EXPLORING THE LIVED EXPERIENCE OF ADULTS USING PRESCRIPTION OPIOIDS TO MANAGE CHRONIC NON-CANCER PAIN

by

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SCHOOL OF HEALTH AND HUMAN PERFORMANCE

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TITLE: EXPLORING THE LIVED EXPERIENCE OF ADULTS USING PRESCRIPTION OPIOIDS TO MANAGE CHRONIC NON-CANCER PAIN

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DEDICATION

I dedicate this thesis to my rocks that kept me grounded, especially...

to Mom and Dad for reminding me of the importance of hard work and determination;

to my grandma B—I will always be your free spirit, who knows what my next journey will be;

to my friends for their motivation and encouragement and always reminding me of the light at the end of the tunnel;

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ABSTRACT

The use of prescription opioids for chronic non-cancer pain is complex. Opioids have the potential to alleviate discomfort and increase one's overall ability to function but, long-term use also has potential physical and psychological impacts. The purpose of this study was to explore the lived experience of adults who use prescription opioids to manage chronic non-cancer pain. Nine participants were recruited and interviewed. Participants were asked to describe how using prescription opioids had affected their lives. Interviews were recorded, transcribed and analyzed thematically using Interpretative phenomenological analysis (IPA). Eight themes emerged from the data: the process of decision making, physical effects of using opioids, social consequences of using opioids, guilt, fears, ambivalence, self-protection, and acceptance. Using opioids made pain more manageable and improved function for most of the participants. Nevertheless, using opioids was also associated with stigma, guilt, fears and ambivalence about their future as persons with chronic pain.
LIST OF ABBREVIATIONS USED

CNCP  Chronic Non-cancer Pain
IPA    Interpretive Phenomenological Analysis
PMU    Pain Management Unit
QEII   Queen Elizabeth Health Science Centre
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CHAPTER 1          INTRODUCTION

Chronic pain is one of the most common reasons to access the healthcare system (Boulanger, Clark, Squire, Cui, & Horbay, 2007; Vallerand & Nowak, 2009). However, due to its complex nature chronic pain continues to be a challenge for the individual with pain and for health care providers (Gallagher, 1999). Chronic pain is defined as ongoing or recurrent pain that has been present for at least three months or that has persisted longer than the time expected for tissue to heal (Merskey & Bogduk, 1994). While the physical symptoms of chronic pain are often managed adequately by prescription opioids, little is known about the emotional, social and psychological impacts opioid use has on an individual with chronic non-cancer pain (Veillette, Dion, Altier & Choinere, 2005). Clinical research supporting the use of prescription opioids as a management strategy for chronic pain has become more common over the last 20 years (Henry, 2008). In turn, there has been a dramatic increase in use of opioids for chronic pain (Silversides, 2009; Vallerand, 2003) and an increase in individuals misusing to their prescription opioids in Canada (Fischer, Rehm, Patra, & Firestone-Cruz, 2006). This is a huge concern for both individuals with chronic pain and physicians who prescribe them.

There are approximately seven million Canadians taking prescription opioids for their chronic pain, but many continue to suffer and struggle to find adequate relief (Lynch & Watson, 2006). Although opioids are prescribed for chronic pain, and have been proven to decrease pain levels, some individuals take a lesser dose than prescribed for a variety of reasons including fear of addiction or guilt; as a result they may never find the relief they need (Broekmans, Dobbels, Milisen, Morlion & Vanderschueren, 2009;
Manchikanit, Siram, Trescot & Giodano, 2008). The under-treatment of chronic pain conditions continues to be a major concern within our healthcare system (Lynch et al., 2008). Consequences of under-treated chronic pain include needless physical and emotional distress, increased burden to the health care system, economic costs and strain on relationships (Barkin et al., 1996; Henry, 2008). In 2002 only 32% of primary and palliative care physicians in Canada admitted that moderate to severe chronic pain was well managed (Boulanger et al., 2002). In order to better support patients who are using opioids, physicians need to understand the complexities of using prescription opioids for chronic non-cancer pain.

1.1 Purpose

The purpose of this study was to develop an understanding of individuals’ lived experience of using prescription opioids to manage chronic non-cancer pain (CNCP). Smith, Flowers and Larkin (2009) describe a lived experience as, “tantalizing and elusive…never accessible, as we witness it after the event” (p.33). When individuals engage with an ‘experience’ of something major in their lives, they begin to reflect on the significance of what is happening. Exploring the lived experience allowed the researcher to engage in these reflections and look at how the participants made sense of a major transition in their life (Smith et al., 2009). The research question being asked was, “What is the lived experience of adults using prescription opioids to manage chronic non-cancer pain?” More specifically, the researcher explored how using prescription opioids impacted psychological, emotional, social and physical aspects of the lives of individuals with CNCP conditions.
The use of prescription opioids for the management of acute and cancer related pain is well established in the literature (American Chronic Pain Society, 2009; Canadian Pain Society, 1998; Chou, et al., 2009b), yet very little has been researched on the impacts of prescription opioid use, specifically from a qualitative perspective. Not only does this gap in research leave many healthcare professionals reluctant to prescribe opioids but many individuals hesitant to take them due to stigma, adverse affects and risks of addiction and dependency (Gardner & Sandhu, 1997; Hutchinson, Moreland, Williams, Weinman & Horne, 2007; Katz, 2008). To date, only one published qualitative study has been located that specifically asked individuals with chronic pain how the use of prescription opioids has impacted their lives (Vallerand & Nowak, 2009). The results of this study revealed that even though prescription opioids can increase one’s functional abilities and improve quality of life, using prescription opioids is very complex (Vallerand & Nowak, 2009). This study revealed the personal experiences and the complexities involved in using prescription opioids. By focusing on the experience of using prescription opioids to manage CNCP, the present study begins to build on the limited amount of qualitative literature published to date.

1.2 Significance of the Study

This research is relevant to Nova Scotians who suffer from CNCP and health professionals involved in their care. It is estimated that as many as 182,000 Nova Scotians live with chronic pain and this number continues to increase (Nova Scotia Chronic Pain Working Group, 2006). The direct health care costs for individuals who have chronic pain in Canada are estimated to be more than $6 billion per year (Canadian Pain Coalition, 2011). By 2025, with the aging population, these costs can be expected to
rise to more than $10 billion per year (Phillips & Schopflocher, 2008). The Nova Scotia Chronic Pain Working Group’s Action plan (2006) revealed that the majority of physicians are not equipped to deal with chronic pain due to the lack of adequate pain training and lengthy waitlists to see a pain management specialist in Nova Scotia. Dr. Roman Jovey, Steering Committee Member and Past President of the Canadian Pain Society, agrees that chronic pain is a growing problem within Canada:

   Our growing pain crisis will only intensify if we don’t provide appropriate treatment to people on a timely basis. Pain is hurting Canada — on both an individual and societal level — and it is a national embarrassment that our medical system pays so little attention to a problem that is so common and costly (“Pain hurts our economy,” 2009, para. 3)

There is a need for better pain management in Nova Scotia. Early intervention is needed to reverse or prevent chronic pain. In addition, lack of pain management services contributes to the misuse of opioids (Nova Scotia Chronic Pain Working Group, 2006).

Prescription opioid use has received considerable negative attention in media reports (Whelan, Asbridge & Haydt, 2011). This negative attention has left individuals with chronic pain who take opioids appropriately feeling stigmatized, as if they might be doing something wrong (Slade, Molloy, & Keating, 2009). The fear of addiction may cause patients who are currently using opioids to attempt to stop their opioids without advising their doctors. This stigma associated with opioids may also effect patients who are doing well on this medication to worry that the adverse publicity might encourage their doctors to stop prescribing opioids (Broekmans et al., 2009). However, the vast majority of people in pain, who use their opioid medications properly, benefit from
reduced pain and an improved quality of life (Eriksen, et al., 2006; Katz, 2008).

Giving an opportunity for individuals with CNCP to tell their stories about opioid use allows health care professionals to better understand the complexities involved in living with chronic pain. The results of this study will not only contribute to current research, but hopefully enhance healthcare providers’ understanding of the positive and negative aspects of using prescription opioids for individuals with CNCP.

1.3 Summary

To further explore the ways in which opioids affect health and well being of those living with chronic pain, further research is needed. Current research, although limited, demonstrates the potential benefits that opioids can provide someone experiencing chronic pain (Vallerand & Nowak, 2009); however, there are many complexities involved in using them daily. The research presented in this thesis expands this knowledge base. The next chapter reviews current evidence in the areas of chronic pain and prescription opioid use. Chapter three explains the methodology used in shaping this research as well as the study design, and ethical considerations. Chapter four provides an in-depth description of each participant and their lived experience of having CNCP. This chapter was written to capture the rich data collected throughout the interviews describing the pain journey of the each participant and the complexities of living with CNCP. The findings of the study are given in Chapter five. In Chapter six, the findings of the research are discussed within the context of the current literature focussing on the meaning of chronic pain and opioid use in relation to stress and coping and the movement towards acceptance of the experience. The study limitations and health promotion
implications of this research from a chronic pain perspective and the use of prescription opioids are discussed.

It is anticipated that the results of this study will provide opportunities to better understand the complexities of using prescription opioids for CNCP. Through publication, it will contribute to the limited research available on how opioid use impacts quality of life from an individual’s perspective. Because this is an exploratory study, it will identify areas of further inquiry for future research.
CHAPTER 2    LITERATURE REVIEW

This chapter presents a review of the relevant literature related to CNCP and prescription opioid use. It begins by defining chronic pain and discusses prevalence, consequences, coping and management strategies. This chapter also defines prescription opioids and describes aspects of opioid use for CNCP including barriers, effects and risks of addiction and dependency. The importance of capturing the individual’s perspective about this often-contentious topic is also captured to conclude this chapter.

2.1 Chronic Non-Cancer Pain

Chronic Non-Cancer Pain (CNCP) is defined as pain that has been present for at least three months or lasting longer than the expected time to tissue healing or resolution of the underlying disease (Merskey & Bogduk, 1994). More specifically, it is often conceptualized as a symptom of diseases and can occur because of conditions involving ongoing nociception or damage of the pain pathways, such as in neuropathic pain (American Chronic Pain Society, 2009; Lynch & Watson, 2006). However, in many cases, CNCP occurs in the absence of a specific pathology or diagnosis, making it even more difficult to treat (Vallerand & Nowak, 2009). Some of the more common types of CNCP include osteoarthritis, rheumatoid arthritis, low back pain, shoulder and neck pain, headache, myofascial pain syndromes, chronic regional pain syndromes, phantom limb pain, neuropathic pain, diabetic neuropathy, temporomandibular joint disorder, angina pectoris, and chronic visceral pain syndromes (Henry, 2008). Although the term CNCP encompasses pain associated with a wide variety of conditions, the overall treatment goal is to decrease pain and improve physical functioning. CNCP not only has physical consequences but over time has psychological, emotional, social, occupational and
recreational consequences which in turn affects the individual’s quality of life (Clarke & Iphofen, 2007). Other terms previously used for this type of pain include chronic non-malignant pain, persistent pain and chronic benign pain (Smith & Osborne, 2007; Vallerand & Nowak, 2009). For the purpose of this study the term chronic non-cancer pain will be used.

2.1.1 Prevalence of Chronic Pain

Not only is chronic pain a significant burden that negatively affects an individual’s well-being (Gerstle, All, & Wallace, 2001; Vallerand & Nowak, 2009) and is also “a major public health problem and has reached epidemic proportions in Western society” (Smith & Osborn, 2007, p. 518). Pain is among the most disabling problems globally (Goldberg & McGee, 2011). A survey of approximately 46,000 Europeans showed that the prevalence of chronic pain ranged from 12% to 30%, with the highest rates in Norway, Poland and Italy, and the lowest in Spain, Ireland and the UK (Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006). A survey of over 17,000 Australians revealed prevalence rates of males and females with chronic pain to be 17.1% and 20% respectively (Blyth, March, Brnabic, Jorm, Williamson, & Cousins, 2006). In 2002, persistent pain affected approximately 29% of Canadians (Moulin, Clark, Speechly, & Morley-Foster, 2002). A more recent telephone survey revealed 38.4% of Canada’s general population reported having pain on a daily or near daily basis (Toth, Lander, & Wiebe, 2009).

A survey conducted with 242 patients with CNCP reported significantly lower quality of life in comparison to a healthy population (Elliott, Renier, & Palcher, 2003).
Due to the lack of understanding about chronic pain management and the complexities involved, over time, the individual will encounter many physical and psychosocial consequences as a result of their chronic pain (Henry, 2008).

2.1.2 Consequences of Chronic Pain

Although chronic pain typically stems from an initial injury or condition, it can be described more accurately as a life situation than a sudden event (Clarke & Iphofen, 2007). Regardless of cause, the impacts of chronic pain can be devastating for individuals in a variety of ways (Hensing, Sverker, & Leijon, 2007). Chronic pain is associated with unnecessary physical, psychological and emotional distress (Veillette et al., 2005). Many individuals with chronic pain experience sleep disturbances, decreased cognitive and physical function, interference with activities of daily living, decreased productivity, increased anxiety and decreased quality of life (Barkin et al., 1996; Blyth et al., 2001; Kugelmann, 1999; Smith & Osborn, 2007, Vallerand & Nowak, 2009). Chronic pain causes feelings of depression, isolation and disruptions in social relationships (Barkin et al., 1996; Moulin et al., 2002; Thomas & Johnson, 2000). Results of a qualitative study with individuals with CNCP conducted by Osborn and Smith (2006) described the experience of chronic pain as “living with a body separate from the self” (219). Participants spoke about a heightened awareness of the pain in a particular place on the body but they focussed on the psychological disconnectedness they experienced from that body part. The more an individual experiences negative physical and psychological consequences of their pain, the more likely they are to seek help in managing it (Lee, Chronister, & Bishop, 2008).
2.1.3 Management of Chronic Pain

The overall goal of managing chronic pain is to provide sufficient relief in order for the individual to live and function at a level of comfort with minimal limitations (Vallerand, 2003). When an individual is experiencing pain, they seek out a variety of different coping mechanisms in order to reduce their pain and regain their psychological and physical wellbeing (Unruh & Henriksson, 2002). Individuals coping with chronic pain, experience an ongoing process of appraisals of stress with cognitive, behavioural, and emotional coping responses, and subsequent reappraisals of the stress (Lazarus & Folkman, 1984). Finding a successful pain management strategy to manage the stress of chronic pain can be a very difficult and frustrating process. Both patients and health care professionals involved in their care become frustrated when treatments are ineffective and physical and psychological pain becomes prolonged (Thomas & Johnson, 2000). In an attempt to decrease chronic pain, both non-pharmacological and pharmacological coping strategies are often used. Non-pharmacological strategies include: exercise, relaxation, massage, applied heat, spirituality, leisure activities etc. Pharmacological strategies include: prescription cannabis and opioids. Although opioids are shown to greatly benefit individuals with CNCP, numerous other treatment options are often attempted prior to and in combination with opioid use as a primary mode of pain management (Vallerand & Nowak, 2009).

2.2. Prescription Opioids and Chronic Pain

Due to the subjective nature of chronic pain, it is often difficult to diagnose and is poorly managed (Gallagher, 1999). Prescription opioids, when used appropriately, have
the ability to alleviate pain and potentially help the individuals living with CNCP to regain the positive aspects of their life while decreasing the focus on pain (Gardner-Nix, 2003; Vallerand, 2003).

Opioids are defined by the National Institute of Drug Abuse (NIDA) as the controlled drugs or narcotics most often prescribed for the management of pain. They are natural or synthetic chemicals based on opium's active component morphine and work by mimicking the actions of pain-relieving chemicals produced in the body (NIDA, 2010). The most commonly used opioids for the management of pain in Canada are: codeine, morphine, oxycodone, hydromorphone, fentanyl and methadone (Lynch & Watson, 2006). The goal of long term opioid therapy for chronic pain is to improve the quality of life for the individual with pain (Canadian Pain Society, 1998).

For some individuals with CNCP, deciding to use prescription opioids long term to manage their pain can be a very difficult decision. Prescription opioid use for the management of CNCP has been a very contentious and highly debated topic over the past several years in professional literature and in the media. Nevertheless, opioid prescriptions have increased substantially over the last 30 years (Eriksen et al., 2006; Manchikanti & Singh, 2008; Vallerand, 2003).

The use of opioid analgesics for chronic pain was introduced following evidence from randomized control trials that opioids could provide long term pain relief for those with CNCP (Jovey et al., 2003). In 1993, the College of Physicians and Surgeons of Alberta became the first professional licensing body in North America to publish guidelines for opioid use in chronic non-malignant pain (Jovey et al., 2003). Currently in
Canada, prescription-opioid consumption has increased by about 50% between 2000 and 2004 (International Narcotics Control Board, 2009). Canada is the world’s third-largest opioid analgesic consumer per capita (International Narcotics Control Board, 2009).

Although the use of prescription opioids has become more common for chronic pain, there are still physicians who remain hesitant to prescribe them and individuals hesitant to use them leaving many pain sufferers without adequate relief (Gunnarsdottir, Donovan & Ward, 2003; Katz, 2008; Katz et al., 2007). A telephone survey of approximately 2010 random Canadian adults revealed that 80% reported experiencing moderate to severe pain yet only 22% of them were being treated with an opioid analgesic leaving over half of those with CNCP without adequate pain relief (Moulin et al., 2002).

2.3 Barriers to Opioid Use to Manage CNCP

Although CNCP is a common reason patients consult healthcare providers, it is frequently inadequately treated for a number of reasons, leading to needless physical and emotional distress and decrease in quality of life for the individual seeking help (American Academy of Pain Medicine, 2009; Gerstle, All, & Wallance, 2001; Lynch et al., 2008; Sullivan & Ferrell, 2005). Although an individualized treatment approach which focuses on physical rehabilitation and psychological strategies is commonly used for pain management, “medication often remains a cornerstone of chronic pain treatment” (Broekmans et al., 2009, p. 115). The increase in opioid prescribing has been accompanied by increases in misuse, abuse, serious injuries and overdose-related deaths among people taking these drugs (Glajchen, 2001; Gunnarsdottir, Donovan, & Ward,
2003; Vallerand and Nowak, 2009). Common barriers to opioid treatment for CNCP include difficulty accessing pain specialists with permission to prescribe opioids, inadequately prepared clinicians, and fear and guilt of patients’ regarding risks associated with dependency and addiction (Glajchen, 2001). These barriers stem from misconceptions and lack of guidance and education related to the use of prescription opioids for chronic pain (Chou et al., 2009a; Katz et al., 2007; Rathmell & Jaimison, 1996; Vallerand & Nowak, 2009).

2.3.1 Healthcare System

A major barrier to adequate treatment is long patient waitlists to see specialists which sometimes can be as long as eight months (Lynch et al., 2008). A qualitative study done in the south of England with 20 participants who attended two pain clinics looked at their experience within the healthcare system (Walker, Holloway & Sofaer, 1999). The themes included: long wait periods for referrals, feeling insignificant, getting nowhere, sense of loss and losing faith. A recent review of the literature comparing wait times in Canada for treatment of chronic pain care and patient quality of life was completed (Lynch et al., 2008). Results identified that wait-times for treatment at publicly funded pain clinics across Canada are unacceptable. It was reported that, “the patients experience a significant deterioration in health related quality of life and psychological well being while waiting for treatment for chronic pain during the 6 months from the time of referral to treatment” (Lynch et al., 2008, p. 97).

2.3.2 Healthcare Providers
Healthcare providers can play an important role in providing appropriate information for individuals with CNCP; however, a study surveying Canadian physicians revealed that 68% do not believe moderate to severe chronic pain is well managed in Canada (Boulanger et al., 2002). Contributing to this alarming statistic is the lack of education for healthcare providers specifically dedicated to pain management and treatment. A study by the Canadian Pain Society compared the hours of pain education for students in Health Sciences and Veterinary programs in 10 major universities throughout Canada. Outcomes from this study show that medical schools in Canada provide little training in pain management with an average of 16 hours over four years of course work compared to the 87 hours of pain training in Veterinary school (Watt-Watson et al., 2009). Inadequate training of physicians in Canada jeopardizes the safety of chronic pain patients who are seeking expert opinions and care (Dubois, Gallagher, & Lippe, 2009). “Although the need for improved care of pain is well documented, and the effectiveness of appropriate pain treatment through comprehensive pain centers is established, the healthcare system’s performance in preventing and treating non-cancer pain remains generally poor” (Gallagher, 1999, p. 577).

2.3.3 Adverse Effects of Opioids

There is a growing body of evidence that support the use of opioids for the management of CNCP (Chou et al., 2009; Lynch & Watson, 2006; Katz, 2008). However, in addition to the benefits opioids can provide, opioids also produce adverse physical effects. Common side effects from opioids include sedation, nausea, perfuse sweating, constipation, and vomiting (Lynch & Watson, 2006; Vallerand, 2003). Little is known about the current prevalence rates of cannabis use for pain disorders in Canada;
however, many individuals who use opioids, also use prescription cannabis (Abrams, Couey, Shade, Kelly, & Benowitz, 2011; Ware, Doyle, Woods, Lynch, & Clarke, 2003). Cannabis used in conjunction with opioids for pain has been shown to decrease the amount of opioids needed to reach an analgesic effect and counter the negative side effects a person with pain experiences from opioid use (Abrams, et al., 2011; Cichewicz, 2004). A survey completed with individuals using cannabis for CNCP in 2001 supports claims that pain, sleep and mood are frequently improved by cannabis use (Ware et al., 2003). More research is needed to further confirm the therapeutic benefits of both cannabis and opioid use for CNCP.

2.3.4 Risks of Addiction, Dependency and Diversion

Prescription opioids are widely feared within our society because they are associated with addiction (Glajchen, 2001); however, they are also the most effective medications for relief of pain and frequently used to treat pain (Gallagher & Rosenthal, 2008). Many physicians and health care professionals are reluctant to support the use of opioid medication by patients with chronic pain because of the concerns about adverse effects such as addiction (Gallagher, 2004; Wiedemer, Harden, Arndt, & Gallagher, 2007). Individuals with chronic pain who use prescription opioids will exhibit physical dependence to opioids if opioids are suddenly withdrawn. Exhibiting physical dependence is often wrongly labelled as being addicted (Ballantyne & LaForge, 2007). Physical dependence is defined as “a state of adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist” (Savage, Joranson, Covington, Schnoll, Heit & Gilson, 2003, p. 662). In contrast,
addiction is “a primary, chronic, neurobiologic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations, such as impaired control over drug use, compulsive use, and continued use despite harm, and/or craving” (Savage et al., p. 662). The confusion between physical dependence and addiction, and the misconceptions associated with opioids taken for pain often create barriers for many individuals seeking medical attention for chronic pain. A person who is using opioids for pain but misusing them by not taking them as prescribed may also be at risk for being perceived as addicted because they may search for more medication due to severe breakthrough pain.

The term “prescription medication” or “pain killers” evokes a negative reaction due in part to the media portrayal of the use of opioids as problematic or leading to addiction (Peppin, 2009; Wilsey, Fishman, Crandall, Casamalhuapa, & Bertakis, 2008). This negative connotation of opioid medication means that individuals who take opioids appropriately to treat chronic pain may feel stigmatized or labelled (Holloway, Sofaer-Bennett, & Walker, 2007; Katz, 2008). These individuals may be made to feel as if they might be doing something wrong and may hide their need for opioid medication from family members, co-workers, and employers, resulting in low patient adherence and unrelieved pain (Broekmans et al., 2009). On the other hand, the fear of addiction may cause patients currently using opioids to attempt to stop their opioids, or not adhere to the appropriate therapeutic dosing without advising their doctors, which in turn will hinder their treatment or management regime.

It is estimated that the risks of developing addictive behaviour towards their prescription medication by chronic pain patients is approximately 4% (Butchart, Kerr,
Heisler, Piette, & Krein, 2009). Fleming et al. (2007) examined the rate of substance-use disorders in 801 adult patients using daily opioids to manage CNCP. Results revealed that only 3.7% met DSM-IV clinical criteria for an opioid-use disorder, either abuse (0.6%) or dependence/addiction (3.1%). Broekmans et al. (2009) conducted a systematic review of 14 studies on medication adherence in patients with CNCP. The study suggested that medication underuse (29.9%) is more likely to occur than medication overuse (13.7%). It is important as a healthcare professional to understand and be able to communicate the difference between addiction and physical dependency. Not knowing these differences can create a barrier to a person in pain in receiving adequate treatment (Gunnardsdottir, Donovan & Ward, 2003).

Many people who have chronic pain, use prescription opioid medications properly and therefore benefit tremendously from reduced pain and an improved quality of life. Although there is a risk of opioid addiction within the pain population who use opioids, a practical balance between opioid risk reduction and optimal pain treatment can be reached (Katz et al., 2007). Gourley and Heit (2008) believe it is important for the healthcare professional, the pharmacist and the chronic pain individual to all take responsibility to achieve effective pain management through opioid therapy. This collaboration creates a balance between the prevention of the misuse of prescribed opioids and the assurance of the availability of these medications to all who need them for the relief of pain can be achieved (Gourley & Heit, 2008).

To adequately manage CNCP with prescription opioids, understanding the adverse effects and the benefits of prescription opioids is essential. Using prescription opioids for the management of CNCP does not guarantee complete pain relief or
elimination of the psychosocial issues that often results from chronic pain conditions but, they do allow many individuals to regain a sense of independence and control over their lives (Passik, 2009).

2.4 The Individual’s Perspective

One important component to understanding a patient with chronic illness involves “getting inside the experience of such (chronic) illness” (Price, 1996, p. 275). Because chronic pain is a subjective phenomenon with no true quantitative measure, the experience of the patients’ experience varies tremendously (Clark & Iphofen, 2007). Understanding how chronic pain has affected all aspects of a patient’s life and establishing effective pain management through the use of opioids may help improve the patient’s overall quality of life (Vallerand, 2003).

There is a great deal of literature using quantitative measures to assess the pain experience (Strong, Sturgess, Unruh & Vicenzino, 2002). Although these tools are useful in measuring certain aspects of pain they do not represent the complexity of an individual’s unique experience with chronic pain.

One study directly explored the impact of opioids on chronic pain patients’ quality of life and revealed that opioids in fact improved one’s quality of life and levels of functioning (Vallerand & Nowak, 2009). Understanding more about the potential advantages opioids offer individuals with chronic pain is essential for a more effective management plan of CNCP (Vallerand, 2003).

The effects of using opioids from a patient’s perspective have not been well documented in research in the context of CNCP. This significant gap in research represents a deficit in knowledge, given the high prevalence of CNCP. Along with the
high prevalence of CNCP, there has been a significant increase in the use of chronic opioid therapy. The need for ongoing qualitative exploration of individuals’ experiences to begin to understanding this complex phenomenon is imperative. To enhance the quality of care of individuals with chronic pain and the confidence of prescribing physicians it is necessary to explore the experience of opioid therapy has on adults with chronic non-malignant pain (Vallerand & Nowak, 2009).
3.1 Methodological Approach: Interpretive Phenomenological Analysis

The term phenomenology was first established within the practice of philosophy in the 18th century (Dowling, 2005). Over time, phenomenology has evolved into both a philosophy and a qualitative research method used to understand, interpret, and describe particular phenomena (Morse & Field, 1995). “From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings” (van Manen, 1990, p. 5).

The most common method of data collection in phenomenological research is the in-depth interview (Smith et al., 2009). “Interviews are particularly suited for studying people’s understandings of the meanings in their lived world, describing their experiences and self-understanding, and clarifying and elaborating their own perspective on their lived world” (Collingridge & Gantt, 2008, p. 393). The descriptions produced help the researcher to better understand the deeper meaning of the participants’ experience (Lopez & Willis, 2004). Although there are many qualitative methods to research such as grounded theory, narrative account research and ethnography, Interpretive Phenomenological Analysis (IPA) is the preferred qualitative approach for this study (Smith et al., 2009). IPA thrives on the views and perceptions of what the experience is like for the participants as individuals and assumes that “the words participants employ when talking about a phenomenon can tell you something about the phenomenon itself” (Osborn & Smith, 2006, p. 218).

The evolution of phenomenology in the last century has been dynamic and it
continues to expand and develop. Lopez and Willis (2004) describe phenomenology as a “philosophical movement” (p. 728) referring specifically to the ever changing ideas and theories advanced by many different phenomenologists. Throughout the evolution of phenomenology, different concepts and methods of phenomenology have emerged; however, they all share a particular interest in what the lived experience is like within one’s life world (Smith et al., 2009). The life world refers to “being what is experienced pre-reflectively” (Tan, Wilson, & Olver, 2009, p. 3). It is often difficult, especially for novice researchers, to distinguish between descriptive phenomenology, hermeneutic phenomenology and IPA without fully understanding their roots.

3.1.1. Descriptive Phenomenology

Phenomenology started out as a descriptive process of understanding one’s lived experience of a particular phenomenon (Smith et al., 2009). The main process involved in descriptive phenomenology focus first on the researcher gathering concrete descriptions of a specific experience from the study participants. Secondly, the researcher must adopt the attitude of phenomenological reduction (Dowling, 2005) with the final goal of seeking commonalities or universal essences within the data produced by each research participant (Lopez & Willis, 2004).

Edmund Husserl was one of the first philosophers to use a descriptive approach to phenomenology which he adopted from Franz Brentano’s writings in the early 1800’s (Dowling, 2007). The three main ideas that help to define descriptive phenomenology are essences, intentionality, and phenomenological reduction (Koch, 1995; Racher & Robinson, 2003).

Phenomenology is a reflective study of the essence of consciousness as
experienced from the point of view of the person being asked (Fade, 2004). Dahlberg (2006) described essence as “a structure of essential meanings that explicates a phenomenon of interest” (p.11). Husserl believed that the essence of a phenomenon can be understood by revisiting a person's conscious experience prior to any reflections or thoughts through interaction between the researcher and the participant (Wojnar & Swanson, 2007).

In order to describe a particular phenomenon, Husserl believed one must intentionally focus one’s awareness and come face to face with that experience (Laverty, 2003). In other words, it is believed that all human activity is guided with intention and as humans we are always thinking about something whether we are conscious of it or not (van Manen, 1990). There is an inseparable connection among humans and the world and to understand this connection, researching the lived experience is essential (van Manen, 1990).

van Manen (1990) stated, “Phenomenology must describe what is given to us in the immediate experience without being obstructed by pre-conceptions and theoretical notions” (p. 184). Knowing that pre-understanding or personal biases could potentially get in the way of revealing pure descriptions of a lived experience, Husserl focused on the importance of phenomenological reduction (Dowling, 2007). Phenomenological reduction is successful when the researcher is able to “successfully abandon his or her own lived reality and describe the phenomenon in its pure universal sense” (Wojnar & Swanson, 2007, p. 173). This process is referred to by some phenomenologists as bracketing or epoche (Moustakas, 1994). In the bracketing or epoche process, it is
important to first acknowledge what we know, our judgments and understandings, and set it aside for a clear way of understanding (Moustakas, 1994).

3.1.2 Hermeneutic Phenomenology

Like descriptive phenomenology, hermeneutic phenomenology is concerned with the life world or human experience as it is lived through a particular lens (Smith et al., 2009). However, it takes the process of describing the phenomena to another level of interpretation by both the researcher and the individual being studied. Hermeneutic phenomenology searches for deeper meanings within the data to enhance understanding and unmask hidden themes (Lopez & Willis, 2004; Moustakas, 1994).

Martin Heidegger, who was once a student of Husserl, modified and developed his approach to phenomenology (Wojnar & Swanson, 2007). However, he challenged many of Husserl’s beliefs. Heidegger did not agree that phenomenology is solely descriptions of an individual’s account with a particular phenomenon. He believed that humans are interpretive by nature and that it was impossible to separate interpretation from their personal background or experiences (Wojnar & Swanson, 2007). This idea that humans and the world are inseparable is also known as “being-in-the-world” (Lopez & Willis, 2004, p. 729). The goal of hermeneutic phenomenology is not to re-live another’s experience but rather to identify within the text the possible experiences of living in the world through different contexts (van Manen, 1990).

Husserl trained Heidegger in the processes of understanding essence, intentionality and phenomenological reduction (Laverty, 2003). Hermeneutic phenomenology takes understanding a lived experience beyond describing the essence. Heidegger’s phenomenology focuses on Dasein, which refers to “the essential nature of
human beings” in the world (Tan et al., 2009, p.4). In other words, it focuses on the interconnection between individuals and the contexts that influence the lived experience (Wojnar & Swanson, 2007). It is essential to take into consideration the context in which one’s life world exists to fully understand experience. Rather than ignore what is already known, it is important to use that knowledge to guide investigations and analysis (Koch, 1995). To elaborate on this concept, Heidegger did not believe it was possible to bracket assumptions, pre-understandings and judgments, but rather that through reflection researchers make explicit their knowledge and understandings (Lopez & Willis, 2004). Most hermeneutic phenomenologists do not agree that it is possible to set aside or bracket their experience and understandings and many believe that personal knowledge is what makes the research meaningful in the first place (Lopez & Willis, 2004).

Heidegger emphasized the concept of constitutionality which describes that the interpretations of the data are not solely that of the researcher but “a blend of the meanings articulated by both participant and researcher within the focus of the study” (Lopez & Willis, 2004, p. 730). From Heidegger’s point of view, the researcher’s beliefs and knowledge are embraced and are seen as necessary for research to occur in the first place. Trying to bracket or remove this knowledge is impossible and undesirable.

The analytical process of understanding and interpreting the data is often referred to as moving through the hermeneutic circle (Dowling, 2005; Laverty, 2003; Wojnar & Swanson, 2007). This process involves “moving back and forth between the data” (Wojnar & Swanson, 2007, p. 175) through the whole and parts of the experience to gain a deeper understanding of the meanings.

To summarize, hermeneutic phenomenology places significant emphasis on
describing and interpreting to fully understand lived experiences beyond by description alone (Tan et al., 2009). Hermeneutics revolves around the understanding that the researcher and the participants come together through the process of interviewing, interpreting the data and moving back and forth through the hermeneutic circle to develop accurate interpretations of the experience being studied.

3.1.3 Interpretive Phenomenological Analysis

Over the last two decades phenomenology has made a significant shift from being viewed as a philosophical approach in qualitative research to a more qualitative methodology in health psychology (Smith, et al., 2009). Jonathan Smith was the founder of interpretive phenomenological analysis (IPA) which stems from ideas based on Husserl’s descriptive phenomenology, the evolution of hermeneutics and idiography (Smith et al., 2009).

Like descriptive and hermeneutic phenomenology, IPA is phenomenological as it aims to discover and understand the lived experience of a particular human experience (Smith et al., 2009). Smith draws on Husserl’s views that there is an inseparable relationship between the researcher and the participant (Larkin et al., 2006). Contrary to Husserl’s views regarding bracketing, in IPA research “the researcher’s beliefs are not seen as biases to be eliminated but rather as being necessary for making sense of the experiences of other individuals” (Fade, 2004, p. 648). As the evolution of phenomenology continues, healthcare researchers are realizing the importance of using qualitative research methods, such as IPA to begin to understanding the lived experience or certain phenomena (Biggerstaff & Thompson, 2008). Hermeneutic phenomenology contributed greatly to the development of IPA. Heidegger’s belief that humans are
interpretive by nature was also at the forefront of Smith’s direction of IPA. As interpretive beings, it is nearly impossible to separate ourselves from the world or bracket our pre-understandings to understand the true lived experience (Larkin et al. 2006). Smith supported the hermeneutic circle described by Heidegger and described the process of moving back and forth through the data as iterative (Smith et al., 2009).

The development of IPA combines both descriptive and hermeneutic concepts. In order to gain insight into the participant’s lived experience, he or she must describe that experience to fully understand an experience but interpretation by both the researcher and participant must occur (Smith et al., 2009). This dualistic approach of both description and interpretation is essential. As Smith said, “Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen” (Smith et al., 2009, p. 37). IPA differs from both Husserl and Heidegger’s main goal of looking for commonalities within the data in that IPA studies each case individually in its entirety before moving on to a detailed analysis of another case (Smith & Osborne, 2007). By studying each case individually in combination with bracketing existing thoughts and biases, the researcher experiences the data in its purest form which enhances the interpretation. The overall goal of IPA is to give a voice to those less heard and to use the narrative account to not only explore, describe, and interpret, but also to situate the participant’s experience in a context that makes sense to that particular experience (Larkin et al., 2006).

3.2 Rationale for Choosing IPA

Interpretive phenomenology analysis (IPA) offers a framework for developing insight into the unique experiences of individuals, taking into consideration that patient’s
context. Using in-depth interviews to collect data allows the researcher to enter the participants’ life world and facilitates the discussion of relevant topics wanting to be explored (Smith et al., 2009). Approaching the topic of opioid use through an interpretive phenomenological lens sheds light on how patients are experiencing their everyday lives with the use of opioids to manage their chronic pain conditions. Often times, the experiences of individuals who suffer from a certain debilitating condition or who are from a marginalized population are neglected or suffer needlessly due to their social context. Giving individuals who suffer from chronic pain an opportunity to tell their story reveals not only the lived experiences they face daily but also empowers those participants whose voice may never have been heard. In IPA, the researcher seeks to understand how the participant’s life world and the idea of being-in-the-world has influenced the choices they make, specifically with opioid use, and takes into account various contexts that may influence their decisions (Lopez & Willis, 2004).

3.3 **Research Questions**

The primary research question being asked was, “What is the lived experience of adults using prescription opioids for the management of chronic non-cancer pain?”

The secondary questions are:

1) What does it mean to use prescription opioids to manage CNCP?

2) How has prescription opioid use impacted the lives of individuals with CNCP?

3) How has one’s quality of life changed since beginning prescription opioid use to manage CNCP?

These secondary questions along with the primary research question enhanced the design
of the interview guide (Appendix A: Interview Guide) which was used with each participant to lead the interviews.

3.3 Study Design

3.3.1 Sample

For this study, the participants were adults aged 18 years and older who were using prescription opioids daily to manage CNCP. Specific opioids referred to in the study included but were not limited to codeine, morphine, oxycodone, hydromorphone, fentanyl and methadone. Nine participants were recruited for the study, four males and five females. Maximum variation was desired in this study sample with various durations of pain, types of pain, and prescription opioids being used. Diversity in ages, employment status, support systems and overall experiences was desirable. The importance of having participants who have diverse experiences was to identify similarities and differences in themes in order to generate a broad spectrum of issues related to the research question and secondary questions of this study.

Exclusionary criteria for this study included language and cancer diagnosis. Those who did not speak English were excluded as the researcher is only English speaking. Individuals with cancer related pain were not recruited for this study as the study focused only on CNCP.

3.3.2 Recruitment

Participants were recruited directly from the Pain Management Unit (PMU) at the QEII in Halifax, Nova Scotia using purposive sampling. Using purposive sampling ensured that participants were selected based on a particular criteria to offer access to a
particular perspective on the phenomenon being studied (Patton, 2002; Smith et al., 2009). An Eligibility Checklist (Appendix B: Eligibility checklist) outlined the specific inclusion criteria. Specific inclusion criteria was met by the participants in order to be eligible for this study.

A recruitment letter about this study was given to current patients of the PMU during their appointments inviting them to participate in the study (Appendix C: Recruitment Letter). Participants were given the researcher’s email address and phone number as a main contact if they decided to participate in the study. As a secondary recruitment strategy, posters advertising the study were displayed in both the treatment rooms and the waiting area of the PMU to enhance recruitment (Appendix D: Recruitment Poster). For individuals who retrieved contact information from the poster advertisement and contacted the researcher, a detailed description of the study was provided over the telephone. If additional information was requested from the participant, a letter of information was mailed or e-mailed to them explaining in more detail the study being conducted.

Upon initial contact, the researcher reviewed the eligibility checklist with the participant to confirm that they met the eligibility requirements to participate in the study. If they were eligible and willing to participate, an interview date and time was set up. The recruitment and data collection took approximately 4 months.

3.3.3. Data Collection

Data was collected through semi-structured interviews lead by the primary researcher. The overall goal of semi-structured interviews is to allow the participant to freely respond to questions. Additional questions and prompts provide a guide for the
researcher as the answers to the questions cannot always be predicted (Morse & Field, 1995). The narrative accounts produced by the participants were the main sources of data used in the analysis. The participants were asked to take part in two in-depth interviews in which they were asked to describe their personal experience of using prescription opioids to manage their CNCP. The interviews were conducted through face-to-face or telephone conversations. All face-to-face interviews were completed in a treatment room at the PMU of the QEII in Halifax. The preferred method of data collection was face-to-face interviews. Only one participant requested a telephone interview. The option of a telephone interview allowed for maximum inclusion of those who wanted to participate but were unable to travel for the interview. This approach had benefits and limitations. A telephone interview did not require the participant to leave their home especially if chronic pain was severe. The drawback was that the researcher did not have access to the informal communication (hand gestures, facial expressions etc.) of the participant which could have enhanced the story being told. Overall, the benefits of incorporating a telephone interview outweighed the potential of losing a valuable voice in my study. In this case, the participant was requested to choose a private place and time to receive the telephone call and the interviewer audio recorded the telephone conversation.

Prior to beginning the interviews, an introduction of the researcher and description of the study was given to build rapport and allow the participant to feel more comfortable with the researcher. An explanation of the study was outlined and informed consent (Appendix E: Informed Consent) reviewed verbally by the researcher and written consent was obtained. The participants were informed that they were not required to participate in the study and they may stop the interview at any time or refuse to answer
any questions. They were informed that if they chose any of these options previously stated their services or treatment options received at the PMU would not be jeopardized.

The narratives provided in-depth perspectives related to the experience of what it is like to live with CNCP and the impacts of opioid use. During the interviews field notes were taken by the researcher. Field notes captured observations relevant to the data and provided an opportunity for the researcher to write down any additional prompts or questions that arose. The interviews were lead by an interview guide consisting of the following 5 questions:

1. Could you please tell me about your experience with chronic pain?
2. How has your pain affected your life?
3. How did you go about deciding you would use opioids to manage your pain?
4. What is it like to take opioids for chronic non-cancer pain?
5. How would you describe your life now compared to before you began using prescription opioid?

The interview guide also contained prompts related to each question in order cue the researcher to enquire about responses given by the participant. An effort was made to conduct a second interview with each participant after the researcher had coded and analyzed themes from the first interview. Only four of the nine participants returned for a second interview. Once the data from the first interview was analyzed by the researcher, a written summary of the analysis was mailed or emailed to the participant. The participant was given approximately 2 weeks to review the interpretations made by the researcher before an attempt to schedule a second interview was made. The purpose of the second interview was to validate interpretations made and clarify misconceptions of the
meanings of the interpretations. Some examples of interview questions that were used in the second interview after reviewing findings from the first interview were:

1. Are the ideas and themes that were identified from your first interview accurate?

2. Upon completing our first meeting, did you have any other comments or ideas that you wanted to discuss? If so please describe them.

3. Is there anything you would like to ask me?

Upon completion of both the interviews, participants were given an opportunity to ask any questions of the researcher. They were thanked for their time and contributions to the study.

To describe the sample, a demographic and medical data form was completed by each participant prior to beginning the interviews revealing information about age, sex, marital status, occupation, origin or cause of pain, number of years in pain, type and amount of opioid currently using, and length of time of daily opioid use (Appendix F: Medical and Demographic Information). For the individual who participated through the telephone interview, the researcher asked the participant the questions on the form and filled the answers in herself with the responses provided by the participant. The researcher also obtained informed consent verbally after reviewing the informed consent document that was mailed to the participant prior to the interview.

3.3.4 Data Management
After completing the interviews, the audio data was transcribed verbatim by the researcher on a digital file in Microsoft Word. After each interview was transcribed, it was checked against the original audio data by listening to each interview and reading the transcript simultaneously to ensure accuracy. Pseudonyms were assigned to replace any identifying information (such as names and places) to protect the confidentiality of the participants and any other person who was identified. Notes were taken regarding changes in voice and tone and significant pauses that could be of importance during the interpretation phase of analysis (Morse & Field, 1995). All hard copies of identifying information such as screening tools, consent forms, socio-demographic questionnaires, and transcripts were locked up in the researcher’s workspace. Electronic copies of data were kept on a password protected personal computer and backed up on an external hard drive which was also stored in a locked space with only access by the researcher.

3.3.5 Data Analysis

To interpret the data collected from the interviews, thematic analysis was used. “Thematic analysis refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (van Manen, 1990, p. 78). In other words, thematic analysis is a method for identifying, analyzing and reporting patterns or themes within data. Thematic analysis involves “flexible thinking, processes of reduction, expansion, revision, creativity and innovation” (Smith et al., 2009, p. 81). Data was organized electronically using Microsoft Word and analyzed by the researcher using the six step analytic process of interpretive phenomenological analysis (Smith et al., 2009). These six steps worked towards revealing both the individual’s experience, and the common experiences and shared
meanings of using prescription opioids to manage their CNCP. The following is an outline of the six steps.

Step 1- Reading and re-reading: To begin, listening to the audio-taped interview and reading through the transcript simultaneously to ensure transcription was accurate against the recording was done. The transcribed interview texts were read through several times. “Repeated reading also allows a model of the overall interview structure to develop and permits the analyst to gain an understanding of how narratives can bind certain sections of an interview together” (Smith et al., 2009, p. 82). The re-reading process also allowed the researcher to become immersed themselves in some of the original data to ensure that the participant remained the focus. In order to remain focused on the data, a reflective journal was used to help the researcher bracket any of her own ideas and separate them from the communication of the participants.

Step 2- Initial noting: Once familiar with the transcripts, notes were taken on anything of interest within the data that related to the research topic. For example, metaphors being used, or specific words that are common within the data were noted. Each electronic transcript was put into a chart in Microsoft Word to help organize notes during the analysis and interpretation. This step in the analysis began to identify specific ways by which the participant talked about, understood, and thought about their personal experiences and concerns. A line-by-line content analysis was conducted within Microsoft Word and a column labelled “exploratory comments” where descriptive, linguistic and conceptual comments was made alongside the data to facilitate coding, categorization, and synthesis of the data. Descriptive comments included key words, phrases or explanations which helped to identify the structure of the participant’s
thoughts and experiences. Linguistic comments included metaphors used, the tone of the participant’s voice, repetition of thoughts and pauses within the data that helped to connect descriptive notes to conceptual notes. Conceptual comments involved the researcher beginning to question the data and looking for the overarching themes of the particular data set. The overall goal of this step was to produce a detailed set of notes and comments about the data looking at the context of issues and identifying more abstract concepts and patterns.

Step 3- Developing emergent themes: In this stage of analysis, mapping the interrelationships, connections and patterns between exploratory notes within each individual transcript occurred. A shift from working primarily with the transcript to working with the initial notes was made which helped develop emergent themes. Having analyzed the transcript as a whole, the researcher moved to a deeper, more detailed, reading of the data. A column labelled “emergent themes” was located beside the exploratory comments from the previous step. This column included a concise, interpretive statement made by the researcher of the important message(s) within the exploratory notes which was then developed into an emerging theme within the data.

Step 4- Searching for connections across emergent themes: The emerging themes within a particular transcript were then organized chronologically. This allowed the researcher to visually see the participant’s meanings and connections by clustering the themes together. Once themes were identified, a summary of findings were typed up and either emailed or mailed to the participant to review. An attempt at setting up a second interview to review the findings and allow for further questioning occurred.
Step 5- Moving to the next case: Once analysis of one case was completed, the next step involved moving to the next participant’s transcript and the process was repeated. It was important to treat the next transcript completely separate from the previous one. When analyzing multiple transcripts one after another, bracketing the ideas and themes that emerged from the previous analysis was important in ensuring accurate interpretation of the data. A notebook was kept during the analysis process to record and attempt to bracket any further thoughts or feelings about the data.

Step 6- Looking for patterns across cases: After the analysis was conducted with each case, the next step involved looking for patterns across all cases being studied and connecting themes were identified. These patterns were identified as themes and subthemes outlined in the results.

The interpretation of research is an essential part of the data analysis process. The final analysis was seen as the product of that engagement with the data and interpretations made in collaboration by both the researchers and participants (Osborn & Smith, 2006). Data analysis was an ongoing process through the data collection stage in order to prepare summaries for a second interview with the participants.

3.4 Trustworthiness of the Study

The integrity and trustworthiness of this study was maintained through the following quality and rigor checks. Immediately before and after the interview, the audio recorder was checked to ensure it worked properly and that the voice of the participant was clear. The field notes taken during the interview were reviewed by the researcher immediately following the interview to ensure that they were accurate and clearly written in order to be understood at a later point.
3.4.1 Credibility & Dependability

Credibility refers to the confidence in the truth of the data and the corresponding findings. Inevitably, the analysis is a joint product of the participant and the researcher (Smith et al., 2009). Credibility or how reliable the findings are in relation to what the participants experience was established by attempting to conducting a second, follow up interview with each participant. During this process, also known as member checking, each participant was given their original transcript and a summary of the researchers findings to review. The second interview was intended to validate the themes with the participant as well as to achieve clarity and reveal any additional data. However, the second interview was only achieved with four participants. A maximum of four attempts to email and/or telephone the other participants were made but were unsuccessful in completing the second interview.

3.4.2 Transferability

To determine the transferability of this research, in-depth descriptions of all aspects of the research, including the participants, methods of data collection and analysis and limitations were provided in this document. An audit trail can be traced consisting of initial notes made, the steps taken to collect, manage, analyze and report data, including an interview schedule, digital copies of interviews, electronic transcripts, information about sampling, tables of themes, draft reports and final report. These detailed descriptions allows other researchers the opportunity to determine the appropriateness of applying the results of this study to another. The transferability of findings was compared with existing literature illustrating the parallels to other studies (Beck, 1993) and identify gaps in current research regarding the use of opioid therapy for CNCP.
3.4.3. Confirmability

Confirmability is ensured when findings are grounded in the data and representative of participants’ experiences rather than researcher biases and interest (Lincoln & Guba, 1985). This study has utilized a series of methods that ensure the fulfillment of these measures of trustworthiness. It is important to acknowledge the subjective nature of the study and the personal values, experiences and understanding of the issues of the researcher. Because the researcher’s background involved working with individuals with chronic pain who suffer from opioid addiction, it was important to identify personal biases and presumptions and make them explicit and known to those who were involved with the research project.

3.5 Ethical Considerations

Prior to recruitment of participants for this study, ethical approval from Capital Health Ethics Board at the QEII was obtained. At the start of each interview, an informed consent form was verbally reviewed and a signed copy obtained. The participants were informed that their participation was voluntary and that they had the right to decline to answer any question presented and that the tape recorder could be turned off at any time if they wished. Participants were also assured that their participation or withdrawal from the study would not jeopardize or affect their treatment or services from the PMU. Prior to beginning the first interview, the purpose of the study was reviewed and terms needing clarification were defined to avoid any misunderstandings. Participants were given an opportunity to ask any questions prior to beginning the interview. Due to the nature of chronic pain and understanding that interviews can be lengthy, participants were able to take breaks as needed in order to stretch or relieve some pain through light walking.
For the participant who preferred a telephone interview, a written consent form was mailed to them and verbal consent was received and recorded over the telephone prior to beginning the interview. The researcher prepared a listener-friendly explanation of the study with time for questions.

Participants were informed of the risks associated with this study. Due to the nature of the discussion, many of the participants experienced short term psychological discomfort or anxiety due to the thoughts, feelings, and experiences shared during the interview. Some examples of experiences that caused discomfort during interviews were a sense of loss of independence, loss of relationships, or traumatic experiences that initiated pain. To mitigate further potential harm, the participants were encouraged to speak with their physicians regarding their situation if needed. It was important to inform participants of situations where confidentiality would be broken due to the safety of the participant. These particular situations including identifying intent to harm themselves or others, or revealing ongoing child abuse or abuse of any adult in need of protection. Sharing of this information did not occur.

The content and questions that were asked during the interviews were asked at an eight grade level of comprehension. Interviews were conducted in an assigned room within the PMU at the QEII. For the participant who participated via telephone, it was important for the participant and researcher to find a location within their office or home to have the interview quiet and free of distractions and interruptions. The researcher has past experience with interviewing but conducted a pilot test with the study interview guide to insure appropriateness and flow of the questions. Information linking the transcripts to participants were kept in a separate secure location.
The power imbalance that may exist between the researcher and the participants must also be acknowledged. The purpose of the interview is to gather data and not to change participants or provide treatment. As an interviewer it was important to remain neutral and refrain from using counselling techniques and recognize that the participants are the experts within their situation.

In interpretive phenomenology, many researchers would say it is impossible to set aside or bracket their experiences or pre-understandings. Therefore it was important that the researcher be reflective and open to challenging her personal knowledge to remain true to the data and thus bring forward an interpretation that represents the experience of participant not the researcher (Smith et al., 2009). In order to achieve this, the researcher maintained active listening skills to the best of her ability during the interviews and the participant who was the expert, remained the sole focus. Upon completion of the interview, the researcher reflected on possible interpretations of the data through reflective writing and note taking. This task was important during the study to ensure accurate results and interpretations of the data collected from each participant.

3.6 Funding

This study was funded through Nova Scotia Health Research Foundation from September 2010 - August 2011.

3.7 Dissemination of Findings

Articles developed from these findings will be submitted to peer-reviewed academic journals such as The Journal of Pain, Pain Research and Management, and the Canadian Journal of Anaesthesia. As well, a presentation of this study was made at
Dalhousie University’s Department of Anaesthesia Research Day, Crossroads Student Research Conference and has been accepted for a poster presentation at the Canadian Pain Society Annual Conference.
CHAPTER 4              THE PARTICIPANTS

4.1 Overview

This chapter introduces the nine participants who took part in this study. The nature of their pain, the specific pharmacological and non-pharmacological methods of relief they are using and the effects of chronic pain is captured. Chapter five then examines their lived experiences of using prescription opioids for the management of CNCP.

4.2 Interview Overview

4.2.1 Time and Location

Interviews were conducted from mid March until late June of 2011. On average, the first interviews (9) were approximately 40 minutes in length and the second interviews (4) were approximately 20 minutes. All but two interviews took place in a treatment room at the Pain Clinic of the QEII in Halifax, NS. Two telephone interviews were conducted by the principal investigator in her apartment where she was alone and could maintain confidentiality and control the environment.

4.3 Participant Profiles

The participants’ demographic and medical data is summarized in Table 1. The average age of the participants was 52 years, with ages ranging from 40 to 68 years. The participants had the following chronic pain conditions: neuropathy, sciatica, migraines, low back pain, fibromyalgia, temporomandibular joint disorder, multiple sclerosis, lupus, ruptured discs, and arthritis. Most participants had multiple sources of pain. The duration of pain ranged from 4 to 40 years with the average being 18 years in pain. Prescription
opioids used to manage the various chronic pain conditions included: fentanyl patch, hydromorphone, methadone, dilaudid, cannabis, ms-contin, statex, morphine, Tylenol 3, and morphine sulphate. Six of the participants were on long-term disability and unable to work due to their chronic pain condition. Two were still able to work full time and one was currently not working because she had been self-employed and was now unable to complete the tasks associated with her work.

Table 1  Summary of data collected from demographic form

<table>
<thead>
<tr>
<th>Participant</th>
<th>Diagnosis</th>
<th>Pain (yrs)</th>
<th>Medication(s)</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Neuropathy- legs Sciatica- Rt. leg, lower back Migraines</td>
<td>40</td>
<td>Fentanyl Patch Hydromorphone</td>
<td>Long Term Disability</td>
</tr>
<tr>
<td>2</td>
<td>Back pain- work injury Sciatica- Rt. Leg R. Knee joint replacement Neck pain- degenerate discs Fibromyalgia due to MVA</td>
<td>45</td>
<td>Hydromorphonecontin Methadone Dilaudid</td>
<td>Long Term Disability</td>
</tr>
<tr>
<td>3</td>
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<td>40</td>
<td>Cannabis (oral) Sativex</td>
<td>Long Term Disability</td>
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<td>4</td>
<td>Multiple Sclerosis Headaches Spasticity- arms and legs</td>
<td>23</td>
<td>MS-Contin Tylenol 3 Gabapentin Morphine Sulfate Cannabis (oral)</td>
<td>Long Term Disability</td>
</tr>
<tr>
<td>5</td>
<td>Numbness/tingling in legs and hips Lower Back pain</td>
<td>5</td>
<td>Morphine- MS IR</td>
<td>Self employed (restricted)</td>
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<td>Lupus- back pain Degenerative discs</td>
<td>30</td>
<td>Fentanyl Patch Cannabis (oral)</td>
<td>Long Term Disability</td>
</tr>
<tr>
<td>7</td>
<td>Lower Back Pain</td>
<td>4</td>
<td>Morphine Cannabis (oral)</td>
<td>Full Time</td>
</tr>
<tr>
<td>8</td>
<td>Pancreatitis Ruptured Tendon- L. Foot Ruptured Discs Scoliosis- spine Arthritis- knees</td>
<td>14</td>
<td>Methadone Morphine sulphate Cannabis (oral)</td>
<td>Long Term Disability</td>
</tr>
<tr>
<td>9</td>
<td>Back pain Ruptured Discs Hip pain- replacement Left Shoulder- rotator cuff</td>
<td>26</td>
<td>Dilaudid Hydromorphone</td>
<td>Full Time</td>
</tr>
</tbody>
</table>
Throughout the interviews, each participant discussed various ways in which CNCP has affected their physical abilities, their emotional and psychological well-being, their relationships, their employment and their overall quality of life. These descriptions were consistent with and support the research that has been published to date around the experience of chronic pain and how it affects one’s overall quality of life (Gertle, All, & Wallace, 2001; Smith & Osborne, 2007; Thomas & Johnson, 2000; Vallerand & Nowak, 2009).

4.3.1 Participant One

Participant one was a 56-year-old female with CNCP for more than 40 years. She suffered from chronic migraines, spinal stenosis and sciatica. Her pain began to worsen at the age of 29. After experiencing a year of excruciating pain and unable to find relief through various therapies such as physiotherapy, chiropractor, nerve blocks and exercise, she decided to have back surgery. She described her pain following surgery: “I knew that you have pain right after surgery, the surgical pain and that all settled. However, the pain that happened when all that settled down was 10 times worse than what I went through that whole year.” With an unsuccessful back surgery, she began to lose hope that she would ever get back to being physically active again. At six months post surgery, and still not having adequate relief, she decided to have a second surgery involving a spinal fusion and a laminectomy in hopes of regaining her life back. She described it as “…the beginning of the end of me,” and has been in pain ever since. This period was very emotional for her as she described:

This just broke my heart. yah ahhh, just talking about it, I'm getting emotional talking about it because it, that part of it, those emotions seemed like yesterday.
You can’t, you can’t shake that off. Your whole life is suddenly changed by someone who took too much bone out of your back and you don’t know what to do about it.”

As the pain continued to worsen, she was forced to go on long-term disability because she was not physically able to continue working. She described her experience of pain prior to using opioids:

Before the medication I was in a lot of pain and you know what, it was breakthrough and everything and I was trying to cope but I was losing. What I was losing was my sanity. I was so tired I couldn’t eat, I couldn’t sleep…Pain does destructive things to the human body and I wouldn’t, I would have never have thought that when I was first diagnosed. It’s a thief. It robs you of sleep, nutrition, love, family and friends, ummm, concentration, like your, your physical-ness, like your physical activities…

She described not only the physical agony she experienced but also the emotional, psychological and social distress she endured prior to using prescription opioids.

Participant one had been using long acting opioids for the past 20 years to help manage her pain and was currently using the Fentanyl Patch and Hydropromophone daily. She still struggled with taking opioid medication daily because of the side effects and the social stigma associated with them. However, she has accepted them as part of daily life as they had given her enough relief to be able to function independently again. She summed it up as:
I’m not sure if I’d survive [without the medication] because at this point my head is so tired from this um, cause your constantly thinking, you can’t do things, like there is no spontaneity in your life anymore, you have to be a real good planner, you have to be prepared to disappoint people and I still hate that aspect of it.

Although participant one found relief through opioid use, she continues to struggle with both the physical and psychological effects from her chronic pain daily.

4.3.2 Participant Two

Participant two was a 68-year-old female who had experienced chronic back pain for the last 45 years. Her pain started as a back injury at work resulting in a protruding disc in her spine. She had a successful disc surgery that relieved her pain and was able to return to work. Three years after her surgery she experienced a difficult birth with her first child and began to experience sciatic nerve pain and pain in her right leg, which she continues to experience on a regular basis. For five years following the birth of her child, she had difficulty finding adequate support from doctors in a rural community. She decided it would be best to move into the city to be able to access services to help relieve some discomfort and pain. Shortly after moving to the city, she was involved in a car accident resulting in severe whiplash and low back pain that was later diagnosed as degenerative discs in her neck, fibromyalgia and arthritis. After eight years of searching for relief on her own, she connected with the PMU. She began acupuncture which helped her cope for a few years but the pain didn’t go away. In 1981, a surgeon recommended having a spinal fusion to stabilize her back. After some hesitation and lengthy discussions
with her doctor and husband, she decided to have the surgery. Following a year of relief from her pain and feeling hopeful, the pain gradually returned as she described:

I was so discouraged that I really thought that the fusion was going to look after this and it didn’t. And now I had, pretty well constant pain in the right leg, the sciatic pain. That was a low point because I found it difficult to accept that the surgery was not going to be the fix that I thought it was.

She wasn’t coping well. She had a few other significant falls after her pain returned and reconnected with the PMU. She began nerve blocks and was using Tylenol 3 and 4. Although she tried various interventions including acupuncture, exercise, and surgery, she described her pain in the following way:

Nothing took it away. I can not remember the last time I did not have pain. It’s just been there. It’s been part of me for so long now that I don’t remember not having pain.

She continued with the nerve blocks for a couple of years but the doctor performing the nerve blocks punctured the dura of the spinal column. This injury caused severe headaches resulting in more severe pain and the Tylenol 3 and 4 were no longer effective. When she began taking stronger opioids, she was very hesitant to take as much as she was prescribed:

I had initially held back [taking the prescribed dose] thinking well maybe I don’t need this much or maybe I’m not as bad as I think I am and maybe I can do without. I found out that I wasn’t, that I did need them. And when I did start to
take them as prescribed it gave me a whole level of comfort that I hadn’t experienced for years.

Participant two described the negative effect of pain on her social life:

Well when I started having pain that interfered with my life, some of my friends found it awkward or difficult to be around me. They didn’t like to see me in pain. Everybody says you can see it in my eyes. And when my eyes would start to cloud or do whatever they would do, they would get uncomfortable. Two in particular just drifted away, just literally drifted away, no explanation. Just turned up busy, unavailable and I learned from somebody else that the problem was they couldn’t stand to see me going through what I was going through.

Although a few of her friends were not able to support her during her times of need, she had very supportive family members in her life.

To help manage her pain, participant two takes hydromorphocontin, methadone and dilaudid daily and she participates in leisure activities such as exercise, painting, scrapbooking and volunteering. Overall she expressed being very grateful for having a supportive family and friends and was thankful to have found a pain management strategy that has helped. She has a better overall quality of life and has regained a sense of purpose and satisfaction again that was once lost due to her pain.

4.3.3 Participant Three

Participant three was a 49-year-old male who was diagnosed with Legg Perthes Syndrome at the age of nine. Following a diagnosis, he had an unsuccessful surgery in an attempt to correct his condition and has had chronic pain ever since. He remained active
in sports growing up but in his early twenties, the frequency of participation became less and less due to his worsening pain. At the age of 24 he had an osteotomy on his right hip, which was unsuccessful. Seven years later the pain had affected his life so much that he found a doctor who agreed to do a full hip replacement even though he was so young. He described waking up pain free for the first time in 22 years following this procedure:

…right from the time I woke up, the pain was gone. I knew it was gone. There was pain from the incision and the cutting of tissues and muscles, though the pain that I had suffered since the age of nine was gone for the first time.

He was able to become active again and participate in sports and work full-time. Unfortunately, three years later, he was involved in a motor vehicle accident leaving him with severe whiplash, nerve damage in his neck, back and shoulder. He was later diagnosed with fibromyalgia, temporomandibular joint disorder and a mild traumatic brain injury. He struggled to find a sense of purpose because he had to give up various activities he enjoyed doing and was unable to return to work. He was referred to the PMU and tried nerve blocks, epidurals and various opioid medications but found they were not successful in relieving his pain. Following the accident and attempting to find relief, he began to suffer from severe depression, and isolated himself from family and friends. He described this depression in the following way:

Those days were really dark with depression. I spent numerous days and hours just driving around the city to avoid talking to people. In reflecting back on that now, very sad to think that I spent that time away, that was away from my family too, and it was lonely, just trying to find yourself.
Being the main financial provider for his family and not being able to work really affected the dynamics of his family:

I lost my business, I had to turn in all my records without any compensation and that was my future, that was my life. And I had to take all my RSPs and I had to cash them in to survive and any other retirement money or any savings. So everything has been depleted out of there…So going from a very secure income to one you’re not sure of or it might even be a quarter of what you were bringing into the household made dramatic changes with a young family and life going on.

After many unsuccessful trials with various prescription opioid medications, this participant began smoking prescription cannabis daily to manage his chronic pain. He now participates in daily exercise in the pool, and uses laughter and music to help him cope. He finds a sense of purpose and satisfaction by volunteering his time as an advocate within the pain community.

4.3.4 Participant Four

Participant four was a 56-year-old female who was diagnosed with Multiple Sclerosis (MS) 23 years ago and she hasn’t walked unaided since this time. For the past 10 years she has been experiencing chronic headaches, temporomandibular joint disorder, and experiences sensory pain and numbness throughout her body. She had difficulty deciphering the root of her pain due to the various sensations she experiences. She discussed how hard it was to be diagnosed:

When I became ill I was a very active person you know, I had a, a good solid marriage two little kids, one a, one an infant basically. I was not able, I mean
immediately upon becoming sick, I couldn’t be left alone with the children, which added a lot of stress to the family….Pain affects one psychologically, I mean you can’t do your job either; your job as a mother, a friend, a wife or your actual job.

A few years after her diagnosis, she began experiencing severe headaches that affected her vision. At that time she was prescribed Tylenol 2 but they were not sufficiently helpful. She was then referred to the PMU for further assessment and treatment. In order to get adequate pain relief, she was prescribed Tylenol 3, Percocet and MS-Contin. Nine years ago she began using prescription cannabis to help manage her MS symptoms and pain. Approximately seven years ago, she began receiving Botox injections in her legs and which reduced the use of some medications she was using for spasticity. She currently uses; MS-Contin, Tylenol 3, Gabapentin, Statex and Cannabis. She is highly involved in her treatment and management of pain.

Certainly without the pain medications I wouldn’t be able to do any of this. Like I would just be, laying in a little corner screaming cause it was so incredibly painful. The pain management unit has been fabulous because they have offered us all kinds of modalities. I don’t know how useful these things are in and of themselves but I think breathing is really important because you get tense and you have to relax.

She strongly believed that “doing something is better then doing nothing,” referring to the various alternative therapies she does to find relief from pain and the symptoms of MS. She practices relaxation and breathing techniques, participates in biofeedback, hypnosis, psychotherapy, physiotherapy, acupuncture, chi gong, yoga, horseback riding
and enjoys paper art at home to help her cope. Overall, she had a very positive attitude and was well supported by friends and family members.

4.3.5 Participant Five

Participant five was a 60-year-old female who was diagnosed 5 years ago with mild neuropathy in her feet and legs. Her pain continued to worsen and she began experiencing pain in her back. Two years ago she had an MRI in hopes of finding a cause for this pain. This test revealed that she had blockages in her top 5 vertebrae that prevented her from moving freely. These blockages caused a great deal of pain and discomfort. The doctor recommended surgery to clear the blockages but because she had liver damage, there were too many risks involved in having the procedure at that time.

She said:

I’m anxious to have the surgery now that I have my head around having back surgery. Basically because it may alleviate some of the discomfort and pain that I have in my legs and get me back to more activity because I’m used to being very active.

She tried various treatments and management strategies but struggled to find relief from her pain:

So the Tylenol wasn’t getting any rid of it, nothing was getting rid of it! I tried everything down to acupressure, massage, everything. Nothing got rid of this pain.

The discomfort began to affect various aspects of her life:
The whole pain issue in terms of my lifestyle has been tremendously compromised. Lack of mobility, both my leg pain and the discomfort, the numbness in my legs and my back pain, I could not even function. I haven’t been able to work for a number of years…and I loved my job.

Her pain took away her ability to work, which had affected her tremendously not only financially, but emotionally as she described:

I want to get back to work. I can’t wait to get back to work. And basically I have to get rid of the acute pain to be able to work on a regular basis. So that’s how its sort of, it’s had a very negative impact and I’m a real positive person, so I’ve been dealing with it, trying to deal with it in a very positive way. But I went through about four years ago a very down time, like I was really, getting very down and depressed.

She travelled around the world with her job and was very passionate about what she did and has struggled to find meaning and personal satisfaction. Being in chronic pain forced her to move back to Nova Scotia, which was difficult because she did not know many people in the province and felt she lacked a support network and sense of community. Being self-employed and not being able to work was extremely stressful. She described her stress in the following way, “my mobility has been compromised, my finances have been compromised, my security and I have been very stressed.”

Participant five currently uses Morphine-MS IR daily to help relieve her pain. She also uses various alternative modalities to relieve her pain such as physiotherapy, massage, exercise, meditation, counseling and swimming. She described having a good
support system, “I’ve got a really good supportive team but I’m also doing a lot of work myself. And I’ve done a lot of work.” She is very proactive in her pain management plan and optimistic and hopeful that one day she will be pain free.

4.3.6 Participant Six

Participant six was a 40-year-old female who was diagnosed with Lupus at the age of 10 and has experienced joint and back pain since then. She described how her pain worsened when she began working:

…it just went downhill from there, I was on my hands and knees at work and couldn’t function. I couldn’t even think straight…and it affects my life to where I’m, everything I find is a bigger deal ah like to do my laundry, everything takes me longer then the normal person.

She also suffers from deteriorating discs in her back and is currently on long-term disability. It took a year for participant six to see a specialist at the PMU. There she began trials of using opioids. She began with codeine and morphine but she couldn’t tolerate the side effects of these medications. She was then prescribed the Fentanyl Patch. She described:

I’m tired from it sometimes but it is a god sent really, because without it I think I would probably be in the ground right now. It does help me with the pain level, more so than the morphine I think. And you don’t have that up and down feeling with it all the time.

Although the Fentanyl Patch has relieved some pain, she does experience side effects such as excessive sweating and fatigue. In order to counter these side effects, she uses
Cannabis daily. She described cannabis as a “god send” and an important component of her pain management. She finds it difficult to try to keep up physically with people because of her pain, “I don’t complain a lot about stuff, I keep it to myself. But I’m always trying to keep up with everybody, so it makes it hard sometimes you know.” She described her pain as unpredictable and she finds it stressful to follow through with her plans:

You know, it affects everything. Your day consists of sometimes not being able to plan things because you’re not feeling well enough to do it, cancelling things cause you’re not well enough to do it. You know stuff like that. It’s very frustrating, people don’t understand, they don’t, they don’t get it.

Participant six described having a great relationship with her husband who also has chronic pain. She enjoys doing artwork, stain glass and rug hooking for leisure activities which help her keep busy. She is very optimistic and proactive and adapts her daily schedule based on her pain levels.

4.3.7 Participant Seven

Participant seven was a 42-year-old male who experienced chronic low back pain 4 years ago. His pain began at work when he switched from a very sedentary job to a job that required repetitive lifting all day. After a year in this position, he had to leave work because his pain had grown so severe. He was off work for 2 months when he was, as he described, “bullied back to work.” He returned to work for another year, pushing himself through his back pain but again, had to go off work and is currently still unable to work. He discussed how pain effects all aspects of his life especially his sleep. He is only about
to sleep for approximately 3 hours per night. He described the mornings as being the hardest because his body is so sore and stiff.

Participant seven is currently prescribed morphine through his family doctor and uses it daily to help manage the pain. He does not feel that he is receiving adequate relief from the morphine but says without it he probably wouldn’t be able to walk or get out of bed. He is also using cannabis daily to help counteract the side effects of the morphine such as sweating, loss of appetite and fatigue. He expressed being frustrated with not having consistent answers from healthcare professionals about his chronic pain:

I’ve had one surgeon say that I do need surgery and one say that I don’t. So it’s like, you know, this is a big thing. You’re talking about fusing my back. So I’m a little bit frustrated that I’m getting conflicting stories now.

He was on a waitlist for the PMU for a year and a half and during that time he tried acupuncture, chiropractic, physiotherapy, and exercise, but wasn’t able to find relief. He is currently seeing a specialist at the PMU and is still waiting to see if he will need surgery in the future.

4.3.8 Participant Eight

Participant eight was a 60-year-old female who has been in pain for 14 years. She woke up one morning with excruciating pain in her upper left quadrant of her stomach and was taken to the hospital. She was given morphine for her pain and went through various tests and x-rays. She was told she had a tumour but when she went in for surgery to remove it, the surgeon couldn’t find the growth. As a precaution, they removed part of her pancreas, her spleen and parts of her bowels. Three months later she woke up with
excruciating pain again and went back to the hospital. She was given morphine for the pain and was referred to a doctor for nerve blocks. She was switched from morphine to the Fentanyl Patch for her pain but eventually neither the patch nor the blocks were relieving her pain. She was unable to work due to her pain and began feeling helpless as she described below:

I couldn’t go to work, the job was there but I couldn’t go. I mean I was, let’s just say I was devastated. When I wasn’t crying I was hurting and ah, life wasn’t very good. And no one understood, cause if you can’t see pain, you don’t understand pain. So nobody knew, nobody understood. They just felt that I was just, faking pain that was so excruciating that you just pass out.

Three years after her pain began, she was seen at the PMU where she began methadone. She found great relief from her pain but the methadone made her very drowsy and she lacked ambition or motivation. She became depressed because of the consequences she was experiencing from her pain and was referred to a psychiatrist. She began using antidepressants with her methadone, which became very problematic for her. Due to the drowsiness and fatigue she experienced, she was involved in a car accident because she fell asleep at the wheel. She was re-assessed and her medications were adjusted accordingly.

Currently, the main source of her pain today is pancreatitis, scoliosis of her spine and arthritis in her knees. For the past three years she has experienced pain from ruptured discs of her spine and a ruptured tendon in her left foot. She is currently using methadone
and morphine-sulphate daily to help manage her pain. She is also using cannabis daily to help manage the nausea from the opioids and finds it very effective.

Although she still struggles with her pain and balancing her side effects of opioids, she has been able to find some relief through leisure activities such as painting, crocheting, knitting and listening to relaxation tapes. She also relies on her pets for emotional companionship and support during the day when her husband is at work. She described the support she receives from her husband in the following statement, “Thank god for him. He’s been my rock through this, cause he does understand.”

4.3.9 Participant Nine

Participant nine was a 41-year-old male who injured himself 15 years ago from a power lifting accident that caused bulging discs in his back. He was advised to have surgery to fuse his discs but he decided not to pursue the surgery. One year later, his pain was unbearable so he began using Dilaudid 4’s prescribed by his doctor. The opioids took his pain away enough that he decided to return to playing sports. He described that decision in the following way, “It was the biggest mistake I have ever made.” He injured himself even further and his bulged discs became herniated discs causing him even greater pain. For relief he tried using ice packs, heat, massage and saw a chiropractor: “but nothing seemed to help.” At that time his prescription was increased to Dilaudid 8’s. He continued to participate in sports, which caused his herniated discs to became ruptured discs and damage to his rotator cuff. At that time he began using hydropmorphine with Dilaudid to help cope with his pain. In 2000, he was involved in a motor vehicle accident resulting in pain in his hip and legs. In 2010, he was diagnosed
with vasculitis. Following a successful hip replacement surgery, he experienced a significant amount of pain relief and was able to decrease opioid doses significantly.

He currently uses Dilaudid, Dilantin and Hydromorphone daily. He described how opioids work well for his pain, “there are benefits and well I can say the pros outweigh the cons in this case. Ummm, because I wouldn’t be able to do anything without them.”

He is still able to work full time with limited abilities and finds it difficult some days to complete his daily tasks such as household chores.

4.4 Summary

When asked the question, “How has pain affected your life?” participants discussed the impacts chronic pain has had from not only a physical perspective but also from emotional, psychological, financial and social perspectives. In keeping with interpretive phenomenology, all participant interviews were analyzed separately to fully understand opioid use in the context of chronic pain management. All data revealed in this chapter were consistent with published research that explored the experience of living with a CNCP condition(s) (Osborn & Smith, 2006; Strong, Sturgess, Unruh & Vicenzino, 2002; Vallerand, 2003).

The information outlined above introduced the nine individuals who participated in the interviews and briefly captured their individual pain journeys. Overall, the participants within this study were excited about telling their stories and having the opportunity to voice their opinions, experiences and concerns about CNCP and the use of opioids. They were motivated to participate because of their desire to help others.
Sometimes the desire was to help others in similar circumstances by sharing their stories; others participated to help the researcher, or to contribute to the limited data on the experience from an individual’s perspective. After the interviews and follow up conversations the participants expressed satisfaction and enjoyed sharing their stories with the experience despite the complexities and emotions involved with the topic. One of the participants described the experience as “being the most painless thing I have done in years!” Chapter five presents the results through six themes that evolved through each interview analysis using an interpretive phenomenological lens.
CHAPTER 5 RESULTS AND FINDINGS

5.1 Overview

True to qualitative research, the participants’ responses guided the findings of the study. During the interviews, the participants discussed their personal experiences of using prescription opioids daily for the management of their CNCP. As described in the previous chapter, CNCP devastates the lives of those who are affected. Throughout the journey of seeking pain relief, all participants had experienced many emotional, psychological and social consequences of chronic pain and prescription opioid use. Eight major themes and several subthemes were constructed throughout the data analysis phase and are displayed in Table 2. Each theme discussed was revealed by analyzing each individual’s unique story of using opioids to manage CNCP.

An overarching theme of finding balance was embedded within the themes. Participants attempted to find balance between pain and function, and also by trying to balance the negative effects of the opioids with manageability of pain. Finding balance meant achieving stability between daily functioning and pain management in order to achieve the optimal relief and a better quality of life. This balancing act was very difficult as participant three explained:

There were a lot of plates. Like the guy in the circus running around you’re trying the acupuncture, the massage, in the pool, seeing the psychologist, taking some pharmacology, and where are we going? Because as a pain sufferer, we’d love not to be in pain! And we try anything and exhaust almost all our finances to try to find that cure.
Most of the participants within the study were able to find some balance overtime but it was more difficult for some to achieve this solely through opioid use. Participant two discussed how difficult it was to find balance psychologically with her opioid use. She struggled with using her opioids as prescribed, and by not using them appropriately, they did not find adequate relief:

I had initially held back thinking well maybe I don’t need this much or maybe I’m not as bad as I think I am and maybe I can do without. I found out that I wasn’t. That I did need them and when I did start to take them as prescribed it gave me a whole level of comfort that I hadn’t experienced for years. And then I realized, ok, this is a quality of life I hadn’t had for while so if the drugs give it to me then that’s great.

Finding balance acted as a pivotal point for interpretation of the overall meaning of coping with chronic pain and the consequences of prescription opioid use in order to find a quality of life that was sustainable for participants.

Participants were identified by a participant number to maintain their confidentiality. Quotes from the interviews were used to support the key themes and subthemes throughout this chapter.

Table 2 Themes and Sub-themes

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5.2 Theme 1: Process of Decision Making

Making decisions about the treatment and management of chronic pain can be extremely stressful. Decision making is not a static process. It is a continuous process integrated in the interaction between the individual and their environment. A variety of beliefs, feelings, and behaviors influenced the participants’ decisions about using prescription opioids and this is reflected in the data. In seeking relief from CNCP, participants continuously appraised how their CNCP impacted their life and debated ways they could attempt to cope. During this appraisal process, all participants decided to try prescription opioids and/or cannabis to help manage their CNCP. Managing chronic pain not only involved the physician; the patient also needed to assume an active role in the process. Participants discussed the interactions with their physicians and how that influenced their decisions. Eight of the nine study participants currently used prescription opioids to manage their chronic pain conditions and of those eight, four of them also used cannabis. One study participant used only cannabis after previous unsuccessful trials with opioids. The subthemes to follow describe how the participants began their opioid and/or
cannabis use.

5.2.1 Deciding to use opioids

The use of prescription opioids to manage CNCP is an often contentious issue, making this decision for some study participants even more difficult. Some participants were offered prescription opioids fairly quickly after being diagnosed with pain while others experienced opioids to be a last resort in finding relief. Most of the study participants began using opioids because their physicians suggested it. The following quotes are two examples of participants’ decision to use opioids:

The duragesic patches [Fentanyl] didn’t last very long. The blocks didn’t last. The blocks, well I was allergic to them. So here I was, nothing that was working. I went back to morphine injections and that made me sick…at the clinic Dr. (name) came up with methadone. She said let’s give it a try and see what I can do (Participant eight)

So I finally got in here [PMU] to see doctor [name] and she put me on, I think she put me on codeine first. And then I kept throwing all the pills up all the time so then I went from codeine to morphine and that still wasn’t doing any good for me. I was constantly throwing up the medication and so she tried me on the duragesic patch [Fentanyl] and since then, I don’t throw up my medications anymore (Participant six)

Although it took several attempts with various opioids before finding adequate relief, these participants decided to continue using opioids despite the adverse side effects they experienced.
The decision to use prescription opioids was described by some, as a result of desperation or as a last resort for relief from their CNCP. Ten years ago, participant six was given short term opioids to help her pain subside but they made her physically sick. She described her feelings of being hopeless in response to her pain:

It got to the point that it just got so bad at the hospital that I became suicidal. Like very suicidal! And I finally [after one year] got into the pain clinic and they were able to get me in a regimen with my pain medication.

Participant two was desperate to find pain relief but still hesitant to use opioids. She said:

This was the first time I was given drugs to use on a regular basis. I was a little concerned about that but realized that I was…(pause), I don’t want to use the word helpless but I was really unable to function very well because of the pain. And I was concerned that if I started these drugs, where would it end? I was becoming aware that I had a condition that was not going to go away and there was not a treatment that was going to relieve it. It was a matter of dealing with it in the best way possible and that was up for grabs at this point.

Some participants described short term use of prescription opioids throughout their life to manage various acute or postoperative pains, which made them less hesitant to use them long term. Participant nine explained his past with having to use opioids:

My doctor first prescribed Robaxocet but it was a prescription grade. And, ah, you know cause I’ve had other surgeries. I’ve had two knee surgeries on my left knee from high school football and I had pain medicine while I was in the surgery and while I was recovering in the hospital.
Similarly, participant four described when she first deciding to use opioids long-term: “I think the opioids really was a no brainer. It didn’t really affect anybody. I mean, we were already on you know, large quantities of Percocet, so you know the morphine was a no brainer.” Participant four continued to describe how she felt following a surgery that was unrelated to her chronic pain:

> So off I went for the surgery and I, when I woke up, I realized I wasn’t in any pain and it had been the first time in a number of years that I’ve been pain free. And it was the morphine and I had mentioned that to Dr. (name) and she said, well let’s switch to morphine then.

In this case, the participant initiated the conversation about switching from the opioids she was previously using prior to surgery to morphine for optimal relief.

The process of finding adequate relief can be difficult and frustrating for some individuals when dealing with a life altering condition such as chronic pain. Finding adequate relief was often a balancing act between living with tolerable pain and managing the negative effects of opioids. Some participants began using cannabis in addition to their opioids in order to find that balance.

### 5.2.2 Deciding to use cannabis

After completing the interviews, it was revealed that over half of the study participants used prescription cannabis in conjunction with their opioids, with the exception of one participant who only used cannabis. All participants who used cannabis had government issued licenses and most participants were introduced to the use of
cannabis for pain through their pain specialists. Participant six described her difficulty when deciding to use cannabis:

Dr. [pain specialist] actually suggested it. Yah, she actually suggested it. I had a hard time with it at first. I actually had to go to therapy to actually start using it. An, ah, now I just feel very empowered, very empowered. I feel like I know a lot about my own medication, my own body, what I’m putting into it and it’s a natural plant, it’s a natural you know. And it actually does amazing stuff [for pain].

The decision to use cannabis was obviously difficult for this participant but the benefits of cannabis use outweigh the side effects of opioids she had experienced. Participant four benefited greatly from cannabis use as she had been able to cut down some of her other medication for her MS:

About nine years ago, I got the legal right to use marijuana. Again, doctor [name], she was the one who suggested it and fill out the forms for me. I found it very effective. I have been able to reduce some of the other drugs.

In most cases, cannabis use was initiated by the pain specialist. But there were also social opportunities for use. Participant three began smoking cannabis socially with friends, which lead him to experience a level of pain relief he had never had before:

I had friends that smoked marijuana on a regular basis, not for pain. I’ve been and smoked with them before in the past and never got high. Couldn’t figure out why I didn’t get a feeling and these guys were getting feelings. Though it wasn’t until I
started learning and reading and researching that I seen that there was something there.

He later had a conversation with his pain specialist about cannabis use and received a government license to use prescription cannabis daily to help cope with his pain. The use of cannabis to counter the adverse effects of opioids is discussed in a later subtheme on managing adverse effects.

Overall, the participants were actively involved in their pain management decisions and carefully weighed the benefits against the burden of the use of opioids and/or cannabis. It was often difficult for participants to find a balance between the benefits and burden of their opioid and/or cannabis use. Theme 2 discusses more specifically the benefits and burdens of prescription opioid use.

5.3 Theme 2: Physical Effects of Opioids

For most participants in this study, prescription opioids had an extremely positive effect on their physical pain; however, many participants also reported many negative side effects from opioid use. Described below are the positive and negative effects of using prescription opioids from the participants’ perspective. Also discussed are the other medications needed in conjunction with prescription opioids to help manage pain and adverse effects of medications.

5.3.1 Positive Effects

Participants described opioids as having an overall positive effect on their psychological and physical wellbeing. With the use of opioids, most were able to regain a quality of life that was once lost through their pain journey. Often this quality of life
meant living with comfort and regaining the ability to perform physical tasks such as mowing the lawn, or house cleaning again. The participants below illustrated some of these positive effects. Participant two emphasized how prescription opioids enabled her to do more:

I have to say that these drugs give me a quality of life that I did not think I would ever have again. It allows me to live my life to the fullest I can, to take part in things…and be as active as I can. I can’t picture doing it without the drugs now.

She referred to opioids as giving her back a quality of life that she thought was impossible to regain after years of experiencing pain. She fully accepted the role opioids played in her life and acknowledged that she needs them daily.

Participant nine described how prescription opioids gave him the ability to enjoy some of the leisure activities he once participated in:

Now mowing the lawn is fun. I like it cause I actually, I don’t know. I mean I could do things. I mean I couldn’t play hockey anymore, which I mean, at my age, at 38, that was fine. But umm, to mow the lawn or rake the lawn without pain medicine, it was too much to bear.

Participant seven spoke about the pain relief from opioids but focused more on his disappointment that they didn’t relieve all his pain. Opioids decreased enough of the pain to allow him to regain function but they did not eliminate the pain:

It helps. I mean I shouldn’t say it doesn’t do anything. To tell you the truth, I probably wouldn’t be here right now if I wasn’t taking it. I probably wouldn’t be
able to walk or get out of bed cause the times that I do let my dose go or don’t take it, it just, I can tell right away and umm so if it wasn’t for that [opioids] I would have no quality of life.

The positive effects of prescription opioids were confirmed over and over as they allowed many participants to regain the ability to perform daily activities and live with some ease from their pain. However, the negative effects that accompanied opioid use were very difficult to deal with for some participants.

5.3.2 Negative Effects

The positive effects of using prescription opioids often outweighed the adverse effects of using them daily. Like many medications, opioids came with physical side effects as participant one described:

It’s been very successful, rough at the start…the side effects are a bitch. I hate them. I hate the constipation. I hate the itching. I hate the nausea. I still throw up sometimes.

Similar to participant one, participant seven summarized his experience using morphine, “Yeah, it has given me somewhat a little bit of mobility but it definitely comes with a lot of crappy stuff too.” When asked more specifically about his opioid use, participant seven responded by saying:

It comes with consequences and side effects for sure. It’s, you know, I wish it didn’t have but, the sweating alone is just ah, it just, it’s so uncomfortable to wake up and your pillow is just soaked with sweat and your bed. And I know that
mostly, it’s gotta be from the morphine and it makes you moody and cranky and everything.

Similarly, participant eight explained how opioids affected her mood and physical appearance:

I looked depressed because of all the stuff. Not being able to work, not being able to do anything. Because drugs make you drowsy. Drugs take away your ambitions you just want to sit, ah, and I cry.

Throughout the study, commonly mentioned feelings were fatigue, sluggishness and having a lack of motivation to do anything because of the opioid medication. Participant four discussed fatigue as being the worse side effect of her medication:

It’s very difficult for me to separate pain as a symptom from all my other symptoms. And one of my, probably my most debilitating symptom is fatigue. But pain breeds fatigue so you can’t completely separate those and pain medications add to fatigue.

Opioids had an impact on one participant’s sexuality. Participant nine explained the impact of opioid use on his sexual function and then the secondary impact on his intimate relationship:

When I was first on opiates I couldn’t, couldn’t have an erection. And once I got used to the medicine I could have the erection but I couldn’t have an orgasm or anything like that. So it affected the relationship in a manner that I wasn’t ready for because the woman I was living with at the time thought she was inadequate.
Participant six also spoke about the side effects from opioids disrupting her sexual life with her partner who also had chronic pain: “My sex life, it hasn’t been there lately. Because we are both in chronic pain all the time, you know. He has the sweats all the time, I’ve got the sweats all the time.”

To help offset the side effects of prescription opioids that were discussed above, most participants used other medications to help cope.

5.3.3 Managing adverse effects of opioids

Common adverse reactions in patients taking opioids for pain relief discussed by participants included: nausea, vomiting, drowsiness, sweating, itching and constipation. To offset these effects, participants used cannabis and other medications in combination with their opioids.

Use of Cannabis: Five of the nine study participants described using cannabis to manage the adverse effects of prescription opioids. Profuse sweating was a common problematic side effect of opioid use. Participant six described this problem:

I’m very embarrassed to go into grocery store, to go anywhere, to do anything, cause I’m soaked all the time. So a lot of the times in the afternoon, I’ll have to lay down and get a blanket and I have to take marijuana and that will usually within a minute, the sweats are gone. Like that. And I’m feeling a little bit back to normal again.

Participant seven also used cannabis for pain relief and to manage the side effects of opioids use:
...that [cannabis] helps me some days believe it or not. I would say almost as much as the morphine does. It helps with my appetite which I don’t have any of, usually, because of the medication. And the pain, both and just stress, general stress from being in pain I think all the time. So it does help with my energy, and it helps with my anxiety, it helps with my sweating.

Many participants used cannabis to help offset the nausea which was detrimental to one’s social life as described by participant eight: “You can’t go do anything. You can’t go out with anybody to eat. You know, because you don’t know when you’re going to be sick.” She used cannabis to help offset the nausea she experienced from her methadone:

Well the marijuana is only for the nausea cause with methadone...the nausea is unbelievable and that’s never stopped. The pain is under control to a degree with the methadone, but, the nausea, the vomiting, I had that the whole ten years, that’s still there. I’ve been using marijuana and that is great. Really good for nausea, the vomiting, it’s excellent.

Although the use of cannabis had a positive effect in lowering the pain and helping curb side effects of opioids, using it daily also had negative effects as described by participant three:

…it [cannabis] is very, very hard on the body. Smoking and hacking and coughing and being a criminal cause I have to hide around the side of the house and hide it [cannabis] from everybody. And this is my pain relief and it’s really sad when you think that you have to go that route to get some relief and then you
get the odor that comes from it and then you get the stigmatism that comes from it.

Not only did participant three experience the same negative physical effects of daily smoking he also had psychological discomfort in feeling like a criminal sneaking around because he was smoking cannabis in public. This issue of having to hide physically and emotionally was mentioned throughout the study. This feeling of living in secrecy was due to the stigma associated with both prescription opioids and cannabis. This will be discussed later in this chapter.

Use of other medications: Aside from cannabis, other non-opioid medications were briefly discussed to help minimize side effects. Participant eight mentioned her frustration with all the medications she was taking at one time, “…I can never really remember. There were so many drugs because you have to take so many other things to offset what you take.” Although the number of medications needed was often discussed as being overwhelming and frustrating, they were needed for optimal relief. For example, participant two discussed not wanting to take medication at all but realized that it was what she needed in order to find adequate relief from pain and the side effects of the opioids:

I really don’t want to be taking drugs but I realized I couldn’t live the way I was living either. So I started it [opioids] and initially I was itchy and I had constipation and I learned how to deal… the itchiness went away in a couple weeks and the constipation I had to learn to deal with, modified it with what I ate, mild laxatives.
Participant eight discussed having difficulty with the side effects and having to use additional medication on top of her opioids:

Opiates also have another bad side effect, constipation, really bad on you. So, ah hemorrhoids develop, big ones. So that’s another problem is use the bathroom, you just got to take all kinds of stool softeners. Like I take ten a day.

Similarly, participant one struggled with constipation and had to take additional medication for relief:

What was going on with the slow release morphine, you know everything has side effects. Oh it was the constipation. That is a real issue with all opioids. It’s a nightmare for us. I’ve never had to swig so much milk and magnesium in the morning. And I almost lose it and it’s so chalky and pink and I get the cherry flavour thinking it’s gonna [help], but I still almost lose it taking it in the morning.

Although opioids were able to relieve a tremendous amount of physical pain, the participants highlighted the continuous cycle of seeking other management strategies in hopes of achieving a tolerable quality of life. As mentioned previously, not only did prescription opioids have adverse physical effects, participants discussed many social consequences which made finding balance more of a challenge.

5.4 Theme 3: Social Consequences of Opioid Use

Participants spoke about many social consequences of using opioids. These consequences stemmed from the stigmatization of chronic pain and the negative association given to prescription opioid use. Feeling stigmatized occurred in experiences
with the healthcare system and with family and friends. Participants were frustrated by
the lack of sufficient medical training in pain management.

Participant one conveyed her general frustrations with the healthcare system:

    We don’t have a pain specialist training program in Canada. We DO NOT HAVE
    IT YET! Medical students still only take an hour of pain management in their
    entire 7 years and of course their specialty, and FIDO is looked after with better
    pain management than humans cause vets take about 5 hours. This is totally
    unacceptable! It’s destructive, it puts people at risk, it shortens our life...I think
    we’re not valued as much when you have a chronic condition. Whether it’s
    chronic pain or it can be or have a chronic problem with diabetes and MS and it
    takes away I think our value in society when we’re stuck with that label of
    chronic pain.

Participant seven shared his opinion of his prescribing doctor: “I don’t think she knows a
damn thing about pain myself. I don’t think she understands any bit of it. I think she’s
afraid of it.” Similarly, participant four felt constantly interrogated by healthcare
professionals she saw, having to explain and justify her opioid use with resident doctors
when her family doctor wasn’t available:

    I frequently have difficulty with the residents explaining why these drugs, this
    many drugs, blah, blah, blah. Finally Dr. [family physician] wrote a note in my
    file--stop harassing [participant’s name]. This is what she gets and why she gets
    it. And they did stop but it was inconvenient. For instance, they would not
    prescribe me three months at a time. I would be dispensed one month at a time.
And for someone who had been taking the same drugs for 10 years I felt, I found that condescending.

Participant eight discussed the difficulty she had with her medication management following a surgery that was unrelated to her chronic pain.

… nobody knew how to deal with chronic pain you know. So I went from one thing to the other, nothing for pain until I screamed and hollered for them to give me a little bit of Demerol. And, then after Dr. (surgeon) orders me meds, then they OD me. I mean I went from one thing to the other. It scares you for the next time you go to the hospital. These people don’t know anything about chronic pain.

Participant nine also summed up his concerns about the perceived lack of knowledge some prescribing doctors have about chronic pain and opioid use:

What I find interesting about pain management and pain medicine is that there are a lot of doctors that administer this pain medicine but don’t understand pain. And that alone frightens me.

Inconsistency within the healthcare system and the limited knowledge of prescription opioid use for CNCP created difficulties for participants needing help. These difficulties not only evolved from professional’s lack of knowledge but were highly connected with the stigma associated with prescription opioids in the media and society in general.

Media were discussed as contributing to the stigma associated with using opioid medication by reporting on the harms prescription opioids caused through addiction and
misuse. This stigma negatively impacted participants as they often felt judged rather than supported by healthcare professionals because of opioid use. Participant one expressed anger about the media contributing to the stigma of opioid use:

I get mad when I see the articles in the paper about people, and oh everybody in pain is addicted. And the stats, I always say only one to four percent of people in chronic pain ever get addicted to the medicine and that happens for a number of reasons. And you know what? I wouldn’t give a shit if I was addicted to the medicine. Like, at this point, 30 yrs of this who the hell cares?

Participant nine felt stigmatized in the emergency room following a fall:

They [ER staff] said, “Well we know that you’re on a lot of pain medicine, so we can’t give you any.” I said, “I didn’t ask you for any. I just want to know what’s wrong with me.” So I almost felt like, I felt like I was being treated like a junkie in the emergency room when I was in an accident because they found out I was on pain medicine. They automatically assume that I was coming in to try to sneak an extra prescription or something.

 Participant one was also stressed by her experience in the emergency room:

Apparently there is a book, they write your name down if you’re, if you come there [emergency room] too much… but god, what if I had to, what if I had to come there every week until this thing settled down. Do you know what? I wouldn’t. That was so stressful in itself, cause I never knew how I would be treated.
Participant seven mentioned similar lack of support from his family physician:

I think she’s [prescribing doctor] just freaked out about all the shit in the news and a couple bad apples are making it hard for people who legitimately need pain medication…but other than that she’s supportive and she sent me to the pain clinic here and all that.

This stigma influenced providers and patients alike. For example, methadone is used to treat chronic pain but it is also often used in a harm reduction model of care to assist those addicted to heroin to come off of heroin. Participant eight discussed how she felt when given methadone:

…when you get methadone you definitely, you know, what do you call those people? What do they call those people? When you’re on methadone… junkies! [people say] She was a heroin addict and is now on methadone trying to get off of it. I’ve had that said to me in the city, at the hospitals, that you know, the reason I was taking that, you know, I have a problem. And as an RN, that’s a big problem right? And I said, “My god! What are you talking about?” I said, “I don’t do that, I have chronic pain.”

Participant nine also shared some of the same biases as society at large, that methadone was used for people addicted to heroin and in treatment to get off heroin. When methadone was suggested to participant nine, his own views became a barrier to his willingness to consider taking methadone for pain:

…at one time they were talking about putting me on methadone pills. And I was like wait a minute. Dr. [name of pain specialist] wanted that and he said it’s a
better and longer lasting pain medicine. Right then and there I said, “Oh methadone! People are going to think I’m a heroin addict, or coke addict, or something like that.” So that’s when I started thinking, well wait a minute, what are people really saying or really thinking and that’s when I started thinking how am I going to be viewed by people?

Unfortunately, many individuals with chronic pain who take opioids may wrongly be labelled as addicts, even if they do not meet the actual criteria of addiction. In order to cope with these feelings of being judged or labelled many participants learned various strategies as a way of coping and finding balance between relief and consequences. This is further discussed in theme seven. Described in the next section is the guilt that was reported by some participants when using prescription opioids.

5.5 Theme 4: Guilt

Although the use of prescription opioids relieved some of the participants’ chronic pain, three individuals said they felt guilty about using them. One participant diminished the severity of her own pain by comparing it to the cancer related pain she witnessed during the last few months of her mother’s life:

My biggest hang up was me. I guess I could relate to my mother. I guess I would say my pain is nowhere near what my mother’s did, what my mother went through. And she had to take the narcotics cause she had a terrible bout with breast cancer…and I saw all the medication she was on and I kept saying to myself, I don’t have cancer it’s just back pain, you should be able to do this without taking those drugs. Well that didn’t last long.
She struggled to justify using opioids for herself because she did not have something tangible and straightforward like cancer, to warrant her use. Participant six also described feeling guilty and experienced a lot of stress and anxiety about taking prescription opioids:

> It’s a big deal for me to have to go on these medications because I felt very bad. You know you hear all this stuff about narcotics and stuff so I felt like I was a bad person for a long time actually.

She continued on with her story, adding that she sought out a psychologist in order to work through her difficulty understanding why she felt guilty. She used the phrase “when you hear all this stuff about narcotics” referring to the negative undertone about addiction associated with opioids. This worry of being labelled as an ‘addict’ added to her guilt about using opioids.

Participant nine had a different sense of guilt because of his opioid medication. He had a nephew who was experiencing daily pain but didn’t find relief from his own medication. Knowing participant nine used opioids, his family members pressured him to share his opioid medication with his nephew. Participant nine expressed his frustrations with this pressure:

> He’s asked me for some pain medicine when his Percocet don’t work and I say “I’m not allowed to give that you. I’m sorry. I can’t. It’s against the law. I can go to jail…” And then I get in trouble for not helping out. And what I mean by getting in trouble, is I get flack from my sister in law because they know I can help him with the pain but they also know I shouldn’t… But she doesn’t look at
what if a police officer sees me doing that, I’m in deep trouble. I run the risk of losing my pain prescription. I run the risk of being charged ‘cause technically it is drug dealing. So there is a lot on my shoulders.

Participant nine felt tremendous guilt for not helping a family member but was more fearful about the legal risks to himself if he did help. Participant three also felt that he was constantly looking over his shoulder due to the risk involved with openly smoking cannabis daily to relieve his pain:

Though there are times, especially these days that I get paranoid, can someone smell it on me or do my eyes look red? That’s the other one, do my eyes look red? Well who cares but I’m more paranoid over those aspects.

Guilt also occurred when an individual experienced conflict at having done something that was believed to be wrong by others. The guilt the participants felt was highly shaped by social impressions of people who use opioids. In addition to guilt, fear developed in many of the participants as a result of their opioid use.

5.6 Theme 5: Fears

During the interviews, many study participants discussed either their own personal fears of using opioids or the fears expressed by their loved ones. Whether fear was of addiction or dependency or becoming victimized because of possessing opioids, participants discussed these fears as being very stressful and frustrating. Participant one expressed her frustration of the fear instilled in the public by the media stories about opioid abuse:
I’m so sick of seeing those OxyContin and codone stories in the front of the paper that make everybody hide under the sheets if they are taking opioids because we are painted as druggies in many instances…

The participants typically attributed to media as the problem of creating stigma, as mentioned in the previous section, and also fuelling fears by emphasizing abuse, addiction, crime and death associated with opioids. Media rarely illustrated the benefits of opioids those living with pain.

5.6.1 Addiction/dependence

All participants discussed concerns about addiction to or dependence on prescription opioids during the interviews. They were generally aware of the risks involved in taking opioids. Some knew people who had begun misusing their prescription opioids and thus were hyper-vigilant about their own use. Although one might anticipate that a person living with poorly managed chronic pain would be eager to try opioids, the participants had reservations about using them and were concerned about becoming addicted or dependent. Participant five was very hesitant about using opioids to manage her pain because of the way they made her feel:

I really don’t want to take hydromorphone because that’s also addictive. And I had a very bad reaction to it and umm, not bad reaction but it didn’t, it sort of, it made me very loopy.

Participant two was afraid of becoming dependent on opioids because she had seen it happen to people she knew:
I was afraid of getting hooked on the drugs. I was afraid of becoming dependent. And I knew that my condition was not going to get better and I realized that if I got on these drugs, I could be in for a series of problems with them. I knew about addiction and I knew of people who have been caught in this web and I was just really leery of it.

Participant nine also has a heightened awareness of the addictive potential of opioids because of friends he has seen become addicted:

You know I have to be careful on how I take this ‘cause I’ve seen a lot of good people get addicted to pain medicine. I’ve seen a lot of lives destroyed because of it. And a good buddy of mine died because of it, buying pills off the street.

Similarly, participant six spoke about a family member who misused their opioid medications:

My husband’s mother committed suicide and she was always on pills that made her dozy and slurring. So we have a lot of stuff going on with that where we’ve dealt with people with addictions cause [husband’s name] mom was addicted to a lot of ummm, I don’t know she just had a lot of problems and the doctor just gave her whatever she needed to. So that causes a lot of…you’re scared to take stuff, you’re scared that you know, to take too much stuff cause something bad might happen.

Participant nine spoke about the fear his former partner had about his opioid use getting out of control:
The woman I was living with is a [name of occupation], and she knows how addictive these pills were and she actually took them from me. She was giving them to me, but wasn’t giving them to me, to the point where I actually needed them ‘cause I was in significant pain for three years because she didn’t want me to become addicted to them.

The main fears discussed were about addiction and dependency. Fears were revealed not only by the participants but also those around them including family members and friends. However, fears also stemmed from accessing and possessing opioids.

5.6.2 Being Victimized

All participants were aware, or became aware, that opioids were also used as recreational or street drugs. Some participants told stories of themselves or other individuals who had been victims of a crime involving opioid medications. The daughter of one participant witnessed such a crime. She observed an individual being mugged outside a pharmacy for his opioid medication after he picked up the medication from a pharmacy for a relative with cancer. The participant expressed her concerns as follows:

… I became a little bit anxious and felt a bit vulnerable because we pick these drugs up and, you know, my kids pick them up, my husband picks them up, I pick them up, my homecare worker. I spoke to my pharmacist about this and he, and suggested maybe I just get them delivered. And he said, “Oh but then they will know where you live” which was a little anxious making.

The same participant spoke about an incident when a pharmacist openly discussed her opioid medications with her in the pharmacy:
The pharmacists spoke loudly and in the presence of others how my MS-Contin prescription was not complete and that I would be getting the balance later but here is what you’ll need for the next two weeks. And I did feel vulnerable because there were people around watching me fill out the form and knowing what the drug I was taking.

Her anxiety was heightened because the safety of her husband and children were also compromised because they often picked up her medication for her.

Participant nine was directly victimized himself: “One time we came home and the house was broken into and ah, basically my pain medicine was gone. So someone knew…” He specified feeling directly targeted because of his possession of opioids within his home.

Participant three summed up the impact these crimes have on the pain community as a whole:

We’ve really had a hard time as a pain community to get access to medications due to the fact of the legalities and misuse of property from outsiders. So that’s the start of the bad name. But if you are fortunate to get it, then it’s like oh geez, we have to worry about someone else trying to steal this stuff. And I’ve heard stories of people. Someone scooped their meds or watched them get their meds [from the pharmacy] and when they came out, scooped them out of their hand. And who pays the price? And it’s the pain person.

In addition to the stress of CNCP and opioid use, consequences of this stress were continuously appraised and the search for successful strategies were explored in hopes of
finding balance. Finding adequate ways to overcome these additional stress can be frustrating and time consuming. Various strategies were discussed by participants in order to protect themselves from further stress.

5.7 Theme 6: Self-Protection

Learning to cope is not an unusual element of chronic illness. Theme two captured how participants managed the physical side effects of using opioids; however participants also described various social and psychological consequences associated with using opioids. The participants spoke about the stress they experienced because of the lack of support and understanding of their opioid use from both healthcare providers and loved ones. This lack of support and understanding often stemmed greatly from stigma and fears associated with opioid use as previously discussed. In order to cope, participants protected themselves by not disclosing their opioid use to prevent further stress. Participant one described why she did not tell her family about her opioids use:

I do it for my own protection by not telling them because I see how they react by reading something in the paper…and it’s just their ignorance. And I don’t have time. Well they know what’s going on but they don’t get it to this day. So you have to pick your battles. They’re not one of them and if they don’t get it now they are never going to get it cause I’ve been a member of the family, well forever, and chronic pain, well 30 years they had to get it so I kind of don’t talk about it.

Participant eight discussed the emotional pain and difficulty she experienced with her mother who did not understand her opioid use:
You just have to learn to deal with it. Like it’s your mother, she’s 80 years old, she’s never understood before she’s not going to understand now. So, I just keep it at an arm’s length, you don’t say too much. You know, don’t tell her anything more then I have too. Don’t expect anything with it I guess.

Participant eight limited what she shared. Similarly, participant nine has felt the need to protect himself from potential employers when interviewing for a job:

…and I don’t tell anyone if I go for a new job interview, I don’t tell anyone that I take pain medicine. I don’t even tell anybody I have epilepsy until I’ve been hired. I’ve lost jobs because of it in the past.

Participant six described not being truthful as leading to increased isolation: “So it was hard to always be secretive and then I started to isolate myself from people and I didn’t like that so I was just honest.” She recognized the impact the secrecy had on her and was more honest about her pain and opioid use but others were not open about their opioid use.

Some participants felt as if they were ‘wearing a mask’ to protect themselves from discrimination or judgment. Most had accepted that they need to use opioids daily but they hid their use from others. This self-protection meant that participants often felt the need to act in ways that did not reflect how they really felt. For example, participant one spoke about how she hid what she was feeling when she required treatment from her local emergency room:

…I’m thinking ok, there may be those addicts and they may slip by you but everyone that’s coming to the ER is not a friggin’ addict, what’s wrong with you
guys? You know, but of course I would never be grumpy or grouchy, you’re always like “oh thank you dear” you know trying to be sweet and I have to act, put on a show when dealing with this horrible issue and trying to be nice to them cause I may not be treated well.

Participant three voiced his concerns about having to move from a rural neighbourhood, where he could smoke his cannabis openly in the yard, into the city where finding privacy to smoke cannabis might be an issue:

It’s gonna be interesting coming into a small area. I’ve got an acre where I can hide in the woods a little bit, when you come into the city all of a sudden I know that I’m gonna have the pressure on me. Where are you gonna go to smoke your cannabis? Cause guaranteed I cough from it but if you’re living in a little tight community, you’re not gonna be able to do it. I don’t look forward to having to redevelop hiding spots and I shouldn’t have to but again that’s the way the public views the use of it.

As noted in chapter four, chronic pain affected participants’ physical abilities, which in turn resulted in emotional and psychological distress. This theme described one way in which participants coped with the emotional struggles and the stigma of using opioids. As a way to cope and find balance, some participants decided not to discuss what they were going through to protect themselves emotionally from feeling judged or misunderstood by loved ones. Others described the feeling of being more secretive or hiding behind a mask to please others. This combination of stigma, fear and guilt led to a general feeling of ambivalent especially about opioid use.
5.8 Theme 7: Ambivalence

Over the period of seeking relief for pain, many participants discussed a feeling of ambivalence about their relationship between chronic pain, opioid use and self. This ambivalence was about whether they would be cured, how long they would need to use opioids or their overall care by a professional or physician. Participant three expressed feeling lost: “I had no direction on where I was going and I was just living one hour by the hour and, and again a lot of isolation.”

Some participants described an internal battle specifically about their opioid use. Participant two commented on the natural hesitation about opioid use: “They don’t want to get into the drug scene so they hold back not realizing they aren’t helping themselves.” Participant six talked about how she hasn’t fully accepted her pain and the need to use opioids daily:

I think it’s more of a power struggle, to see who’s stronger. Whether it’s me or the [pain], and not only that but I just hate that I have to take something to get through the day. I have to put this patch on every couple days just to get through or I’d be in the ground right now, you know, so ya its hard it’s very hard.

Participant six and seven shared similar views about using opioids as they continue to battle their pain and test their limits around how long they can go without taking their medication before its unbearable. Participant seven described his approach:

It’s always a fighting game, you know how long can I go without having to increase it [opioids] or even taking my medication. I normally don’t take it till five or six o’clock my second dose at night but sometimes I try to take it as late as
I can so I’ll sleep a little bit longer but it’s always a fighting game with the pain right?

Participant six had the same views: “I still fight with myself, like I still let it go to the very, as long as I can, there is always that fight, like I’m stronger than you sort of thing. And I never win though.”

Participant five also discussed her hesitation with medication:

I am using it [opioids] for pain management, but I want to get away from that. And I’m very aware that I want to get away from it. And I will be very active in trying to continue to figure out ways to get away from it.

She feels optimistic that one day she will not need to use opioids to manage her pain.

Whereas, participant seven continued to struggle with accepting his inability to accomplish tasks he used to be able to do. He is upset about having to use opioids long term:

I’m 42 and I can’t even wash my own god damn truck if I wanted too. Or if I did I’m gonna pay for it. And I’ve got nobody else who’s gonna cut my lawn for me other then me so, it’s hard. It’s easy to say don’t do it but what are my alternatives, taking morphine the rest of my life?

All participants in this study experienced being in a state of ambivalence at one point or another throughout their pain journey. Some participants still remain hopeful that their pain will end but most of the participants interviewed have come to a place of acceptance that they will experience pain and need opioid medication for the rest of their lives.
Seeking balance was the ultimate goal for participants and in order to do so, acceptance of using opioids was essential.

5.9 Theme 8: Acceptance

Searching for relief from pain was often described as exhausting and frustrating for most of the participants. Their pain dictated their life. The journey in seeking relief was full of trial and error with pharmacological, physical and alternative therapies. Individuals in this study often expressed their desire for a “cure.” However, once their condition was deemed chronic, it was essential to move towards acceptance and begin to learn to live with tolerable pain in order to function. Participant three described his acceptance: “I still hope that one day there is something out there for me, but I have to accept the part that I can’t do what I used to do. I have to accept those limitations on me.” Following the period of uncertainty, like participant three, some participants were able to accept that they were going to be living with pain and would need to use opioids for their rest of their lives. The following section describes the participants who stated that they had accepted that they needed to use opioid medication daily for the management of their chronic pain.

Aside from the daily struggles experienced with opioids, they were seen as being the reason most of the participants have regained a tolerable quality of life. Participant two described this by reflecting on how she was prior to opioids: “Before medication [opioids] I could not take part in a lot of life.” Participant eight goes into greater detail about how thankful he was to have opioid medication to help cope with his pain:
But opiates, that’s my way of life. There would be no life if I didn’t have this.
And I thank god for them because without them I’d be…well I wouldn’t be. I just
couldn’t go on. I would have committed suicide a long time ago. And I say that
truthfully cause you could not live like that, with that constant, constant pain. But,
with the opiates it’s made it possible to be able to have a part of a life, you know.

Participant three was unsuccessful in finding pain relief with opioids himself but
explained his acceptance of opioid use by others who could benefit from them:

I was one that thought the same way about these pain meds and the addictiveness
of it and the side effects, what can happen to you long term. Though, after you
learn what these meds can do and that these meds actually take away a percentage
of the pain. It has allowed a number of individuals to regain their life- to be able
to drive, be able to become an artist or a craft person.

Participant three summarized how he had regained his life through cannabis use: “So
cannabis has really benefited me in different situations. It’s just, it puts me in the
forefront rather than staying behind.”

Participant nine had reconciled the positive and negative aspect of opioid use and
accepted that overall they were helpful to manage his pain:

For me, personally there are benefits and well I can say the pros outweigh the
cons in this case. Ummm because I wouldn’t be able to do anything without them
and I know that and my doctors know that too. Because when I don’t have pain
medicine or, one time when I didn’t have the pain medicine I was off my feet
literally for a week, in bed, not moving and I would have to crawl on my forearms to the bathroom cause of the pain in my legs from my back.

For many participants, the realization and acceptance that they will always live with some degree of pain was difficult. Participant one stated: “I’m happy with my decision, with opioids. I finally got over the fact that it’s not a cure-all and I have to do other things besides medication…” For some participants, an important component to finding relief from chronic pain was having various modalities in conjunction with opioids to help manage and maintain balance. Participant one described: “medication can work, but it has to be used as a list of ten things you have to do for your pain, you cannot depend on pain medication to take it all away.” Additional pain management techniques discussed ranged from easy everyday activities such as stretching, taking a warm bath, or using heat pads to transcutaneous electrical nerve stimulation machines, acupuncture, and Botox.

Some participants knew that they would experience greater pain if they did certain physical tasks but believed the satisfaction of accomplishment was worth the physical pain experienced. Participant seven described this in his own life: “I force myself to go out and cut the lawn, or do the wash, or wash the dishes or whatever it is, but umm, other then that it’s a trade off basically.” He finds balance mentally in trying to maintain independence by accomplishing his chores but will face physical consequences from his pain later. Acceptance of pain and the persistent negative consequences of opioid use lead to a continuous cycle of appraisal and reappraisal of their stress in hopes to find relief and balance.
Summary

Descriptions of the lived experience of each of the nine participants opened up the dialogue of what it truly means to be an individual using opioids daily to manage CNCP. Although each participant’s experience was unique and individual, many parallels were revealed throughout the interviews. Each participant began using opioids for a variety of different reasons whether it was over time as the chronic pain progressed or being introduced to it because of an acute episode of pain or postoperative pain. All participants experienced the negative side effects of using opioids as well as directly or indirectly being affected by the social stigma associated with them. Many participants realized shortly after beginning their opioid therapy that the opioids didn’t completely relieve their pain and they would still have a certain degree of pain and discomfort they would have to manage. This realization was often shocking for the participants. Although not all participants expressed fear of becoming addicted to their opioids personally, they did understand the general concerns from the physicians, other individuals with pain and the general public.

Figure 1  The Relationship Between Themes
Figure 1 depicts the relationship between the seven themes and the overarching theme of finding balance. Ultimately the stress of CNCP influenced the participants’ decision to begin to use prescription opioids. However, participants were presented with many additional stressors or consequences of their opioid use that constantly challenged their decision making and influenced their ability to cope and find relief. These additional stressors made it difficult for participants to find a balance between their CNCP, opioid use and a tolerable quality of life. In order for the participants to find a tolerable quality of life, many coping strategies were attempted which continually influenced and often challenged their decision to use opioids. The overall goal was to find balance between their pain and use of management strategies, including opioids and/or cannabis, in order to achieve an adequate quality of life. In finding balance, most of the participants were able to accept that they will need to be using opioids or cannabis indefinitely to manage their pain, but they remained hopeful that one day, a cure or less invasive treatment will be found. Finding balance was not a fixed state but a position that was in flux and responsive to new stressors that might be presented to someone living with chronic pain.
6.1 Overview

The present study’s findings indicate the complexities of using prescription opioids for the management of CNCP. Chapter four portrayed each participant’s past journey of CNCP to help understand his or her life experience before using prescription opioids. The stories told by the participants revealed that the struggle with CNCP and opioid use was a dynamic, non-linear process which was influenced by many internal and external factors. Chapter five described eight themes that were constructed through the process of reflective and thematic analysis and the overarching theme of finding balance. For most participants, the positive benefits of using opioids outweigh the negative consequences as most of the participants continued to use opioids.

The qualitative findings of this study are difficult to compare with similar studies as there has been limited research published on the experience of using prescription opioids for CNCP. In this chapter, the emergent themes revealed by the participants are contrasted with the existing literature focussed on the processes of stress, appraisal, and coping as it relates to the experience of CNCP and using opioids daily. In this chapter, implications that using prescription opioids may have for chronic pain management and the field of health promotion are discussed. The chapter concludes with an overview of study limitations and future directions.

6.2 Stress, Appraisal & Coping

In order to understand the process of coping with stress, the meaning of the stressful situation must be understood (Park & Folkman, 1997). Meaning is an
individual’s perceptions of the potential significance of an experience (Fife, 1994). Like many illnesses, chronic pain is open to a variety of meanings and interpretations, both physical and emotional (Thomas & Johnson, 2000). Cassell (2001) wrote that meanings are often shaped by past or present experiences. The meaning of both CNCP and opioid use were influenced by the participants’ present medical situation and the meaning of pain within that context, the implications of opioid use, and their appraisal of past experiences with pain and opioid use. As described in chapter 4, participants remembered their early experiences of pain as intolerable which sometimes triggered a sense of desperation to seek a cure. Although pain relief was the ultimate goal, most participants expressed ambivalence about using opioids daily because of the various consequences that they might experience. Park and Folkman (1997) described two types of meaning in the context of stress and coping: global meaning and situational meaning. Global meaning is a generalized level of beliefs, and expectations built through an accumulation of life experiences. Situational meaning refers to the significance of a particular occurrence in terms of its relevance between the person and environment. Global meaning highly influences aspects of situational meaning (Park & Folkman, 1997). These two concepts of meaning influenced the coping strategies used by participants in this study to relieve stress.

Stress is defined as a transactional phenomenon dependant on the meaning of the stimulus to the individual experiencing the stress (Park & Folkman, 1997). Lazarus (1991) argued that stressors are demands made by the internal or external environment that upset balance, thus affecting physical and psychological well-being and requiring action to restore balance. Stressful experiences begin with an external stressor and are
mediated by one’s appraisal of the stressor. Appraisal is followed by an evaluation of the psychological, social or cultural resources available to help a person cope and reappraise the stress. This non-linear process is known as the Transactional Theory of Stress (Lazarus & Folkman, 1984). Stress does not affect all individuals equally; therefore the appraisal and coping process is different for everyone. Participants in this study experienced two main stressors: chronic pain and prescription opioid use. When faced with the stress of chronic pain, participants were often left struggling to understand how they would return to their previous life with this new stress. Almost immediately following initiation of pain, the process of appraisal began.

Cognitive appraisal refers to the way in which individuals evaluate the meaning of a specific event with respect to its personal significance (Park & Folkman, 1997). There are two basic types of cognitive appraisal: primary and secondary appraisal. Primary appraisal refers to an individual’s response to stress often motivated by the importance of the person’s beliefs or goals that are threatened, harmed, or challenged in a given stressful situation. Secondary appraisal is an individual’s evaluation of their ability to alter a stressful situation and manage the negative reactions (Glanz, Rimer, & Lewis, 2002).

Primary appraisal involves an evaluation of how significant a stressor or threat is to the individual’s wellbeing. Evaluating the potential for physical or psychological harms, or damage or injury associated with future consequences is a threat appraisal. Harm-loss appraisal is the perception of actual physical or psychological harm, damage or injury. These two types or appraisal are considered negative appraisals. The current study revealed negative appraisals of both chronic pain and opioid use. Chapter four
described the negative consequences of CNCP. Many physical and social consequences of opioid use were discussed in chapter five such as guilt, fear, and feeling stigmatized. These consequences led participants to feel ambivalent about using opioids and uncertain as to whether they could find a tolerable quality of life again. Similarly, ambivalence to use opioids for CNCP was revealed in a study by McCracken et al. (2006) where 120 patients were under using their opioid medication because of concerns over side effects. CNCP can impair quality of life and can result in a reducing in and withdrawal from activities that are intrinsically rewarding, such as work and physical and social activities (Gerstle, All, & Wallace, 2001). As participants were able to begin controlling aspects of their pain they were able to eventually shift towards a more positive appraisal of their pain and opioid use despite the additional stress they faced. Challenge appraisal is described by Unruh, Ritchie and Merskey (1999) as a test of one’s strength with the potential for mastery, growth and gain associated with a stressful event such as pain. Many participants discussed the transition from viewing the consequences of their opioid use as harmful to a higher level of challenge along with acceptance of their pain and need for opioids. Threat, harm-loss, and challenge appraisals, although different, are not mutually exclusive and often co-exist when experiencing a stressful situation (Unruh & Richie, 1998). The participants in this study often experienced pain as a stressful and likely threatening experience associated with harm or loss. Comments such as “going from a very secure income to one you’re not sure of” or “I didn’t need that stress on top of having surgery…but it’s all parts that you endure as a chronic pain patient,” illustrate this type of appraisal.

In contrast to primary appraisal that focuses on the significance of a stressor,
secondary appraisal focuses on an individual’s evaluation of the stressful event in terms of what can be done to change the situation, possibilities and effectiveness of coping resources and expectations regarding outcomes (Park & Folkman, 1997). Primary and secondary appraisals interact to determine the perceived stressfulness of a situation (Lazarus & Folkman, 1984). Upon assessing the severity of their stress, an evaluation of appropriate ways to cope began. According to the Transactional Model of Stress and Coping, emotional and functional effects of primary and secondary appraisals are mediated by coping strategies (Glanz, Rimer, & Lewis, 2002). Lazarus and Folkman (1984) defined coping as any effort to manage a stressful experience regardless of whether the outcome of the strategy is useful. The ways in which individuals with CNCP cope with stressors can predict pain severity, ability to function, and psychological well-being (Eccleston, 2001; Glanz, Rimer, & Lewis, 2002). Ramirez-Maetre et al. (2008) found an association that those who appraised their pain as harmful or a threat often used passive coping techniques. The use of passive coping techniques such as avoidance, are associated with high levels of pain intensity and impairment and lower levels of functioning. Similarly, those who appraised their pain as a challenge were associated with active coping leading to low levels of pain intensity and impairment and higher levels of functionality and well-being (Hassinger, Semenchuk & O’Brien, 1999; Jensen & Karoly, 1992). These findings of threat, harm loss and challenge appraisal parallel those in this present study.
Figure 2 illustrates that stress, appraisal and coping process are linked to both chronic pain and opioid use not in linear relationships but a continuous cycle. Individuals will attempt to cope with stress by responding to it. Sometimes this coping behaviour is helpful and the stress subsides. But other times, the behaviour is unhelpful and the stress is reinforced, making the appraisal of the situation and stress more and more negative. This intertwining of appraisal and coping will create a vicious cycle that will maintain the stress. The emotional and physical response to stress also plays a role in maintaining the vicious cycle. The process of deciding to use opioids for some participants was associated with the many unsuccessful attempts to control or cope with their pain which led to greater stress in their life. The effects of coping strategies on emotional and functional
outcomes of a health threat and the accompanying stress may depend on a person’s dispositional coping style and perceptions of support in the environment (Stanton, Revenson, & Tenen, 2007). The need to use a variety of coping strategies to manage both physical and emotional stress was commonly discussed throughout the study. Perceived control over illness has been shown to improve physical well-being by increasing the likelihood that the person will adopt recommended health behaviours (Glanz, Rimer, & Lewis, 2002). However, participants could not always control the source of stress that was challenging the coping response. This stress often comes from external barriers that pose threats to their well-being. Due to the social stigma associated with prescription opioids, participants were often faced with additional stress from external sources (Katz, 2008). Even if an individual is able to find balance between their pain and opioid use, external stressors are unpredictable and contribute to the continuous cycle of stress, appraisal, coping and reappraisal the participants experienced.

This study illustrates the relationship between cognitive appraisal, coping strategies and physical, emotional and social consequences of CNCP. All participants, whether they appeared to be managing their pain or still seeking a cure, had developed additional coping strategies beyond opioid use. A study by Molton et al. (2007) that revealed that older adults tend to use a wider range of strategies more frequently to cope with chronic pain that younger adults. These findings are similar to the findings of this study when comparing the appraisal and coping processes of the current participants. The participants’ discussion about living with persistent pain, coming to a decision to use opioids and/or cannabis, and then living the consequences of using these medications, involved a circular and interactive process of appraisal, coping and reappraisal.
Depending on how successful participants were in finding adequate relief, a gradually shift was made by many participants towards acceptance of pain and opioid use.

### 6.3 Acceptance

The overwhelming life world changes caused by chronic pain can put individuals into a state of uncertainty or ambivalence. Leading a normal life despite chronic pain, is almost impossible without accepting new limitations or learning to find a tolerable level of pain to live with. Not all individuals with CNCP are able to accept that there may be no cure for their pain (Clarke, & Iphofen, 2007; LaChapelle, Lavoie, & Boudreau, 2008). Vallerand (2003) described the movement towards acceptance of pain as being essential to continued functioning in daily activities. Groomes and Leahy (2002) argued that acceptance is related to two aspects of the stress appraisal process: challenge/gain from the situation and past experience with the situation. The present study revealed that those participants who had chronic pain and were using opioids for several years were more accepting of their current situation than those who were newly diagnosed. Although acceptance has been shown to benefit one’s overall wellbeing, little is known about how individuals arrive at a state of acceptance (LaChapelle et al., 2008).

Pain-related beliefs and attitudes are predictors of adjustment among chronic pain patients. Jensen and Karoly (1992) found patients who believed themselves to be disabled by their chronic pain demonstrated significantly lower levels of activity and psychological well-being and higher levels of professional utilization. Participants in this study described a hesitation about accepting their “new body” and potential need to use opioid medication daily for the rest of their lives. Upon being diagnosed with a chronic
pain condition, and not fully understanding that their pain may never go away, the participants began searching for a cure. This is consistent with other studies (Clarke & Iphofen, 2007; LaChapelle et al., 2008; McCracken & Vowles, 2006). This reaction often dominated some participants’ lives. It was often not until a participant came to accept that their chronic pain would not be cured that they were able to begin regaining some control. Following a stage of dwelling on and searching for a cure, most participants had an attitude of “getting on with life” despite their pain and consequences of opioid use. Most participants in this study believed they had some control over their pain which influenced their movement towards accepting the need for opioids. Similar to findings from a study by LaChapelle et al. (2008), participants in this study discussed their shift in beliefs about their pain as being influenced by their diagnosis, social interactions and supports, knowledge about their pain management and self-care. Acceptance of pain is described as a process of changing behaviour patterns that are focused less on trying to control the experience of pain and more directed towards living healthy (McCracken & Vowles, 2006).

Based on the analysis of the interviews, it was evident that the experience of moving towards acceptance of their CNCP and opioid use was facilitated by the appraisal of many internal and external factors. Internal factors included challenging beliefs about opioid or cannabis use and the emotional and physical side effects experienced when using opioids. External factors included unsupportive family or friends or feeling challenged within the healthcare system. Often, the participants described acceptance of their new life in chronic pain and using opioids as being the only way to move forward. However some participants were still held back in a state of ambivalence and were
searching for a cure. The participants who have been using opioids for their chronic pain for many years often made comparisons of how their life with pain before using opioids to life with their opioid use for managing pain. Their life before opioids represented a very dark time of isolation, depression and uncertainty and the present was more positive with more motivation and purpose in life. These findings are similar to Vallerand and Nowaks’ (2009) findings where those individuals described being thankful for their opioid therapy regimen as it allowed them to regain their life. Also paralleling these findings, this study revealed that in order for participants to make a shift towards acceptance, they spoke about the need to change their focus from constant pain and seeking a cure to actually finding purpose and living their life again.

A few participants were hesitant about fully accepting their new life with pain or the need to use prescription opioids daily. They described acceptance as “giving up” on finding a cure for their pain. Acceptance can be seen as a strategy to control pain and reconcile the battle between self and pain to move forward and live a productive life (Tul, Unruh, & Dick, 2010). Over time, acceptance was achieved through a deliberate and active change of everyday life but it was a difficult process of prior unsuccessful management attempts for many participants. Thompson and McCracken (2011) stated that although attempts to control chronic pain or other unwanted psychological experiences associated with it may be unsuccessful, acceptance did prove to be an important, beneficial process to pain management. For most in the present study, acceptance meant adapting to their new limitations, embracing a sense of empowerment, and understanding that they are fighting a battle that they will likely lose if they keep fighting against their pain. One participant described this battle with her pain: “there is
always that fight, like I’m stronger than you sort of thing. And I never win though.” In learning to adapt to pain rather than fighting it, participants were able to gain more control over chronic pain. Some participants no longer felt the need to hide their pain and opioid use from people as they once did. Participants emphasize the importance of acceptance of their chronic pain as being the beginning steps to regaining control over their lives, treatment and overall wellbeing.

The importance for the individual to take initiative to make positive changes is imperative in chronic pain management. Participants who have accepted their pain, discussed letting go of expectations and re-evaluating priorities. Participants were able to let go of the need to please others at the expense of their own body’s needs and accepted that doing activities at a slower pace and taking time to rest was crucial to their pain management regime. Similar to many of the individuals in the present study, Participant three reflected on his pain journey towards acceptance: “I still hope that one day there is something (a cure) out there for me, but I have to accept the part that I can’t do what I used to do. I have to accept those limitations on me. Though, until I accepted it, a lot of things didn’t change.” Risdon et al. (2005) described acceptance from a community sample of chronic pain patients as acknowledging limitations and realizing that there is more to life than pain and relinquishing the fight against battles that cannot be won.

Finding balance between control of pain and acceptance that pain will not fully go away is a difficult but important aspect of finding physical and psychological relief.

6.4 Finding Balance

Chronic pain affects all aspects of a individual’s life. Seeking balance is essential
to maintain stability and achieve a quality of life that is tolerable (Gerstle, All, & Wallace, 2001). Balance in relation to pain was defined by Vallerand and Nowak (2009) as the act of achieving equilibrium between pain management and level of functioning in life domains. Finding balance meant different things to different participants. The ultimate goal for participants was to be able to find a balance between manageable pain levels and abilities to carry out everyday activities. For some, this meant using alternative health therapists in conjunction with using opioids to find relief from their pain. For others it meant limiting certain activities or adapting them to a tolerable level so they could participate. In gaining some control over factors that contributed to their pain and accepting their pain, some participants began re-engaging in physical and leisure activities. Although they needed to pace and adapt many activities to accommodate their pain, participants were able to find purpose and meaning in activities such as painting, exercise, and volunteering. As they changed their approach to the challenges they faced and as they moved from passive coping to active coping, they were able to reconstruct their meaning of pain and opioid use.

As discussed previously, some participants discussed a “failed expectation” of opioids. They were shocked that opioids did not relieve all of their pain and were left wondering what more they could do. In order to find a balance, additional coping strategies were needed. They were able to decrease their pain though both problem-focused strategies such as exercise, meditation, limiting or adapting their activities, and emotion-focused strategies such as creating healthy boundaries to decrease stress, and find social support through loved ones and support groups. The participants learned that they needed additional active coping strategies in conjunction with their opioid
medication to decrease their pain to a level where they could function and find meaning in their lives again. Finding balance was a very lengthy yet important process for participants to endure because pain is so destructive. It often interrupts functional relationships, threatens sense of security and identity, and contributes to the experience of feeling uncertain about one's future (Robb, 2006). This process enabled participants to regain control of their own well-being and recognize that they need to contribute to the management of their pain and experience of using opioids. When this physical and psychological control was regained, the participants described feeling “empowered.” Opioids were reported by participants to help them re-engage in meaningful activities. For example, participants who appeared to manage their pain and cope well in their life embraced life and saw their chronic pain as a nuisance but not as an impossible burden.

Based on the reviewed literature and present findings, it is evident that there are two aspects to reappraisal specific to this study. The first is the process of engaging in passive coping and experiencing a failed expectation of opioid use for pain relief, and the second being the process of acceptance of opioid use and finding balance through meaningful activities. When an individual encounters a stressor and the context in which it occurs, the way in which he or she reacts can either promote or inhibit health related practices to overcome that stressor. The process of achieving balance is cyclical at times moving forward and at others falling back. A better understanding of how individuals with chronic pain react to stressors will enhance the development of effective strategies and programs for individuals with chronic pain to enhance their psychological and physical well-being.

6.5    Implications for Health Promotion
There are several implications for incorporating a health promotion lens into both the management of CNCP and opioid use. The present study revealed similarities of both the impacts of chronic pain on one’s life and the impacts of using opioids. Given the prevalence of chronic pain and increased use of prescription opioids, pain clinicians and researchers need to pay close attention to these other aspects of pain such as emotional, cognitive, and social benefits and consequences (Haythornthwaite, 2006).

This study showed that chronic pain affects every aspect of an individual’s life including their work, their emotional, mental, physical and social health, as well as, their relationships with family and friends. To date, there have been remarkable advances in our understanding of pain; however, chronic pain still remains a significant problem of epidemic proportions worldwide (Goldberg & McGee, 2011; Ives et al., 2006; McCracken, 1998, Vallerand, 2003). Sessle (2011) relates this epidemic to not only a lack of adequate management but also to lack of awareness about the burden of chronic pain, limited education to healthcare professionals, access to care by individuals with chronic pain and limited funding and research.

Health promotion is defined as:

the process of enabling people to increase control over, and to improve, their health. In order to reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment (WHO, 1986).

To take this definition further, health promotion involves strategies that include health education, social marketing, mass communication, political action, community
organization and organizational development (WHO, 1986). The first three strategies are aimed specifically at individual behaviour changes, while the last three focus more on enabling changes within the population and the environment. Health promotion initiatives are increasingly complex in their goals and approaches. They frequently attempt to achieve broad environmental change as well as individual behaviour change. Current health promotion strategies favour a multilevel (individual, regional, community, and individual) approach that employs multidimensional (physical, social, mental, and spiritual) framework of health to achieve and sustain health for everyone (Barr, et al., 2003).

A comprehensive, multidimensional approach is essential to reduce the burden of chronic pain and the consequences associated with opioid use (Barr et al., 2003; Katz, 2008; Slade, Molloy, & Keating, 2009). Multilevel strategies need to occur simultaneously to support these changes. In 2006, Nova Scotia Chronic Pain Working Group recognized the importance of research that advances our understanding of the treatment of chronic pain and the need to evaluate strategies and programs in the province to determine program effectiveness. The Canadian government has recently developed and is preparing to release a National Pain Strategy that recognizes the need for a coordinated approach to pain management in Canada. Outlined in this approach are four key target areas including: awareness and education, access, research and ongoing monitoring. These four areas will focus on addressing awareness, prevention, health literacy, education of healthcare professionals, early access to care and research and monitoring.

6.5.1 Awareness and Education
One of the most reported barrier to adequate pain management for those with CNCP is lack of guidance and education related to the use of prescription opioids for chronic pain (Chou et al., 2009a; Glajchen, 2001; Gunnarsdottir et al., 2003; Katz et al., 2007; Rathmell & Jaimison, 1996; Wilsey, et al., 2003; Vallerand & Nowak, 2009). The current system for training physicians is very weak and outdated. Currently, veterinarian students receive five times more education about pain than medical doctors in Canada (Watt-Watson et al., 2009). This gap in pain education not only compromises patient safety, leaving many individuals with CNCP undertreated, but many health care professionals are under-qualified to assess and treat pain (American Academy of Pain Medicine, 2009; Slade et al., 2009). Lack of trained professionals and lack of pain management services contribute to stigmatization of individuals with CNCP. Training programs are needed to raise awareness of the experience of CNCP and to provide direction to create more supportive environments for using prescription opioids. The target audiences should include health and allied professionals including police, social assistance staff, employers, and educators.

This study revealed that stigma and disbelief experienced by participants was often described as more difficult to manage than the actually physical pain itself. The stigma associated with chronic pain alone can be enduring and potentially disabling (McCaffery & Pasero, 2001). When individuals with chronic pain require opioids to assist with management of their pain, then stigmatization is even more likely to be due to concerns about the potential for addiction accurate or otherwise (Fornili & Weaver, 2008). These patients may suffer for years before their pain is adequately managed. The present study’s findings highlight stigma not only experienced due to chronic pain but
also due to opioid use. The benefits of opioids are well documented for those who experience CNCP (Eriksen et al., 2006; Gardner-Nix, 2003; Lynch & Watson, 2006; Katz, 2008; Vallerand, 2003; Vallerand & Nowak, 2009). Health care professionals may be the only advocates for some individuals who are stigmatized, including those who have both problems of chronic pain and problems of addiction. Patient advocacy by practitioners can take many forms, from the level of the individual patient to a national level. Health promotion specialists could play an important role in building the communities capacity and knowledge of chronic non-cancer pain and opioid use through education and awareness workshops.

A comprehensive health promotions approach is most effective in stigma reduction (Cheng, Kotler, & Lee, 2011). This approach must include the development of supportive policy frameworks, social marketing programs characterized by increasing contact with individuals with personal experience, research, and training. A supportive policy framework that focused on ensuring income, support, housing, employment, and accessible treatment is needed to help support individuals with CNCP. Social marketing is one of the most effective ways to positively affect attitudes (Cheng, Kotler, & Lee, 2011). Social marketing is the delivery of relevant messages that will resonate with target audiences, encourage the public to recognize, acknowledge and disclose their own problems or those of family members, and provide information that will help the audience to access help. These kinds of initiatives create greater acceptance for conditions and their treatments (Cheng, Kotler, & Lee, 2011).

The media has largely contributed to the heightened stigma and concern regarding the use of prescription opioids (Peppin, 2009; Whelan, Ashbridge & Haydt, 2011). This
stigma is done by often focusing on the negative aspects of opioids such as addiction or diversion, rather than reporting on or including the success many individuals with chronic pain have had with using prescription opioids without becoming addicted (Peppin, 2009). Social marketing or public education through mass media, targeted programs including workplace, schools, and service industries as well as one-on-one communication strategies will be effective in creating greater public understanding and reducing stigmatization. Further programs must be developed which reach out to diverse communities and are tailored to their specific needs.

Raising awareness about chronic pain as a disease and the benefits of opioids from a health promotion lens may potentially decrease the under treatment and misdiagnosis of pain. These issues need to be among the major priorities for health promotion in the future. A better understanding of the magnitude and characteristics of opioid use for CNCP can contribute to improved pain management programs and enable both health care professionals and individuals who are using opioids for CNCP to better understand the needs and supports required to reach an optimal state of health.

Promoting health is a shared responsibility that requires the coordinated action of many sectors working together to improve well-being. Building the capacity of individuals, health care professionals and the general population regarding CNCP and the benefits of opioid use is imperative. Providing educational opportunities and raising awareness of the benefits of using opioids with adults with CNCP is an integral part of decreasing the stigma and working towards a solution for better pain management (Goebel et al., 2009).
6.5.2 Access and Treatment

As the search for effective treatments or management strategies is often lengthy and exhausting, efforts to support the emotional, social, and psychological consequences have been minimal in proportion to the severity of the problem (Gallagher, 1999). Access to pain relief is a fundamental human right and wait times for pain care in Canada grow longer by the day (Lynch et al., 2008). Although efforts to improve treatment of CNCP have focused on increasing access to opioids, this movement has not been matched by attempts to increase access to other effective management techniques such as psychological, physical, or multidisciplinary treatment methods (Vasudevan, 2005). An integrated approach to pain management in Nova Scotia is needed.

There is increasing evidence supporting the use of an interdisciplinary approach to managing CNCP (Guman et al., 2001; Thomas & Johnson, 2000). Traditionally, chronic pain management was approached from a biomedical perspective, with a focus on pathophysiology (Lynch & Watson, 2006). However, this approach does not address the psychological, emotional and social complexities of chronic pain (Gallagher, 1999; Kleinman, 1988; Thomas & Johnson, 2000). Best practice guidelines of chronic pain treatment include a multidisciplinary management strategy focussing on a biopsychosocial approach (Gatchel et al., 2007). With this approach has come an increasing emphasis on the importance of self management with a focus on acceptance of pain rather than pain reduction (McCracken & Eccelston, 2005).

Similar to other individuals living with other chronic illnesses, those with chronic pain need to be key players in their own health care. As revealed in this study, individuals
who use opioids for CNCP found that opioids did not take away all the pain. In order to find comfort with a tolerable level of pain, individuals must use a variety of coping strategies to find this balance. There has been a shift from the notion of a passive patient to a more active partner in healthcare, working alongside the healthcare team to enhance the experience of chronic illness. Collaboration between the patient and healthcare provider to develop management plans that incorporate cognitive and behavioural techniques such as relaxation, exercise, and leisure, have been shown to improve functioning, mood and to decrease pain intensity (Ersek, Turner, Cain & Kemp, 2004). This collaboration will not be successful without the patient assuming an active role in their own management. Individuals with chronic illness can self-manage but they need support to manage effectively. Teaching individuals to achieve accurate appraisals and seek appropriate coping resources involves information seeking and use of social support.

Self-management is becoming a more common term in healthcare and an extremely popular intervention in health promotion (Lorig & Holman, 2003). Self-management programs provide adults with education and tools to enable them to cope with chronic diseases such as diabetes, heart disease, respiratory diseases, arthritis and chronic pain (McGillion, Watt-Watson, LeFort, & Stevens, 2007). The programs help participants handle stress, better manage their medications, discuss the benefits of and encourage physical activity and good nutrition, and communicate more effectively with health care providers (Cameron, 2012). A successful self-management program incorporates three tasks: medical or behavioural management, role management and emotional management (Bodenheimer, Lorig, Holman & Grumbach, 2002). Specific for individuals with CNCP, medical management refers to the use of prescription opioids or
cannabis. Role management refers to maintaining, changing or creating new meaningful behaviours or adapting life roles for the individual. The third task of emotional management requires one to deal with the emotional aspect of having a chronic condition. Fear, guilt, frustration, anger, and sadness were common emotions expressed throughout this study. Controlling the physical aspects of chronic pain may not always be possible. Therefore, learning to incorporate these three self-management tasks is required to manage a condition such as CNCP. It is also hoped that increasing self-management programs for those with chronic illness versus those with acute conditions can ease the economic burden imposed on health systems.

Access to specialized pain clinics is very limited in Nova Scotia. A recent Canadian survey identified six months as the median wait time for a first appointment in public multidisciplinary pain treatment facilities. This means that 50% of patients have to wait six months or more (with a range of up to five years) for access to appropriate pain treatment, with 30% of clinics reporting waitlists of more than one year and vast areas of the country remaining under serviced (Choiniere et al., 2010). Individual’s who have to wait for a during of 6 months from the time of referral to a specialists experience a significant deterioration in health related quality of life and psychological well being treatment (Lynch et al., 2008). Self-management programs have been shown to be effective management programs for those with chronic pain (Du, Yuan, Xiao, Chu, Qiu, & Qian, 2011; Hurley, Walsh, Mitchell, Nicholas, & Patel, 2012). A study by LeFort et al., (1998) found individuals with chronic pain who participated in a 3 month self management program experienced short term improvements in pain, dependency, vitality, aspects of role functioning, life satisfaction, and in self efficacy and resourcefulness.
compared to those on a 3 month wait list. Given the scope and cost of chronic pain as well as the personal suffering, there is a need for low-cost, accessible and effective interventions that will help people find ways to cope and manage better (LeFort et al., 1998).

Currently, our healthcare system is not organized in a way that enables people to maximize their skills and self-manage as effectively as they are able. More research is needed to better understand how individuals with CNCP cope with their symptoms and consequences of opioid use as they relates to the broader social and cultural context is important to improve management outcomes. Self-management policies and programs need to recognize the stress that people experience as they experience a chronic illness. Viewing chronic illness management from a comprehensive lens may improve opportunities to support patients in certain contexts, and enhance self management (Townsend, Wyke, & Hunt, 2006).

6.5.3 Research

To increase our understanding continued research is needed to explore the experience of prescription opioid use from the individuals’ experience. Findings from this study and alike future research can assist health care providers to understand not only the physical effects opioids may have on their pain but also the social and psychological stress experienced in the process of seeking pain relief. By increasing this unique understanding, health care professionals’ ability to provide adequate support for patients not only with physical treatment but also from a psychological and emotional perspective could be enhanced.
As mentioned before, numerous studies have looked at opioid use from a professional standpoint but lack focus from the perspective of the individual using opioids (Goebel et al., 2009; Lynch & Watson, 2006; Katz, et al., 2007; Rosenblum, et al., 2008; Vallerand, 2003). Research in the future should focus on examining ways to alleviate barriers and disparities within the healthcare system for those seeking support and treatment of chronic non-cancer pain.

6.6 Study Limitations

Due to the small sample size, describing the lived experience of the participants in this study may not be true to all those using prescription opioids for the management of their chronic non-cancer pain therefore generalizing is not possible. Replicating this study within other settings and more diverse populations will provide a broader understanding of the individual’s perspective of the daily use of opioids.

It is important to consider some of the limitations of this study. The interpretive analysis of this project attempted to reveal new understandings of using opioids to manage CNCP. However, capturing experiential accounts relied on participants’ memories, for some over 20 years ago. These accounts of specific moments in time were sometimes vague due to lapses in memory. Van Manen (1990) cautions that gathering descriptions of lived experiences can be challenging. During the interviews, some participants gave casual explanations or generalized about the topic being spoken about rather than describing their own personal experience. As a novice researcher, I found it difficult at times to prompt the participant to reflect on their own experience in order to capture the true meaning for that individual.
All participants seemed eager to commit to participating in two interviews. However, only four of the participants returned for a second interview. It was not possible to reach some participants through telephone and email. Four attempts were made and then efforts were discontinued. The second interview was important to verify with the participant that interpretations of the data were accurate and to allow them to further elaborate or contribute additional thoughts to the conversation.

6.7 Conclusion

Chronic pain is a unique and individual experience. It is only through the individuals experience that chronic pain and the experience of using opioids can be understood in all of its complexities (Clarke, & Iphofen, 2007). In keeping with principles outlined in IPA, this understanding was cogenerated and shaped both by interaction and interpretation of the researcher and participant. Opioids are very powerful and effective in the management of some kinds of pain; however, as demonstrated in this study, not all pain is relieved with opioid use. Those who did experience relief from opioids often experienced adverse effects from the medication as well. The overall goal of pain management no longer is to just decrease ones pain, but to recognize the need for improving psychological and emotional functioning as well. As demonstrated in this study, opioids cannot be the only mode of treatment for individuals with chronic pain, but used as a tool to reduce pain. This reduction of pain then enables individuals to better cope with their physical and psychological pain through a variety of other modalities in conjunction with opioids.
This study highlights the importance for health promotion professionals to be a part of the shift in how our society addresses chronic pain and opioid use. Health promotion professionals can begin enabling those with chronic pain to better self manage their illness and begin building capacity of healthcare professionals and communities to better understand the benefits of opioids for CNCP. Building this capacity can allow for better design of interventions (i.e. policy and/or program) and begin to reduce the stigma associated with the use of prescription opioids.

6.8 Afterword: Analytic Reflection

My past experience working as a Recreation Therapist in the field of addictions sparked my interest in knowing more about individuals who use prescription opioids to manage various chronic pain conditions. Working in a Medical Detoxification Unit, I met many individuals who were admitted for addiction to or dependency on prescription opioids but also experiencing chronic pain. Working with this population, I gained a new perspective on the severity and prevalence of chronic pain. The lack of support and guidance within the healthcare system for individuals who not only suffer from chronic pain but also have an opioid addiction became evident. My interest in this area grew rapidly as the exposure to the complexity of chronic pain and prescription opioid use became apparent. After a year and a half of working on the detox unit and talking with individuals with chronic pain about their experience of using prescription opioids, it became clear that there was more to the experience than simply pain relief. The experience of using opioids has a deeper psychological, social, emotion and physical impact on one’s overall quality of life.

Due to my limited education on chronic pain and opioid use I spent my first year as a master student dedicated to exploring the literature on and studying both chronic pain
and opioid use. I completed a pain course and an independent study on phenomenology where I had the opportunity to complete an interview with someone who has chronic pain and has had experience with prescription opioids. Having these learning opportunities paired with my past work experience helped me balance my understanding and opinions of using prescription opioids for chronic pain. Being new to research, I am still developing skills in data collection, interviewing, data analysis and writing. In order to lessen the impact of these limitations on my study, I frequently consulted and received feedback from my supervisor and received guidance from my committee members who I cannot thank enough. Exploring both the positive and negative aspects of opioid use in ones life presented a double edged sword: while the medication are essential for well being, independence and for performance of daily activities they also give rise to negative physical, emotional and social consequences. I hope that this study gives a voice to the experience of those individuals who are often not heard and will positively influence the treatment and care they receive in the future.
REFERENCES


Walker, I., Holloways, I., & Sofaei, B. (1999). In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *International Association for the Study of Pain, 80*, 621-628.


APPENDIX A: Interview Guide

Review the informed consent and interview structure:

- This session may last 45-90 mins and as was indicated when you consented to be interviewed, it will be audio recorded.
- Our interview is confidential. Names and contact information of study participants are kept confidential. Your consent form will be stored in a locked file cabinet. The audio recording will be transcribed in such a way that all identifying information will be deleted. In this way no one will be able to identify you or people you describe during the interview.
- Please be aware that if you tell me of any current abuse or risk of abuse of someone under the age of 16, the law requires that I must make an official report of this information.
- Also if you disclose and current homicidal or suicidal thoughts, I am required to report that information.
- Before we begin the interview, I would like to review the kinds of questions I’m going to ask. I am interested in learning more about how the use of prescription opioids has affected your life in a variety of different ways, physically, emotionally, socially ect.
- Do you mind if I take notes during our interview?
- Any questions about how we’re going to spend our time today?

[Interviewer to ask: Do you have any questions or concerns before we begin?]

Questions:

1. Could you please tell me about your pain?
   
   Prompt: When it started, diagnosis, pain now compared to pain before

2. How has your pain affected your life?
   
   Prompt: Relationships, occupation, leisure activities, ADL

3. How did you go about deciding you would use opioids to manage your pain?
   
   Prompt: doctors, support system, concerns
   - risks, being judged by others, side effects

4. What is it like to be a patient taking opioids for chronic non-cancer pain?
   
   Prompt: identity, secrecy, fear, relief

5. How would you describe your life now as a pain patient compared to before you began using prescription opioids?
   
   Prompts: controllability, pain severity, functionality, relationships
APPENDIX B: Eligibility Checklist

Exploring the lived experience of adults using prescription opioids to manage chronic non-cancer pain

A research study is underway for people using opioids to manage chronic-non-cancer pain conditions. This study is for patients of the Pain Clinic at the Queen Elizabeth II Health Science Centre only. If you choose to take part in this study you will be involved in two interviews with the researcher with the opportunity to share your experiences of using opioid medication to manage your chronic pain condition.

1. Would you like to participate in this research study which involves 2 in-depth interviews (approx. 1 hour each) over the course of 2 months?  YES____ NO____

2. Are you a patient at the QEII pain unit?  YES ___ NO____

3. Are you 18 years or older?  YES___ NO ____

4. Are you currently using prescribed opioids?  YES___ NO ____ (ie. codeine, morphine, oxycodone, hydromorphone, fentanyl and/or methadone)

5. Are you able to read, write and speak in English?  YES___ NO____

If you answer yes to all of these questions you are able to take part in this study. Please read the attached Information Letter to learn more about the study and expectations.
Dear Patient of the Pain Clinic,

I am writing to you about a research study being conducted by Ms. Erica Brooks, a Masters student at Dalhousie University within the Faculty of Health and Human Performance.

The purpose of this important study is to gain a better understand of the experience of using prescription opioids to manage pain from a patient’s perspective. There is more information enclosed and it is important for you to know that participation in this study is completely voluntary and if you decide not to take part, your treatment at the pain clinic will not be affected in any way.

Thank you for your time and your participation is greatly appreciated,

Dr. Mary Lynch,
Director, Pain Management Unit, QEII Health Science Centre
APPENDIX D: Recruitment Poster

DO YOU HAVE A CHRONIC NON-CANCER PAIN CONDITION AND USE PRESCRIPTION PAIN MEDICATION TO MANAGE IT?

If so, we would like to hear from you.

We invite you to participate in a research study exploring what it is like to use prescription medication to manage your chronic non-cancer pain. You must be 18 years of age or older and willing to tell your story about how prescription medication use has affected your life.

Each participant will be required to participate in 2 in-depth interviews lasting approximately 1 hour each over a 2 month period.

Note: You may discontinue the study at any time and your services or treatment will not be affected.

If you are interested and want more information please contact:

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APPENDIX E: Informed Consent

Study Title: Exploring the lived experience of using prescription opioids for the management of chronic non-cancer pain

Principal Investigator: Erica Brooks, B.P.H.E  
M.A. Candidate, Health Promotion  
Dalhousie University  
Contact Information: (902)406-0550 or erica.brooks@dal.ca

Supervisor: Dr. Anita Unruh, PhD  
Professor, Health and Human Performance  
Dalhousie University  
Contact Information: (902)494-3829 or anita.unruh@dal.ca.

Study Sponsor: Nova Scotia Health Research Foundation

PART A

1. Introduction

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don’t understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

We do not know if taking part in this study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. We will always give you the best possible care no matter what happens.

If you decide not to take part or if you leave the study early, your usual health care will not be affected.
PART B

2. Why is this study being done?

The purpose of the study is to gain an in-depth understand of a patient’s experience of using opioids to manage chronic non-cancer pain. Specifically, the research question being asked is, “What is the lived experience of adults using opioids for the management of chronic non-cancer pain?” For this study, specific opioids include codeine, morphine, oxycodone, hydromorphone, fentanyl or methadone. Overall, the researcher would like to explore your experience with pain and understand how opioids have impacted this experience.

3. Why am I Being Asked To Join This Study?

You may participate in this study if you are eighteen (18) years or older, English speaking, and willing to share your personal experience. You must have a chronic non-cancer pain condition and be receiving prescribed opioids (codeine, morphine, oxycodone, hydromorphone, fentanyl and methadone) from the Pain Unit at the QEII in Halifax, Nova Scotia.

4. How Long Will I Be In The Study?

You will be asked to participate in two interviews. It is expected that the interviews will take approximately 45-90 minutes to complete and will be scheduled at a time this is convenient for you. The second interview will occur approximately 2-3 weeks following the first interview.

5. How Many People Will Take Part In The Study?

This study is taking place only at Capital Health within the Pain Unit. It is expected that 8-10 participants will be selected however each interview will private with only the participant and the researcher present.

6. How Is The Study Being Done?

This study will use in-depth face to face or telephone interviews. During the interview, you will be asked to speak freely about your experience of living with chronic non-cancer pain and how opioids have had an impact on your daily living. At the end of the interview, a second interview will be scheduled. The purpose of the second interview is to review findings from initial interview and you will be given the opportunity to review results and remove anything you feel was misinterpreted or express additional thoughts.

The interview questions will cover topics about your pain, how well your pain is managed and how taking opioids has affected your life. Example of types of questions include but are not limited to, “What is it like to be a patient taking long-term opioids for chronic non-cancer pain?”, “What problems have you encountered?” and “How well is your pain controlled?” Two interviews will be completed. The first interview will last approximately one hour where
you will be invited to share as much as you feel comfortable and the second as a follow up interview once the researcher has had time to review data.

7. What Will Happen If I Take Part In This Study?

Participation in this research involves committing to meeting with the researcher for two interviews. The interviews will be conducted at the Pain Unit at the QEII and will last approximately 45-90 minutes. After providing your written permission, the interviews will be audio reordered. Approximately 1-2 months after the first interview, you will be asked to participate in a second interview where you will receive a copy of the researcher’s interpretations and be asked whether you agree with her interpretations of the comments you made during the first interview.

8. Are There Risks To The Study?

There is minimal risk involved in participating in this study. You may find the interview questions during the course of the study upsetting or distressing. You will be asked to discuss your experience using opioids to manage chronic non-cancer pain and how it has affected your life which may bring up personal issues such as your social life, relationship, or personal health. This may lead to psychological discomfort because of the thoughts, feelings, experiences and/or emotions you may share during the interview. You do not have to answer those questions you find too distressing. It is important to emphasize that you will only be asked to share information that you feel comfortable talking about. There are only two reasons your confidentiality may be broken: (1) If you reveal information about the abuse or neglect of a child or adult in need or protection, the law requires the researcher (Erica Brooks) to report this information to the appropriate authorities, and; (2) If you identify and intent to harm yourself or others, health services or police may be notified. These are the risks of participation.

9. What Happens at the End of the Study?

At the end of the study, the results will be disseminated at various conferences and potentially published.

10. What Are My Responsibilities?

As a study participant you will be expected to:
- Follow the directions of the Principal Investigator
- Provide socio-demographic information
- Provide written consent to participate
- Attend and participate in 2 interviews over the course of approximately 2 months at the Pain Clinic in Halifax, NS.
- Be willing to share your experiences of using opioid medication

11. Can I Be Taken Out Of The Study Without My Consent?

Yes. You may be taken out of the study at any time, if:
➢ There is new information that shows that being in this study is not in your best interests.

➢ The Capital Health Research Ethics Board or the Principal Investigator decides to stop the study.

You will be told about the reasons why you might need to be taken out of the study.

12. What About New Information?

It is possible (but unlikely) that new information may become available while you are in the study that might affect your health, welfare, or willingness to stay in the study. If this happens you will be informed in a timely manner and will be asked whether you wish to continue taking part in the study or not.

13. Will It Cost Me Anything?

Compensation

You will not be paid to be in the study. You will get a small amount of money to cover parking on study visit days. Please bring your receipts with you.

Research Related Injury

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the Principal Investigator, the research staff, the study sponsor or involved institutions from their legal and professional responsibilities.

14. What About My Right to Privacy?

Protecting your privacy is an important part of this study. A copy of this consent will be put in your health record.

When you sign this consent form you give us permission to:

- Collect information from you
- Collect information from your health record
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The study doctor and members of the research team will see health and study records that identify you by name.

Other people may need to look at the health and study records that identify you by
name. These might include:

- people working for the sponsor* - You may ask to see the list of persons working with the sponsor (if applicable)
- the CDHA Research Ethics Board and Research Quality Associate

Use of records.

The research team will collect and use only the information they need to complete the Study. This information will only be used for the purposes of this study.

This information will include your:

- date of birth
- sex
- employment
- medical conditions/diagnosis
- medications
- information from study interviews and questionnaires

Your name and contact information will be kept secure by the research team in Nova Scotia. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study. Information collected for this study will kept as long as required by law. This could be 7 years or more.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed.

After your part in this study ends, we may continue to review your health records. We may want to follow your progress and to check that the information we collected is correct.

Information collected and used by the research team will be stored by the Primary Researcher at Dalhousie University. The Primary Researcher is the person responsible for keeping it secure.

You may also be contacted personally by Research Auditors for quality assurance purposes.

Your access to records

You may ask the study doctor to see the information that has been collected about you.

15. What If I Want To Quit The Study?

If you chose to participate and later change your mind, you can say no and stop the research at any time. If you wish to withdraw your consent please inform the Principal Investigator. All data collected up to the date you withdraw your consent will remain in the study records, to be included in study related analyses. *A decision to stop being in the study will not affect your treatment within the clinic.*

16. Declaration of Financial Interest
The sponsor is paying the Principal Investigator and/or the Principal Investigator’s institution to conduct this study. The amount of this payment is sufficient to cover the costs of conducting the study.

17. What About Questions or Problems?

For further information about the study call Erica Brooks. Erica Brooks is in charge of this study at this institution (she is the “Principal Investigator”). Erica Brooks’ telephone number is (902) 406-0550. If you can’t reach the Principal Investigator, please refer to the attached Research Team Contact Page for a full list of the people you can contact for further information about the study.

The Principal Investigator is Erica Brooks.

Telephone: (902) 406-0550

Email: er367808@dal.ca

Your Research Coordinator is Dr. Anita Unruh.

Telephone: (902) 494-3829

Email: anita.unruh@dal.ca

18. What Are My Rights?

After you have signed this consent form you will be given a copy.

If you have any questions about your rights as a research participant, contact the Patient Representative at (902) 473-2133.

In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.

PART C

19. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the study called:

   Exploring the lived experience of adults using opioids to manage chronic non-cancer pain

I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction.
This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time.

______________________       ____________________
Signature of Participant                    Name (Printed) Year    Month    Day*

______________________       ____________________
Witness to Participant’s                 Name (Print) Year    Month    Day*
    Signature

______________________       ____________________
Signature of Investigator          Name (Print) Year    Month    Day*

______________________       ____________________
Signature of Person Conducting     Name (Print) Year    Month    Day*
    Consent Discussion

______________________       ____________________
Signature of Participant’s              Name (Print) Year    Month    Day*
    Authorized Legal Representative

I Will Be Given a Signed Copy of This Consent Form

Thank you for your time and patience!
APPENDIX F: Demographic and Medical Information

Name:____________________________ Date of birth:____________________________

Gender: (please circle) Male Female Transgendered
Other:_____________________

How would you describe yourself: (please check one)

- Aboriginal
- Asian
- Black or African-Canadian
- Hispanic or Latino
- White or Caucasian
- Other _____________________

In what category does your household fit? (please check one)

- Less than $10,000
- $10,000-$40,000
- $40,000-$70,000
- $70,000 or more
- Not willing to disclose

What is your highest level of education completed? (please check one)

Some grade school

- Completed high school
- Some college/technical/trades training
- Completed college/technical/trades training
- Some university
- Completed university
- Other:_____________________

Are you currently employed? (please circle)

Full-time Part-time Student Unemployed
How long have you been a patient in the Pain Clinic: ____________________________

Type of Pain or Diagnosis

1) __________________________________________________
   Duration: ___________________________________________
   Location: ___________________________________________
   Severity of Pain (please circle):
       No pain  0  1  2  3  4  5  6  7  8  9  10  Worst pain imaginable

2) _________________________________________________
   Duration: ___________________________________________
   Location: ___________________________________________
   Severity of Pain (please circle):
       No pain  0  1  2  3  4  5  6  7  8  9  10  Worst pain imaginable

3) _________________________________________________
   Duration: ___________________________________________
   Location: ___________________________________________
   Severity of Pain (please circle):
       No pain  0  1  2  3  4  5  6  7  8  9  10  Worst pain imaginable

Please list what medications are you currently taking and amounts?

Medication: ___________________________ Dose: ___________________________

Medication: ___________________________ Dose: ___________________________

Medication: ___________________________ Dose: ___________________________

Medication: ___________________________ Dose: ___________________________

Medication: ___________________________ Dose: ___________________________