support systems grew as well (Wailoo, 2015). As a result, systems-level forces sought ways to eliminate the collective suffering while reducing the financial impact of CNCP. These forces resulted in an overreliance on chronic opioid therapy, thus contributing to the current opioid crisis.

Leading up to the 1980s, healthcare providers used a variety of treatments to manage chronic pain; however, the most common treatment was cognitive behavioural therapy (CBT) (Dasgupta et al., 2018). A series of systems-level changes occurred in the political and medical sectors that positioned opioids as the new gold standard (Meldrum, 2016) pushing other treatments, such as CBT, to the wayside. First, the President of the American Pain Society termed pain as the “fifth vital sign”, stating that healthcare providers should do more to monitor and treat pain (Campbell, 1995). The fifth vital sign campaign resulted in the quantification of pain (Bernard et al., 2018) and supported views that pain relief was a fundamental human right (Brennan et al., 2007). To leave pain untreated was considered a poor medical practice that could result in litigation (Brennan et al., 2007). Second, The Joint Commission implemented new benchmarks for adequate pain relief in American hospitals thus requiring mandatory pain assessments (Jones et al., 2018). The new benchmarks and the growing number of individuals with chronic pain fostered the need for efficient and effective pain relief via opioids (Dasgupta et al., 2018; Jones et al., 2018). Patient satisfaction expressed through satisfaction surveys determined if hospitals received federal funding (Jones et al., 2018). The increased pressure for higher patient satisfaction pushed physicians into prescribing opioids more frequently (Bernard et al., 2018; Jones et al., 2018). Fourth, multiple new versions of opioid drugs flooded the market

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offering physicians and patients a variety of alternatives to original opioids such as morphine (Chou et al., 2015; Jones et al., 2018).

The final push towards opioid reliance originated with profit-driven, aggressive, and misleading pharmaceutical sales tactics (Dasgupta et al., 2018). The techniques used by pharmaceutical companies reduced public and medical fears of opioids, reinforced the safety of opioids (Jones et al., 2018), and encouraged their use through elaborate kickback programs (Dasgupta et al., 2018). Many prescribers took full advantage of the kickbacks and increased their prescribing practices (Dasgupta et al., 2018). By this stage of the opioid epidemic, many individuals were dependent on chronic opioid therapy and began to transition to stronger, cheaper street drugs (Mars et al., 2014).

Some physicians prescribed opioids without understanding the risks as a result of the perceived benefit of opioid use, pressure from external forces, and misconceptions about chronic pain and opioids (Wailoo, 2014). A few of these misconceptions included the belief that chronic pain buffered individuals from potential opioid addiction, only long-term use resulted in addiction, and only individuals with specific characteristics were at risk (Volkow & McLellan, 2016). Additionally, other factors contributed to the overreliance of opioids such as the declining availability of interdisciplinary pain management teams and lack education for healthcare staff on pain management and addiction (de Leon-Cassola, 2013; Morone & Weiner, 2013).

To add to the list of misconceptions about pain relief, the conflation of cancer and non-cancer pain led to significant implications for pain treatment. In 1986, the World Health Organization's analgesic ladder for cancer pain legitimized the use of opioids as a way to compassionately manage pain (Ballantyne et al., 2016). The moral desire to treat and manage pain combined with the success of opioid cancer pain management resulted in the application of

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the analgesic ladder to CNCP. Although it was necessary to relieve pain of those suffering, the application of the analgesic ladder ignored the biopsychosocial complexities and multidisciplinary needs of CNCP, and created an overreliance on opioid pain management by the medical community (Jones et al., 2018).

As opioid prescribing increased, the responses to untreated chronic pain appeared to be successful (Jones et al., 2018); however, the provision of pain relief came at a cost. Overzealous prescribing practices led to increased rates of overdose and death as well as unintended consequences such as hyperalgesia, chemical dependence and tolerance, substance abuse, and prescription drug diversion (Jones et al., 2018). For example, opioid-related deaths increased 245% over 19 years in Canada (Gnomes et al., 2014) and 345% over 15 years in the United States (Gnomes et al., 2018). More specifically, over 33,000 Americans (Wickramatilake et al. 2017) and 2,000 Canadians (Busse et al., 2017) died from opioid overdose in 2015 alone. With the mortality rate climbing, healthcare providers expressed concern regarding overzealous prescribing practices (Jones et al., 2018) and sought ways to decrease opioid consumption.

Responses to the Opioid Crisis

Opioid use, overdoses, and deaths have climbed considerably over the past 20 years creating one of the most significant Canadian public health challenges in the past few decades (Public Health Agency of Canada, 2021). The overzealous prescribing of opioids for CNCP played a crucial role in the increased rates of overdose and death that created ongoing public health emergency termed the opioid crisis (American Society of Addiction Medicine, 2016; Gnomes et al., 2014a; Gnomes et al., 2014b). In the aftermath of dramatic increases in opioid-related overdose and death, government and health authorities began to question the appropriateness of opioid therapy as a treatment for CNCP (Dassieu et al., 2019; Jones et al.,

2018). Inevitably, systems-level authorities implemented policies and programs designed to decrease opioid prescribing rates, prevent diversion, and protect opioid users from drug-related harms (Harbaugh & Suwanabol, 2019). Along with additional initiatives outside of the scope of this study, these programs and policies included: (a) prescribing guidelines, (b) prescription drug monitoring programs (PDMPs), (c) legal and professional sanctions, (d) rescheduling specific opioids, and (e) denial of opioid coverage/reimbursement (Centers for Disease Control, 2018; Jones et al., 2018; Wickramatilake et al., 2017). Similar prescribing guidelines were adopted in Canada including restrictions on the quantity and type of opioids prescribed, the use of sedatives with opioids, and risk assessment practices such as urine screening and treatment agreements (Busse et al., 2017). The following sections discuss the systems-level responses that have negatively affected those with CNCP.

Prescribing Guidelines

Perhaps the most critical systems-level response to the opioid crisis was the recommendation of prescribing guidelines as they influenced whether or not physicians prescribed opioids as well as the maximum doses allowed. Although many prescribing guidelines exist, the 2016 Centers for Disease Control and Prevention (CDC) prescribing guideline is the only one endorsed by the College of Physicians and Surgeons in Canada (Busse et al., 2017). Similar to the CDC's (2016) prescribing guidelines, the 2017 Canadian Guideline for Opioids for Chronic Non-Cancer pain (Busse et al. 2017) encouraged prescribers to consider all available non-opioid treatments first. If opioids were medically necessary, Busse et al. (2017) recommended: (a) guidelines for starting or combining opioid and non-opioid therapies; (b) considerations for opioid use in patient populations with psychiatric or substance use disorders; and (c) rotation opioid therapies. Like the CDC's guidelines, Canadian guidelines also proposed

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maximum prescription doses, opioid contracts, mandatory drug testing, and tapered doses for prescriptions over recommended maximums (Busse et al., 2017).

Prescription Drug Monitoring Programs

Another important measure to reduce opioid use was the implementation of prescription drug monitoring programs (PDMPs) (Wickramatilake et al., 2017; Busse et al., 2017). PDMPs are electronic databases that provide a means to record and monitor patients receiving multiple prescriptions from physicians and pharmacies (Harbaugh & Suwanabol, 2019; Wickramatilake et al., 2017). Following implementation, PDMPs monitored abuse, curbed doctor shopping, and prevented diversion of drugs to non-prescription users. Government and medical authorities also used PDMPs to monitor physician-prescribing practices to prevent overzealous prescribing practices (Harbaugh & Suwanabol, 2019). Data from PDMPs provided snapshots of physician prescribing behaviour and patient use of opioids noting problematic behaviour (Makary et al., 2017). Health authorities have provided this data to licensure boards or law enforcement in the past resulting in legal and professional sanctions for physicians and criminal investigations of patients (Wang & Christo, 2009).

Legal and Professional Sanctions

Another systems-level initiative to reduce the risk of opioid-related harm and diversion has been the threat of criminal prosecution or malpractice investigation (Brennan et al., 2007). Multiple doctors in the United States have faced criminal proceedings because of instances of opioid-related mortality or heavy prescribing practices (Brennan et al., 2007). While only a few cases of criminal prosecution of physicians exist, the pursuit of criminal proceedings intended to send a message to the medical community to encourage safe prescribing practices and reduce the number of opioids available for diversion (Reidenberg & Willis, 2007). Consequently,

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physicians have reported prescribing opioid less frequently out of fear of criminal prosecution or losing their medical license (Reidenberg & Willis, 2007).

Rescheduling and Removal of Specific Drugs from Coverage

In addition to prescribing guidelines, PDMPs, and legal and professional sanctions, the United States Drug Enforcement Agency (DEA) rescheduled certain opioids such as hydrocodone combination products from Schedule III to Schedule II (Fleming et al., 2018). Prior to the rescheduling motion, hydrocodone products were not subject to the same monitoring practices as Schedule II opioids making them easier to prescribe (Fleming et al., 2019). Fleming et al. (2018) found that the rescheduling of hydrocodone products did indeed have the intended effect of altering prescribing behavior, with many physicians selecting less effective pharmaceuticals or over-the-counter alternatives. Similarly, Health Canada has targeted narcotics like Tramadol for rescheduling under the control of Narcotics Control Regulations creating barriers to access for chronic pain patients (Health Canada, 2021).

Other initiatives to change prescribing behaviors included reducing coverage for specific opioids. For example, Ontario removed long-acting and maximum strength opioids from provincial drug benefit programs (Morin, Eibl, Franklyn, & Marsh, 2017). Inevitably, individuals with CNCP had to decide whether their pain warranted paying out-of-pocket for relief, thus deterring the prescription and fill of certain drugs.

Although implemented in good faith, systems-level responses such as prescribing guidelines, PDMPs, and legal sanctions have resulted in a period of opioid pharmacovigilance, or the cautious monitoring and prevention of drug-related harms (Dassieu et al., 2019; Knight et al., 2017). The most recent shift to pharmacovigilance has been characterized by excessive monitoring and barriers to access of opioid pain management discussed throughout the section

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above. These systems-level responses to the opioid crisis have shown small improvements in the rates of opioid prescribing but have not had the same effect on opioid abuse (Jones et al., 2016; Wang & Christo, 2009). While pharmacovigilance has not culminated in the desired effect on opioid abuse, government and medical authorities continue to create barriers to accessible chronic opioid therapy. These barriers have created considerable hardships for individuals relying on opioids to manage CNCP.

Outcomes of Systems-level Responses to the Opioid Crisis

While intended to protect individuals on chronic opioid therapy, systems-level responses to the opioid crisis resulted in unintended consequences for those who rely on opioid pain management (Canadian Pain Task Force, 2019). Individuals with CNCP may not have access to non-pharmaceutical pain management resources due to the stigma surrounding psychological treatments, socioeconomic status, or availability of alternative pain treatments. Without access to opioids, many individuals continue to experience difficulties managing their chronic pain (Antonious et al., 2019), thus lowering their overall quality of life.

The literature available on this topic has begun to explore the effects of opioid restrictions on those with chronic pain; however, the isolated studies have not yet explored the in-depth psychological or social experiences of chronic pain following the opioid crisis. To date, the literature has reported specific outcomes of opioid restrictions such as reinforced stigma, reduced access to alternative pain management, unmanaged CNCP resulting from the under treatment of pain, and increased physical and emotional risk. The following section provides information on the surface effects of the systems-level responses to the opioid crisis.

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Reinforced Stigma

The experience of stigma is a common outcome of both chronic pain and opioid drug use. Prior to the opioid crisis, the use of opioids to treat chronic pain was highly contested by the medical community. The disagreement over the efficacy and safety of chronic opioid therapy created barriers to access for chronic pain patients and reinforced institutionalized stigma, or stigma resulting from healthcare providers. A qualitative study by Vallerand and Nowak (2010) reported that individuals with CNCP had experienced stigma from their family and friends, workplace, and healthcare providers. Additionally, individuals using chronic opioid therapy reported conflation between their pain treatments and addiction within their healthcare interactions (Vallerand & Nowak, 2010).

Although individuals using chronic opioid therapy faced stigma prior to the opioid crisis (Antoniou et al., 2019; Vallerand & Nowak, 2010), participants in a recent qualitative study reported a shift in their identity from “legitimate chronic pain patient to addict” (Antoniou et al., 2019, p. 17) as a result of systems-level interventions to reduce opioid prescribing. Antoniou et al. (2019) demonstrated that individuals with CNCP felt that systems-level responses and the media portrayal of the opioid crisis reinforced existing stigmas surrounding opioid use. Similar to the institutionalized stigma stemming from healthcare providers reported in Vallerand and Nowak (2010), Antoniou et al., (2019) found that stigma from healthcare providers created a barrier to seeking treatment.

In addition to the reinforcement of stigma, individuals with CNCP reported changes in their doctor-patient relationship, being viewed as an addict or accused of drug-seeking behavior, and a loss of autonomy over medical decisions following the implementation of prescribing guidelines and PDMPs (Antoniou et al., 2019). Antoniou et al. (2019) also demonstrated that

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individuals with CNCP felt their physicians began to question their credibility and the legitimacy of their pain, and distanced themselves in order to avoid professional scrutiny. Similarly, a review of the extant literature on the topic of chronic pain and stigma found that disbelief of pain can result in increased stigma, isolation, emotional distress, and depression (Newton et al., 2013). The noticeable changes to the perception of chronic pain and opioid use in the healthcare community created far-reaching effects for those with CNCP, thus potentially contributing to negative pain outcomes through stigmatization.

Reduced Access to Pain Management

Despite the availability of non-pharmaceutical treatment options available for CNCP (e.g. psychotherapy, physiotherapy, exercise, mindfulness, massage), individuals with limited financial means are not able to access alternative treatments following a loss of access to opioid prescriptions. According to Dassieu et al. (2019), individuals with a history of drug abuse and CNCP wanted non-pharmaceutical treatments but were unable to access them due to their associated costs. In another study, general clinic physicians reported a lack of resources to treat CNCP with anything but opioids since primary care does not cover non-pharmaceutical treatments (Knight et al., 2017). Given the cost associated with alternative treatments and the limited financial means often associated with CNCP, reducing access to opioids may result in unmanaged chronic pain.

Undertreatment of Chronic Pain

Initiatives intended to reduce opioid prescribing created barriers to legitimate access to chronic opioid therapy. For example, prescription guidelines recommend testing non-opioids first, which may not alleviate pain. Individuals requiring higher strength treatments may be denied the necessary treatment as a result of the recommendations (American Pain Society,

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1996). Also, existing literature has foregrounded the impact of the tapering of existing prescriptions down to the recommended maximums as recommended by prescribing guidelines (Darnall et al., 2019). It is worth noting that individuals with existing prescriptions under the maximum dose have also experienced aggressive tapering (Darnall et al., 2019). Consequently, individuals using long-term chronic opioid therapy have been destabilized by the aggressive tapering of opioid doses resulting in withdrawal symptoms, hyperalgesia, significant loss of function, and emotional distress (Busse et al., 2017; Darnall et al., 2019). Reports also indicate increased suicide rates in chronic pain populations (Darnall et al., 2019).

Additionally, physicians' awareness of prescription monitoring systems and fear of legal or professional sanctions has created barriers to opioid access (Knight et al., 2017). In a study by Knight et al. (2017), physicians expressed relief as a result of PDMPs because they could use new opioid policies as a reason to discontinue or deny opioid prescriptions. Regardless of their relief, physicians were aware of how the opioid policies threatened the integrity of the therapeutic alliance (Knight et al., 2017) thus impacting patient's willing to seek further treatment. Even if the physician was willing to prescribe opioids, many individuals found that the pharmacy would decline to fill their prescription (Antoniou et al., 2019).

As a result of changes to prescribing behaviours, individuals experienced a loss of access to opioids or changes to existing opioid prescriptions (Flemming et al., 2019; Gudín & Lee, 2014), discontinued automatic refill access meaning individuals with CNCP were required to visit their prescribing physician, and increased healthcare utilization and its associated financial costs (Gudin & Lee, 2014). Consequently, Brennan et al. (2007) stated that individuals with untreated CNCP may experience maladaptive pain outcomes thus reducing their overall quality of life (Brennen et al., 2007). Also, those with CNCP require greater healthcare utilization and

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may need to travel to find a doctor willing to treat them, which may lead to workplace absenteeism thus exacerbating economic challenges (Phillips, 2009; Roditi & Robinson, 2011).

Increased Risk Behaviours Resulting from Unmanaged Pain

Over and above the implications already discussed, responses to the opioid crisis left some individuals with no choice other than illegal sources of opioids, illicit street drugs, or living with unmanaged pain. Some individuals with CNCP felt they had no other recourse than to seek illegal sources of opioids or use illicit street drugs to reduce their pain thus exposing themselves of the inherent risk associated with criminal enterprise (Dasgupta et al., 2018). To strengthen this point, Meldrum (2016) stated that following systems-level responses to the opioid crisis, heroin use increased drastically especially among middle-class individuals. Lastly, individuals with CNCP are more likely to experience suicidal thoughts and behaviours as a result of feelings of helplessness, hopelessness, and desires to escape pain (Tang & Crane, 2006). Given the propensity of suicidal ideation among those with CNCP, decreased access to legitimate pain relief may exacerbate existing increased risk of suicide in those with chronic pain (Antoniou et al., 2019).

Summary of Literature

Chronic non-cancer pain affects millions of individuals worldwide. Individuals who cannot access adequate pain relief are subjected to negative physiological, psychological, and social pain outcomes that significantly lower their quality of life. All individuals with chronic pain are at risk for negative pain outcomes; however, research has consistently demonstrated that specific social determinants such as poverty, gender, and age can predispose marginalized groups to a higher risk of negative pain outcomes. For these individuals, access to

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treatment is difficult resulting in untreated chronic pain and greater risk of depression, anxiety, and suicidal ideation.

Over the past 30 years, political and medical authorities have foregrounded the undertreatment of chronic pain and reframed pain relief as a human right and medical responsibility. The resulting shifts in medical culture encouraged healthcare providers to relief the physiological source of pain as well as the psychological and social suffering of the individual. Although research has demonstrated the effectiveness of interdisciplinary pain treatment, political and economic forces have acted to reduce the number of interdisciplinary pain treatment teams in favour of quick acting alternatives such as opioids. The desire to treat pain, availability of opioids, cost of alternative therapies, and unethical pharmaceutical sales tactics resulted in an overreliance on chronic opioid therapy making alternative therapies inaccessible to certain populations. In consequence, chronic opioid therapy became the only accessible or effective form of pain relief for some individuals. As a result, the rates of opioid abuse, overdose, diversion, and mortality increased substantially resulting in the opioid crisis.

As opioid-related overdose and death continued to increase, the same systems-level forces that pushed opioids as a gold standard treatment for chronic pain sought ways to stagnate prescribing behaviours and opioid use. These initiatives included prescribing guidelines with recommended maximum doses, initiating prescription drug monitoring programs, and legal and professional sanctions for overzealous prescribing. Consequently, government agencies and medical authorities were able to slow the rate of opioid prescribing, and thus limit the number of opioids available for abuse and diversion.

While systems-level responses to the opioid crisis proved effective at reducing access to opioids, they also resulted in unintended consequences for those relying on chronic opioid

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therapy to manage their pain. Decreased access to opioids left many with increased stigma, reduced access to alternative treatments, undertreated and unmanaged chronic pain, and negative pain outcomes. Those unable to seek relief may have resorted to unconventional means such as illegal opioids or illicit street drugs. In some cases, unmanaged chronic pain resulted in suicide. By way of government and medical authority intervention, some individuals have been abandoned by the medical community, and left to suffer the consequences of negative pain outcomes. They have become the unintended and silent victims of the opioid crisis.

The existing studies on the impacts of the opioid crisis on the experience of chronic pain have not yet explored the psychological and social implications resulting from systems-level initiatives to stem opioid use. As a result, there has been limited data to inform policy creators of the psychological and social outcomes of unmanaged chronic pain resulting from a lack of accessible treatments. The research discussed in the following section focused on the psychological and social implications of chronic pain management during the opioid crisis using interpretative phenomenological analysis.

Chapter 3. Methodology

In the following chapter, I provide an overview of interpretative phenomenological analysis (IPA), which is the methodology selected for this study. First, I will give a general overview of IPA including the theoretical underpinnings and interpretative frameworks germane to this methodology. Second, I will provide a detailed rationale as to why IPA is best suited to explore the lived experiences of the impact of the opioid crisis on CNCP. Third, I will highlight opportunities to enhance the quality of IPA studies as well as detail the ethical considerations specific to this research project. Fourth, I will describe the (a) sample and recruitment plans, (b) data collection strategy, and (c) analysis procedures as recommended by other IPA researchers (Smith & Osborn, 2007) and used in this study.

Overview of Interpretative Phenomenological Analysis

As a variant of phenomenological research, IPA emphasizes the subjective, shared experiences of specific phenomena (Shinebourne, 2011). More specifically, IPA provides an in-depth account of participants' experiences through a participant-oriented (Alase, 2017), adaptable, flexible, and inductive approach to data collection and analysis (Noon, 2018; Pringle et al., 2011). Further, IPA researchers aim to explore the connection between how participants embody, describe, react to, and make meaning of their lived experiences (Alase, 2017; Smith, 2011). In short, IPA researchers are fully committed to exploring the detailed and in-depth account of one's personal experience (Alase, 2017).

Philosophical and Theoretical Underpinnings

There are three theoretical underpinnings tied to IPA methodology, which are influenced by the philosophies of Husserl, Heidegger, Merleau-Ponty, and Sartre. The three theoretical underpinnings salient to IPA include: (a) phenomenology, (b) hermeneutics, and (c) idiography

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(Pietkiewicz & Smith, 2014). First, IPA originates from the phenomenological approach of exploring how participants perceive and make sense of their contextually bound experiences (Alase, 2017; Noon, 2018). Second, IPA utilizes hermeneutics, or practice of interpretation, to access the inner worlds of participants' (Noon, 2018). Specifically, IPA uses a double hermeneutic (Smith, 2011) approach to interpret the participant's interpretations of their experiences (Noon, 2018; Pietkiewicz & Smith, 2014). More specifically, a double hermeneutic entails the researcher interpreting the participant interpreting their experiences. Third, IPA attempts to gain an in-depth understanding of each case through detailed accounts of the participant's experiences (Noon, 2018; Pietkiewicz & Smith, 2014). With these three fundamental principles, IPA (a) culminates in an insider's perspective of a specific phenomenon, (b) gives a voice to participants' inner lives, and (c) provides an interpretation of these experiences within the broader social, historical, and cultural contexts (Larkin, Watts, & Clifton, 2006).

Interpretative Frameworks

In addition to the theoretical underpinnings of IPA, the three interpretative frameworks germane to IPA that inform its research and analytic processes include: (a) constructivism or constructivist paradigm (discussed in the previous section), (b) cognitive theory, and (c) critical theory. Additionally, research on chronic pain and the opioid crisis must consider the role of disability theory given that those with CNCP experience marginalization and stigma associated with chronic pain and disability. Consequently, I applied disability theory as a metatheory to this research endeavour.

In addition to constructivist theory, IPA has a theoretical connection to the cognitive paradigm, which also aligns with current pain models and treatments. Interpretative

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phenomenological analysis and cognitive theory share a similar focus on conscious mental processes (Smith & Osborn, 2007). More specifically, IPA aims to (a) identify how individuals make sense of their experiences of being-in-the-world (Eatough & Smith, 2011); (b) gather accounts of experiences from a situated, embodied, and conscious individual (Larkin et al, 2011); (c) explore how individuals think about and describe their experiences; and (d) discover how their sense-making impacts their behaviour (Smith, 1996).

Specific to the research discussed in this thesis, I used critical and disability theories as additional interpretative lenses to guide research decisions and interpretations. Critical theory encourages the researcher to attend to his or her positional authority (Madison, 2011) and offers an interpretative lens to foreground power imbalances that impact the focus of the research (Creswell & Poth, 2018). Further, research using critical theory may contribute to social justice by identifying (a) how individuals define problems, (b) how institutions support and maintain problems, and (c) what potential solutions are available (Denzin, 2017).

Rationale for Interpretative Phenomenological Analysis

Originally developed for research in health psychology, IPA is well suited for studying the experience of chronic pain from the sufferer's point-of-view (Smith, 1996). I was initially interested in IPA because of the exploration of complex nature of personal experience (Smith, 2011). Additionally, IPA stems from theoretical and interpretative frameworks that match my own worldview and those of chronic pain management. Further, the use of IPA allowed me the opportunity to bracket my own experiences with chronic pain to promote objectivity and connection to the participants (Tufford & Newman, 2010). Lastly, IPA has enough structure to create trustworthiness while remaining flexible in the data collection and analysis processes, which I detail in the following section.

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In addition to the alignment between my worldview and research values and those of IPA, the goals of IPA correspond to the desired outcomes of researching chronic pain experiences. The idiographic and phenomenological nature of IPA focuses on individual accounts and the commonalities and differences in experiences across cases (Alase, 2017; Biggerstaff & Thompson, 2008). By highlighting similarities and disparities among participants' experiences, IPA may be used to develop an essence of the actual experience. Although each individual's pain experiences are contextually bound and subjective, there were commonalities in how individuals have experienced the systems-level interventions following the opioid crisis. Understanding the commonalities and differences in how individuals have experienced the outcomes of the opioid crisis is critical to understanding the contextual nature of the chronic pain experience. Additionally, IPA aims to explore that which outsiders cannot directly know - the inner workings of one's experience. Since chronic pain researchers cannot directly know how individuals experience or make sense of chronic pain, they require a methodology that can provide them with an insider's perspective of that experience.

In addition to the alignment between methodological aims of this study, the theoretical and interpretative frameworks of IPA align with the frameworks and models used in the research and application of chronic pain management. For example, the current gold standard psychological treatment for chronic pain is cognitive behavior therapy, which posits an interconnection between how people think and feel about their chronic pain and the resulting behavioural outcomes (Roditi & Robinson, 2011). Similarly, IPA's theoretical connection to cognitive theory emphasizes the importance of how individuals embody, talk about, and react to specific experiences (Smith, 2011).

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In addition to the role of cognitive theory in IPA and chronic pain management, the phenomenological and hermeneutic underpinnings of IPA help bring understanding to the meaning individuals attach to their chronic pain experiences. Understanding how individuals make sense of their pain experiences and the meaning they attach to them may help inform the development of future chronic pain treatments and policies governing these treatments. Further, many individuals with CNCP may not fully grasp the reasons behind the systems-level interventions. As the researcher, I provided credibility and authority to the participant accounts by grounding their experiences within the existing literature on the opioid crisis.

In summary, the theoretical and interpretative underpinnings of IPA make it uniquely ideal for the exploration of CNCP within the context of the opioid crisis. More specifically, the three theoretical foundations of IPA guided my discovery of the inner, conscious experiences of chronic pain since I could not access it directly as a researcher. Additionally, the cognitive lens characteristic of IPA aligns with the current medical frameworks used to evaluate positive and negative pain experiences. As such, I used IPA to explore the conscious experiences of those with CNCP. Further, critical theory foregrounded the social, political, and cultural forces that resulted in the marginalization of those with CNCP, thus affecting their access to resources and quality of life.

Opportunities to Enhance the Quality of IPA Studies

In general, the popularity of qualitative inquiry has grown considerably over the past decade, and IPA has gained attention for its flexible and adaptable approach to research (Yardley, 2000). Unlike positivist researchers who champion unbiased research, constructivist researchers maintain that the researcher is contextually bound to the research and brings his or her personal values and assumptions into the study. As a result, different criteria are used to

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evaluate the trustworthiness of qualitative research. That said, there are many differing perspectives for enhancing the integrity of qualitative research. I used Yardley's (2000) view, which proposed to strengthen the quality of qualitative research through (a) rigour and commitment, (b) sensitivity to context, (c) transparency and coherence, and (d) impact and importance. In the section following, I detail how I enhanced the quality of my research on the lived experiences of CNCP following the opioid crisis.

Commitment and Rigour

Yardley (2000) posited that commitment and rigour are characteristics of high-caliber qualitative studies. More specifically, commitment and rigour are enhanced through in-depth engagement, methodological competence, and attention to the data collection and analysis processes. Commitment involves comprehensive and robust engagement with the topic under review as a researcher and through personal experience (Yardley, 2000). Rigour results from complete and thorough data collection and analysis including: (a) using an adequate sample, (b) focused analysis, and (c) triangulation of methods (Creswell & Poth, 2018; Shineborn, 2011; Yardley, 2000).

For this study, I demonstrated my commitment to researching the area of CNCP through a robust literature review. Given my personal experiences with chronic pain, I have experienced the marginalization and stigma attached to disability within a healthy society. Further, I have experienced the challenges associated with the positivist-centred and overtaxed medical community. My educational background (i.e., undergraduate degree in psychology) and experience as a researcher have positioned me to explore the lived experiences of chronic pain and give a voice to those experiences. In addition to personal commitment as a chronic pain sufferer, I spent considerable time over the past year conducting this study, engaging participants

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in the research process, and ensuring that the outcomes of research benefit participants and the pain management community.

In addition to my commitment to the research at hand, I enhanced the rigour through support from extant literature, member checking or collaboration with the participants and the pain management community, and thorough data collection and analysis yielding thick descriptions of participants' lived experiences. By engaging multiple methods, I validated and reinforced the interpretations made through the data analysis process.

Sensitivity to Context

An additional aspect of quality qualitative research requires the researcher to (a) demonstrate sensitivity to the sociocultural context of the participants; (b) focus on their lived experiences; (c) attend to the ethical considerations characteristic of critical research; and (d) ground the research in the relevant literature (Yardley, 2000). As demonstrated in chapter two, I have spent considerable time reviewing the literature on various topics including the opioid crisis and chronic pain management. Consequently, I started this research endeavour by critically reviewing and synthesizing the literature to formulate the research question to explore the lived experiences of CNCP following systems-level interventions for the opioid crisis. Additionally, IPA culminates in a thick description of participants' lived experiences that are as close to their understandings of their experiences as possible (Alase, 2017). That said, IPA and phenomenological research require interpretation since inner experiences cannot be directly known. Consequently, I engaged in member checking by offering the opportunity for participants to check the transcription of their interviews. Lastly, individuals with chronic pain experience stigma and marginalization. As a result of conducting research with marginalized participants, I engaged the research ethics board and members of the pain management community to review

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recruitment posters and the interview schedule to ensure that the research outcomes do not subject participants to undue risk or further marginalization.

Transparency and Coherence

In addition to the previously mentioned strengths of IPA research, quality IPA research also provides the reader with transparency and a coherent argument. For this research, I built transparency through reflexive endeavours such as creating an audit trail for research decisions and bracketing. For example, Yardley (2000) asserted that transparency in qualitative research should entail clear descriptions of each stage of research. To this end, I documented my research journey by recording my reactions to participant disclosures, transcription codes, and the coding process for independent audits of the data analysis process (Yardley, 2000; Smith et al., 2009).

As an additional means of ensuring transparency within the research process, I engaged in reflexive processes such as bracketing my presuppositions and experiences with chronic pain. Bracketing, or epoche, is a phenomenological concept termed by Husserl, where researchers attempt to set aside their prior assumptions or beliefs (Creswell & Poth, 2018). In IPA studies, the researcher engages in bracketing to foreground presuppositions about the research matter, thus minimizing their effect on the study outcomes (Tufford & Newman, 2010). Although bracketing prior experiences and understandings of chronic pain is not equivalent to researcher objectivity in positivist research, it can contribute to the quality of qualitative research.

While it is important for me to acknowledge and bracket my existing experiences and assumptions about the medical system, bracketing my knowledge of the existing literature and my experiences with chronic pain may also benefit the study at hand. For example, augmenting interview questions with my existing knowledge of the CNCP enriched the disclosure of participants' experiences (Tufford & Newman, 2010). I was able to pull from my experiences

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and understanding of the CNCP to probe participants for more explanation. Additionally, bracketing may benefit the research process by (a) widening the types of information attended to or (b) listening for divergent experiences. Moreover, bracketing reduced the impact of bias and preconceived notions during the data interpretation phase, thus amplifying the actual accounts of participants' experiences. As discussed in this section, bracketing is paramount to the researcher as an instrument of the research study as it calls for the researcher to be keenly aware of their own biases, assumptions, and worldviews (Creswell & Poth, 2018; Tufford & Newman, 2010).

As an individual with chronic pain, my experiences of the medical system and chronic pain management influenced how I viewed the participants' experiences. During data collection and analysis, I found myself comparing my experiences with those of the participants. In many instances, the participants' experiences resonated with my own, which may have impacted how I interpreted the data collected from interviews. During the interview process, I noted the emotional reactions and thought processes I experienced as a result of participants' disclosures and reviewed these reaction records before analyzing the transcripts. Reviewing these records foregrounded the emotionality and desperation expressed by the participants as they described their experiences. There were moments during the interviews where I felt intrinsically connected to the participants because of our shared experiences with chronic pain and the grief resulting from a loss of sense of self. Conversely, I found it difficult to understand the overreliance on opioids because I have found alternative treatments to manage my pain. While I can relate to the challenges of chronic pain, I have never experienced the loss of access to pain management.

Furthermore, I situated the data analysis within my own experiences after the analysis was complete. Consequently, I noted several similarities between myself and the participants that likely affected my interpretation of the data. One experience in particular is the participants'

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engagement in identity management within medical settings. As a result of this study, I recognize that I too engage in identity management with my doctors. Similar to the participants, I adapt my behaviours to appear more compliant, strategically disclose emergent medical information, and change my physical appearance to look healthy. Reflecting on my personal experiences of identity management in a medical setting helped facilitate an empathic understanding of the participants' experiences. While my vast experience with chronic pain management likely shaped my analysis of the participants' experiences, it also contributed to my overall understanding of the subject matter.

Given that the reader must be able to make sense of the researcher making sense of the participant's experiences, a coherent argument closely aligned with the principles of IPA is also necessary for enhancing quality in this study. Consequently, I spent considerable time (a) reviewing the theoretical and interpretative frameworks germane to IPA; (b) seeking alignment between the epistemological and ontological foundations of IPA and my own beliefs about reality and knowledge construction; and (c) determining the fit between the research question, philosophical positions of the methodology, and research decisions. The steps already taken in this research closely align with the requirements of a coherent study as proposed by Yardley (2000). As a result of my efforts to build transparency and coherence into this research, the reader should be able to follow my audit trail and situate the research within the context of the philosophical, theoretical, and interpretative underpinnings of IPA.

Impact and Importance

The last criteria of quality or trustworthiness of a qualitative inquiry are the impact and importance of the study itself. Smith (2009) acknowledged that the reader plays a significant role in determining a study's utility. For example, the usefulness of a study is validated by the

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intended audience and the community the research intends to serve (Yardley, 2000). Specific to this study, IPA was a conduit to amplify the voices of those who have been impacted by systems-level changes to CNCP treatment options. By foregrounding participants' experiences of chronic pain management during the opioid crisis, this study validates their experiences as well as highlights how systems-level forces create barriers for those with CNCP. Consequently, the chronic pain community may find the research process and its outcomes impactful and important through the validation of their experiences.

In addition to creating impact and importance for the chronic pain community, I also endeavoured to yield research outcomes that encourage future research on the topic of CNCP and systems-level health interventions. The current body of literature from the perspective of those with CNCP is limited; therefore, this study contributes to the existing literature and possibly foregrounds the need for more research to examine the impact of systems-level interventions on CNCP. Research on systems-level responses to the opioid crisis may also encourage healthcare and policymakers to explore alternative treatment options, thus broadening the impact of my initial exploration.

In summary, I have provided my steps to build quality into this study through the application of Yardley's (2000) framework. By anticipating criticisms of qualitative literature, I endeavoured to foster trustworthiness through attention to (a) sensitivity to context, (b) commitment and rigour, (c) transparency and coherence, and (d) impact and importance. Through the engagement of multiple quality assurances, I did my best to ensure that the outcomes of this research will inspire future generations of researchers to explore differing perspectives within challenging sociocultural contexts. In doing so, this study grounds future

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research opportunities on the impact of systems-level interventions on the lived experiences of those with CNCP.

Pre-Data Collection and Sampling for IPA

After reviewing many articles that included IPA data collection and analysis strategies, I selected Smith and Osborn's (2007) IPA strategy as it provides detailed directions for novice IPA researchers. In the section following, I provide an overview of the data collection and analysis for a study on the lived experiences of individuals with CNCP amid the opioid crisis. First, I discuss the ethical considerations for conducting this study, intended sample size and criteria, and recruitment strategy. Second, I describe my pre-data collection procedures, interview schedule creation, and member checking process. Third, I provide an overview of my data collection process and Smith and Osborn's (2007) guidelines for data analysis.

Ethical Considerations for Research with Vulnerable Populations

According to the TCPS 2 (2018) for conducting ethical research, research using populations of interest (e.g., marginalized individuals) require additional ethical considerations. For the present study, a community of interest, or individuals with chronic pain and disability, were included in the sample. I obtained approval from Athabasca University's Research Ethics Board by providing detailed information on ethical considerations for this study. With the participants in mind, I included additional considerations for a sample with chronic pain and disability. For example, participants for this study may have limited mobility due to chronic conditions or functional impairment as a result of CNCP. Consequently, I considered the needs of the participants by using online synchronous tools to host interviews. Additionally, participants in this study were asked to share their experiences about their physical and mental health and interactions with healthcare providers. As a result of the sharing of confidential

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medical information, I disclosed how the information would be securely stored and protected and who will have access to the data.

Once the interviews were scheduled, I provided detailed consent information to the participants to review before the interview. Providing the consent information prior to the interview gave participants additional time to consider the study, ask questions, and make a decision on whether or not to participate. The consent form (Appendix B) included (a) context and background of the study; (b) privacy and confidentiality concerns such as data storage and anonymity; (c) option to withdraw from the study at any time; (d) risks associated with the research; (e) intention to record the interviews, and (f) the contact information for the principal researcher. For those interested, I obtained consent to contact participants to share the results of this research endeavour. Lastly, I obtained permission to record interviews and use the data towards the completion of my graduate thesis and program.

Sample Size and Inclusion Criteria

Interpretative phenomenological analysis researchers apply an idiographic focus in order to yield detailed, in-depth accounts of participant experiences (Noon, 2018). As stated by Smith et al. (2009), three to six participants is an ideal sample for a masters-level IPA research. As a result of the time and resources available to this project, I recruited four participants for this study. Additionally, IPA requires a purposive and homogenous sample so that that the research focuses on a group of individuals with similar experiences with the phenomena under review (Noon, 2018). For this study, the inclusion criteria included participants who have (a) been diagnosed with CNCP; (b) used chronic opioid therapy prior to the implementation of systems-level interventions; (c) experienced difficulties with chronic opioid therapy following systems-level opioid crisis interventions; and (d) had no substance use or addiction prior to their

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participation in this study. Specifically, the participants in this study had a history of acceptable and responsible chronic opioid therapy use prior 2016 or the implementation of systems-level changes to opioid prescribing practices.

Recruitment

The recruitment strategy for this study changed significantly as a result of initial recruitment barriers that resulted from a national lockdown due to the Covid-19 pandemic. One participant was recruited from a faculty member's recommendation. Originally, I had intended to recruit additional participants from doctors' offices and pain management clinics. As a result of government-imposed restrictions for medical offices, I changed this strategy and used special interest groups such as Help AB, a pain advocacy group located in Alberta, Canada. The remaining three participants volunteered as a result of introductions from Help AB.

Interviews

As a flexible methodology, IPA typically makes use semi-structured interviews to gather insight into the participants' first-hand experiences about the area of interest (Smith & Osborn, 2007). Semi-structured interviews encourage dialogue between the researcher and participants through open-ended questions and a flexible interview guide, thus allowing the conversation to go in the direction indicated by the participant's responses (Smith & Osborn, 2007). Smith and Osborn (2007) also contend that semi-structured interviews may culminate in more abundant data, increased empathy, and broader scope than structured interviews. At the theoretical heart of IPA, semi-structured interviews promote mutually constructed accounts of participants' experiences.

As stated by Smith and Osborn (2007), semi-structured interviews are beneficial to qualitative research because they facilitate rapport with the participant, guide the conversation,

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encourage novel discussions, and produce detailed accounts. That said, I constructed a flexible interview schedule (Appendix D) that encompassed several areas of exploration including their (a) pain experience, (b) interactions with the medical field prior to recognition of the opioid crisis, and (c) perceived impact of the opioid crisis on physical and mental health. By utilizing open-ended questions to explore these areas, I gained a detailed account of their CNCP before and after the opioid crisis. It is worth noting that the interview schedule was used as a guide to ask questions, and therefore, was not prescriptive for what the participants chose to discuss (Smith & Osborn, 2007).

To ensure my interview questions were relevant and meaningful to the population under study, a participant reviewed the interview questions prior to beginning my interviews. Although member checking typically occurs to verify transcripts and analyzed data (Birt et al., 2016), a review of the interview guide ensured that no marginalizing language was used and that the questions would encourage rich accounts from the participants. Due to her experiences with CNCP and advocacy for the chronic pain community, I felt this individual provided valuable perspective on the general tone of the interview questions.

Data Collection

After collecting the information of interested participants, I reached out to those who qualified for the study and invited them for an initial discussion and interview. Since IPA interviews are highly detailed, I scheduled each interview for one hour and thirty minutes (Smith & Osborn, 2007), allowing for time to discuss the consent process and answer questions. Once an initial interview was scheduled, I provided the consent form for participants to review before the interview. To ensure the participants provided informed consent, I explained the information on the consent form, risks associated with participation, autonomy to withdraw participation or

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data, and the member checking procedure and sharing of results. After answering any questions, I obtained documented consent. Following the informed consent process and requesting permission to record the interview, I began the conversation.

A semi-structured interview guide was used for this study. The interview schedule consisted of six open-ended questions used to guide the conversation (see Appendix A). More important than the answers to the interview questions, I encouraged open dialogue and allowed the participant to guide the mutual conversation as much as possible. As recommended by Smith and Osborn (2007), the interview schedule started with a broad, open-ended question that encouraged the participants to talk about their experiences with chronic pain management prior to the opioid crisis. By using minimal prompts, I provided the participants with a place to start their story without determining the direction of the conversation (Smith & Osborn, 2007). Following an overview of their CNCP experiences, I asked five questions about the opioid crisis and its impact on their CNCP outcomes and overall quality of life. By starting the interview with prompts regarding experiences with CNCP before the opioid crisis, I funneled (Smith & Osborn, 2007) participants' accounts from broad to specific in hopes of building a fulsome account of their experiences with CNCP following the systems-level interventions. The interviews occurred online using Zoom synchronous meeting technology and were completed between May and August 2020.

Following the interview completion, a transcription service transcribed recorded interviews. When the transcription was complete and I was satisfied with the accuracy of the transcribed interviews, I provided a copy of the transcript to a participant that requested a review of the transcribed interview during the consent process. After the participant reviewed and approved the transcript, I began the data analysis process.

Data Analysis

Given the idiographic nature of IPA research, I engaged in detailed analysis on each case prior to moving onto the next (Willig, 20013). The IPA data analysis process for this study engaged two forms of coding: (a) cumulative coding or patterns within a transcript and (b) integrative coding or patterns across transcripts (Larkin et al., 2006). The data analysis process was further broken down into six steps proposed by Willig (2013), which included:

1. reading and familiarization of the initial transcript and free textual analysis using descriptive and linguistic coding
2. developing emergent themes
3. exploring deeper connections through structured analysis
4. creation of a summary table
5. reviewing the next case
6. identifying patterns across transcripts

Initial Reading and Analysis

Smith et al. (2009) asserted that the data analysis process with IPA is an “iterative process of fluid description and engagement with the transcript” (p.81). With this in mind, I began the data analysis phase by reading and rereading the initial transcript to gain insight into the participant’s overall experience. Once familiar with the transcript, I started coding by completing free textual analysis in the right margin of the initial transcript (Smith & Osborn, 2007). Smith et al. (2009) also called this process descriptive, linguistic, and conceptual coding, which described the process of noting items of surface level importance to the participant or researcher. More specifically, I annotated items of importance including (a) significant findings (e.g. contradictions or similarities); (b) language use (e.g. echoes and amplifications); and (c) the

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participant's emotional responses and abstract notions about the context of the participant's experiences (Smith et al., 2009; Willig, 2013).

Developing Emergent Themes

In this stage of data analysis, Willig (2013) recommended identifying and labeling emergent themes that represent the overall nature and meaning of the participant's experience. Following Willig's (2013) recommendations, I reviewed sections of text annotated in the previous step and identified the overall themes for each section of text. Once all sections were completed, I labeled the sections of text to summarize the experiential quality of the participant's experiences.

Structured Analysis

Once emergent themes are identified and labeled, Willig (2013) recommended creating structure in the analysis by grouping emergent themes into related clusters. Smith et al. (2009) recommended multiple ways of finding connections between emergent themes including identifying the frequency and function of themes and creating higher-level themes for clusters that belong together. The goal of this step in the analysis process was to explore how the participant made sense of their experiences (Willig, 2013). Consequently, I explored possible connections between emergent themes and grouped themes together based on their frequency, function, and relationship to one another. Additionally, I identified a label, key words, and supporting quote for each theme cluster.

Summary Table Creation

In this step of data analysis, I created a summary table of the theme clusters identified in the previous step. Willig (2013) recommended only including theme clusters that represented the participant's experience with the phenomenon in this study. As a result, theme

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clusters that didn't characterize the participant's experience with CNCP during the opioid crisis were omitted from the summary table. The theme cluster label, identifying key words, and quote with location were copied into the summary table for the initial transcript.

Moving on to Following Cases

After completing the summary table for the initial transcript, I moved on to the next case. The cases were organized based on the chronological order of the interview completion. Then, I completed steps one through four of the data analysis process discussed above. As much as possible, I attempted to bracket any insights gained from previous transcripts.

Identifying patterns across transcripts

In this stage, Willig (2013) recommended integrating the completed summary tables into one inclusive list of master themes that characterize the experiences of the entire sample. I intended to create an overarching understanding of the participants' experiences as a whole. The integration process also required that I explore convergences and divergences in experiences between participants noting their similarities and differences. The table of superordinate themes that resulted from the data analysis process is provided at the start of the results section.

Writing the Results and Discussion

According to Larkin and Thompson (2012), the next stage of IPA is to create a narrative account of what is being said by the participants. Similarly, Creswell (2013) called this section the composite description of the phenomenon. Both Larkin and Thompson (2012) and Creswell (2013) described this section of the write up as the "what" and "how" of lived experience. For example, Larkin and Thompson (2012) asserted that the narrative account foregrounds (a) "objects of concern" (p. 108) or what is important to participants and (b) "experiential claims" (p.108) or how participants assign meaning to what is important to them.

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The narrative account for this study arose from the table of superordinate themes providing a clear description of what the participants experienced and how they experienced it (Larkin & Thompson, 2012). This account should distinguish between what participants said they experienced, my interpretations, and the similarities and divergences in participants' experiences (Larkin & Thompson, 2012). Additionally, each hermeneutical interpretation must be linked to an excerpt from a transcript (Larkin et al., 2006), thus grounding the interpretation in the words of the participants. Further, Larkin et al. (2006) recommend including both the similarities within and across participants' transcripts. At this stage of the write up, theoretical concepts were also included to flesh out the interpretation of what participants experienced and how they experienced it (Larkin et al., 2006). The outcome of this phase was an insider's perspective of how individuals with CNCP experienced the systems-level interventions of the opioid crisis.

Chapter 4. Results

The following section presents the findings from interviews with four research participants. This section presents an overview of the personal characteristics of the participants and their general experiences with CNCP before the opioid crisis. Following the participants’ background information, this section will describe the participants’ experiences with CNCP amid the opioid crisis by discussing themes that emerged from the interview data. Specifically, the three superordinate themes discussed are (a) managing chronic pain prior to the opioid crisis, (b) impacts of the opioid crisis on chronic pain management, and (c) experiences of CNCP management following systems-level interventions. Within each superordinate theme, subthemes are presented to provide a rich description of the participants experiences with chronic pain during the opioid crisis (see Table 1).

Table 1

Superordinate Themes and Subthemes from the Data

Superordinate Theme	Subthemes
Managing Chronic Non-Cancer Pain (CNCP) Prior To the Opioid Crisis	Uncontrolled CNCP resulted in a decreased quality of life through occupational, physical, mental, and social impacts Experienced strong feelings of hopelessness and anger as an outcome of unmanaged CNCP Family unit was impacted by the participant’s uncontrolled CNCP Tried numerous unsuccessful treatment options before obtaining pain relief from chronic opioid therapy Experienced significant emotional reactions to first instance of relief from CNCP Managing CNCP increased quality of life including occupational, physical, mental, and social impacts Perception that the prescribing guidelines targeting the opioid crisis resulted in decreased access to opioid treatments for CNCP

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Impacts of the opioid crisis on chronic pain management	<p>Perception that the College of Surgeons and Physicians controls access to opioid treatments, not doctors</p> <p>Inconsistent application of prescribing guidelines between physicians</p> <p>Changes in prescribing behaviours as a result of physicians' fear of legal sanctions (i.e., threatening to discontinue treatment, patient dumping, and hesitancy to prescribe)</p> <p>New requirements to receive treatment (i.e., sign opioid agreements, take drug tests, undergo risk assessments)</p> <p>Conflation between addiction and chemical dependence by physicians or other medical staff</p>
Experiences of CNCP Management Following Systems-Level Interventions	<p>Experienced a lack of empathy, help, and quality care from medical providers</p> <p>Experienced change in relationship with medical providers</p> <p>Experienced the denial of opioid treatments and sought alternative sources of pain control (i.e., holistic measures or street drugs)</p> <p>Experienced extreme instances of institutionalized stigma</p> <p>Participant felt medical providers misunderstood and did not believe the participant's situation, needs, or pain.</p> <p>Experienced a loss of autonomy over care and struggled to make decisions about treatment options</p> <p>Experienced suicidal ideation or attempted suicide as a result of uncontrolled pain and decreased quality of life after access to opioids was denied.</p>

Background Information

Four individuals consented to participate and completed interviews. To maintain the confidentiality of the participants, limited demographic information will be provided (see Table 1). All participants in this study were female, and their ages ranged between 34 and 61 years. All four participants interviewed attempted multiple different alternative pharmacotherapies before starting opioids. Additionally, all participants began chronic opioid therapy prior to the implementation of the opioid prescribing guidelines in 2016 (Busse et al., 2017) and had no history of addiction. Finally, two of the participants were employed at the time of the interviews.

Table 2*Participants' Demographic Information*

	Sex	Age	Diagnosed with CNCP	Started Opioid Therapy
Participant 1	Female	61	Yes	2005
Participant 2	Female	34	Yes	2014
Participant 3	Female	53	Yes	2008
Participant 4	Female	undisclosed	Yes	undisclosed

Experiences of Chronic Pain Before the Opioid Crisis

Participants began the interview by describing their experiences with CNCP prior to the start of the opioid crisis. As participants discussed their initial experiences with CNCP, several themes emerged across participants including (a) the loss of quality of life through occupational, physical, mental, and social effects of unmanaged CNCP; (b) testing out multiple unsuccessful treatments prior to opioid therapy; and (c) experiencing an increase in quality of life after finding effective opioid treatment (see Table 2). The following section presents a narrative account of the participants' journey towards effective pain management and the impacts of prolonged uncontrolled pain.

The initial theme to emerge from the data analysis pertained to the decrease in quality of life that resulted from difficulties accessing effective CNCP management. The participants in this study described their experiences of prolonged suffering while trying to obtain a diagnosis and find doctors able to treat their ongoing pain. For example, participant 3 discussed the difficulties accessing adequate treatment and stated "I would have preferred to manage without medication if there was a way to do it but the quality of life is just so impacted by not taking medication". Although participant 3 would have preferred non-pharmaceutical approaches to

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pain management, her quality of life was so significantly impacted that she had no other options outside of opioid pain management. Further, participant 3 highlighted the grief she experienced as her quality of life declined while trying to overcome barriers to effective treatment.

You start out in life expecting certain things to be available to you. Just having to deal with those losses is like having to live through grief, like death of parts of you. So, if you also have pain with that, it's pretty hard to cope with life in general. (Participant 3)

Participant 3's narrative account suggests that a loss in quality of life and the presence of unmanaged chronic pain can impact one's identity and decrease the ability to manage daily challenges.

Although each participant subjectively defined their quality of life, they all shared similar experiences that they attributed to their perception of a decreased quality of life. These experiences focused on the occupational, physiological, mental, and social difficulties brought on by unmanaged chronic pain. Participant 2 summed up her challenges by stating "I can't deal with this. I can't walk. I can't function. I can't think". This excerpt poignantly summarizes the most common areas of functioning that were impacted by unmanaged chronic pain. Participant 2 describes her experiences with unmanaged chronic pain prior to the opioid crisis in present tense possibly indicating that she is reliving the experience of not being able to function as desired. Similarly, each participant described how specific challenges to occupational, physical, mental, and social functioning led to a decreased quality of life. Although all four participants reported challenges in the four areas of functioning listed above, the participants opted to discuss one or two areas of their lives most impacted by a lack of effective treatment and unmanaged CNCP. The following sections provide an overview of the challenges to occupational, physical and mental, and social areas of functioning.

Occupational Impacts of Unmanaged Chronic Pain

As participants described the loss of quality of life resulting from unmanaged CNCP, multiple themes emerged within this area of experience (see Table 3). Although the significance of occupational difficulties varied between participants, all four participants spoke about limitations to their ability to work or provide for their families. The participants also directly related their ability to work to their quality of life. In the following excerpt, participant 3 described her life prior to CNCP impacting her ability to work.

My pain got worse in the third decade of my life; and before that, I was able to manage [the pain] quite well. I had a good career and a good life and [I was] active. I was a runner; and yeah, life was good and then I had pain but I was undiagnosed and it wasn't so debilitating that I couldn't work or something. (Participant 3)

Participant 3's narrative excerpt above provides insight into her memories of her life prior to prolonged CNCP. Although she experienced chronic pain at that point, she was still able to work and be active, which was critical to her quality of life.

Since the ability to work was related to perceived quality of life, the loss in their ability to work resulted in negative life experiences for all four participants. Some participants discussed how occupational challenges resulted in negative affect and a sense of loss. Participant 2 and three both viewed their careers as meaningful personal variables and experienced grief when their CNCP prevented them from continuing to work. For example, participant 2 experienced feelings of grief and disappointment when she is no longer able to work as a result of unmanaged CNCP.

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And it was clear I wasn't gonna be able to return to work, which was a big emotional situation for me. You said you wanna hear about the feelings, that was like a death in my family to me. That is the death of my career and life as I knew it before. (Participant 2)

Participant 2's comparison of her ability to return to work to death in her family demonstrates the emotional implications of career disruption that chronic pain sufferers experience. Her metaphorical use of a death in the family represents the strong connection she has with her career. When her ability to work declined, she experienced a grieving process akin to losing a family member. It is likely that participant 2 was grieving a loss of her career as well as a loss of who she was prior to her chronic pain indicating that her ability to work was tied to her individual identity.

As participants described the links between occupational function and quality of life, specific barriers to occupational functioning emerged. The participants found that the time and energy spent trying to obtain a diagnosis and find treatment for their chronic pain impacted their ability to work thus lowering their quality of life. All four participants tried multiple doctors and different treatments prior to starting opioids. For example, participant 4 described the process of seeing and losing multiple doctors when trying to find an effective treatment for her CNCP. Participant 4 stated, "The doctor that I had given up on me. He was like the umpteenth doctor." Attending numerous unproductive medical appointments was commonplace among all participants. Similar to participant 4's experiences, participant 2 stated, "I was missing so much time at work going to doctor's appointments and begging my doctor to test me for this and not assume it's autoimmune based". The narrative excerpts provided by participants two and four suggest that obtaining adequate treatment for CNCP may require a great deal of time and financial and emotional resources, which may impact the ability to continue gainful employment.

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Moreover, they both expressed frustration at the long and uncertain process of trying to find a solution to their chronic pain.

Physical and Mental Impacts of Unmanaged Chronic Pain

In addition to occupational challenges, participants also related a loss of physical and mental functioning to their decreased quality of life. All four participants described the physical and emotional outcomes of enduring chronic pain for extended periods of time. As evidenced in the following quote, participant 4 experienced an increase in other health issues that affected her quality of life.

It was obvious that I was vacant. I was pale, I shook when I stood up, I vomited all the time. I hardly ate. I lost hair. Hair was falling out all over the place and my skin was fragile. It would get bruised or it would crack or it would be peeling off and leaving raw open wounds and it so was evident to everybody. (Participant 4)

Previous literature on unmanaged CNCP has demonstrated decreased immune response and increased comorbid health issues (Brennan et al. 2007), which might provide an explanation for participant 4's increased health challenges. Additionally, most participants in this study disclosed experiencing a decrease in physical activity. Decreases in physical activity may have further complicated the participants' experiences with unmanaged chronic pain as well as other health-related diagnoses (D'Arcy, 2010).

Similar to the physiological outcomes of unmanaged chronic pain, participants also experienced mental and emotional challenges as they continued to endure unrelenting pain, disability, and a loss of their sense of self. All four participants discussed feelings of hopelessness, frustration, and anger as their chronic pain went untreated and quality of life

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declined. In the following quote, participant 2 described her conversation with her doctor after reaching a breaking point because of uncontrolled CNCP.

Look, I'm at the point where you gotta find something, and if you don't, I'm done, I'm gonna take my life. I can't deal with this. I can't walk. I can't function. I can't think. I've been an active mom to four kids for 20 years. So, I've been a busy person, I've been an active person, I have two dogs as well. (Participant 2).

The narrative excerpt above provides insight into participant 2's feelings of desperation about her declining quality of life. Participant 2 reached a point where she considered suicide as the only solution to her unrelenting pain. Her conversation with her doctor about her thoughts of suicide spoke to the frustration and hopelessness she had experienced due to prolonged suffering.

Impact of Unmanaged Chronic Pain on Social and Relational Experiences

The final theme to emerge regarding the participants' quality of life was the impact of CNCP on their ability to socialize and participate in family interactions. More specifically, three participants disclosed that their physical and mental deterioration led to reduced opportunities for socialization and increased stress on their family units. The literature on chronic pain has previously demonstrated that the quality of interactions for the pain sufferer and their social partners is impaired by unmanaged pain (Doane et al., 2018). In the excerpt below, 4 describes the effects of unmanaged CNCP on her family.

Everybody around me was scared. I had two children and I was a single mom but I was living with my parents 'cause I needed assistance. My oldest son came into my room asked me if I thought it was okay to be buried in my jeans because he thought that if he had to pick out the clothes to bury me in, he didn't think I would want to wear a dress. (Participant 4)

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Participant 4's excerpt highlights the emotional toll others experienced while watching her endure unrelenting pain. Her interactions with her child were characterized by fear and hopelessness as a result of the shared experience of unmanaged chronic pain. Participant 4's description of this conversation has an underlying tone of despair as she and her young child are discussing her death as a consequence of the inability to manage her health concerns. This conversation goes beyond the current experience into a prediction of the future as experienced by her young children.

Although the four participants discussed the social outcomes of their unmanaged chronic pain, their descriptions mostly pertained to their relational identity as a caregiver to their children or significant other. For the participants with children, their descriptions of unmanaged chronic pain centered around their inability to provide financially, emotionally, or physically to their children. For example, participant 4 stated, "I still did the best I could to remain a part of their lives". In the previous quote, participant 4 describes her desire to remain connected to her children despite her failing health. The desire for connection in their relationships was prevalent across all four participants. Additionally, participants two and four described situations in which the roles of parent and child reversed resulting in their children taking care of them. It is likely that the role reversal and corresponding loss of relational identity led participants to focus their disclosures on their relationships with their children.

Similar to participant 4, other participants experienced a decrease in the quality of their social interactions with others as their pain was left untreated. Participants' disclosures about improvement in their quality of interactions with others following opioid treatment further supported themes about the impact of CNCP on socialization. In the quote below, participant 2 spoke to the effects of effective pain control on her interactions with her husband.

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My husband said, this is the first time in a long time I've been able to have a conversation with you where you're not angry, you're not frustrated, you're not... you know like we can actually talk. So, it made a big difference. (Participant 2)

The frustration and anger present in participant 2's social interactions are commonplace among participants in this study and individuals with CNCP (Baily et al., 2015). Similar to participant 2's experiences, other participants noticed an improvement in their ability to be fully present and available to others in their lives.

Improved Quality of Life as an Outcome of Opioid Treatment Access

The final theme to emerge in the participants' general experiences with CNCP was a significant improvement in their quality of life resulting from effective opioid treatment (see Table 2). All four participants engaged in unsuccessful non-opioid treatments before starting opioids. Participants two, three, and four reported a strong emotional reaction to their first exposure to opioids after experiencing decreased pain and increased functional ability.

Additionally, all four participants reported improvement in their physical, psychological, and social functioning. For example, participant 4 disclosed that opioids were the key to managing pain and comorbid health issues.

We've gone up and down on opioids, I've come off of them to see if I could manage without them and what we had learned is that if we don't manage the pain, we can't control the seizures. We don't manage the pain, we can't control my gut and digestion, so they were linked together that critically. (Participant 4)

Participant 4 perceived a link between unmanaged pain, general health, and quality of life. Specifically, accessing effective CNCP treatment enabled her to manage the ongoing pain that exacerbated other health issues. Additionally, participant 4 stated, "For the first time, I was

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empowered with the ability to choose when to treat the pain. And I was empowered with the ability to prevent catastrophic failure”. The ability to access opioids and control the amount and timing of pain relief resulted in feelings of empowerment over pain-related outcomes. The participants’ experiences of accessing opioid treatments and the corresponding pain relief highlighted the connection between effective treatment access and maintaining a good quality of life for chronic pain sufferers.

Table 3

Superordinate Theme for Managing CNCP Before the Opioid Crisis

	Participant 1	Participant 2	Participant 3	Participant 4
Uncontrolled CNCP resulted in a decreased quality of life through occupational, physical, mental, and social impacts				
Experienced strong feelings of hopelessness and anger as an outcome of unmanaged CNCP				
Family unit was impacted by the participant’s uncontrolled CNCP				
Tried numerous unsuccessful treatment options before obtaining pain relief from chronic opioid therapy				
Experienced significant emotional reactions to first instance of relief from CNCP				
Managing CNCP increased quality of life including occupational, physical, mental, and social impacts				

Impacts of the Opioid Crisis on Chronic Pain Management

After providing insight into their general experiences of CNCP, participants discussed how their access to treatment options changed because of the opioid crisis. The experience of managing chronic pain following systems-level interventions for the opioid crisis was consistent across the four participants in this study. Six themes (see Table 4) emerged from the participants' narrative accounts, which focused on their perceptions of the opioid crisis and their experiences of decreased treatment access because of systems-level interventions. The themes included in this area are (a) prescribing guidelines decreased opioid access; (b) the shift of control over treatment options from their doctors to the College of Surgeons and Physicians (College); (c) inconsistent application of prescribing guidelines; (d) doctors' fear of regulatory sanctions; (e) new criteria for maintaining access to chronic opioid therapy; and (f) change to relationships with medical providers. The following sections discuss the participants' experiences of managing their chronic pain amid the opioid crisis.

Perceptions About Control Over Opioid Access

The most common theme to emerge from participants' accounts of the opioid crisis was the perception that systems-level interventions reduced their access to chronic opioid therapy. Each participant reported specific ways in which their province's College (British Columbia or Alberta) or their prescribing physician created barriers to treatment access. For example, participant 1 felt the requirements for prescribing opioids changed as the College implemented new or revised existing measures to reduce opioid prescribing. In the following excerpt, participant 1 describes the frustration and anxiety that resulted from the College's revisions of prescribing guidelines.

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So, every time I would go see my pain specialist, the college would have moved the goalpost. And the anxiety I lived with, not just when I went to the doctor, but every single day, I was anxious, I felt so much loss of control. (Participant 1)

As demonstrated in the above quote, participant 1 constantly worried about the College's control over her physician's prescribing behaviours as it threatens the continuation of her existing treatment. Participant 1 aptly described her experience with the changing requirements by stating, "I actually had reduced some of my pain medication, but that was never enough for the college". Regardless of her responsible opioid use, she still experienced barriers to access. Given that systems-level interventions were intended to reduce opioid usage, this makes the restrictions seem senseless and arbitrary to participant 1.

Additionally, participant 1 also felt that the College made decisions about her treatment access based on their mandate to decrease opioid overdoses rather than her quality of life. In the quote below, she expresses her beliefs about the College's control over opioid treatment options.

It's the college that holds the ultimate cards, and if they are taking a perspective that my quality of life is not as important as making sure we don't overdose somebody inappropriately, then what choice do I have. (Participant 1)

Participant 1's perception of the college's lack of concern over her health and the need to meet the College's requirements resulted in significant experiences of anxiety, fear, and loss of control for participant 1. These experiences increased her apprehension about the medical system resulting in avoidance of medical services. For example, participant 1 attempted to go unnoticed by her doctor by only providing information when prompted and strategically managing the information she provided. Further, she did not actively engage the pain specialist thus only attending appointments by necessity. Participant 1's avoidance of medical interactions may have

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unintentional consequences in the future as she does not necessarily seek out help when needed. The fear of the medical system and corresponding avoidance is commonplace among the participants.

Impact of the Fear of Sanctions on Treatment Access

In addition to controlling the process and requirements for chronic opioid therapy access, all four participants felt the College controlled treatment access by monitoring doctors' prescribing behaviours and imposing legal sanctions on overzealous prescribers. All four participants reported that prescription monitoring programs reduced or threatened their access to chronic opioid therapy by threatening their physician with sanctions. Participant 2 believed that monitoring programs created a general fear among doctors and stated, "The doctors are afraid too. They're afraid of losing their license. They said "they'll just take our license and ask questions later." They don't trust the college. They don't trust the government.". Like participant 2, other participants in this study shared their perception that doctors are afraid of sanctions, which impacts prescribing behaviours. Three participants reported that their doctors eventually faced regulatory reviews or sanctions by the College thus confirming their fear of the College.

For two participants, the College's prescription monitoring programs resulted in a loss of medical providers when their doctor faced sanctions for opioid prescribing. For example, participant 4 stated, "my doctor came under fire from the College of Physicians and Surgeons who sanctioned him. They gave three months' notice to patients to find a new doctor". In addition to losing her doctor, participant 4 experienced difficulties finding a replacement prescriber because of her history of opioid use. After losing her doctor to sanctions, participant 4 discovered other doctors refused to take her on as a new patient because of her history of chronic opioid therapy.

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I started looking in the city to try to find a doctor, which should give me more options, right? It should give me more options. The last day that I had any medication left, 37 doctors had refused to take me. (Participant 4)

Participant 4 attributes her difficulties finding another doctor to her medical complexity and doctors' fear of being sanctioned for overzealous prescribing should they continue her existing prescriptions. Additionally, participant 4 believed that her use of chronic opioid therapy led doctors to assume that she was addicted to opioids thus treating her like an addict. Participant 4's experiences demonstrates that the opioid-related stigma pervasive in the medical system may result in discriminatory barriers to medical treatment access based on medical history.

Comparable to participant 4's experiences, participant 1's doctor was reviewed and sanctioned by the College for overzealous prescribing. Consequently, the College required her doctor to make several changes to her existing opioid treatment.

He [doctor] tells me that a representative from the college has reviewed all his patient files and he [College Representative] reviewed mine, and he [College Representative] wants you off of one of the meds and down in your dose. And it's like the blood leaves my body because bad enough, I'd have to give up one, but to go down in dose.

(Participant 1)

In the excerpt above, participant 1 describes her shock and fear after being told she would have to give up one of her prescriptions and decrease the dose of the other. Given that she had been using the combination of opioids to manage her CNCP for several years, the College's requirements created devastating consequences to her health and quality of life through aggressive tapering.

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In addition to the College directly imposing sanctions, participant 1 reported that a medical specialist threatened to report her physician for prescribing opioid treatment access. After disclosing that she was taking morphine for chronic pain management, her anesthesiologist stated, “I should really report your doctor, you shouldn't be getting this [morphine]”. The threat posed by the medical specialist not only threatened the continuation of treatment for participant 1, it significantly affected her emotional state by undermining her autonomy over care options. Further, participant 1 described her internal experiences as the other doctor continued to ask her questions about her chronic pain treatment. Participant 1 stated, “so I thought, what if he does report my doctor? I felt threatened, I felt powerless, and I felt voiceless. I just have to take it”. Consequently, participant 1 went on to say that she is wary of being honest in future interactions with medical staff as her honesty could result in legal ramifications for her prescribing physician.

Participant 1’s self-protective behaviour of selective disclosure poses both health and moral ramifications. As previously demonstrated by the data, participants are already treated like drug-seeking addicts. Dishonesty about what medications they are taking might result in feelings of guilt or experiences of cognitive dissonance between their desires to be seen as a responsible user and their behaviours to maintain their prescriptions (i.e., lying or failure to disclose). Further, participant 1’s lack of transparency could result in severe health implications should her treating physician be unaware of her opioid use. Regardless of the outcome for participant 1, her experiences with inconsistency between doctors affected her willingness to engage in transparent dialogue with her medical team.

Experiences of Inconsistency in Interpretation and Application of Prescribing Guidelines

In addition to shifting criteria for opioid treatment and the threat of legal sanctions, other barriers to treatment access included the subjective interpretation of prescribing guidelines. All

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four participants reported that the prescribing guidelines were inconsistently interpreted and applied between doctors. Most of the participants reported that the inconsistency in interpretation and application of guidelines resulted in conflict between their doctors resulting in disruptions to their medical care. In the following quote, participant 2 describes feeling caught in the middle of a conflict between her general practitioner and pain specialist regarding opioid prescribing.

The pain specialist that I had seen was to be a one-time thing, so he made a list of suggestions to my GP. And basically, my GP said, well, I'm willing to do everything except I'm uncomfortable prescribing these narcotics at bottom of the list, especially the two together, the hydromorphone and hydromorph contin. (Participant 2)

Since her general practitioner was uncomfortable with prescribing opioids, participant 2 was forced to shift her medical care to her pain specialist before she could follow his recommendations for opioid therapy.

Similarly, participant 4 experienced a conflict between prescribers that caused her family doctor to threaten to discontinue her care. Participant 4 aptly described the ultimatum given by her family practitioner, “he [family practitioner] said that if I chose to go that pathway [opioid] and seek help from that doctor [neurologist], he would stop being my family physician”. Consequently, Participant4 was required to choose between effective treatment and the continuation of her relationship with her long-term healthcare provider. Given that she had spent years building a relationship with this provider, she felt forced to forgo opioid treatment to keep her family practitioner. The choice to decline opioid treatment resulted in additional health complications from long-term unmanaged CNCP.

All four participants reported that their medical provider applied the guidelines based upon previous patient experiences, personal beliefs about opioids, and subjective prescribing

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behaviours rather than their needs as a CNCP patient. For example, three participants summarized conversations with their doctors in which they were compared to a previous patient who had overdosed on opioids or was addicted to narcotics. Below, participant 2 summarizes a conversation in which her doctor initially denied her opioid access as a result of a prior experience with a patient who overdosed.

He says it only takes once for a person to die from taking two medications, two narcotics, and that really stops you from continuing that practice. So, I would prefer not to be responsible for that. I had to try everything on the list first. (Participant 2)

Despite having no history of addiction or overdose, participant 2 was denied access to opioid treatments. The excerpt above highlights the impact of doctors prescribing based upon previous outcomes with other patients rather than the patient at hand.

In addition to prescribing treatments based on previous patient outcomes, some participants reported subjective bias in their doctor's descriptions of opioid use and users. The personal viewpoints of doctors influenced their willingness to prescribe opioids based on the patient's needs. In the excerpt below, participant 4 described a primary care network doctor (PCN) who expressed anti-opioid rhetoric when explaining his opposition to chronic opioid therapy.

The internal medicine guy was totally anti-opioid and spewing how he viewed the guidelines to be and told you that everybody who took it [opioids] for more than a year was an addict. Told you that if you continue to take it, it's [opioids] gonna kill you.

(Participant 4)

Participant 4 added that only one doctor in the PCN was willing to prescribe opioids. If that specific doctor wasn't available, she couldn't access opioid treatments. In conclusion, the

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inconsistent interpretation of the guidelines and personal views on opioids reduces opioid treatment access for those managing chronic pain with opioids.

Additional Requirements for Maintaining Opioid Therapy

In addition to physician monitoring, systems-level interventions for the opioid crisis monitored patient opioid use and created additional requirements for CNCP patients using opioid therapy. Following the implementation of systems-level interventions, each participant in this study has experienced new barriers to maintaining existing opioid prescriptions such as opioid agreements, family history questionnaires, pharmacy requirements, and drug testing. For example, participant 2 completed a risk assessment as well as signed an opioid agreement. Participant 2 stated, “when my GP took over the care of my narcotic medication, he made me fill out an opioid agreement. In that agreement, there's a little questionnaire to rate me and my risks”. Despite no history of addiction, the opioid agreement questionnaire concluded that participant 2 was at high risk for addiction and drug abuse because of a family member’s history of addiction and her history of childhood trauma. Being labeled high-risk for reasons outside of her control left participant 2 feeling defeated and revictimized. Evaluations of this nature perpetuate the stigma associated with trauma and family addiction.

Similarly, participant 1 reported additional and invasive requirements to maintain her access to opioid therapy. More specifically, participant 1 was informed by her doctor that she would be listed on a national registry of users.

My GP left everything as is, and he just kept warning, "Things are gonna get worse, they're gonna get harder, they're gonna get tighter. I find out I'm gonna be on a registry, a national registry because I take this. (Participant 1)

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The above excerpt supports participant 1's perception of the changing requirements and violations to her patient privacy as a result of invasive practices such as national registries. Consequently, participant 1 began tracking her opioid usage to prove her responsible usage. Given that the participants in this study reported being treated like addicts, the use of a national registry for opioid users reinforces their experiences of distrust from doctors. Participant 1 felt that tracking her usage was the only way to prove that she was not an addict. Additionally, participant 1 experienced increased anxiety when attending medical appointments. Participant 1 stated, "I also found that my anxiety was so high when I would see these doctors and I felt so vulnerable". The constant fear of new criteria and losing her access to effective treatment created additional physical and emotional stress.

In addition to opioid agreements and risk assessments, Participant 4 completed drug testing to prove that she wasn't taking street drugs. In the excerpt below, she described the additional criteria required to maintain her existing prescriptions.

Every time I went in, I had to pee in a cup to prove that I wasn't doing street drugs. Every time I went in, I had to sign the stupid form that he created saying that I wouldn't get medication from any other doctor for any circumstance other than him. (Participant 4)

Despite her history of responsible opioid therapy use, participant 4 felt that she was treated like an addict as a result of mandatory drug testing. In general, the participants in this study find the new requirements invasive as they are added to a national registry and monitored extensively through drug testing, risk assessments, and questioning by medical staff. Their medical information is no longer a private matter shared with their doctor and their history of opioid therapy use is warning label attached to their medical file.

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Participants also find it difficult to meet the changing criteria set by the College and doctors. Not only do participants need to contend with the College’s requirements for opioid access, they are also having to navigate their doctors’ personal opinions and fears about opioid prescribing. All four participants disclosed experiencing frustration and emotional exhaustion with the number of barriers they must overcome to maintain their existing treatments. Naturally, some participants report feeling coerced into consenting to the new requirements as a lack of agreement or advocating for themselves would limit their access to effective treatment.

Table 4

Superordinate Theme for the Impacts of the Opioid Crisis on Chronic Pain Management

	Participant 1	Participant 2	Participant 3	Participant 4
Perception that the prescribing guidelines targeting the opioid crisis resulted in decreased access to opioid treatments for CNCP				
Perception that the College of Surgeons and Physicians controls access to opioid treatments, not doctors				
Inconsistent application of prescribing guidelines between physicians	✓	✓	✓	✓
Changes in prescribing behaviours as a result of physicians’ fear of legal sanctions (i.e. threatening to discontinue treatment, patient dumping, and hesitancy to prescribe)	✓	✓	✓	✓
New requirements to receive treatment (i.e. sign opioid agreements, take drug tests, undergo risk assessments)	✓	✓		✓
Conflation between addiction and chemical dependence by physicians or other medical staff	✓	✓		✓

Experiences of CNCP Management Following Systems-Level Interventions

In addition to experiencing barriers to opioid therapy, systems-level interventions for the opioid crisis affect the physical, psychological, and social well-being of the participants in this study (see Table 5). The themes that emerged from participants' accounts include (a) a decrease in the quality of medical services; (b) impacts to participants' relationships with medical providers; (c) seeking alternative sources of pain control; (d) experiences with institutionalized stigma and discrimination; (e) autonomy loss over medical decisions, and (f) suicidal ideation and planning. The following section describes the participants' experiences that resulted from decreased opioid therapy access following systems-level interventions.

Impacts to Quality of Care and Relationships with Doctors

The first theme to emerge when discussing the personal outcomes of the opioid crisis highlights the effects of systems-level interventions on the participants' interactions with medical providers and the quality of chronic pain healthcare. For example, participant 1 reported that the opioid crisis changed her relationships with her doctors and reduced the quality of care she received for her chronic pain. More specifically, participant 1 felt she had to adapt her behaviour during appointments to placate doctors as they held the power to remove her access to effective treatments.

Because I also found that my anxiety was so high when I would see these doctors and I felt so vulnerable, like I could never not do what they wanted, otherwise I'd look like I wasn't cooperative and I was a drug addict. (Participant 1)

Further, participant 1 referenced her attempts to be collaborative by stating, "I never felt anything was my choice. I had to present as cooperative, not get worried and flustered like this is

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just an addict needing their meds”. Participant 1’s fear of doctors attributing her concern and corresponding self-advocacy to addiction resulted in her engaging in self-protection by strategically presenting a calm façade. Rather than engaging in open, transparent dialogue about her concerns and need to continue opioid therapy, participant 1 avoided providing certain details about her opioid use to avoid calling attention to herself. Consequently, she felt that she was not in a position to challenge the decisions made by doctors or talk openly about her chronic pain treatment as they could limit her opioid access should they determine she was uncooperative.

Similarly, participant 2 also experienced changes to her relationships with medical providers and quality of her medical care because of systems-level interventions. Participant 2 reported that doctors no longer empathized with her chronic pain and treated her like an addict seeking drugs. Consequently, she felt the need to change her behaviour to avoid confirming doctors’ suspicions about drug-seeking. In the following quote, participant 2 described the anxiety that resulted from her fears of appearing like an addict.

But the whole time, I'm worried. I'm worried all the way there, I'm worried while sitting in the chair. I'm worried that they're going to look at me like I'm some sort of a drug seeker that's just looking for pain medication. The pain is bad. Yes, I want the pain to stop, but I'm not asking you to get me high for days and days. (Participant 2)

As a result of her experiences of being treated like an addict, participant 2 started to avoid medical visits despite emergent medical needs. Participant 2 stated, “people with chronic pain don't necessarily go to the ER. No, No, we avoid it [emergency room] like the plague”. For participant 2, urgent care doctors incorrectly assumed that she was seeking more narcotics rather than seeking help for a new or existing medical condition. The above quote highlights how previous urgent care doctors might mislabel chronic opioid therapy users as addicts when

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seeking non-routine medical care. Consequently, the impacts of systems-level interventions on the patient-doctor relationships have resulted in a general avoidance of medical interactions for the participants in this study.

The disclosures provided by participants one and two regarding their doctor-patient interactions speak to how they have managed their identities as chronic opioid users. Given that they have previously been treated like addicts when seeking medical help, their interactions with medical providers were characterized by fear and hesitancy of disclosing too much information about their opioid use. Despite their historical responsible opioid use, both participants described adapting their physical and social presentation to avoid appearing like drug-seekers.

Participant 3 added that she experienced increased suspicion from doctors following systems-level interventions. In the following quote, participant 3 described her experience with increased suspicion while advocating for herself and a sick family member.

There's this weird level of suspicion, like I would want to take more medication than I'd need. Whereas all people with chronic pain seem to want, at least the ones I know and talk to, is to be functional and have the best quality of life that they can have. They want to be as productive as possible. (Participant 3)

The excerpt above demonstrated how the participant's needs were met with suspicion and hesitancy by medical staff.

In addition to the decreased quality of interactions with medical providers, participant 4 felt that she had to sacrifice the quality of care after being turned down by many doctors. In the following excerpt, participant 4 described having to compromise her quality of care through changing to a doctor willing to continue existing opioid treatment.

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I am not a drug seeker. I am a treatment seeker. It happens that a drug is needed for treatment, but I had to sacrifice quality of care to be able to stop having seizures, be able to have sleep, and to be able to function enough to care for the child that I was raising.

(Participant 4)

By calling herself a “treatment seeker”, participant 4 highlighted the intentions behind seeking access to chronic opioid therapy. Her intention was not to use drugs but rather to reduce chronic pain and enhance her functionality.

Along with being refused by multiple doctors and trading quality of care for treatment access, participant 4 reported instances of predation by a doctor willing to prescribe opioids in exchange for a social relationship. In the following excerpt, participant 4 summarized her interactions with this physician.

He kept making a suggestion that we should go out and talk about the work that I do and how impressed he was. He kept making it rather inappropriate suggesting that this kind of informal relationship would secure my ability to get medication through my relationship [with him]. I need you to know; at that moment, I was facing the withdrawal symptoms.

(Participant 4)

The excerpt above highlights the vulnerable position CNCP patients may face as opioid prescriptions become more difficult to access. Further, this vulnerability may leave CNCP patients open to other forms of risk-taking behaviour such as accessing street drugs.

Sourcing Alternative Forms of Pain Relief to Manage Pain

Another theme to emerge from participants’ experiences of the opioid crisis was seeking alternative forms of pain management. Most of the participants sought alternatives to supplement their opioid treatments when their access to chronic opioid therapy was threatened or removed.

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Moreover, participants reported that doctors did not provide alternatives to supplement or replace opioid access thus shifting the responsibility for alternative treatments to themselves. For example, participant 1 sought additional options to supplement the pain management provided by opioid therapy. Participant 1 reported accessing naturopathic medicine, massage, injections, and physiotherapy on her own. Additionally, she explained how she had to advocate for herself because her doctors did not advocate on her behalf. Participant 1 stated, “you go out and explore all of these different opportunities, to support yourself, in addition to the medication. So, you're advocating for yourself, which the doctors aren't even doing”. Assuming responsibility for sourcing alternative treatments is a large undertaking for these participants given that they were managing chronic health conditions, disability, and losing access to effective treatments. Further, without adequate medical knowledge, finding effective and safe alternatives proved challenging to some participants.

When safe alternatives to opioid therapy was beyond reach, some participants accessed street drugs to manage their pain. For example, participant 4 reported buying black market opioids, illicit drugs, and marijuana to manage her pain after losing her prescription opioid therapy. In the following excerpt, participant 4 described her descent into street drug use after losing her opioid prescription when her doctor was sanctioned.

I could afford enough to manage the crisis and I discovered Bitcoin and going through the dark web so that I can decrease my cost and an advocate for chronic pain patients became a street drug user. (Participant 4)

Without access to safe and effective opioid therapy, participant 4 believed her only option for pain relief was through high-risk street drug use. Further, participant 4 stated, “I got the black-market drug into my system, I had the ability at least to start to fight again, except this time I

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cheated”. Once she was able to obtain pain relief, she regained her ability to advocate for herself and search for a doctor who could help her access prescription opioid therapy.

Experiences of Institutionalized Stigma

All four participants in this study reported numerous instances of opioid-related institutionalized stigma when accessing medical care. For example, participant 4 poignantly stated, “I have faced every comment, bias, prejudice”. Participant 2 added that her experiences with institutionalized stigma included instances where doctors arrived at conclusions based on bias rather than her medical history. Participant 2 disclosed, “I have seen doctors jump to conclusions about me, that have no basis within my medical file, that are medically dangerous”. Similarly, participant 1 shared that medical staff assumed her self-advocacy was related to drug-seeking rather than treatment-seeking. One doctor noted in her patient file that she appeared to be upset by their decisions regarding her treatment access. As a result, she felt the need to monitor what doctors added to her medical file to ensure incorrect assumptions weren’t recorded.

Another experience of institutionalized stigma reported by the participants included medical providers viewing opioid addiction, chemical dependence, and use as if they were all the same. As a result, participants reported avoiding opioids out of fear of being treated like addicts despite no history of addiction or abuse. Participant 4 added that her doctor said that once she started opioid therapy, she would become an addict. Participant 4 said, “my family doctor told me that the only outcome was that I was gonna wind up an addict and that the opioids always make headaches worse, the more that you take the worse that it gets”. As a result of the conflation between addiction and use, Participant 4 avoided chronic opioid therapy until another medical provider educated her about the difference between dependence and addiction.

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In addition to experiencing institutionalized stigma from medical providers, some participants reported stigma from family and friends regarding their opioid use. For example, participant 2 described an interaction between her husband and a neighbour who was aware of her opioid use. Participant 2 stated, “she [neighbour] heard that I was on this stuff [opioids] and tried to convince my husband that I'm an addict. So as soon as you take opioids, you're an addict. You have a problem”. Participant 2 proceeded to describe her experiences with stigma in a social context.

It's always a gamble when you talk to people about your medications because everyone has an opinion and has either heard a story of somebody who overdosed or they themselves have been an addict of some sort, and they put that on you. (Participant 2)

The excerpt above foregrounds the widespread knowledge of opioid use and the opioid crisis. Consequently, participant 2 became wary of sharing information regarding her opioid use because others would respond with stories of overdose and addiction. While others shared their stories about opioid addiction out of concern for participant 2, addiction and overdose weren't the natural outcome of her chronic pain treatment. It might have felt as if her friends and family assumed that her opioid use would lead to addiction and overdose regardless of her responsible use to date. As a result of opioid-related stigma, some participants in this study reported that their social circles decreased after starting opioid therapy.

Participant 3 also reported experiences of opioid-related stigma that resulted in hesitancy to disclose opioid use to others, even her doctors.

I don't tell people that I take the opioids, I won't, because it changes how people view me.

I shudder to tell doctors who should know better that I take opioids, because I'm afraid.

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Well, it changes their view of me, instead of listening to what I say or believing what I say. (Participant 3)

Participant 3's excerpt above highlighted her fear of disclosing her opioid use and the medical implications of opioid-related stigma. As a result of using opioids to manage her chronic pain, medical providers might not believe that her experience of pain is real and attribute her reports of pain to drug-seeking behaviour. Impression management was common among all the participants in that they were vigilant about what they shared about their opioid use, who they shared it with, and the impress they gave off to others. Each participant described situations where they carefully adapted behaviours to avoid coming across as an addict seeking drugs or an uncooperative patient. In addition to assuming a self-advocacy role to ensure their medical needs were met, they had to give the impression that they were an ideal opioid therapy user who presented no risk to themselves or others.

Loss of Autonomy Over Medical Decisions

Another theme to emerge from the participants' experiences of the systems-level interventions was the loss of autonomy over medical decisions. When asked about their experiences of chronic pain management during the opioid crisis, all four participants agreed that systems-level interventions reduced or removed their abilities to make decisions about treatment outcomes. For example, participants 1 and 3 described their desires to control treatment outcomes, which were questioned by doctors when they requested to maintain opioid therapies. Likewise, participant 2 experienced difficulties when suggesting treatment directions. When describing her loss of autonomy over treatment options, participant 2 said, "they won't even let me suggest, this is what I want". On one hand, participants were required to assume control over their treatment outcomes when they lost a doctor due to sanctions or needed to explore different

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avenues for treatment when their opioid access was threatened. On the other hand, the systems-level interventions for the opioid crisis such as the prescribing guidelines reduced their opportunities to select treatment options based upon their individual needs. As doctor's became wary of overprescribing and legal sanctions, the participants experienced reduced control over their treatment outcomes.

Participant 4 added that her doctor assumed that she was suicidal when she decided to forgo cancer treatment because she could not handle more pain. Participant 4 said, "I opted not to have treatment and when I told my doctor that, he decided that I was suicidal. I'm not. I don't wanna die." This quote supports the loss of autonomy over medical decisions that was routinely experienced by the participants in this study. Further, doctors disregarded participant 4's desires for end-of-life care when she was strongly encouraged to agree to resuscitation despite her preference for no extreme life-saving measures. Participant 4's experiences suggests that her doctors assumed that she was incapable of deciding for herself what extreme measures should be taken in the event she required life-saving measures. Despite her previous suffering and illness, participant 4 felt that she was not allowed a dignified end to her life.

Experiences of Suicidal Ideation and Suicide Planning

The final theme to emerge from the participants' accounts of the opioid crisis was the experience of suicidal ideation or planning as a result of losing opioid access. Three of the four participants reported suicidal or end of life thoughts following threats to treatment access. For example, participant 1 stated, "I actually believe that it might get to the point where I'd have to kill myself". In the following excerpt, participant 1's thoughts of suicide were embedded with the opioid-related biases and institutionalized stigma she had previously experienced.

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I kept saying to myself, "If you ever had to kill yourself, you better not make it just a cry for help" because you've got enough meds in your drawer to kill myself. And if I don't do the job right, they won't give me my meds. (Participant 1)

The excerpt above demonstrated that participant 1 felt she might have no choice other than suicide should her doctor discontinue her access to opioid treatments. If she didn't succeed in killing herself, her overdose would reinforce the assumptions made by her doctors that she was just another addict amidst the ongoing opioid crisis.

Participant 2 reported experiencing end-of-life planning when she was faced with barriers to opioid access. More specifically, participant 2 felt she needed a backup plan should she lose her access to opioid treatment when her doctor was sanctioned. Participant 2 stated, "I thought that this might be my saving grace, I suppose, if my life ever degrades to that point where I can't get the help that I need". Participant 2 believed that losing her access to opioid treatments would set her back to the uncontrolled pain she experienced prior to starting opioids. Consequently, she determined that she couldn't go through that experience again and would take the necessary steps to end her life if needed.

Participant 4 added that the fear of losing access to opioid treatments resulted in a change in how she viewed her illness-related outcomes. As a result of not trusting the system to manage her chronic pain, participant 4 felt that her only option was to refuse life-saving measures. Participant 4 said, "if a natural course of action brings my life to an early end, I will likely not choose to save it". Although she added that she didn't want to die, she felt she would have no other option if the medical system failed to manage her chronic pain. Participant 4's statements about refusing life-saving treatment foregrounded the end-of-life planning that resulted from threats to treatment access.

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As evidenced by the themes that emerged from the participants' accounts, systems-level interventions for the opioid crisis significantly impacted the participants' abilities to manage their CNCP. Similar experiences across the four participants' accounts foregrounded the unintentional consequences of the opioid crisis such as increased requirements for opioid access, institutionalized stigma, and threats to medical care continuation. Consequently, the individuals in this study experienced detrimental effects of the opioid crisis on their relationships with medical providers and quality of medical care, perception of their illnesses, and hopefulness for positive treatment outcomes.

Table 5

Superordinate Theme for the Experiences of CNCP Management Following Systems-Level Interventions

	Participant 1	Participant 2	Participant 3	Participant 4
Experienced a lack of empathy, help, and quality care from medical providers		✓	✓	✓
Experienced change in relationship with medical providers	✓	✓	✓	✓
Experienced the denial of opioid treatments and sought alternative sources of pain control (i.e., holistic measures or street drugs)	✓		✓	✓
Experienced extreme instances of institutionalized stigma	✓	✓	✓	✓
Experienced a loss of autonomy over care and struggled to make decisions about treatment options	✓	✓	✓	✓
Experienced suicidal ideation or attempted suicide as a result of uncontrolled pain and decreased quality of life after access to opioids was denied.	✓	✓		✓

Chapter 5. Discussion

The purpose of this study was to explore the experience of chronic pain management during the opioid crisis with specific emphasis on the impact of systems-level interventions on chronic opioid therapy access. The following section discusses the results of this study within the context of the extant literature on the opioid crisis and chronic pain management.

The participants' experiences reported in this study strongly align with the existing literature on unmanaged chronic pain and builds on the limited understanding of how the opioid crisis has impacted chronic pain sufferers. The current research has repeatedly demonstrated that unmanaged chronic pain affects the physical, psychological, and social functioning of individuals with CNCP (Brennen et al., 2007; Doane et al., 2018; Duenas et al., 2016). This study supports the existing literature by demonstrating that unmanaged chronic pain does result in significant physical and psychological suffering as well as impacts on the overall quality of life.

Before the opioid crisis, the participants in this study experienced challenges accessing opioid treatments because of physician hesitancy and underwent a tedious process of seeking diagnosis and treatment, a finding consistent with De Sola et al. (2020). De Sola et al. (2020) demonstrated that the treatment journey was long and complicated due to the invisible nature of chronic pain. Also, the participants in De Sola et al. (2020) struggled with not being believed or taken seriously during their initial process of accessing treatment resulting in complications in their relationships with healthcare providers. Similarly, the participants in this study felt unheard and disbelieved, saw multiple doctors in an attempt to get diagnosed, and struggled with non-effective treatment options. These negative experiences early on in their diagnostic process resulted in fear and hesitancy regarding doctors and the medical system.

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The process of testing various, non-opioid treatments resulted in prolonged suffering through unmanaged chronic pain, disability, and other health complications for the participants. As participants continued without effective pain management, multiple areas of their lives declined leading to a reduced quality of life. This finding is meaningful because the current systems-level interventions for the opioid crisis (i.e., prescribing guidelines) recommends prescribing opioids only after non-opioids are unsuccessful at managing chronic pain (Busse et al., 2017). Thus, the requirement to test multiple non-opioid treatments as per the guidelines may negatively impact the wellbeing and quality of life of chronic pain patients.

The participants' experiences before starting opioids highlight specific areas of functioning most impacted by unmanaged chronic pain. Specifically, participants reported that physical pain and disability had the most impact on their quality of life because functional disability made consistent employment, caring for families, and conducting daily activities nearly impossible. Like the participants in Brooks et al. (2015), the participants in this study wanted to manage their chronic pain so that they could regain functionality and resorted to opioids only when the pain was unbearable. Also similar to findings of Brooks et al. (2015), the participants in this study expressed gratitude for the functional improvements gained by using opioids.

In addition to the physical outcomes of unmanaged chronic pain, participants reported that their unmanaged chronic pain before and after the opioid crisis negatively affected their ability to socialize and resulted in severe consequences for their families. A literature review by Duenas et al. (2016) concluded that chronic pain patients experience poorer social and family-related outcomes because of reduced social interaction and stress on the family unit. The participants in this study reported similar experiences with decreased family interactions as their

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health declined due to unmanaged chronic pain. Further, the participants reported increased dependency on their families as their children assumed caregiving roles and expressed concern over their parents' wellbeing, a finding consistent with Duenas et al. (2016). The results of this study have provided further support to the existing literature on the pervasive impacts of unmanaged chronic pain lending credence to the necessity of access to CNCP treatments.

After accessing chronic opioid therapy, the participants experienced improvements to their quality of life as they were better able to manage their pain. The results of this study suggest that the participants' goals for opioid pain management were realistic and directed at carrying out daily routines rather than an absence of pain. As a result of modest expectations for pain relief, the participants in this study perceived an improvement to their overall quality of life after they accessed opioids. This finding was comparable to that of De Sola et al. (2020) in that both sets of participants understood that opioids would not remove their chronic pain, but rather make it more manageable enabling them to resume daily activities. Although the participants in Brooks et al. (2015) had greater expectations for the pain control provided by opioids, their participants and those in this study attributed their drastic improvement in their quality of life to the pain management provided by opioids.

Unfortunately for the participants in this study, the improvement to their quality of life was temporary as the opioid crisis-initiated changes to treatment access and created barriers to effective pain control. A key focus of this investigation was the experiences that resulted from systems-level interventions for the opioid crisis. According to the participants, the most impactful systems-level intervention was the implementation of prescribing guidelines by the College of Physicians and Surgeons. Specifically, the participants experienced challenges with inconsistent interpretation and application of the guidelines by prescribers, continual changes to

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the existing guidelines, and lack of consideration for their individual health needs. For some participants, the inconsistent interpretation and application of the guidelines created conflict between medical providers resulting in significant delays in their treatment access. More importantly, the prescribing guidelines created a consistent barrier to treatment and threatened the participants' abilities to autonomously manage their chronic pain. Consequently, the participants viewed the College and prescribing guidelines as adversaries to their overall wellbeing. For the participants, the College's blanket attempt to manage the opioid crisis was a threat to their livelihood and quality of life. Consequently, they spoke about the College as an uncaring and authoritarian figure in the medical system.

In addition to the inconsistent interpretation and application of prescribing guidelines, participants also experienced challenges related to prescription drug monitoring programs. Prescription drug monitoring programs, originally intended to reduce doctor shopping and overdoses (Volkow & McLellan, 2016), have become a way to monitor prescription behaviours and impose legal sanctions on overzealous prescribers. The results from this study indicate that doctors' fears of legal sanctions were passed on to the participants through an increased hesitancy to prescribe opioids, threats to remove or reduce their opioid treatment, and aggressive tapering of existing opioid prescriptions. Additionally, some of the participants in this study experienced a loss of their physician to legal sanctions and were subsequently refused by other doctors due to their opioid use. Further, statements made to the participants by their doctors indicate that prescribers viewed the monitoring programs as a punitive oversight of their prescribing behaviours that could result in licensure loss. As such, the participants' doctors refused to continue existing opioid prescriptions out of fear for their careers. Consequently, this

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study found that PDMPs create an invisible threat to CNCP management because they shape medical decisions based on what is safe for the doctor rather than what is best for the patient.

Over and above the existing struggles associated with the systems-level interventions, the participants in this study reported taking ownership of sourcing alternative forms of pain management once opioids were threatened or removed. The findings in this study suggest that doctors are not able to refer the participants to other prescribers or recommend alternatives to opioid pain control, which proved detrimental to the participants' wellbeing. Oslund et al. (2009) demonstrated the effectiveness of interdisciplinary pain management programs by combining traditional and alternative forms of medicine such as physiotherapy, psychotherapy, and occupational therapies. The participants in Oslund et al. (2009) experienced a dramatic improvement to their physical, social, and psychological functioning as a result of alternative therapy use. Further, a literature review by Hassan et al. (2020) demonstrated that integrative therapies such as cannabinoids, acupuncture, and therapy played a significant role in reducing opioid reliance and improving pain outcomes in individuals with chronic pain.

Following systems-level interventions, the participants in this study were forced to assume responsibility for sourcing pain management options without the requisite medical knowledge. Some of the participants had the financial means and access to alternative measures similar to those used in Oslund et al. (2009) such as physiotherapy, massage, and psychotherapy. For other participants in this study, assuming responsibility for alternative forms of pain control resulted in illicit and risky behaviours such as street drug use. More simply put, the participants resorted to whatever was available to manage their chronic pain in the absence of recommendations from qualified professionals, requisite medical knowledge to identify appropriate treatments, and means to access those alternatives. The high-risk responses to

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barriers to opioid access go beyond the conclusions of Oslund et al. (2009) by demonstrating the outcomes of not providing alternative pain management strategies. Moreover, the findings of Hassan et al. (2020) support alternative treatments as a way to avoid the negative outcomes of systems-level interventions as experienced by the participants in this study. Accordingly, greater collaboration between medical providers and further training on opioid alternatives are necessary when implementing systems-level initiatives that impact opioid access. The participants may have experienced improved pain outcomes and not resorted to drastic measures to manage their pain if alternatives had been provided like those examined in Oslund et al. (2009) and Hassan et al. (2020).

In addition to the foreseen impacts of systems-level interventions (i.e., reducing opioid access), participants experienced some unintended consequences of the opioid crisis. The dissemination of information about the opioid crisis created widespread knowledge about the rates of opioid-related overdose and death. Studies by Antoniou et al., 2019 and Vallerand and Nowak (2010) suggested that the opioid crisis has reinforced existing stigma about opioid use leading chronic pain patients to experience institutionalized stigma from the medical system as well as friends and family. Like the findings for Brooks et al., (2015) and De Sola et al. (2020), participants experienced increased stigmatization from close contacts when their friends and family expressed concern over their opioid use. Additionally, participants in this study reported experiencing institutionalized stigma as a direct result of their opioid use, a finding also consistent with the existing literature (Brooks et al., 2015). While they reported general hesitancy about opioids prior to the opioid crisis, the participants found that the systems-level interventions resulted in increased stigma and discrimination and poorer treatment by medical providers because of their opioid use.

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Given that individuals with chronic pain must manage long-term relationships with the medical system, they benefit from positive interactions with healthcare providers (De Sola et al., 2020). The participants in this study disclosed interactions characterized by discrimination and poor treatment due to opioid-related stigma. Consequently, this study's findings suggest that the poor treatment by medical providers affects the doctor-patient relationship and leads to interruptions in healthcare access and less transparent communication by chronic pain patients. As a result of their experiences of institutionalized stigma, the participants avoided medical interactions by not seeking help for emergent health issues, reducing their social circles, and limiting who they told about their opioid treatment.

Similar to the findings of Brooks et al. (2015), this study suggests that chronic opioid users engage in self-protective behaviours as a result of threats to access and institutionalized stigma. Antoniou et al., (2019) demonstrated that chronic pain patients experienced an identity shift to "addict" as a result of institutionalized stigma and their opioid use. Similarly, the findings of this study indicate that the participants experienced challenges to their identity after being treated like addicts by medical professionals. The use of risk screeners, drug agreements, and a national registry of opioid users likely reinforced their experiences of being treated like addicts in medical settings. The participants felt they had to prove their responsible opioid use by adapting their behaviour and presenting themselves as if they were not people with addiction seeking drugs. Specifically, the participants avoided medical interactions, selectively disclosed information to doctors, and engaged in identity management to avoid confirming the suspicions of medical providers. Further, the participants attempted to go undetected by the College and carefully documented their opioid use to avoid losing their access to their opioid prescriptions.

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Despite their histories of responsible use, participants went to great lengths to manage external perceptions of themselves as responsible chronic pain patients.

Although it was expected that the participants would experience difficulties accessing opioids following systems-level interventions, the severe impacts to their general wellbeing was not anticipated. The constant threat to pain control and loss of opioid access led some of the participants to consider suicide as a way to manage their suffering. Other studies (Racine et al., 2013; Tang & Crane, 2009) provide further insight into why the participants in this study might have resorted to suicide planning when faced with the loss of opioid access. Both Racine et al. (2013) and Tang and Crane (2006) found that pain-related helplessness was a precipitating factor for suicidal ideation in chronic pain patients. The participants in this study engaged in suicidal ideation as a result of having their pain management forcibly removed by systems-level interventions. This outcome of barriers to access suggests that the loss of treatment autonomy, constant threats to pain management access, and lack of pain management alternatives resulted in feelings of helplessness. Additionally, the participants in this study felt that the College maintained all control over their opioid access and would never be satisfied regardless of their attempts to decrease their opioid usage. Consequently, the participants felt helpless to control the outcomes of the systems-level interventions and perceived themselves as at the mercy of an uncaring system. For that reason, most of the participants reported formulating a suicide plan in the event that their health declined following the loss of access to opioids. These findings go beyond the existing literature to suggest that consistent access to chronic pain management and the perception of control over their pain-related outcomes is vital to preventing suicidal ideation in chronic pain patients.

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To summarize, the results of this study supported the outcomes of previous research on chronic pain management in that unmanaged chronic pain results in significant physical, psychological, and economic impairments. These impairments are detrimental to the overall quality of life of CNCP patients and may result in further health complications. Additionally, this research demonstrates that the journey to chronic pain diagnosis and treatment is long and complicated exposing the sufferer to repeated interactions with the medical system. Further, individuals with chronic pain must endure testing of various no-opioid treatments prior to accessing opioids. For those who do not respond to non-opioid treatments, the process of testing treatments creates unnecessary suffering and further disability.

The pain management and the subsequent improvements to quality of life following opioid access were short-lived for the participants as the systems-level interventions for the opioid crisis created new barriers to treatment access. Specific interventions, such as prescribing guidelines and prescription monitoring programs, were most impactful to the participants by increasing institutionalized stigma, reducing access to doctors, and changing their perceptions about themselves as opioid users. As a result of the changes in chronic pain management during the opioid crisis, the participants now engage in identity management, avoid interactions with the medical system, and communicate less transparently with their medical providers. Most importantly, the participants reached a breaking point in their chronic pain management as a result of systems-level interventions. In a desperate response for pain management following the loss of opioids, the participants have resorted to high-risk behaviours such as street drug use and suicidal ideation. Although these systems-level interventions may reduce the risk of opioid overdose and death, there are unintended consequences for those who rely on opioids to manage chronic pain.

Chapter 6. Conclusions

Implications for the Chronic Pain Medical Providers

Many chronic pain sufferers spend a great deal of time obtaining a diagnosis and accessing effective treatment. For some individuals, chronic opioid therapy is the only effective, affordable, and safe option to manage their pain and improve their quality of life. For these individuals, systems-level interventions resulted in unanticipated outcomes such as impacts to the patient-provider relationship, increased institutionalized stigma, strategic identity management, and high-risk behaviours. The findings of this study provide insight into the experiences of managing chronic pain during the opioid crisis thus presenting significant implications for medical practitioners, policy creators, and alternative health-care providers

Medical Practitioners

First, the results of this study have significant implications for medical providers. The themes from this study shows that systems-level interventions for the opioid crisis (a) affected the participants' relationships with their healthcare provider, (b) decreased the quality of health-care, and (c) increased experiences of institutionalized stigma. Specific interventions, such as prescription monitoring systems, posed a threat to both prescribers and their patients using opioid therapies. As the College began monitoring prescribers and imposing legal sanctions for overzealous prescribing of opioids, hesitancy to take on new patients using opioids increased making it difficult for those using chronic opioid therapy to find new doctors. Some participants in this study lost their doctor due to legal sanctions and were declined by multiple doctors leaving them without access to adequate healthcare. Other participants reported experiencing their doctor's fear of legal sanctions through repeated threats to their opioid prescriptions. In

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short, the participants felt that their doctors chose treatment options based on risk to professional standing rather than the participants' medical needs.

The outcomes of prescription monitoring systems not only affected the quality of healthcare provided but also participants' relationships with their doctors. The fear of regulatory sanctions affected participants willingness to disclose health-related concerns to their doctors. As they faced repeated threats to existing opioid prescriptions or the loss of their doctor to sanctions, participants strategically withheld medical-related information, which creates significant and unnecessary risk to the participants' health. Consequently, it is critical for medical providers to be aware of how their professional fears of sanctions impact the quality of care provided and their relationships with their patients.

Second, the participants in this study experienced conflict between healthcare providers as a result of disparities in the interpretation and application of prescribing guidelines. The differences in interpretation of the prescribing guidelines affected the participants' access to pain management through increased conflict between healthcare providers on treatment options, delays in treatment access while different providers agreed on treatment options, and threats to existing opioid prescriptions when participants switched providers. The results from this study indicate that conflict between providers might be reduced through greater clarity in the prescribing guidelines and enhanced communication between providers on the best courses of treatment to offer patients. This would prevent delays in treatment while the patient themselves mediated the conflict between providers. Also, participants would have likely benefited from having access to alternative treatments when opioids were decreased or removed. Collaboration between providers might encourage referring patients to alternative forms of pain management.

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Third, systems-level interventions for the opioid crisis increased participants' experiences of institutionalized stigma. As the participants in this study noted, they faced increased suspicion of their opioid usage and were often misinformed about addiction. Their doctors did not acknowledge their responsible use and often treated them as if they had an addiction. Additionally, the participants felt that their doctors did not believe their pain was real. The stigma experienced by the participants impacted how they interacted with their doctors and medical settings. Participants adapted their behaviour to appear compliant even when they disagreed with their doctors and avoided medical interactions. When faced with emergent medical needs, the participants reported actively avoiding seeking medical help because of previous poor treatment. The lack of transparency from the participants and avoidance of medical help poses life threatening consequences for individuals with complex, chronic health conditions. Consequently, medical providers must be cognizant of how their personal and professional opinions on opioids affect their treatment of chronic pain sufferers and increase institutionalize stigma. Further, medical providers should encourage patient transparency by acknowledging how their worldviews impact their patient-provider communication and endeavouring to remain non-judgmental about medical practices. Moreover, institutional stigma may impact how medical providers differentiate between addiction, chemical dependence, and responsible use. As such, medical providers should critically evaluate how they determine addiction among opioid users and consider the metrics to evaluate addiction behaviours.

Fourth, details provided by the participants on their general medical experiences describe issues within the medical system that go beyond the experience of chronic pain management such as personal and professional qualities of doctors. For example, participants were affected by the lack of empathy and consideration for medical autonomy as well as personal bias displayed

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by their doctors. These experiences aren't likely exclusive to chronic pain patients as they involve a lack of sensitivity and professionalism on the medical provider's part. These experiences could be mitigated through increased training opportunities for medical providers on sensitivity, professional conduct, and the patient's medical autonomy. Additionally, participants experienced the dissemination of misinformation and poor communication from their physicians on alternative pain management options and opioid outcomes. Poor communication skills and knowledge on medical alternatives indicate a need for professional development on alternative treatment options and communicating options to their patients. Greater knowledge of alternative treatments may encourage medical providers to offer a more holistic approach to chronic pain management and medical care in general. Moreover, continual professional development on opioid outcomes would help physicians to stay abreast of research on opioid use and communicate accurate knowledge to their patients.

Policy Creators

As the themes in this study demonstrate, the systems-level interventions intended to decrease opioid overdose and death have resulted in unanticipated consequences for chronic pain patients. For the participants in this study, the journey towards effective pain management was challenging prior to the opioid crisis. They faced multiple obstacles while navigating the medical system such as seeing multiple different doctors to find a good fit, difficulties obtaining diagnosis, and testing unsuccessful non-opioid treatments prior to starting opioids. The participants in this study spoke to the suffering they endured as their pain went unmanaged while attempting to access chronic opioid therapy. The physical, psychological, and social outcomes of unmanaged chronic pain impacted their overall quality of life leaving them unable to carry out daily activities. Finally, after overcoming the barriers to opioid access, they were able to start

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opioids and effectively manage their pain. Unfortunately, their pain relief was short-lived as College of Physicians and Surgeons responded to the opioid crisis by limiting access to opioids.

Systems-level interventions, such as prescription monitoring programs, affected the participants by creating additional obstacles to opioid therapy access, changing the patient-provider relationship, increasing prescriber hesitancy, and exacerbating opioid-related stigma. These prescription monitoring programs exacerbated the opioid-related stigma as the participants were required to submit to drug testing, sign opioid contracts, and enter a listing on a national registry of users. The poor treatment of the participants led them to question their histories of responsible opioid use. Additionally, prescription monitoring systems create an invisible threat to doctors through professional monitoring and legal sanctions. The participants in this study believed that fear of repercussions affect prescribers' willingness to continue opioid therapies for existing patients, accept new clients using opioids, and question patients' requests for pain management. The outcomes of prescription monitoring programs have left CNCP patients without access to doctors and effective, accessible pain management.

As indicated by the participants' experiences, those responsible for creating health-related policy should consider how marginalized groups may be impacted by systems-level interventions and take steps to ensure that policies do not create barriers to treatment access. Additionally, one-size fits all policies such as the systems-level interventions for the opioid crisis impact certain groups more than others. Consulting with advocacy groups representing marginalized populations would help policy creators to consider the needs of underserved populations such as individuals with CNCP. Further, improvements to access alternative pain management strategies such as physiotherapy, psychology, and massage need to occur prior to creating barriers to access of opioids.

Limitations

Despite the multiple strengths of IPA discussed throughout chapter three, IPA presents certain limitations including generalizability, language barriers, and subjectivity. First, the generalizability of the small sample size is a common criticism of IPA (Pringle, 2011). Smith et al. (2009) recommended a small, purposive sample for those new to IPA research. This study included four participants, which shared similar backgrounds and experiences with chronic pain. As a result, it may be difficult to generalize the results to other chronic pain patients, especially those not using chronic opioid therapy. While the sample size is valid criticism for generalizing the outcomes of IPA research to the surrounding population, readers are encouraged to focus more on the theoretical generalizability (Smith et al., 2009). Smith et al. (2009) described theoretical generalizability as the ability of the reader to link the outcomes of research to their personal and professional experiences.

The need for adequate communication skills between the participants and researcher is the second limitation of this study and IPA in general (Tuffour, 2017). Tuffour (2017) stated that the research may only provide an opinion about the meanings of the participants' experiences rather than an insider's perspective. During the interview process, the participants in this study did experience challenges articulating their experiences, especially when the disclosure prompted emotional reactions. Although member checking of transcripts and interpretations is essential for ensuring that the outcomes of the study align as closely as possible to the participants' understandings of their experiences, only one participant agreed to review her transcript for accuracy. Additionally, language may present a significant concern for the quality of discussion and interpretation. As a result, this study limited the sample to participants who spoke the same language as the researcher. Despite the fluency of the participants, all four interviews contained

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various colloquialisms and filler words that made transcription and interpretation difficult for the researcher.

Participant recruitment was an unanticipated challenge as recruitment began at the start of a worldwide pandemic. Originally, recruitment was to take place in doctors' offices and pain clinics. Due to Covid-19 isolation measures, medical appointments switched to online and telephone consultations limiting opportunities for poster recruitment. Consequently, I revised the recruitment strategy to include special interest and advocacy groups online. These groups, generally operated by volunteers, also faced volunteer shortages as individuals sheltered in place due to the pandemic. Although there is a significant number of individuals experiencing treatment-related challenges from systems-level interventions, the pandemic likely impacted interest and willingness to engage in research efforts as most individuals were busy adapting to pandemic-related lifestyle changes.

A further limitation for this study is the sample bias resulting from recruitment challenges. After experiencing challenges with recruitment through social media interest groups for chronic pain, I reached out to a chronic pain advocacy group in my province. This group provides support to chronic pain patients experiencing medical-related challenges. Three of the four participants were recruited through this patient advocacy group. As a result, there is likely a sampling bias present given that these individuals were already struggling with systems-level interventions and had engaged external support to maintain treatment access. An additional limitation stemming from the use of these participants might be their understanding and knowledge of the systems-level interventions as a result of engaging in patient-advocacy efforts. With that said, the participant not connected to the patient advocacy group also demonstrated awareness of systems-level interventions and how they had impacted her treatment access.

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An additional limitation of IPA, and perhaps qualitative research in general, is its subjective research approach, whereby the researcher interprets the participants' experiences through his or her lens. Although the subjective approach to IPA allowed me to explore the internal experiences of the participants, there are several conceptual aspects of IPA that result in limitations for this study. First, IPA doesn't explain why the participants experience a phenomenon in a certain way. This study attempted to situate the participants' experiences within the context of the sociopolitical forces that shaped the systems-level interventions for the opioid crisis. There may be other factors not considered that impact how the participants experience the opioid crisis. For example, participants' socio-economic status and geographical location might have limited their access to alternative therapies forcing them to rely on opioids for pain management. Further, provincial idiosyncrasies in opioid use, overdose, and death might have impacted how the participants experienced their local medical systems. Some provinces with lower rates of overdose might have more lenient applications of the provincially-based guidelines.

Second, IPA may only describe the participants' opinions about their experiences rather than capturing the experience accurately (Tuffour, 2017). When describing painful or emotionally intense experiences, the participants may have not fully articulated their thoughts and feelings to prevent reliving their traumatic medical experiences. Additionally, social desirability bias may have impacted the participants' disclosures. For example, the participants might have purposely left out information when describing their experiences with suicidal ideation. The participants in this study provided vague information regarding their suicidal experiences. Given that suicide is socially unacceptable and could lead to a loss of medical autonomy for opioid users (i.e., loss of their opioids), participants might have been hesitant to

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disclose details regarding suicide attempts. Consequently, I was required to interpret the participants' interpretation of their experience based on the limited information they provided.

Third, the inherently subjective nature of the double hermeneutic process means that the researcher's experiences with the phenomena will influence the analysis of participants' experiences. Although bracketing requires the researcher to identify and consider how their assumptions and beliefs may affect the study, bracketing does not necessarily reduce or limit the researcher's impact on the study's outcomes (Birt et al., 2016).

Future Directions

This study highlights how individuals with chronic pain experience the effects of systems-level interventions intended to curb the opioid crisis. The findings of this study, and its limitations, provide a starting place for future research efforts focused on how public health policy affects individuals with chronic pain. Since this study focused on individuals using chronic opioid therapy without a history of addiction, future research might include individuals who have experienced addiction but rely on opioids for pain management. Further, more information on alternative treatments is required to assist those losing access to their opioid therapy. Future studies might include individuals who have not used chronic opioid therapy to explore their satisfaction with and access to treatment options given that they have never experienced opioid pain control.

Perhaps another area for future research pertains to the surprising findings of identity management among the participants in this study. This study supported the findings of previous research (Antoniou et al., 2019) in that the participants strategically managed their identities as chronic opioid users. Further research on patient identity management should investigate the types of identity management that occur in the chronic pain population and how the provision of

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medical services is affected by identity management. A greater understanding of how and why CNCP patients attempt to control external perceptions of themselves might provide insight for improving the practitioner-patient relationship and reducing institutionalized stigma among chronic pain patients.

In addition to the future directions above, this study highlighted a problematic outcome of institutionalized stigma. Given the limited scope of this study, I did not explore the outcomes of the fear-avoidance behaviours that resulted from participants' experiences of institutionalized stigma. Future research might examine the impacts of institutionalized stigma on chronic pain patients' willingness to engage medical resources and their compliance with treatment recommendations. It is possible that certain medical settings, such as emergency rooms and hospitals, are more likely than private practice to engage in acts of institutionalized stigma. Greater insight into CNCP patients' experiences of institutionalized stigma may open the door to more culturally sensitive medical training opportunities.

References

- Alase, A. (2017). The Interpretive Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education & Literacy Studies*, 5(2), 9-19. <http://dx.doi.org/10.7575/aiac.ijels.v.5n.2p.9>
- American Society of Addiction Medicine. (2016). *Opioid Addiction 2016 Facts and Figures*. Retrieved from <https://www.asam.org/docs/default-source/advocacy/opioid-addiction-disease-facts-figures.pdf>
- Antoniou, T., Ala-Leppilampi, K., Shearer, D., Parsons, J., Tadrous, M., & Gomes, T. (2019). "Like Being Put on an Ice floe and Shoved Away": A Qualitative Study of the Impacts of Opioid-Related Policy Changes on People Who Take Opioids. *The International Journal on Drug Policy*, 66, 15-22. <https://doi.org/10.1016/j.drugpo.2019.01.015>
- Bailly, F., Foltz, V., Rozenberg, S., Fautrel, B., & Gossec, L. (2015). The Impact of Chronic Low Back Pain is Partly Related to Loss of Social Role: A Qualitative Study. *Joint Bone Spine*, 82(6), 437–441. <https://doi.org/10.1016/j.jbspin.2015.02.019>
- Bailo, L., Guidi, P., Vergani, L., Marton, G., & Pravettoni, G. (2019). The Patient Perspective: Investigating Patient Empowerment Enablers and Barriers Within the Oncological Care Process. *E Cancer Medical Science*, 13(912), 1–15. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6467453/>
- Ballantyne, J. C., Kalso, E., & Stannard, C. (2016). WHO Analgesic Ladder: A Good Concept Gone Astray. *British Medical Journal*, 352(i20). <https://doi.org/10.1136/bmj.i20>
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*, 5(3), 214-224. <https://doi.org/10.1080/14780880802314304>

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

- Birt, L., Scott, S., & Carvers, D. (2016). Member Checking: A Tool to Enhance the Trustworthiness or Merely a Nod to Validation. *Qualitative Health Research*, 26(13), 1802-1811. <https://doi.org/10.1177/1049732316654870>
- Brennen, F., Carr, D. B., & Cousins, M. (2007). Pain Management: A Fundamental Human Right. *Anesthesia and Analgesia*, 105, 205-221. <https://doi.org/10.1213/01.ane.0000268145.52345.55>
- Brooks, E. A., Unruh, A., & Lynch, M. E. (2015). Exploring the Lived Experience of Adults Using Prescription Opioids to Manage Chronic Noncancer Pain. *Pain Research & Management*, 20(1), 15–22. <https://doi.org/10.1155/2015/314184>
- Busse, J. W., Craigie, S., Juurlink, D. N., Buckley, D. N., Li, W., Couban, R. J., Agoritsas, T., Akl, E. A., Carrasco-Labra, A., Cooper, I., Cull, C., de Costa, B. R., Frank, J. W., Grant, G., Lorio, A., Persaud, N., Stern, S., Tugwell, P., Vandvik, P. O., & Guyatt, G. H. (2017). Guideline for Opioid Therapy and Chronic Non-Cancer Pain. *Canadian Medical Association Journal*, 189(18), E659-E666. <https://doi.org/10.1503/cmaj.170363>
- Campbell, J. N. (1996). American Pain Society 1995 Presidential Address. *Pain Forum*, 5, 85-88. [https://doi.org/10.1016/S1082-3174\(96\)80076-6](https://doi.org/10.1016/S1082-3174(96)80076-6)
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2018). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2*. Retrieved from https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html
- Canadian Pain Task Force. (2019). Chronic Pain in Canada: Laying a Foundation for Action. Retrieved on September 8, 2021, from <https://www.canada.ca/en/health->

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

[canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2019.html](https://www.canada.ca/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2019.html)

Centers for Disease Control. (2016, Mar 15). *CDC Guidelines for Prescribing Opioids for Chronic pain - United States, 2016*. Retrieved from

<https://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm>

Cheatle, M. D. (2011). Depression, Chronic Pain, and Suicide by Overdose: On the Edge. *Pain Medicine, 12*(2), S43-S48. <https://doi.org/10.1111/j.1526-4637.2011.01131.x>

Creswell, J. W. (2013). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (3rd ed.). Sage Publications.

Creswell, J., & Poth, C. (2018). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches* (4th ed.). Sage Publications

Dahlhamer, J., Lucas, J., Zelaya, C., Nahin, R., MacKey, S., Debar, L., Kerns, R., Von Korff, M., Porter, L., & Helmick, C. (2018). Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults—United States, 2016. *Centers for Disease Control and Prevention - Morbidity and Mortality Weekly Report, 67*, 1001–6. Retrieved from

<https://www.cdc.gov/mmwr/volumes/67/wr/mm6736a2.htm>

D'Arcy, Y. (2010). *Compact Clinical Guide to Chronic Pain Management: An Evidence-Based Approach for Nurses*. Springer Publishing. Retrieved from <https://ebookcentral-proquest-com.ezproxy.lib.ucalgary.ca>

Darnall, B. D., Juurlink, D., Kerns, R. D., Mackey, S., Van Dorsten, B., Humphreys, K., Gonzalez-Sotomayor, J. A., Furlan, A., Gordon, A. J., Gordon, D. B., Hoffman, D. E., Katz, J., Kertesz, S. G., Satel, S., Lawhern, R. A., Nicholson, K. M., Polomano, R. C., Williamson, O. D., McAnally, H., Kao, M. C., ... Lovejoy, T. (2019). International Stakeholder Community of Pain Experts and Leaders Call for an Urgent Action on Forced Opioid

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Tapering. *Pain Medicine*, 20(3), 429-433. <https://doi.org/10.1093/pm/pny228>

Dasgupta, N., Beletsky, L., & Ciccarone, D. (2018). Opioid Crisis: No Easy Fix to its Social and Economic Determinants. *American Journal of Public Health*, 108(2), 182-186.

<https://doi.org/10.2105/AJPH.2017.304187>

Dassieu, L., Kaboré, J., Choinière, M., Arruda, N., & Roy, E. (2019). Chronic Pain Management Among People Who Use Drugs: A Health Policy Challenge in the Context of the Opioid Crisis. *The International Journal of Drug Policy*, 71, 150-156.

<https://doi.org/10.1016/j.drugpo.2019.03.023>

Day, M. A., & Thorn, B. E. (2010). The Relationship of Demographic and Psychosocial Variables to Pain-Related Outcomes in a Rural Chronic Pain Population. *Pain*, 151(2), 467-74.

<https://doi.org/10.1016/j.pain.2010.08.015>

de Leon-Casasola, O. (2013). Opioids for Chronic Pain: New evidence, New Strategies, Safe Prescribing. *The American Journal of Medicine*, 126(3), S3-S11.

<https://doi.org/10.1016/j.amjmed.2012.11.011>

De Sola, H., Maquibar, A., Failde, I., Salazar, A., & Goicolea, I. (2020). Living with Opioids: A Qualitative Study with Patients with Chronic Low Back Pain. *Health Expectations*, 23(5), 1118–1128. <https://doi.org/10.1111/hex.13089>

Denzin, N. K. (2017). Critical Qualitative Inquiry. *Qualitative Inquiry*, 23(1), 8–16.

<https://doi.org/10.1177/1077800416681864>

Doane, M., Jaffe, D., Dragon, E., Abraham, L., Viktrup, L., Bushmakin, A. G., & Cappelleri, J. C. (2018). Assessing the Burden of Treated and Untreated Chronic Low Back Pain in Europe. *Annals of the Rheumatic Diseases*, 77, 1807. <https://doi.org/10.1136/annrheumdis-2018-eular.7497>

Duenas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I. (2016). A Review of Chronic Pain

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Impact on Patients, Their Social Environment and the Health Care System. *Journal of Pain Research*, 9, 457-467. <https://doi.org/10.2147/JPR.S105892>

Eatough, V., & Smith, J. A. (2011). Interpretative Phenomenological Analysis. In C. Willig and W. Stainton-Rogers (eds). *The Sage Handbook of Qualitative Psychology*. SAGE Publications.

Finley, C. R., Chan, D. S., Garrison, S., Korownyk, C., Kolber, M. R., & Campbell, S. (2018).

What are the Most Common Conditions in Primary Care? Systematic Review. *Canadian Family Physician*, 64, 832-840. Retrieved from <https://pubmed.ncbi.nlm.nih.gov/30429181/>

Fleming, M. L., Driver, L., Sansgiry, S. S., Abughosh, S. M., Wanat, M. A., Varisco, T. J., Pickard,

T., Reeve, K., & Todd, K. H. (2019). Drug Enforcement Administration Rescheduling of Hydrocodone Combination Products is Associated with Changes in Physician Pain

Management Prescribing Preferences. *Journal of Pain & Palliative Care*

Pharmacotherapy, 33(1-2), 22–31. <https://doi.org/10.1080/15360288.2019.1615027>

Gatchel, R. J., & Howard, K. J. (2018). The Biopsychosocial Approach. *Practical Pain*

Management, 8(4). Retrieved from <https://www.practicalpainmanagement.com/patient/chronic-pain-biopsychosocial-model>

Gatchel, R. J., McGeary, D. D., McGeary, C. A., & Lippe, B. (2014). Interdisciplinary Chronic

Pain Management: Past, Present, and Future. *American Psychologist*, 69(2), 119-130.

<https://doi.org/10.1037/a0035514>

Gatchel, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The Biopsychosocial

Approach to Chronic Pain: Scientific Advances and Future Directions. *Psychological*

Bulletin, 133(4), 581-624. <https://doi.org/10.1037/0033-2909.133.4.581>

Goldberg, D. S., & McGee, S. J. (2011). Pain as a Global Public Health Priority. *BioMed Central*

Public Health, 11, 770. <https://doi.org/10.1186/1471-2458-11-770>

Gnomes, T., Mamdani, M., Dhalla, I. A., Cornish, S., Paterson, J. M., & Jurrlink, D. N. (2014a).

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

The Burden of Premature Opioid-Related Mortality. *Addiction*, 109, 1482-1488.

<https://doi.org/10.1111/add.12598>

Gomes, T., Mamdani, M., Paterson, J. M., Dhalla, I. A., & Jurlink, D. N. (2014b). Trends in High-

Dose Opioid Prescribing in Canada. *Canadian Family Physician*, 60(9), 826-832. Retrieved

from <https://www.cfp.ca/content/cfp/60/9/826.full.pdf>

Gomes, T., Tadrous, M., Mamdani, M. M., Paterson, J. M., & Juurlink, D. N. (2018). The Burden

of Opioid-Related Mortality in the United States. *Journal of the American Medical*

Association Network Open, 1(2). <https://doi.org/10.1001/jamanetworkopen.2018.0217>

Gudin, J., & Lee, A. J. (2013). The Downside of Upscheduling. *Pain Medicine*, 14(11), 1628-1629.

https://doi.org/10.1111/pme.12257_3

Hassan, S., Zheng, Q., Rizzolo, E., Tezcanli, E., Bhardwaj, S., & Cooley, K. (2020). Does

Integrative Medicine Reduce Prescribed Opioid Use for Chronic Pain? A Systematic

Literature Review. *Pain Medicine (Malden, Mass.)*, 21(4), 836–859. [https://doi.org/](https://doi.org/10.1093/pm/pnz291)

[10.1093/pm/pnz291](https://doi.org/10.1093/pm/pnz291)

Hassett, A. L., Aquino, J. K., & Ilgen, M. A. (2014). The Risk of Suicide Mortality in Chronic Pain

Patients. *Current Pain and Headache Reports*, 8, 1. [https://0-doi-org.aupac.lib.](https://0-doi-org.aupac.lib.athabascau.ca/10.1007/s11916-014-0436-1)

[athabascau.ca/10.1007/s11916-014-0436-1](https://0-doi-org.aupac.lib.athabascau.ca/10.1007/s11916-014-0436-1)

Health Canada. (2021). Regulations Amending the Narcotic Control Regulations (Tramadol):

SOR/2021-43 (Canada Gazette No. 7). Retrieved from [https://gazette.gc.ca/rp-](https://gazette.gc.ca/rp-pr/p2/2021/2021-03-31/html/sor-dors43-eng.html)

[pr/p2/2021/2021-03-31/html/sor-dors43-eng.html](https://gazette.gc.ca/rp-pr/p2/2021/2021-03-31/html/sor-dors43-eng.html)

Hooten, M. W. (2016). Chronic Pain and Mental Health Disorders: Shared Neural Mechanisms,

Epidemiology, and Treatment. *Mayo Clinic Proceedings*, 91(7), 955-970.

<https://doi.org/10.1016/j.mayocp.2016.04.029>

Institute of Medicine. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention,*

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Care, Education, and Research. National Academies Press. Retrieved from

<https://www.ncbi.nlm.nih.gov/books/NBK92516/#ch2.s1>.

- Knight, K. R., Kushel, M., Chang, J. S., Zamora, K., Ceasar, R., Hurstak, E., & Miaskowski, C. (2017). Opioid Pharmacovigilance: A Clinical-Social History of the Changes in Opioid Prescribing for Patients with Co-Occurring Chronic Non-Cancer Pain and Substance Use. *Social Science & Medicine*, 186, 87-95. <https://doi.org/10.1016/j.socscimed.2017.05.043>
- Larkin, M., & Thompson, A. (2012). Interpretative Phenomenological Analysis. In A. Thompson & D. Harper (eds), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 99-116). John Wiley & Sons. <https://doi.org/10.1002/9781119973249>
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving Voice and Making Sense in Interpretative Phenomenological Analysis. *Qualitative Research in Psychology*, 3(2), 102-120. <https://doi.org/10.1191/1478088706qp062oa>
- Linton, S. J., & Shaw, S. W. (2011). Impact of Psychological Factors in the Experience of Pain. *Physical Therapy*, 91(5), 700-711. <https://doi.org/10.2522/ptj.20100330>
- Madison, D. S. (2011). *Critical Ethnography: Method, Ethics, and Performance*. SAGE Publications. Retrieved from https://books.google.ca/books?id=Onvr9DstlrEC&dq=critical+theory+madison+2011&lr=&source=gbs_navlinks_s
- Main, C. J., Foster, N., & Buchbinder, R. (2010). How Important are Back Pain Beliefs and Expectations for Satisfactory Recovery from Back Pain? *Best Practice & Research Clinical Rheumatology*, 24(2), 205–217. <https://doi.org/10.1016/j.berh.2009.12.012>
- Makary, M. A., Overton, H. N., & Wang, P. (2017). Overprescribing is Major Contributor to Opioid Crisis. *British Journal of Medicine*, 359(8126), j4792. <https://doi.org/10.1136/bmj.j4792>

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

- Meekosha, H., & Shuttleworth, R. (2009). What's So 'Critical' About Critical Disability Studies?, *Australian Journal of Human Rights*, 15, 47-75. <https://doi.org/10.1080/1323238X.2009.11910861>
- Meldrum, M. L. (2016). The Ongoing Opioid Prescription Epidemic: Historical Context. *American Journal of Public Health*, 106(8), 1365-1366. <https://doi.org/10.2105/AJPH.2016.303297>
- Morin, K., Eibl, J., Franklyn, A., & Marsh, D. (2017). The Opioid Crisis: Past, Present and Future Policy Climate in Ontario, Canada. *Substance Abuse Treatment, Prevention and Policy*, 12(45), 1-7. <https://doi.org/10.1186/s13011-017-0130-5>
- Newton, B., Southall, J., Raphael, J., Ashford, R., & Lemarchand, K. (2013). A Narrative Review of the Impact of Disbelief in Chronic Pain. *Pain Management Nursing*, 14(3), 161-171. <https://doi.org/10.1016/j.pmn.2010.09.001>
- Noon, E. J. (2018). Interpretive Phenomenological Analysis: An Appropriate Methodology for Educational Research? *Journal of Perspectives in Applied Academic Practice*, 6(1), 75-83. <https://doi.org/10.14297/jpaap.v6i1.304>
- Office of Disease Preventions and Health Promotion. (2014). *Report for Health-Related Quality of Life and Well-Being*. U. S. Department of Health. Retrieved from <https://www.healthypeople.gov/2020/about/foundation-health-measures/Health-Related-Quality-of-Life-and-Well-Being>
- Oslund, S., Robinson, R. C., Clark, T. C., Garofalo, J. P., Behnk, P., Walker, B., Walker, K. E., Gatchel, R. J., Mahaney, M., & Noe, C. E. (2009). Long-Term Effectiveness of a Comprehensive Pain Management Program: Strengthening the Case for Interdisciplinary Care. *Proceedings (Baylor University. Medical Center)*, 22(3), 211-214. <https://doi.org/10.1080/08998280.2009.11928516>
- Pietkiewicz, I., & Smith, J. (2014). A Practical Guide to Using Interpretative Phenomenological

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Analysis in Qualitative Research Psychology. *Psychological Journal*, 20(1), 7-14.

<https://doi.org/10.14691/CPJ.20.1.7>

Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative Phenomenological

Analysis: A Discussion and Critique. *Nurse Researcher*, 18(3), 20–24. Retrieved from

<https://pubmed.ncbi.nlm.nih.gov/21560922/>

Public Health Agency of Canada. (2021). *Opioid and Stimulant-Related Harms in Canada*.

Government of Canada. Retrieved on September 9, 2021, from <https://health->

[infobase.canada.ca/substance-related-harms/opioids-stimulants/](https://health-infobase.canada.ca/substance-related-harms/opioids-stimulants/)

Raphael, D. (2009). *Social Determinants of Health Canadian Perspectives* (2nd ed.). Canadian

Scholars' Press Inc.

Reidenberg, M. M., & Willis, O. (2007). Prosecutions of Physicians for Prescribing Opioids to

Patients. *Clinical Pharmacology & Therapeutics*, 81(6), 903-906. <https://doi.org/10.1038>

[/sj.clpt.6100127](https://doi.org/10.1038/sj.clpt.6100127)

Richard, S., Dionne, C., & Nouwen, E. (2011). Self-Efficacy and Health Locus of Control:

Relationship to Occupational Disability Among Workers with Back Pain. *Journal of*

Occupational Rehabilitation, 21(3), 421-430. <https://doi.org/10.1007/s10926-011-9285-5>

Roditi, D., & Robinson, M. E. (2011). The Role of Psychological Interventions in the Management

of Patients with Chronic Pain. *Psychology Research and Behavior Management*, 4, 41-49.

<https://doi.org/10.2147/PRBM.S15375>

Schopflocher, D., Taenzer, P., & Jovey, R. (2011). The Prevalence of Chronic Pain in Canada. *Pain*

Research & Management, 16(6), 445-450. <https://doi.org/10.1155/2011/876306>

Shaw, S., & Anderson, J. (2018). Phenomenological Research in Medical Education: An Overview

of its Philosophy, Approaches, and Conduct. *SAGE Research Methods*.

<https://doi.org/10.4135/9781526447319>

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

- Shineborn, P. (2011). The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis*, 22, 16-31. Retrieved from <https://eds.s.ebscohost.com/eds/pdfviewer/pdfviewer?vid=1&sid=0faac696-96b0-4f8f-9154-e9293b954c6d%40redis>
- Shivayogi P. (2013). Vulnerable Population and Methods for their Safeguard. *Perspectives in clinical research*, 4, 53–57. <https://doi.org/10.4103/2229-3485.106389>
- Shupler, M. S., Kramer, J. K., Cragg, J. J., Jutzeler, C. R., & Whitehurst, D. (2019). Pan-Canadian Estimates of Chronic Pain Prevalence from 2000-2014: A Repeated Cross-Sectional Survey Analysis. *Journal of Pain*, 20(5), 557-565. <https://doi.org/10.1016/j.jpain.2018.10.010>
- Söderlund, A., Sandborgh, M., & Johansson, A. (2017). Is Self-Efficacy and Catastrophizing in Pain-Related Disability Mediated by Control Over Pain and Ability to Decrease Pain in Whiplash-Associated Disorders?. *Physiotherapy Theory and Practice*, 33(5), 376-385. <https://doi.org/10.1080/09593985.2017.1307890>
- Smith, J. A (2011). Evaluating the Contribution of Interpretative Phenomenological Analysis. *Health Psychology Review*, 5, 9-27. <https://doi.org/10.1080/17437199.2010.510659>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive Phenomenological Analysis: A Theory, Method, and Research*. SAGE Publications. Retrieved from <https://books.google.ca/books?id=WZ2Dqb42exQC&printsec=frontcover#v=onepage&q&f=false>
- Smith, J. A., & Osborn, M. (2007a). “Interpretative Phenomenological Analysis”. In J. A. Smith (Ed.). *Qualitative Psychology: A Practical Guide to Methods* (pp. 53-80). SAGE Publications Inc. Retrieved from <https://psycnet.apa.org/record/2003-06442-003>
- Smith, J. A., & Osborn, M. (2007b). Pain as an Assault on the Self: An Interpretive Phenomenological Analysis of Psychological Impact of Chronic Benign Low Back Pain. *Psychology & Health*, 22, 517-534. <https://doi.org/10.1080/14768320600941756>

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Stanos, S. (2012). Focused Review of Interdisciplinary Pain Rehabilitation Programs for Chronic Pain Management. *Psychiatric Management of Pain*, 16(2), 147-152.

<https://doi.org/10.1007/s11916-012-0252-4>

Tang, N. K., & Crane, C. (2006). Suicidality in Chronic Pain: A Review of the Prevalence, Risk Factors and Psychological Links. *Psychological Medicine*, 36, 575-586.

<https://doi.org/10.1017/S0033291705006859>

Thompson, K., Johnson, M. I., Milligan, J., & Briggs, M. (2018). Twenty-Five Years of Pain Education Research-What Have We Learned? Findings from a Comprehensive Scoping Review of Research Into Pre-Registration Pain Education for Health Professionals. *Pain*, 159(11), 2146-2158. <https://doi.org/10.1097/j.pain.0000000000001352>

Tufford, L., & Newman, P. (2010). Bracketing in Qualitative Research. *Qualitative Social Work*, 11, 80-96. <https://doi.org/10.1177/1473325010368316>

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. *Journal of Healthcare Communications*, 2(4), 1-5. <https://doi.org/10.4172/2472-1654.100093>

Tunks, E. R., Crook, J., & Weir, R. (2008). Epidemiology of Chronic Pain with Psychological Comorbidity: Prevalence, Risk, Course, and Prognosis. *The Canadian Journal of Psychiatry*, 53(4), 224–234. <https://doi.org/10.1177/070674370805300403>

Turk, D. C. & Monarch, E. S. (2018). Biopsychosocial Perspective on Chronic Pain. In D. C. Turk & R. J. Gatchel (Eds.), *Psychological Approaches to Pain Management. A Practitioner's Handbook* (3rd. ed) (3-23). Gilford Publications.

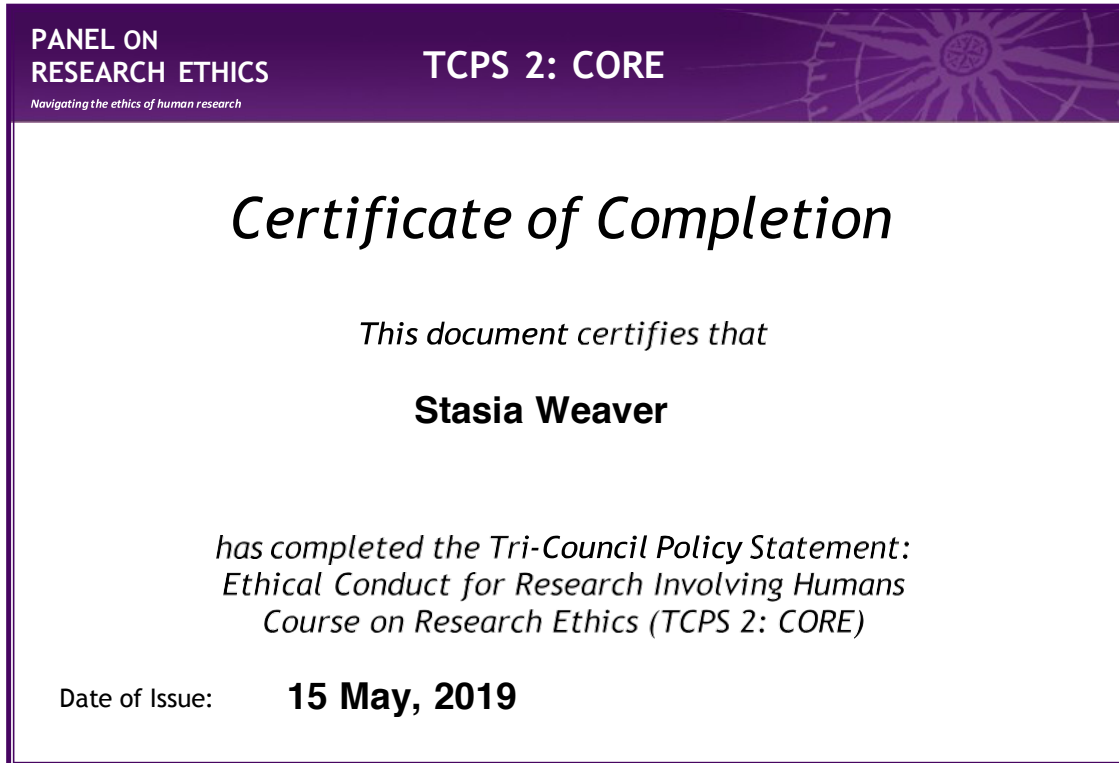
Turk, D. C., Wilson, H. D., & Cahana, A. (2011). Treatment of Chronic Pain. *The Lancet*, 377(9784), 2226-2235. [https://doi.org/10.1016/S0140-6736\(11\)60402-9](https://doi.org/10.1016/S0140-6736(11)60402-9)

Turk, D., Wilson, H., & Swanson, K. (2010). The Biopsychosocial Model of Pain and Pain

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

- Management. In M. Ebert & R. Kerns (Eds.), *Behavioral and Psychopharmacologic Pain Management* (pp. 16-43). Cambridge University Press. <https://doi.org/10.1017/CBO9780511781445>
- Volkow, N. D., & McLellan, A. T. (2016). Opioid Abuse in Chronic Pain - Misconceptions and Mitigation Strategies. *The New England Journal of Medicine*, 374(13), 1253-1263. <https://doi.org/10.1056/NEJMra1507771>
- Wailoo, K. (2015). *Pain: A Political History*. John Hopkins University Press.
- Wang, J., & Christo, P. J. (2009). The Influence of Prescription Monitoring Programs on Chronic Pain Management. *Pain physician*, 12(3), 507-515. Retrieved from <https://pubmed.ncbi.nlm.nih.gov/19461820/>
- Wickramatilake, S., Zur, J., Mulvaney-Day, N., Campopiano von Kilmo, M., Selmi, E., & Harwood, H. (2017). How the States are Tackling the Opioid Crisis. *Public Health Report*, 132(2), 171-179. <https://doi.org/10.1177/0033354916688206>
- Yardley, L. (2000). Dilemmas in Qualitative Health Research. *Psychology and Health*, 15, 215-228. <https://doi.org/10.1080/08870440008400302>

Appendix A: TCPS2 Certificate



Appendix B: Recruitment Poster

PARTICIPANTS NEEDED
FOR RESEARCH IN CHRONIC PAIN MANAGEMENT AMID THE OPIOID CRISIS

Have you:

- ✓ Been diagnosed with chronic non-cancer pain
- ✓ Responsibly used opioid therapy in the past with no history of addiction
- ✓ Experienced issues obtaining chronic opioid therapy following the opioid crisis

We are looking for volunteers to take part in a study of the experiences of managing chronic non-cancer pain following political and institutional changes to opioid prescribing.

As a participant in this study, you would be asked to discuss your experiences of chronic pain management following the opioid crisis. Your participation is **entirely voluntary** and would take up approximately 2 hours of your time.

By participating in this study, you will help us to understand how political and institutional forces to reduce the opioid crisis have impacted the experience of chronic pain management among Canadians.

To learn more about this study, or to participate in this study, please contact:

Principal Investigator:

*Stasia, Masters of Counselling student, Athabasca University
email: sweaver1@athabasca.edu*

This study is supervised by: Dr. Simon Nuttgens (simonn@athabascau.ca)

This study has been reviewed by the Athabasca University Research Ethics Board.



EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Appendix C: Consent Forms

AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS STUDY OF THE LIVED EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

PARTICIPANT CONSENT FORM

February 11, 2020

Principal Investigator (Researcher):

Stasia Weaver
Sweaver1@athabasca.edu

Supervisor:

Dr. Simon Nuttgens
simonn@athabascau.ca

You are invited to participate in a research study about the impacts of government and medical system changes to opioid prescribing on individuals using opioid therapy to manage chronic non-cancer pain. I am conducting this study as a requirement to complete my graduate degree in Counselling Psychology.

As a participant, you are asked to take part in a *video/audio-recorded interview via online conferencing software to discuss your experiences* with chronic opioid therapy before and after government/medical responses to the opioid crisis. If you do not have access to a computer and internet, I am happy to conduct the interview over the phone. Participation will take approximately 2 hours of your time with 1 hour for the interview.

The risks associated with your participation in the study are no greater than thinking about or describing your experiences with managing chronic pain before and after the opioid crisis (2016). Your participation in this study may include sharing information pertaining to your chronic pain and pain-related experiences, interactions with the medical system, and challenges with obtaining chronic pain treatments. Involvement in this study is entirely voluntary and you may refuse to answer any questions or to share information that you are not comfortable sharing. You may withdraw from the study at any time during the data collection period by *emailing me with your request to withdraw*. Once your transcript is finalized and data analysis has started, your data will be included in the study.

You will have an opportunity to request changes to ensure the finalized transcript accurately and honestly reflects your experiences of chronic pain management before and after the opioid crisis. If you opt to review the transcript when completed, I will reach out to provide you with a digital copy of the transcript. If you do not have access to a computer with the internet, I will mail you a hard copy of the transcript.

All information collected in this study will be securely stored on a password-protected computer. Only myself (principal investigator) and my supervisor will have access to the information collected for this research project. Once you have approved the finalized transcript, your name will be removed from the study, and you will remain anonymous, as I will use the pseudonym you select to identify your transcript.

Once completed, you may obtain a copy of the finalized study. If you are interested in a copy of the research study, please let me know at the end of your interview and initial on the appropriate line on the next page.

If you have any questions about this study or require further information, please contact me, (the principal investigator) by e-mail at sweaver1@athabasca.edu or my supervisor by email at simonn@athabascau.ca.

This study has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or by e-mail to rebsec@athabascau.ca.

Thank you for your assistance in this project.



EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

CONSENT:

I have read the Letter of Information regarding this research study, and all of my questions have been answered to my satisfaction. I will keep a copy of this letter for my records.

My signature below confirms that:

- I understand the expectations and requirements of my participation in the research;
- I understand the provisions around confidentiality and anonymity;
- I understand that my participation is voluntary, and that I am free to withdraw at any time with no negative consequences up to the start of data analysis;
- I am aware that I may contact the researcher, research supervisor, or the Office of Research Ethics if I have any questions, concerns or complaints about the research procedures.

Name: _____

Date: _____

Signature: _____

By initialing the statement(s) below,

_____ I am granting permission for the researcher to record the interview's video and audio

_____ I am granting permission for the researcher to record the interview's audio only

_____ I acknowledge that the researcher may use specific quotations of mine, without identifying me

_____ I would like to receive a copy of the finalized research study by email

e-mail address: _____

If you are willing to review the transcribed interview for accuracy, the researcher will contact you at a later time by e-mail or telephone for a brief conversation to confirm that the researcher has accurately understood your comments in the interview, please indicate so below. You will not be contacted more than six months after your interview.

_____ Yes, I would like to review and provide feedback on the interview transcript

EXPERIENCES OF CHRONIC PAIN AMID THE OPIOID CRISIS

Appendix D: Semi-Structured Interview Guide

Interview Schedule (Topic)	Sample Interview Question
Experiences with CNCP prior to the systems-level opioid crisis initiatives.	<p>From my background research, I can see that the implementation of government initiatives to reduce opioid prescribing began around 2016. Although the timing of the opioid crisis may be different for each patient, please thinking of when the opioid-related challenges started for you. For the purposes of this interview, we will consider that period as the start of the opioid crisis.</p> <p>Please tell me about your general experiences with chronic non-cancer pain management prior to the opioid crisis.</p> <p>Prod - For example, you could chose to talk about your diagnosis, interactions with the medical system, challenges you faced as a result of managing chronic pain.</p>
Experiences with treatment access and chronic opioid therapy prior to the opioid crisis.	Describe your experiences with treatment options and chronic opioid therapy prior to the start of opioid-related challenges.
Experiences with chronic opioid therapy, medical system, treatment access, and chronic pain management after the opioid crisis	<p>Tell me about how the opioid crisis affected your ability to manage chronic pain.</p> <p>Prod – How do you feel the opioid crisis has impacted: (a) Your interactions with the medical system or relationship with your doctor, (b) Access to treatment, and/or (c) Ability to ask for opioid treatments or maintain your previous prescriptions.</p>
Experiences with the cognitive/emotional aspects of chronic pain management after the opioid crisis	<p>How has the opioid crisis affected your thoughts or feelings regarding your chronic pain illness?</p> <p>Prod – For example, you may choose to discuss how the opioid crisis changed how you understand your illness, experiences of chronic pain, or treatments.</p>
Experiences with the social aspects of chronic pain management after the opioid crisis	You may have experienced opioid-related stigma given the wide dissemination of opioid crisis information. How has the widespread knowledge of the opioid crisis affected your ability to socialize, work, and live as an opioid user during the opioid crisis?
Impact of opioid crisis initiatives to chronic pain management and quality of life	As someone with chronic pain, how do you feel the events of the opioid crisis such as changes to treatment access or increased stigma have impacted your quality of life.

I want to thank you for taking the time to discuss your experiences with chronic pain during the opioid crisis. To create confidentiality for you, I would like to assign a pseudonym name to any data connected to your participation. Do you have a pseudonym in mind?

Appendix E: Certification of Ethical Approval



CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: 23894

Principal Investigator:

Mrs. Stasia Weaver, Graduate Student
Faculty of Health Disciplines\Master of Counselling

Supervisor:

Dr. Simon Nuttgens (Supervisor)

Project Title:

An interpretative phenomenological analysis study on the lived experiences of chronic pain amid the opioid crisis

Effective Date: April 23, 2020

Expiry Date: April 22, 2021

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

A Project Completion (Final) Report must be submitted when the research is complete (*i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable)*) or the research is terminated.

Approved by:

Date: April 23, 2020

Emily Doyle, Chair
Faculty of Health Disciplines, Departmental Ethics Review Committee

Athabasca University Research Ethics Board
University Research Services, Research Centre
1 University Drive, Athabasca AB Canada T9S 3A3
E-mail rebsec@athabascau.ca
Telephone: 780.675.6718

Appendix F: Certification of Ethical Approval - Renewal



CERTIFICATION OF ETHICAL APPROVAL - RENEWAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: 23894

Principal Investigator:

Mrs. Stasia Weaver, Graduate Student
Faculty of Health Disciplines\Master of Counselling

Supervisor:

Dr. Simon Nuttgens (Supervisor)

Project Title:

An interpretative phenomenological analysis study on the lived experiences of chronic pain amid the opioid crisis

Effective Date: April 8, 2021

Expiry Date: April 07, 2022

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

A Project Completion (Final) Report must be submitted when the research is complete (*i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable)*) or the research is terminated.

Approved by:

Date: April 08, 2021

Carolyn Greene, Chair
Athabasca University Research Ethics Board

Athabasca University Research Ethics Board
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